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## Measuring participation in children and young adults with visual impairment: the development of instruments

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# Chapter 13

Summary and general discussion

This thesis focused on participation of children and young adults with visual impairment. The first section aimed to define the concept of participation for this population, and to gain insight in available interventions to increase participation. The second section aimed to investigate the psychometric properties of patient-reported outcome measures (PROMs) used in this thesis and originating from the conceptualisation of participation in the first section. We refer to these PROMs as the Participation and Activity Inventory for Children and Youth (PAI-CY) and Young Adults (PAI-YA). Figure 1 graphically represents how each chapter contributed to defining the concept of participation and the development and validation of the PROMs.

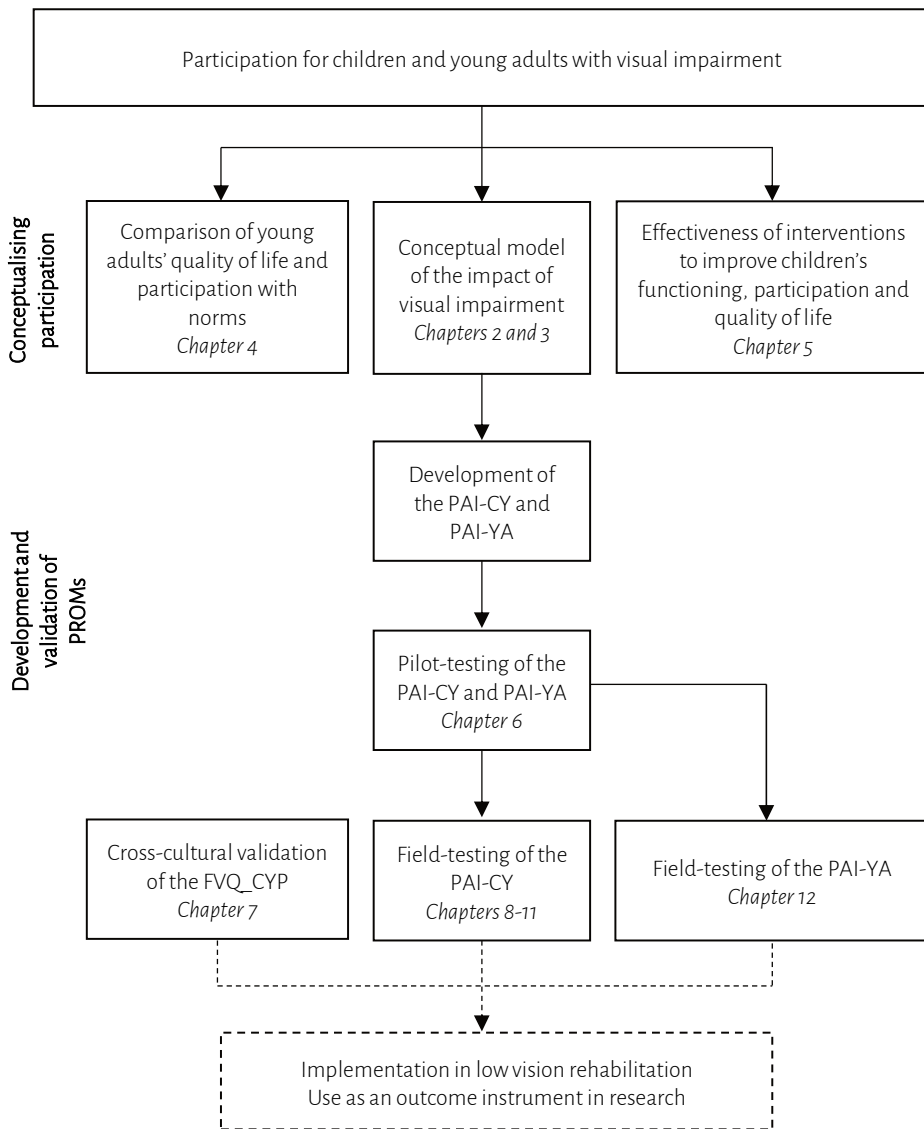


Figure 1. Graphical representation of the studies for the PAI-CY and PAI-YA

This chapter provides a summary and general discussion of the results of the individual chapters. It entails an overview of the main findings in light of previous research, methodological considerations, implications for practice and recommendations for future research. The chapter ends with a general conclusion.

## Main findings

### Impact of visual impairment

Studies aimed at determining the impact of visual impairment on the lives of children and young adults showed that having a visual impairment affects general development,<sup>1,2</sup> motor skills,<sup>3-6</sup> physical activity levels,<sup>7-10</sup> employment,<sup>11-13</sup> and social participation.<sup>14-22</sup> While the impact of visual impairments on specific life aspects of children and young adults is well recognised, less is known about the impact on all life aspects, as described in **Chapters 2 and 3**. In order to investigate this for every life stage, five age-groups were created according to the guidelines of the World Health Organisation (WHO): 0-2 years, 3-6 years, 7-12 years, 13-17 years and 18-25 years. For every age-group, a conceptual model detailing all life aspects affected by low vision was created. Various qualitative methods were used among parents, children aged 7-17 years, and professionals from expertise centres for the blind and visually impaired, including brainstorm sessions, interviews, focus group discussions and concept-mapping workshops. For children, it was found that visual impairment affects both sensorial development as physical, psychological and social wellbeing. However, external factors such as education/employment and the influence of parents could either facilitate or hinder participation. There was variation between the different age-groups. In very young children (0-2 years), difficulties in the attachment process was a main theme, while in children 3-6 years, mobility and independence were often mentioned. General development and increased self-awareness were themes mentioned by parents and professionals for children 7-12 years, while children themselves mentioned social isolation and dependence on others. The finding that the perceptions of adults differed from that of children was also found for adolescents aged 13-17 years, who mentioned longing for independence and insecurity towards future life changes. Elements of these aspects were also mentioned by parents and professionals, but had a different focus. For example, professionals stated that adolescents discarded their limitations, while adolescents mentioned they get sometimes overwhelmed when thinking about their future life. It was therefore concluded that the perspectives of professionals and parents do not always correspond with the perspectives of children and adolescents, confirming the results of other studies.<sup>23-26</sup> For young adults, activities related to study, work, daily living, social skills and relationships were considered most important. The difference in perspectives between young adults and professionals was less pronounced compared to the study in children, although professionals tend to ascribe more importance to the various activities mentioned than young adults, except for leisure time activities. This greater importance indicated by professionals was especially found for activities related to social skills and relationships. It was concluded from this study that young adults need to be considered as a separate group, because they are in the transition towards becoming an adult, a result also found by Van Leeuwen et al. who concluded that (older) adult needs partly overlap, but also differ from needs of young adults in transition.<sup>27</sup>

Professionals from expertise centres for the blind and visually impaired should focus on all life aspects when identifying the needs of parents, children and young adults and consider the different perceptions of children and their parents. It was therefore concluded that these expertise centres would benefit from new instruments based on the conceptual models created in these studies to identify the needs of children and young adults. This could aid goal setting and referral to appropriate rehabilitation programmes, ultimately increasing participation and quality of life.

### **Quality of life of young adults**

People with visual impairment often report lower quality of life than the general population (e.g.<sup>28-31</sup>). However, most of these studies are conducted in older adults, because of the higher prevalence of visual impairment. In this thesis (**Chapter 4**), quality of life and participation of young adults with visual impairment aged 18-25 years (n=172) was compared with normative data, and the association between severity of vision loss and participation and quality of life was assessed. Although results were mostly statistically significant, quality of life of young adults with visual impairment was only moderately affected on some aspects (i.e. physical role limitations and vitality) compared to the general population, but their participation was considerably worse. More severe vision loss was associated with worse physical functioning and vision-related quality of life. Compared to other studies using the same instruments, often conducted in older populations with visual impairment, this study found that young adults rated their physical functioning better, but their mental health and social functioning worse.<sup>28-30,32-34</sup> This study provides insight in quality of life and participation levels of young adults with visual impairment, and again confirms that young adults should be considered as a separate group in low vision rehabilitation care. Using the results of this study, changes in rehabilitation programmes might be initiated, allowing better support for young adults.

### **Systematic review of interventions to improve functioning, participation and quality of life**

In light of the development of instruments in this thesis to assess participation needs of children (and young adults), it is important to understand how these needs can be met by expertise centres for the blind and visually impaired. A variety of interventions for children and their parents have been developed and implemented in low vision rehabilitation services. There is a need for evidence regarding the effectiveness of these interventions. Systematic reviews have been conducted to assess the effectiveness of low vision rehabilitation services, assistive technology, and optical reading aids in children,<sup>35-37</sup> but with limited results mainly due to stringent inclusion criteria. In this thesis, a systematic review on the effectiveness of interventions to improve functioning, participation and quality of life in children with visual impairment was conducted (**Chapter 5**). In total, 66 different studies were included, of which the majority focused on physical performance, oral health, and psychological outcomes. The results suggest that certain interventions, such as physical training,<sup>38-48</sup> sports camps,<sup>49-53</sup> prescription of low vision devices,<sup>54-61</sup> and oral hygiene programmes<sup>62-71</sup> might be effective in improving functioning or elements of participation and quality of life. However, the effectiveness of many interventions, for example offered by expertise centres for the blind and visually impaired, remains unclear. Moreover, there

was a lack of high-quality, well-designed and adequately reported studies, which limits the conclusions that can be drawn. The use of many different outcome instruments hindered the comparison of results.

### **Pilot study of the PAI-CY and PAI-YA**

The conceptual models created in Chapters 2 and 3 resulted in the development of four age-specific PAI-CY instruments (0-2 years, 3-6 years, 7-12 years and 13-17 years) and one PAI-YA instrument (18-25 years). To assess feasibility, acceptability and content relevance, the PAI-CY and PAI-YA instruments were pilot-tested during the regular admission procedure of Dutch low vision services as described in **Chapter 6**. This is considered an important step in the development and validation of instruments, because it can provide valuable information for subsequent field studies.<sup>72-74</sup> Results showed that over 85% of the parents were neutral to positive about all aspects of the PAI-CY such as duration to complete the questionnaire, content relevance and understanding of the items. All children and young adults also rated the various aspects of the PAI-CY and PAI-YA neutral to positive, except for the duration to complete the questionnaire. Professionals of Dutch low vision services were less positive, especially with respect to the ability of the questionnaire to clarify rehabilitation needs. This finding is in line with results from the PAI for adults, in which professionals also had a more critical attitude towards the instrument.<sup>75</sup> However, involving professionals in an early stage turned out to be important, as it resulted in better understanding of the relevance of implementation for themselves and their clients. Furthermore, factors which might influence the future implementation success might be identified by involvement of professionals.<sup>76,77</sup> Based on the results of this study, several changes were made to the PAI-CY and PAI-YA, the most important one being the inclusion of an open-ended question after each domain to clarify rehabilitation needs. The underlying assumption to this additional question is that not every difficulty as reported in the questionnaire necessarily reflects a rehabilitation need.

### **Psychometric properties**

In Chapters 7-12, the psychometric properties of the Dutch version of the Functional Vision Questionnaire for Children and Young People (FVQ\_CYP\_NL), the four age-specific versions of the PAI-CY and the PAI-YA were evaluated using methods from item response theory (IRT), classical test theory (CTT) and network analysis. Table 1 gives an overview of the most important results with respect to the psychometric properties for each of the questionnaires.

**Chapter 7** presents the cross-cultural validation of the FVQ\_CYP. This instrument originates in the UK,<sup>78</sup> and was used as a comparison instrument in the validation of the PAI-CY. In order to be useful as a comparison instrument, the Dutch version of the FVQ\_CYP (FVQ\_CYP\_NL) needed to be cross-culturally validated first. This turned out not to be straightforward. The (Rasch-type) rating scale model used for the original validation of the FVQ\_CYP did not fit the Dutch data. As such, it was decided to assess the psychometric properties of the FVQ\_CYP\_NL irrespective of the model and criteria used in the UK and to use a graded response model. After deleting 12 items and collapsing the response options 'difficult' and 'very difficult or impossible', the FVQ\_CYP\_NL

showed to have high measurement precision and a broad coverage of items measuring children's functional vision. The FVQ\_CYP\_NL was able to discriminate between children with severe visual impairment and blindness compared to children with moderate and mild visual impairment, with the latter experiencing less disability.

The psychometric properties of the proxy-instruments PAI-CY 0-2 years and 3-6 years were evaluated in respectively **Chapters 8 and 9**. This was done using methods from IRT and CTT. A graded response model was applied. After deleting four items in the PAI-CY 0-2 years and collapsing some answer categories for several items, the instrument contains 27 items which showed acceptable psychometric properties. The PAI-CY 0-2 years was able to discriminate between participants differing in comorbidity and degree of visual impairment. However, confirmation of its psychometric properties is necessary in a larger sample. The final PAI-CY 3-6 years contains 40 items, although 35 are included in the scoring. The other five items were considered important for face and content validity according to professionals from expertise centres for the blind and visually impaired, but did not fit the selected IRT model. After collapsing the response options 'very difficult' and 'impossible', the 35 items showed to have sound psychometric properties to evaluate the needs of children with visual impairment by means of a proxy report. A distinction could be made between participants with various degrees of visual impairment and comorbidity, supporting known-group validity.

The PAI-CY 7-12 years, which consists of a self-report version and a proxy-report version, was evaluated using network analysis in **Chapter 10**, because the data violated the most important assumptions of IRT, i.e. unidimensionality and local independence. Prior to the network analysis, some basic psychometric properties, including internal consistency, test-retest reliability and concordance between children and parents were investigated, informing the deletion of eight items. Networks for both children and parents were created, along with visualisations of shared and differential connections. The network structures of children and parents were dissimilar; for children connections evolved around items regarding social contacts and school, whereas for parents mobility, leisure time, acceptance, self-reliance and communication items prevailed. This suggests that children might perceive the concept of participation differently from parents. If rehabilitation programmes focus on those items that are most central (i.e. most connected to other items) in the networks of children and parents, it might positively affect the other items in the network, thereby improving participation levels of children.

The psychometric properties of the PAI-CY 13-17 years, consisting of a self-report version and a proxy-report version as well, were evaluated in **Chapter 11**. For this purpose, methods from CTT were used. Three items were deleted, resulting in a 55-item instrument. The response options 'very difficult' and 'impossible' were collapsed. The PAI-CY 13-17 years showed acceptable basic psychometric properties, and was able to distinguish participants with and without comorbidity, while a trend was observed for worsening scores with more severe visual impairment. However, more work is needed with larger samples, enabling the use of IRT. This will make the PAI-CY 13-17 years more precise and user-friendly.

The PAI-YA, which is intended to be used to evaluate the rehabilitation needs of young adults with visual impairment aged 18-25 years, was evaluated in **Chapter 12** using methods of IRT and CTT. The initial instrument contained 141 items. Most of them were deleted following several iterations of IRT analyses, in which a graded response model was applied, resulting in a 64-item instrument, with 60 items being included in the scoring. The four items that were added were considered to be important for the identification of all rehabilitation needs, and as such vital for the content validity of the PAI-YA. The response options 'very difficult' and 'impossible' were collapsed. The 60-item instrument was able to differentiate respondents who differed with respect to severity of visual impairment, financial situation and sex, with worse scores for those with more severe visual impairment, less financial means and for females.

The studies in Chapters 8-12 have showed that the PAI-CY and PAI-YA have acceptable psychometric properties, and can be used to identify the needs of children, adolescents and young adults in rehabilitation practice or as an outcome instrument in research.



**Table 1.** Overview of the psychometric properties of the FVQ\_CYP\_NL, PAI-CY and PAI-YA

	FVQ_CYP_NL	PAI-CY 0-2	PAI-CY 3-6	PAI-CY 7-12	PAI-CY 13-17	PAI-YA 18-25
n	253	115	237	195	77	186
Items deleted	12	4	17	8	3	81
Items maintained	24	27	35 (+5)	47	55	60 (+4)
Dimensionality				n.a.	n.a.	
Dimensions	1	1	1			1
Explained variance	36%	48%	36%			35%
Violations of assumptions				n.a.	n.a.	
Local dependence	None	1.1-1.2; 5.1-5.2; 6.6-6.7	MO2-MO3; SR1-SR3			RV1-RV2; RV5-CS4; MO5-MO6; CS5-CS8, SR7-RR1; ST2-ST6
Monotonicity	None	4.1	MF2			CS8; LT10
Scalability	None	2.3	None			SC5
Model fit				n.a.	n.a.	
RMSEA	0.061	0.064	0.087			0.057
SRMR	0.062	0.099	0.077			0.072
TLI	0.965	0.965	0.933			0.967
CFI	0.968	0.968	0.937			0.966
Item misfit	None	None	OR2	n.a.	n.a.	n.a.
Item information				n.a.	n.a.	
Highest	FV_11: 4.26	6.4: 8.02	SR5: 4.01			MO15: 4.66
Lowest	FV_28: 2.05	2.3: 0.90	AT1: 1.46			MO6: 1.40
Differential item functioning*		n.a.		n.a.	n.a.	n.a.
Age	FV_24, FV_36, FV_29		VA4, SR3, SE3			
Visual impairment	n.a.		MF2, AT1			
Gender	FV_2, FV_14, FV_29		SR4, MF1, SE3			
Inter-rater reliability	-	-	-			-
ICC				n.a.	0.438	
Weighted kappa				n.a.	0.00-0.67	
Percentage agreement				n.a.	40.6-95.8	
Kendall's W				0.48-0.80	n.a.	

Internal consistency							
High inter-item correlations	None	1.1-1.2; 5.1-5.2; 6.3-6.5; 6.6-6.7	None	Self: none Proxy: none	Self: SC4-F11 Proxy: LT6-MO3, MO1- MO3, SC2-SC6, SR7-SR8 n.a.	None	
Low item-total correlations	None	None	None	Self: PL1, SC4, SC5, LT2, LT4, SL2, AC5 Proxy: SR5	n.a.	n.a.	
Cronbach's alpha	0.93	0.95	0.95	Proxy: 0.96		n.a.	
Test-retest reliability	n.a.						
ICC				n.a.		n.a.	
Proxy		0.920	0.929		0.882		
Self		-	-		0.866		
Weighted kappa							
Proxy		0.60-0.91	0.43-0.85	0.53-0.78	0.37-0.92	-	
Self		-	-	0.10-0.68	-0.05-1.00	0.47-0.87	
Percentage agreement							
Proxy		57.3-90.0%	63.6-89.8%	59.9-93.6%	59.6-93.8%	-	
Self		-	-	55.6-95.7%	51.4-100%	63.1-92.0%	
Concurrent validity	n.a.	n.a.		n.a.			
Participation							
Proxy			-0.70; -0.82		-0.71; -0.87	-	
Self					-0.41; -0.71	0.34; 0.72	
Quality of life			n.a.				
Proxy					-0.29; -0.58	-	
Self					-0.15; -0.41	-0.33; -0.53	
Functional vision			n.a.		0.68	-0.69	

CFI: comparative fit index; RMSEA: root mean square error of approximation; SRMR: standardized root mean square residual; TLI: Tucker-Lewis index

\* underlined items: non-uniform DIF; other items: uniform DIF; n.a. not assessed; - not applicable

## Methodological considerations

The findings in the studies described in this thesis have given rise to some considerations, which are discussed below.

The limited sample size in each of the studies related to the PAI-CY and PAI-YA are a consequence of the rarity of visual disabilities in children and young adults in the Netherlands. Because of the numerically small and difficult to reach population, qualitative methods for the conceptual model on which the PAI-CY and PAI-YA were based, were selected according to their feasibility. We conducted online concept-mapping workshops with young adults and professionals and online brainstorm sessions with parents of children with visual impairment in Chapter 2 and 3, limiting group discussion and participant interaction. Participating children mostly attended special education for the visually impaired, as the response among children attending regular education was very low. However, the majority of the children with visual impairment attend regular education. As such, inclusion of primarily children attending specialised schools might have resulted in overlooking information, however, this was not confirmed in the larger validation studies of the PAI-CY where respondents attending regular education hardly indicated missing any relevant topics or questions in the questionnaire. The targeted sample size for the pilot study described in Chapter 6 was realistic, but it turned out not to be feasible to recruit participants in all age categories during the regular admission period. As such, we also included children and young adults who were already receiving care from expertise centres for the blind and visually impaired. Consequently, a limited number of evaluation forms was available from professionals, and feasibility of administering the questionnaires during the admission period remains to be a topic for further study. Children and young adults already receiving care were also included in the validation studies of the PAI-CY and PAI-YA. These clients may differ from the intended target population (i.e. newly registered clients who receive an intake), because they might already have received rehabilitation, and as such experience less difficulties regarding activities and participation. On the other hand, when expertise centres want to use the PAI-CY and PAI-YA to monitor the needs of existing clients, the population would be more comparable to the population of the validation studies. Nevertheless, it would not have been feasible to include new clients in the validation studies, since the inclusion would have taken too long. The limited sample size also prevented the use of IRT in the studies described in Chapters 10 and 11, assessing the psychometric properties of the PAI-CY 7-12 years and 13-17 years. The small sample size in the validation study of PAI-CY 13-17 years might have been evoked by the data collection methods. Adolescents aged 13-17 years might have felt reluctant to participate in an interview-based administration of the PAI-CY at their homes. In retrospect, the data collection method of the PAI-YA (i.e. internet-based administration of the questionnaire, with the possibility to do a telephone interview or a home visit) might have been better suitable for adolescents, thereby benefiting participation rates. As a result of the small sample sizes, more work is needed to ensure validity and reliability of the PAI-CY 7-12 years and 13-17 years. Recently, Houts et al. proposed using longitudinal IRT models in small samples, which might be a useful application for scale development in children with visual impairment in future.<sup>79</sup> Alternatively, network modelling, which gives a more general dependency

structure between items compared to a factor model, might be used to facilitate the identification of connections between items as a reflection of the measured construct.

Many instruments in the field of ophthalmology or low vision, for example aiming to assess vision-related quality of life or functional vision, have been evaluated using Rasch-type models, such as the rating scale model (e.g.<sup>78,80-82</sup>). Although using Rasch models has several advantages, such as the somewhat smaller sample size necessary, the statistical sufficiency and the straightforwardness of output interpretation,<sup>83,84</sup> we chose to apply IRT models, i.e. the graded response model.<sup>85</sup> Compared to Rasch models in general and the rating scale model specifically, the graded response model is a less restrictive model, making it possible to obtain satisfactory model fit without deleting a relatively large number of items.<sup>83,84</sup> This positively impacts face- and content validity. Furthermore, less constrained models such as the graded response model often provide a more accurate reflection of the data,<sup>83,84,86</sup> while the cognitive processes of selecting a response in a Likert scale also favour the graded response model.<sup>87-89</sup> As such, use of the graded response model is also advocated by the PROMIS (Patient-Reported Outcomes Measurement Information System) initiative, comprising a measurement system of over 300 PROMs.<sup>90,91</sup>

The age-bands of the PAI-CY were based on the guidelines of the WHO: 0-2 years (infants and toddlers), 3-6 years (preschool children), 7-12 years (school-aged children), and 13-17 years (adolescents). Children are continuously developing, even within the age-bands. Especially for the PAI-CY 0-2 years and 3-6 years, some respondents mentioned that the content of the questionnaire was either more suitable for younger or older children. However, clear suggestions on how to improve the questionnaires were not provided. As such, the response option 'not applicable' is warranted in the questionnaires, and respondents should state the reasons for opting not applicable in order to refine the questionnaires for use in specific age groups. Moreover, the age-criteria for the PAI-CY and PAI-YA should not be taken too literally. For example, the PAI-CY 13-17 years might be better suitable for a child aged 12 years who follows secondary education. Likewise, the PAI-CY 7-12 years is better suitable when a child starts to learn reading and writing, in the Netherlands usually from group 3 onwards (at approximately 6 years), whereas the PAI-YA is better suitable when an adolescent/young adult enrolls in further education which in theory could be earlier than at 18 years.

The PAI-CY and PAI-YA are going to be used by Dutch expertise centres for the blind and visually impaired, in order to systematically identify the needs of children, parents and young adults. Ultimately, this should lead to more client-centred care, eventually improving patient outcomes. The use of a structured instrument to systematically identify the needs and client-centred care seems to be at odds with each other; an open, individualised and unstructured approach seems to correspond more to client-centred care. Research has shown that psychosocial topics, such as social relationships and community life, tend to be overshadowed using an open, unstructured approach.<sup>27,92</sup> This finding does not seem to be limited to the Dutch low vision context; similar results were found in the USA<sup>93</sup> and for those with hearing impairment.<sup>94</sup> Studies comparing the use of a structured intake using the PAI for adults versus a semi-structured open intake, found that

more rehabilitation needs were identified using the PAI, accompanied by a better representation of needs related to relationships, recreation and leisure.<sup>27,95</sup> A narrow focus on the domains which are more common, such as mobility and education, cannot be considered client-centred. The use of a structured instrument covering all participation aspects which are important according to the target population can be a significant first step towards client-centred care. However, one should realise that use of the PAI-CY and PAI-YA itself does not automatically guarantee client-centred care, and that not everyone will embrace its use; end-users might prefer an open and unstructured approach, in which attention is given to the emotional aspects and clients can 'tell their story'.<sup>75,96</sup> This was also expressed by some participants in the validation studies of the PAI-CY and PAI-YA, who stated that they were 'not in favour of questionnaires' and hoped that 'the questionnaire does not compromise the conversation'. This stresses the importance of maintaining the conversation between low vision rehabilitation professionals and clients. According to the underlying theory, use of the PAI-CY and PAI-YA, along with feedback of the results and information about subsequent steps will lead to care which is tailored to the specific needs of (parents of) children and young adults with visual impairment.<sup>97</sup> The needs identified by the PAI-CY and PAI-YA can be taken as a starting point in the rehabilitation process, facilitating communication between clients and professionals, and promoting an equal relationship in determining rehabilitation care.<sup>98,99</sup>

## Practice implications

The results of the studies described in this thesis are relevant for Dutch expertise centres for the blind and visually impaired, who face the challenge of implementing the PAI-CY and PAI-YA. Research has shown that the implementation of PROMs is often suboptimal, thereby limiting its effectiveness in daily practice.<sup>100,101</sup> Whether the PAI-CY and PAI-YA will improve client-centred care will depend on the success of implementation. Implementation of the PAI-CY and PAI-YA requires a significant shift in the current workflow of Dutch expertise centres, including the role of professionals, the provision of outcome feedback, and the integration and use of outcomes. At the time the PAI for adults was implemented, it was administered using a telephone interview, for which the Dutch expertise centres developed a platform. One of the complaints that is often heard, is that it is time consuming to administer the PAI and that it comes at the cost of the conversation between professionals and clients. Administration of the PAI-CY and PAI-YA should not compromise the conversation between professionals and clients. Rather, the PAI-CY and PAI-YA should be considered as tools to give guidance and direction towards the content of the conversation. As such, children and young adults preferably first receive diagnostic tests in order to determine whether they are eligible for care at the expertise centres for the blind and visually impaired. If this indeed is the case, parents, adolescents and young adults can complete the PAI-CY and PAI-YA through a web-based internet survey prior to the intake, while for younger children and those not capable of completing the questionnaires online, it might be preferred to administer the questionnaires face-to-face or via telephone, depending on their age and severity of visual impairment. If the PAI-CY and PAI-YA are going to be used to monitor the needs of existing clients, it should be determined at what time interval use of the PAI-CY and PAI-YA would be informative and feasible. The platform at which the PAI-CY and PAI-YA are offered can either

facilitate or hinder successful implementation. In order to prevent the wheel from being reinvented, an existing platform might be used. An example of such an online portal is KLIK (in Dutch: Kwaliteit van Leven In Kaart, i.e. Quality of Life in Clinical Practice).<sup>102-104</sup> KLIK is especially suitable for use in clinical practice, and is currently being used in >25 different health care centres in the Netherlands, in >100 patient groups, including ophthalmology. Approximately 300 PROMs have been implemented in in this portal.<sup>105</sup> This way, the responses can be made available at a glance to low vision rehabilitation professionals, clients and their caregivers, and results might be integrated in the electronic client files.<sup>105</sup> This might facilitate the uptake of the PAI-CY and PAI-YA in the existing workflow of low vision rehabilitation professionals.

Besides the considerations that must be made with respect to when and how the PAI-CY and PAI-YA are administered during the rehabilitation process, it is important to identify facilitators and barriers for successful implementation of the PAI-CY and PAI-YA. Although low vision rehabilitation professionals were involved in the studies to generate content of the PAI-CY and PAI-YA, a pilot study was conducted in which feasibility of the PAI-CY and PAI-YA was assessed during the regular admission procedure of expertise centres for the blind and visually impaired, and low vision rehabilitation professionals were consulted in the removal and maintenance of items in the validation study of the PAI-CY 3-6 years, more emphasis could have been placed on the implementation of the PAI-CY and PAI-YA from start. It might be too optimistic to assume that low vision rehabilitation professionals can and will automatically implement the PAI-CY and PAI-YA in their daily practice, even when knowing that the development of the questionnaires was at their own request. Research shows that health care professionals mainly experience substantial barriers to make PROMs a standard part of practice on the technological, practical and organisational level.<sup>106,107</sup> PROMs for children are even more challenging to implement, because different age-versions and different reporters (self vs. proxy) need to be taken into account.<sup>108,109</sup> When PROMs are implemented, frameworks, models and theories derived from implementation science can be used to identify barriers in the various stages of the implementation process.<sup>110</sup> A recent review concluded that organisations need to invest time and resources in 1) designing the processes and 2) preparing an organisation and its staff for the use of PROMs.<sup>111</sup> Sustainable implementation will only be feasible if ongoing training, interactive meetings and feedback on the use of the PAI-CY and PAI-YA are provided and shared. This requires a long-term commitment of budget, a coherent system and active support from the organisations.<sup>107,112</sup> A bottom-up approach with respect to the implementation can generate insights that are relevant to clients and low vision rehabilitation professionals.<sup>112,113</sup> However, a top-down approach has been suggested to secure successful implementation in the long term.<sup>112</sup>

## Future research

Based on the studies described in this thesis, several recommendations for future research can be formulated.

First, several instruments in paediatric ophthalmology have been developed in recent years to measure functional vision or vision-related quality of life. Table 2 provides an overview of available instruments for 'all-cause generic visual impairments', their target population, the construct they aim to measure and available language versions. Compared to these instruments, the PAI-CY and PAI-YA are unique, in that they are covering the entire age-range from 0-25 years. Moreover, for the PAI-CY, a self-report format is available along the proxy-report format for children aged 7-17 years. The PAI-CY 7-12 years and 13-17 years have already been translated to English and Nepali, and a formal evaluation study to investigate the cultural validity is underway. Now that several instruments for different purposes and populations are available for all-cause generic visual impairment, future research could focus on cross-culturally validating currently existing instruments for use in other countries, which is to be preferred over developing new instruments. When this turns out not to be straightforward, as in the study described in Chapter 7, in which the FVQ\_CYP was cross-culturally validated for use in the Dutch population, the original instrument should be used as a building block and the psychometric properties of the new language version should be assessed using more liberal criteria.

Children, adolescents and young adults with cognitive impairment have been excluded from the validation studies of the PAI-CY and PAI-YA, when this information was known at the expertise centres for the blind and visually impaired. Although some respondents reported to have a cognitive impairment, this was likely to be not a major cognitive impairment, as parents, children, and young adults were able to complete the questionnaires. Further research is required to investigate the feasibility and applicability of the PAI-CY and PAI-YA for children and young adults with major cognitive impairment. If the PAI-CY and PAI-YA are administered to children and young adults with cognitive impairment, the corresponding questionnaire might be selected on the basis of the developmental age of the respondent instead of the calendar age.

As mentioned, the limited sample sizes prevented the extensive evaluation of all questionnaires developed in this thesis. More work with larger samples is needed to confirm the psychometric properties of the PAI-CY and PAI-YA, and evaluate the properties not yet assessed. Alternatively, longitudinal IRT models could be used in order to confirm the psychometric properties when large samples cannot be obtained.<sup>79</sup> A longitudinal design would also allow assessment of the responsiveness of the PAI-CY and PAI-YA. That is, the ability of the PAI-CY and PAI-YA to detect change over time,<sup>127</sup> for example whether an improvement is detected after a rehabilitation programme.

As needs evolve with increasing age, it is likely that (parents of) children and young adults will complete multiple different age-versions of the PAI-CY and PAI-YA throughout their lives. One of the advantages of IRT models is the possibility of calibrating several questionnaires on a common scale, ensuring comparability of ability estimates (i.e. scores) over different forms of a questionnaire,<sup>86</sup> such as the age-versions of the PAI-CY and PAI-YA. Several studies have already reported on the linking of questionnaires (e.g. <sup>128-130</sup>). Future research could use an IRT model to link the age-versions of the PAI-CY and PAI-YA on a common scale, providing data to convert test

outcomes. This would enable the comparability of outcomes over time, using different age-versions of the questionnaires.

**Table 2.** Overview of available instruments for all-cause generic visual impairment in children

Instrument	Country of development	Age-range	Respondent	Intended construct	Available languages
Functional Vision Questionnaire for Children and Young People (FVQ_CYP) V1 <sup>78</sup> & V2 <sup>114</sup>	UK	V1: 10-15 years V2: 8-17 years (1 version for 8-12 years, 1 version for 13-17 years)	Self-report	Functional vision	V1: English, Dutch V2: English
Vision-related Quality of Life of Children and Young People (VQoL_CYP) V1 <sup>80</sup> & V2 <sup>115</sup>	UK	V1: 10-15 years V2: 8-17 years (1 version for 8-12 years, 1 version for 13-17 years)	Self-report	Vision-related quality of life	V1: English V2: English
LV Prasad-Functional Vision Questionnaire (LVP-FVQ) I <sup>116</sup> & II <sup>117</sup>	India	I: 8-18 years II: 8-16 years	Self-report	Functional vision	I: Indian English, Hindi, Telugu, Arabic <sup>118</sup> II: Indian English, Hindi, Telugu
Cardiff Visual Ability Questionnaire for Children (CVAQC) <sup>119</sup>	UK	5-18 years	Self-report	Visual ability	English, Turkish, <sup>120</sup> Mandarin <sup>121</sup>
Impact of Vision Impairment for Children (IVI_C) <sup>122</sup>	Australia	8-18 years	Self-report	Vision-related quality of life	English, Indi <sup>123</sup>
Children's Visual Function Questionnaire (CVFQ) <sup>124</sup>	USA	0-7 years (1 version for 0-2 years, 1 version for 3-7 years)	Proxy-report	Vision-related quality of life	English, Filipino <sup>125</sup>
Pediatric Eye Questionnaire (PedEyeQ) <sup>126</sup>	USA	0-17 years (3 versions: 0-4, 5-11 and 12-17 years)	Self-report: 5-11 and 12-17 years; Proxy-report: 0-4, 5-11 and 12-17 years	Functional vision and eye-related quality of life	English



Another advantage of IRT is the possibility to develop computer-adaptive tests (CATs). In a CAT, only those items which are expected to yield information relevant to the respondents ability are presented to a respondent. This lowers respondent burden, while achieving a high degree of precision.<sup>84</sup> Especially when the PAI-CY and PAI-YA are going to be used to monitor the needs of clients or evaluate their progression, for example after a rehabilitation programme, the development of a CAT might be a valuable application requiring further research.

In the qualitative studies in which the content of the PAI-CY was generated, statements about parental experiences and sensory functioning were also mentioned. As such, a subscale regarding parental experiences was incorporated in the proxy-report versions of the PAI-CY, and a subscale regarding sensory functioning in the PAI-CY 0-2 years and 3-6 years. However, the items in these subscales were not considered to be part of the constructs measured by the other items of the PAI-CY, and as such the psychometric properties of these subscales have not yet been investigated. Future research should investigate whether these subscales have acceptable psychometric properties, and can be used in addition to the 'participation and activity' subscale of the PAI-CY.

The content of the PAI-CY and PAI-YA was developed by end-users, i.e. parents of children with visual impairment, children with visual impairment aged 7-17 years, young adults with visual impairment and low vision rehabilitation professionals. As a result of the involvement of clients, it might be possible that the content of the PAI-CY and PAI-YA does not match the care that can be offered by expertise centres for the blind and visually impaired. For example, the PAI-CY or PAI-YA might indicate that there is a need for support in the performance of hobbies, while the expertise centres might not offer that kind of support. As such, it should be investigated whether the content of the PAI-CY and PAI-YA matches the various low vision services. When this is not the case, changes in existing rehabilitation programmes might be necessary, or new rehabilitation programmes might need to be created.

## Conclusion

The work described in this thesis had two aims. The first aim was to define the concept of participation for children and young adults with visual impairment, and gain insight in available interventions to increase participation. With the qualitative studies conducted among children, parents, young adults and professionals, we now have better insight in what participation for these populations entails, and what the differences are between the different age-groups. The comparison with norm groups gave further insight in the consequences of having a visual impairment in young adults on participation and quality of life. The systematic literature review provided information on the effectiveness of interventions to improve functioning, participation and quality of life of children with visual impairment. From this literature review, it also became evident that more research is needed to evaluate the effectiveness of many interventions. The second aim of this thesis was to investigate the psychometric properties of the PROMs that have been used in this thesis and originated from the conceptualisation of participation. Although future research is warranted to confirm the psychometric properties of the PAI-CY and PAI-YA and

evaluate some properties not yet assessed, we now have four age-specific PAI-CY instruments and one PAI-YA instrument, which can be used in low vision rehabilitation practice to evaluate the rehabilitation needs of children and young adults with visual impairment aged 0-25 years. Furthermore, the PAI-CY and PAI-YA can be used as outcome instruments in research.

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