

WATCH

Wheelchair Outcomes Assessment Tool for Children

Summary Report

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About CHEME at Bangor University

The Centre for Health Economics and Medicines Evaluation (CHEME) was founded in 2001, and is now one of the leading health economics centres in the UK. At CHEME, we aim to promote and sustain high-quality health economics research, maximise opportunities for research grant capture and publications in high impact journals. The centre is active across a range of health economic and medicines evaluation research activities. These are broadly categorised into the following research themes:

- Public health economics and the health economics of psychosocial interventions and other non-pharmacological health technologies, led by Professor Rhiannon Tudor Edwards
- Pharmacoeconomics, pharmaceutical policy and medicines use, led by Professor Dyfrig Hughes

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EXECUTIVE SUMMARY



This project was funded as part of an NHS England research programme to develop patient-centred outcome measures (PCOMs) for use with children and young people. Our aim was to develop a PCOM for NHS paediatric wheelchair and posture services. Over 60,000 children are registered with NHS wheelchair services in England, so identifying and addressing the outcomes of most importance to these users could help services to maximise the benefits achievable within available resources. None of the outcome measures currently in use among rehabilitation specialists are thought to meet fully the needs of wheelchair and posture service provision in the UK in identifying the outcomes of importance for children and young people.

The project team comprised researchers from Bangor University's Centre for Health Economics and Medicines Evaluation (CHEME), and staff from the Shropshire Wheelchair and Posture Service and the two Clinical Commissioning Groups (CCGs) that it serves. Additional input was gained from service users and parents/carers. A questionnaire survey was sent to young wheelchair users (≤ 18 years) and their parents to explore the importance of a range of pre-defined outcomes and to identify novel outcomes. Subsequent face-to-face interviews were conducted to further explore survey responses and to uncover novel outcomes. Participants were also asked to score and record their satisfaction levels for the outcomes they identified as most important.

Questionnaires were completed by 21 young wheelchair users or their parents, followed by 11 interviews. Based on the findings of the survey and interviews, and in consultation with the service providers and service users, the WATCH (Wheelchair outcomes Assessment Tool for Children) questionnaire tool was developed to allow clinicians and therapists to identify, score and monitor individual users' most important outcomes before and after wheelchair provision. The WATCH tool was further refined through piloting in clinic. The final version comprises 16 outcome options, from which service users select their five most important outcomes to be monitored, describe what they wish to achieve, and rate their current satisfaction with each outcome. A follow-up WATCH tool has also been developed to allow monitoring of outcomes after wheelchair provision.

The WATCH tool allows wheelchair users across a wide range of ages and clinical needs to select outcomes of most importance to them and to give an example of what they hope to achieve for each one. It allows a degree of comparability across patients, and ensures that patients focus on achievable outcomes. The simple before and after scoring system should allow service providers to ascertain how well desired outcomes are being achieved, both for individual users and for a specific outcome across service users. The tool should be applicable to children and young people accessing wheelchair services across the UK and other countries.

In conclusion, the project achieved the aim of developing a novel, patient-centred outcome measure, the WATCH tool, which is suitable for use with children and young people accessing NHS wheelchair services. In addition to potentially improving the quality of service provided to young wheelchair users, the development of the WATCH tool could inform the development of novel PCOMs in other service areas.

BACKGROUND

Patient-centred outcome measures (PCOMs) are designed to focus outcome measurement around the needs and priorities of patients – thereby creating measures which reflect the outcomes which are of most importance to patients (NHS England, 2015). Shropshire Clinical Commissioning Group (CCG) were awarded funding to develop a PCOM for children and young people who use wheelchair and posture services, as part of an NHS England development call. The aim of the project was to explore how best to measure outcomes which are relevant to young wheelchair users (≤ 18 years old) and their families accessing NHS wheelchair services. In the UK, 7% of children and young people live with a disability (Department of Work and Pensions, 2017), 20% of which have impaired mobility. Based on UK population statistics (Office for National Statistics, 2017), this means that over 200,000 children and young people in the UK have a mobility impairment, many of whom will use a wheelchair. In England alone, there are 60,000 children and young people registered with NHS wheelchair services (NHS England, 2018).

Addressing clinical need is an important part of wheelchair provision, but unlike many other areas of PCOM development, the clinical needs of young wheelchair users vary, due to the wide range of underlying reasons for wheelchair use and comorbidities. For children and young people with mobility impairments, provision of appropriate equipment to facilitate independent movement and better comfort/posture influences many areas of their lives, thus getting outcome measurement right is essential. Young wheelchair users have a unique perspective on health-related quality of life (HRQoL), thus it is important that their social, developmental and education needs are taken into consideration when assessing outcomes in wheelchair provision (see figure 1; Bray et al, 2017a). Providing the right wheelchair at the right time has been shown to have great impacts on the holistic wellbeing of children and young people (Muscular Dystrophy Campaign, 2010). Inappropriate mobility equipment can restrict children's independence and ability to play and interact socially (Barnardos and Whizz-Kidz, 2006), while early intervention with appropriate independent mobility aids encourages functional mobility improvement (Jones et al, 2003), psychosocial development (Furumasu et al, 2008) and helps to develop communication skills (Butler, 1983; Jones et al, 2003; Jones et al, 2012).

Due to tight criteria for provision and limited budgets, NHS wheelchair services can find it difficult to meet all of the needs of children and young people. At present, some parents choose to fundraise through charities or purchase wheelchairs privately in order to get the equipment that they believe best meets the needs of their child (NHS Improving Quality,

2014). By identifying and addressing the outcomes of most importance to young wheelchair users, it is hoped that wheelchair services can maximise the benefits achievable with the resources available. None of the outcome measures currently in use among rehabilitation specialists are thought to meet fully the needs of wheelchair and posture service provision in the UK, particularly in identifying the outcomes of most importance for children and young people. Measures which focus on wheelchair or assistive technology, as opposed to broader tools used by rehabilitation professionals, do not prospectively identify outcomes of importance to the user or lack suitability for use with children and young people.

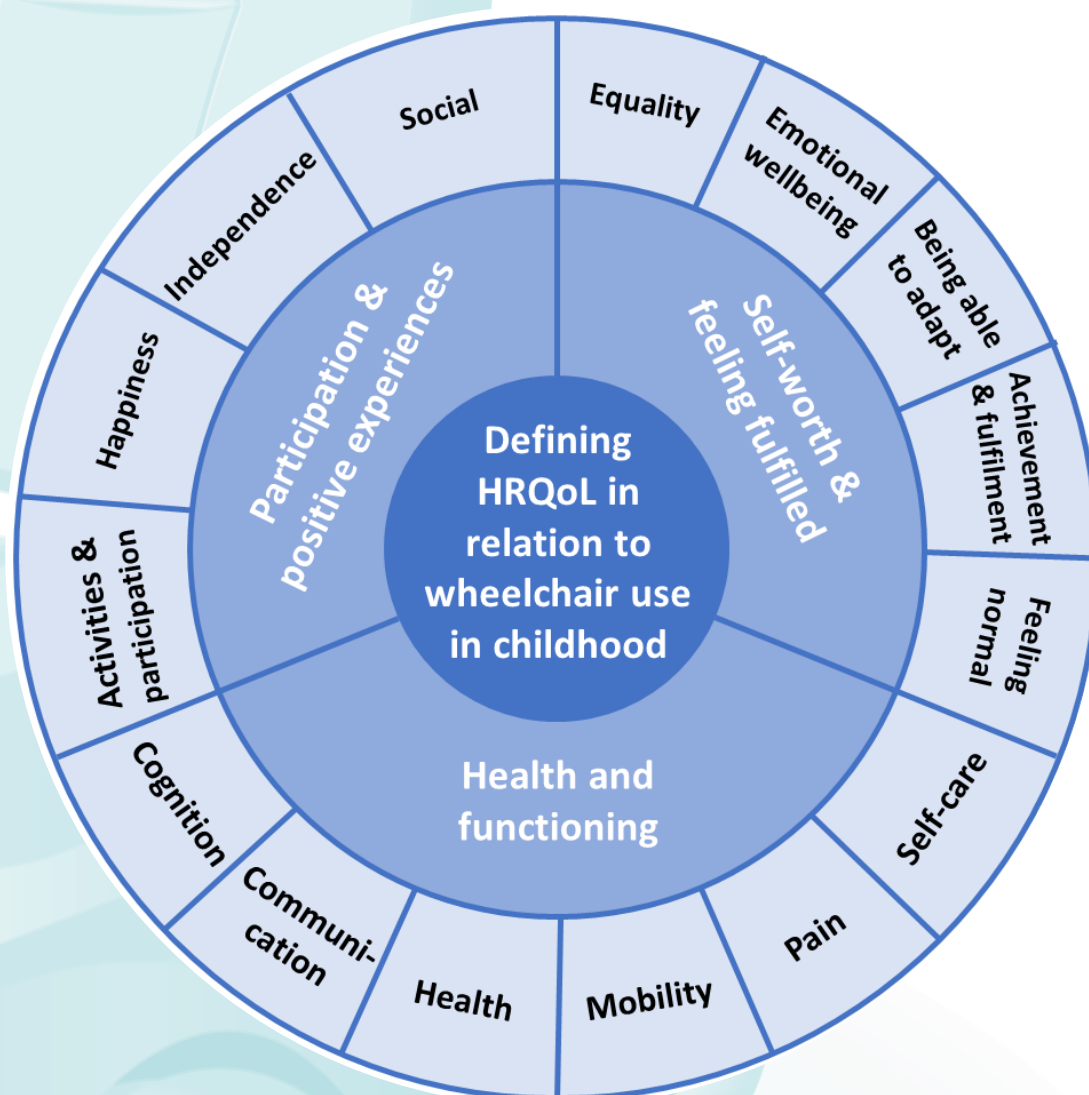


Figure 1: Defining health-related quality of life in relation to wheelchair use in childhood (Bray et al , 2017a)

"The NHS works best when it listens hardest to what is important to patients. I am delighted we are able to support seven organisations across England to work with patients to understand the most important outcomes for children and young people living with such a wide range of conditions and symptoms."

**Tim Kelsey, National Director for Patients and Information
(NHS England, 2015)**

Aim of the project

The overall aim of the project was to develop an outcome measurement tool which could be used to identify and monitor the needs of young wheelchair users (≤ 18 years old) accessing the Shropshire Wheelchair and Posture Service. In order to do so we conducted questionnaire surveys and interviews with young wheelchair users (and/or their parents) in order to understand their opinions about outcomes and wheelchair

provision. This work supports the aims of the 'Right Chair, Right Time, Right Now' campaign in relation to improving outcomes for wheelchair users (Wheelchair Leadership Alliance, 2015; see appendix I), and it is hoped that the project will inform outcomes development work for adults using wheelchair services, and be of relevance to other wheelchair services across the UK and other countries.

Recruitment and sample characteristics

Following receipt of full approval by the Health Research Authority and an NHS ethics committee (REC 17/WA/0078), patients were recruited through the Shropshire Wheelchair and Mobility Service. In June 2017, service staff identified 210 children and young people from their patient database, who had been seen by the service within the past 3 years. Questionnaires and information about the research were sent to parents/carers, or the young person directly if aged 16 or over. Completed questionnaires were returned to researchers at Bangor University, either anonymously or with contact details if respondents consented to further involvement. Respondents were then invited to take part in an interview with one of the research team. Local patient support groups helped by advertising the research through social media.

A total of 21 completed questionnaires were returned. Sixteen respondents consented to be interviewed and 11 interviews took place between July and September 2017, including users from a range of ages, gender and wheelchair usage. See table 1 for sample demographics.

Interviews were planned to include the young wheelchair user and their parent/carer, and in most cases both the mother and user took part. In three interviews, both parents were present for at least part of the interview. Five young people aged 11 or over participated fully in their interviews. In two cases the young wheelchair user was absent due to illness or being in school. Two young wheelchair users were present but were unable to communicate due to their condition, and two younger children were only engaged with the process for part of the interview.

In these, the views expressed were largely those of the parent/carer.

There were various reasons why respondents used wheelchairs; five respondents had a condition affecting their physical and/or neurological development present from birth and which was not expected to improve. In three interviews relating to these respondents, it was noted that the young person attended a special school. Among the respondents stated to be attending state school, two had a degenerative condition diagnosed later in childhood where their need for assisted mobility was likely to increase, and two had a condition causing significant fatigue, which might improve following anticipated surgery. Two respondents did not discuss condition progression at

interview. None required a wheelchair temporarily due to injury.

The initial referral to the Shropshire Wheelchair and Posture Service was by a physiotherapist or occupational therapist in most cases. One respondent was referred following consultation with their General Practitioner (GP) and another by their hospital specialist. Seven respondents described obtaining a wheelchair outside of the NHS. Four mentioned hiring a wheelchair, including through the Red Cross, before realising that assistance was available through the NHS. Three had purchased a wheelchair privately with assistance from a charity or at least partially funded by an NHS voucher. Reasons for private purchase were a perceived lack of choice, or unmet need.

Table 1: Respondent characteristics for children and young people

		Questionnaires (n = 21)		Interviews (n = 11)	
		Mean	Min - Max	Mean	Min - Max
Age (years)		10.14	3 - 17	10.82	5 - 17
		n	%	n	%
Sex	Male	11	52	5	45
	Female	10	48	6	55
No. of wheelchairs	One wheelchair	17	81	8	73
	Two wheelchairs	3	14	2	18
	One pushchair	1	5	1	9
Primary wheelchair	Manual	18	86	8	73
	Powered	2	9	2	18
	Pushchair	1	5	1	9
Frequency of wheelchair use	A little of the time	3	14	1	9
	Some of the time	6	29	3	27
	Most of the time	7	33	5	46
	All of the time	5	24	2	18

DATA COLLECTION

The project used a mixed quantitative and qualitative approach, including questionnaire surveys and semi-structured interviews. The approach was built on previous work conducted by CHEME relating to paediatric wheelchair provision (Bray et al, 2014; Bray et al 2016, Bray et al 2017a, Bray et al 2017b). The questionnaire survey was developed in partnership between the project collaborators. Prior to sending out the questionnaire survey to patients, feedback was sought from the Telford and Wrekin CCG patient engagement team and a small number of young wheelchair users for readability.

The questionnaire survey was designed to collect demographic data such as age and gender, and information about wheelchair use. Respondents were also asked to complete two tasks: rating service aspects and rating outcomes.

Survey task 1: Rating service aspects

In the first task, respondents were asked to rate the importance of eight service aspects, from 1 ('not at all important') to 5 ('extremely important'). These items were based on the 'Wheelchair Charter' proposed by the Wheelchair Leadership Alliance, excluding those items related to staffing and support of services themselves (Wheelchair Leadership Alliance, 2015). The eight service aspects were:

- Future: Services think about what users might need in the future
- Holistic: Services think about all aspects of user's life when supplying a wheelchair (for example home, school and social activities)
- Multiagency: Services work closely with other people involved in users' care (for example school, social services or doctor)
- Partnership: Services work closely with user and parents or carers when assessing needs
- Repairs: Repairs can be done quickly and user is given another wheelchair to use whilst waiting
- Reviews: User is seen regularly by services for review of wheelchair needs
- Training: User receives training on how to use their wheelchair
- Waiting: User does not wait long to get first or new wheelchair once needs have been assessed

Respondents could also list up to five 'other' service aspects that were important to them if they felt that these were not already covered.

Survey task 2: Rating outcomes

In the second task, respondents were asked to rate the importance of 12 aspects of life (i.e. 'outcomes') that a wheelchair could be expected to affect, and which were anticipated to form the basis for the eventual PCOM tool. Respondents were again asked to use a rating scale from 1 ('not at all important') to 5 ('extremely important'). The chosen outcomes in the questionnaire were developed from discussions between the research team and the wheelchair service, and based on work by Bray et al (2017a), who identified 15 ways in which young wheelchair users define health-related quality of life related to mobility impairment (see figure 1). The 12 outcomes were:

- Achieving goals: Helping user to achieve goals and the things that are important to them
- Activities: Helping user to take part in activities and play
- Communication: Helping user to communicate with and interact with people
- Challenges: Helping user to overcome challenges and difficulties in life
- Getting around: Helping user to get around
- Happiness: Helping user to feel happy and less worried and/or sad
- Health: Helping to improve user's overall health
- Independence: Letting user do more without help from other people
- Pain: Helping to reduce user's pain and discomfort
- Self-care: Helping user to perform their personal care tasks (for example getting washed and dressed)
- Social: Helping user to have a better social life
- Society: Helping user to feel part of wider society (for example engaging with people other than family and friends)

Respondents were also given the opportunity to identify up to five 'other' outcomes of importance to them, if they felt there was anything missing from the list. After rating each outcome, respondents were then asked to identify their "top 3" outcomes from the list, and to give a short description of i) what they had hoped their wheelchair would help them achieve; and ii) their actual experience of what their wheelchair helped them to achieve.

Semi-structured interviews were carried out in interviewees' homes and usually lasted 45-60 minutes. An interview schedule was used to guide the interviews. This was designed to build on the questionnaire responses, by probing respondents' experiences of obtaining a wheelchair and asking for more detail about the sections on service attributes and desired outcomes. Once it was established that respondents were able to understand the "top 3" exercise, later interviews also asked interviewees how they felt they would score those outcomes at three time points: i) before ii) just prior to and iii) after wheelchair provision. Interviews were recorded digitally, transcribed verbatim and anonymised.

ANALYSIS & FINDINGS



Key Findings:

- **All pre-specified outcomes on the questionnaire were rated as at least 'important' overall and thus warrant inclusion in the WATCH tool**
- **A small number of other outcomes were spontaneously raised by questionnaire responses and uncovered during the interviews**
- **Children and young adults, or their parents/carers as appropriate, understood the concept of identifying their top outcomes and retrospectively scoring them before and after obtaining their wheelchair**

Data from the questionnaires were reviewed to provide summary statistics on the demographics of questionnaire respondents and also their ratings of the importance of the service aspects and desired outcomes.

In order to analyse the interview transcripts, a 'framework analysis' approach (Ritchie and Spencer, 1994) was undertaken, using the software package NVivo® to organise and synthesise views and experiences into themes. Framework analysis has five key stages: familiarisation, identifying a thematic framework, indexing, charting and mapping/interpretation (Lacey and Luff, 2007). A thematic coding framework was developed in the familiarisation stage, building on the themes identified during the development of the questionnaire, and incorporating new themes as they emerged, until no new themes were identified.

Ranking of service aspects

All scoring levels were used by at least one respondent, illustrating that respondents had a range of views. All service aspects achieved a median score level of at least 'very important', and all were ranked as 'extremely important' by at least one individual. Chart 1 shows their ranking based on the median score and the range.

The two highest ranked service aspects were 'holistic' and 'repairs', which were given a median score of 'extremely important' and a minimum score of 'very important'. 'Training' was ranked lowest of the eight aspects but still achieved a median score of 4 ('very important') overall.

Most 'other' aspects suggested by respondents could be assigned to aspects already listed. Novel service aspects related to the speed of obtaining an appointment and ease of communication with services.

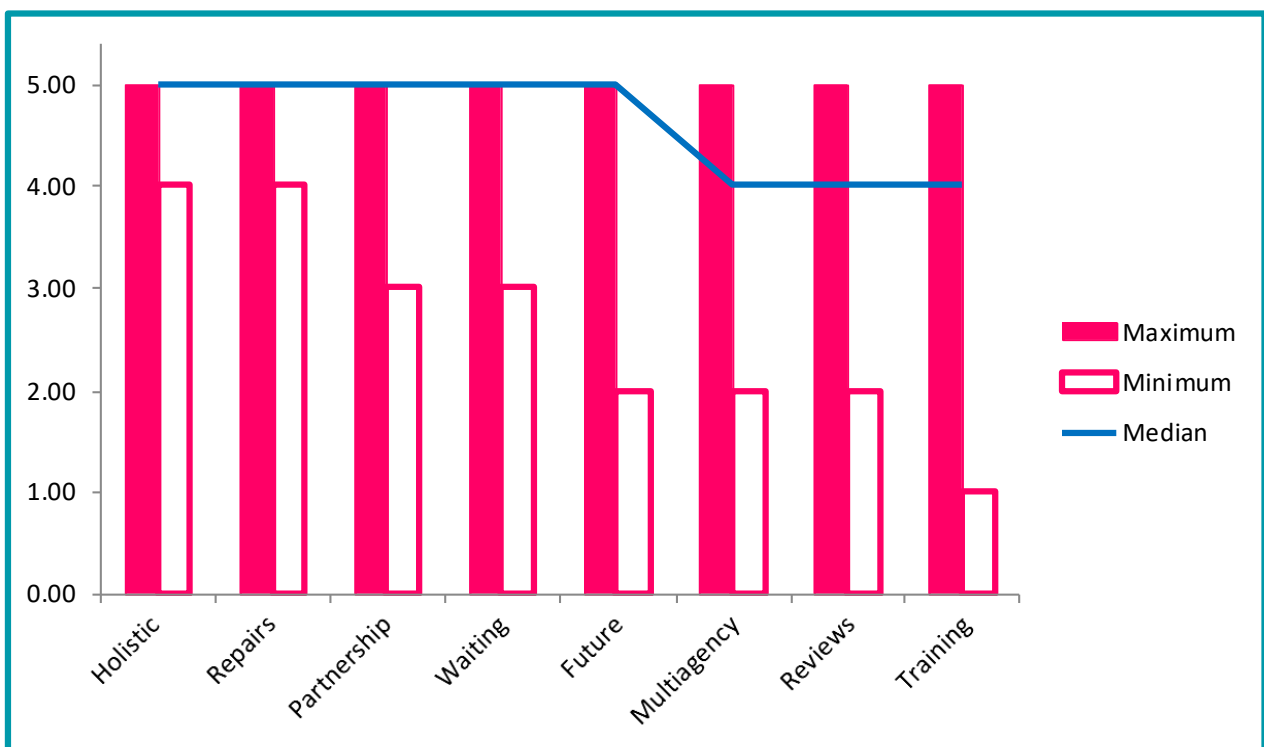


Chart 1: Ranking importance of service aspects (n = 21)

Ranking of outcomes

All scoring levels were used by at least one respondent and all outcomes were ranked as 'extremely important' by at least one respondent. The most important in terms of a median score of 'extremely important' and a minimum score of 'very important' were 'getting around' and 'achieving goals'. Chart 2 presents the relative ranking based on the median score and the range.

'Self-care' was the lowest scoring area with a median score of 'important' and a minimum of 'not important', likely due to the irrelevance of independent self-care in certain age groups or clinical conditions where independent self-care is unlikely. However, as this aspect was considered 'extremely important' by at least one respondent, it was considered that it should remain in the PCOM.

Twelve respondents described 'other' outcomes that they felt were important, but not already listed. In most cases, these related to an aspect already listed, most commonly 'getting around' and 'activities'. Outcomes not considered to be covered by the existing list included:

- Safety: including issues such as lack of a headrest, likelihood of toppling over or steering problems, and also where the wheelchair was being used to enable a child or young person with behavioural issues to go out with the family
- Parent or carer wellbeing: most commonly relating to back problems associated with lifting their child and/or pushing and lifting the wheelchair

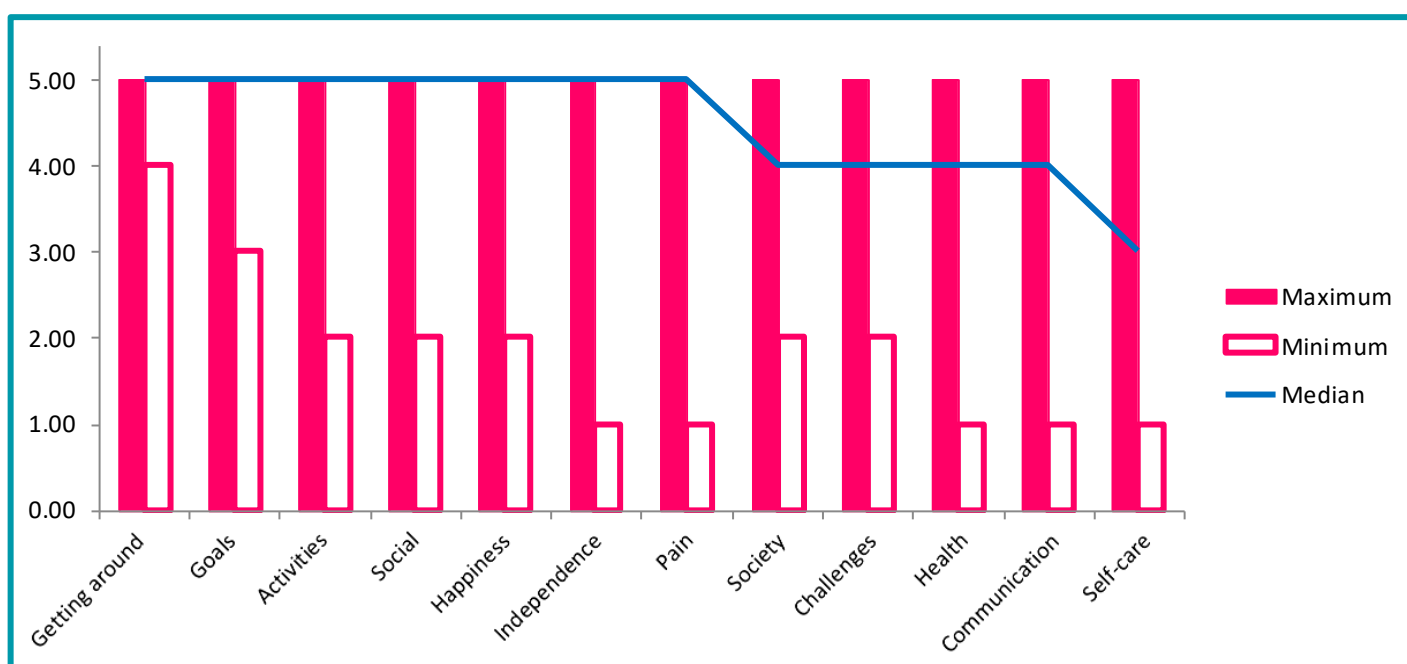


Chart 2: Ranking importance of outcomes (n = 21)

It was envisaged that the WATCH tool would encourage users to identify outcomes that they considered to be of most important to them and to describe what they hoped to achieve. The next part of the questionnaire asked them to select their “top 3” outcomes from the list they had just rated (including any ‘other’ outcomes identified), then to retrospectively describe what they had wanted to achieve with regards to each of their “top 3” outcomes before getting their current wheelchair, and finally to describe the real situation now that they had it.

In terms of assessing ability to understand what was required, only one respondent did not complete this section at all. Sixteen respondents were able to identify their “top 3” outcomes and provide descriptions of what they had hoped for and what was achieved. Three identified and described only one outcome, and one identified their “top 3” but did not provide any details.

The three most commonly cited outcomes, accounting for almost half of respondents’ “top 3” choices, were ‘getting around’, ‘happiness’ and ‘activities’ (see chart 3). As might be expected, ‘self-care’ did not appear in the “top 3” rankings in this small data set, as it had scored lowest in the rankings. Surprisingly, ‘achieving goals’ was also not included in any “top 3”, despite being rated as extremely important overall. Within the ‘other’ outcomes category, three respondents mentioned parent/carer health and wellbeing (in terms of problems lifting the wheelchair user or wheelchair) in their “top 3”.

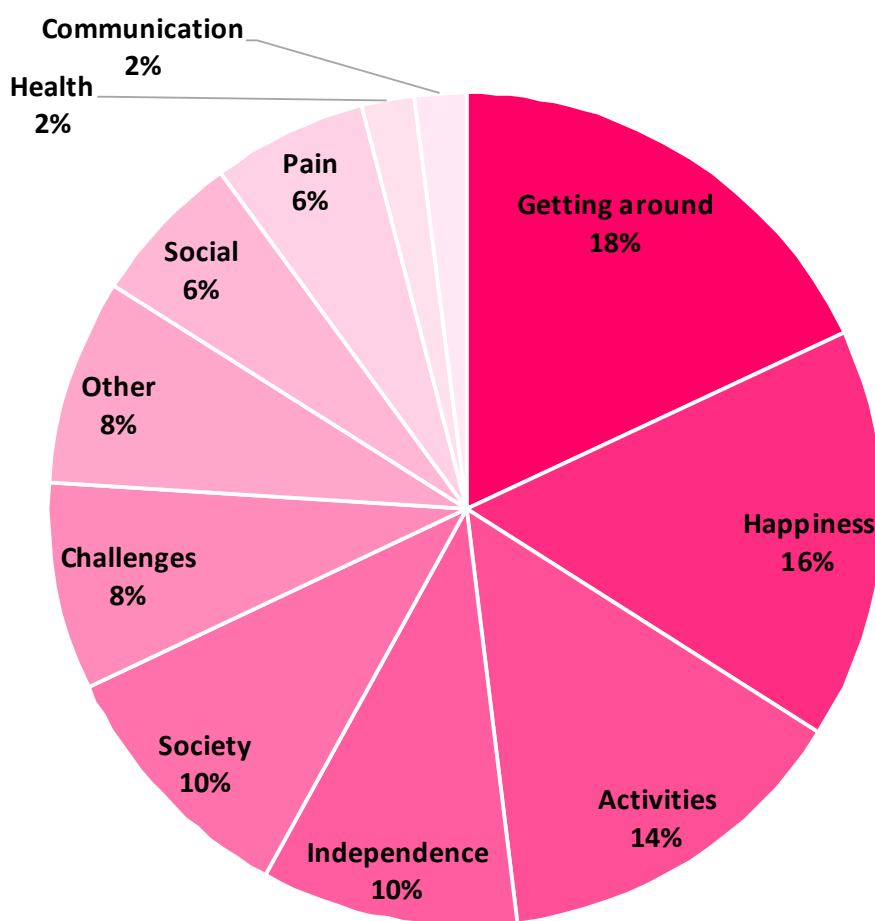


Chart 3: Distribution of “top3” outcomes (n = 50 items by 18 respondents)

Qualitative outcomes

The outcome requirements covered by the questionnaire covered many of the themes discussed during the interviews. Probing respondents' experiences in more depth highlighted the specific reasons for choice of their top outcomes, and also uncovered outcomes of importance which had not been considered explicitly in the questionnaire survey: 'education', 'energy and fatigue', 'parent or carer wellbeing', 'safety' and 'self-esteem and confidence'.

"I find it hard to walk long distances. So I tend to use it at school...Because it's a two-site school and after lessons, I have to walk a lot through the day, and it gets more painful. So I tend to use it for that."

(‘Education’: Male user aged 11-15)

"She knows that she can just go in the wheelchair and it's not going to cause this horrible fatigue. You could just see the weariness on her face, that: 'It's too much for me and I can't do it.' We don't get half of that now. It's just, it's so much better."

(‘Energy and fatigue’: Parent of female user aged 11-15)

"The handles are in the wrong place...Pushing a pushchair, the handles are usually flat or angled, whereas a wheelchair...It's an unnatural position. To be pushing her up hills, because she's quite a weight now, it's very uncomfortable."

(‘Parent or carer wellbeing’: Parent of female user aged 11-15)

"[What] he has done is tipped it over backwards. That's been a bit of a problem."

(‘Safety’: Parent of male user aged 0-5)

"When I'm out with my friends...There would be a point where I would get too tired...And they'd have to push me and I just don't really want that. I'd just rather be able to just go out with them...Would be a different story if I was able to push myself the whole time."

(‘Self-esteem and confidence’: Female user aged 16-18)

Following the interviews, these additional outcomes were added to the prototype WATCH tool. It was decided not to separate mobility inside and outside of the home, as it was felt that this differentiation would be expressed in other outcomes such as 'moving around' and 'activities and fun'. It was agreed to combine 'achieving goals' with 'challenges' in order to avoid too long a list. See appendix II for further examples of qualitative quotes relating to each outcome.

Testing the scoring system

Respondents in eight of the interviews were asked to score their top outcomes in a similar way to that envisaged for final WATCH tool. They were asked to rate out of 10: how they felt before they got their latest wheelchair; how they felt when they were about to get it; and then how they actually felt after using it. Although this task was carried out in retrospect, we wanted to assess how easy it was for users and/or their carers to do this in general, and how they perceived doing this in practice. A rating out of 10 was thought appropriate as used by other measures such as the 'My QuOL-T' (The Health Foundation, 2012).

All respondents understood the process as described by the interviewer. Scores were given by the young wheelchair user or by the parent/carer where the wheelchair user was either too young or unable to score themselves. One young wheelchair user had difficulty in recalling their retrospective status, and thus was unable to provide a score. This should not be an issue in practice, as scoring would be real-time rather than retrospective. As it was felt likely that the tool would cover more than three aspects in actual use, one young wheelchair user was also asked to identify their 4th-6th most important aspects and to score these as well.

Table 2 shows how scoring might be presented, by individual user. All respondents showed some degree of improvement on their top outcomes after receipt of their chair, the vast majority achieving at least 50% of the maximum score of 10 points for each outcome specified. This demonstrated that even among such a small number, a range of levels of satisfaction could be determined using this approach.

Table 2: Retrospective scoring of top outcomes before and after wheelchair provision

Respondent ID	Retrospective*	Anticipated**	Current***	% Max Current****	Current minus Anticipated	Current minus Retrospective
012	15	30	30	100	0	15
015	18.5	30	30	100	0	11.5
016	8	15.5	29	97	13.5	21
008	6	30	24	80	-6	18
007	3	24	19.5	65	-4.5	16.5
014 ¹	NA	30	15.5	52	-14.5	NA
005 ²	0	10	5	50	-5	5
018	0	30	5	17	-25	5

* Estimated outcome score before receiving most recent wheelchair

** Outcome score respondent hoped to achieve before receiving most recent wheelchair

*** Actual outcome score at present (i.e. after provision of most recent wheelchair)

**** Current total outcome score compared to maximum possible score of 30

¹ Respondent did not score Retrospective outcomes

² Respondent only selected one outcome, maximum total score is therefore 10

Prototype development and piloting

A prototype of the WATCH tool was produced, based on the findings of the research and with revisions suggested by the service team, the Telford and Wrekin CCG Patient Engagement Lead for readability and attendees at a West Midlands wheelchair managers meeting. For the prototype tool, it was decided that respondents should select their “top 5” outcomes, rather than “top 3”, and the wording of some of the outcomes was amended (for example, ‘health’ was changed to ‘managing your condition’).

The research team piloted the prototype WATCH tool with three questionnaire respondents, to obtain feedback on ease of use and suggestions for improvement. Members of the wheelchair services team also provided feedback on use with 19 young wheelchair users and their parents attending clinic appointments. Table 3 shows outcomes by count of inclusion in users’ “top 5” outcomes. All but two of the pre-specified outcomes were selected by at least one respondent within their “top 5”, highlighting the range of individual preferences among service users. All satisfaction scores (ranging from ‘very satisfied’ to ‘very dissatisfied’) were used by at least one respondent, thus the prototype tool measured both well-met and unmet needs.

The prototype tool was confirmed to be straightforward to use by the majority of service staff involved in the pilot, and positive feedback included the ability to record patient requirements and expectations, and to encourage discussion.

Table 3: Outcomes ranked by inclusion in Top 5 (pilot data)

	No. of times chosen in “top 5”	% of respondents (n = 21)	% of all “top 5” choices (n = 101)	Median satisfaction*	Mean satisfaction*
Activities and fun	13	62	13	3	2.85
Moving around	11	52	11	3	2.80
Education	11	52	11	3	3.20
Social life	10	48	10	3	3.00
Pain and discomfort	10	48	10	3	3.10
Safety	9	43	9	3	3.25
Energy and fatigue	9	43	9	2	2.22
Managing your condition	8	38	8	2.5	2.63
Independence	6	29	6	3	2.60
Happiness	5	24	5	3	3.00
Parent or carer wellbeing	4	19	4	3.5	3.25
Feeling included	3	14	3	3	2.67
Self-esteem and confidence	1	5	1	4	4.00
Achievement and goals	1	5	1	4	4.00
Self-care	0	0	0	0	0
Communication	0	0	0	0	0
Other	0	0	0	0	0

* Based on a scoring system from 1 (Very Dissatisfied) to 5 (Very Satisfied)

The final WATCH tool

Following the pilot, the prototype WATCH tool was further refined, including some additional changes to the wording of outcomes (see appendix II for all changes). The final WATCH tool (presented in appendix III) consists of an Assessment form (Part A/B), a Follow-up form (Part C) and an Assessor Information sheet. Part A of the Assessment Form lists 16 outcomes of potential importance to young wheelchair users, derived from the questionnaire survey and interview findings, as piloted. When completing Part A, respondents are asked to select the “top 5” outcomes that they consider to be of most importance and relevance to them. There is space for users to add an outcome if they feel that a crucial outcome is not listed.

In Part B of the WATCH tool, for each of their identified “top 5” outcomes, respondents are asked to give an example of what they want to achieve in each outcome. For instance, for the ‘activities and fun’ outcome they may indicate that they would like to play more sports or start a new hobby. Respondents are then asked to rate their current satisfaction level with each outcome, on a 5-point scale from ‘very dissatisfied’ to ‘very satisfied’, with smiley faces to help younger children to understand the concept. Thus the maximum satisfaction score possible would be 25. A five-point, rather than 10-point scoring system was chosen to simplify the WATCH tool and is in line with other measures such as the EQ-5D-5L score (Janssen et al, 2013) and the Child Health Questionnaire (Nugent et al, 2001).

It is intended that the WATCH tool would be used by service staff at the assessment visit for obtaining a new wheelchair. These scores and information would be transferred to the patient’s records. Users will then be followed up three to six months after receiving their new chair and asked to complete Part C of the tool which will list the “top 5” outcomes selected at assessment, and they will be asked to rate their outcome satisfaction having had their new chair for some time. The follow-up need not need to be completed face-to-face but could be by telephone or as a postal/email survey, for example.

The WATCH tool allows individual patient scores at assessment and follow-up to be compared to assess whether (and to what extent) each outcome has improved after receiving a new wheelchair, and also whether the wheelchair has met the user expectations. The scoring could also be reviewed across all users for each outcome assessed in a specific time period, to see the level to which specific outcomes are being achieved across the service. Use of the WATCH tool will be reviewed to assess feedback on its utility from staff and users, with a view to further revision of the WATCH tool and its implementation, if necessary. An electronic version of the tool is available on the WATCH webpage: cheme.bangor.ac.uk/watch

Bangor University will be preparing a journal article for publication, and a one-page summary of the findings will be sent to study participants.

Potential applications

The WATCH tool will allow wheelchair users across a wide range of ages and clinical needs to select outcomes of most importance to them and to describe to staff what they hope to achieve for each one. The use of a pre-defined outcome list allows a certain degree of comparability across patients, and ensures that patients focus on achievable outcomes. The simple before and after scoring system should allow service providers to ascertain the extent to which desired outcomes are being achieved, both for individual users and for a specific outcome across service users.

The tool should be applicable to children and young people accessing wheelchair services in other areas. It also has the potential for development for use with adult users of such services. In addition, the methods used to develop the WATCH tool are applicable to the development of PCOMs in other service areas. Formal costing and quality of life measurements were not feasible within this study, but the findings should help support work that addresses cost-effectiveness in the future.

Limitations

The low response to the initial postal survey meant that the number of users able to provide input to the initial development of the tool within the timeframe was lower than hoped for. However, the outcomes initially proposed were developed from previous work on wheelchair users' needs, particularly that by Bray et al (2017a) among young wheelchair users. In addition, a further 19 users and their families were exposed to the WATCH tool at the pilot stage.

The work was aimed at users of one particular NHS service provider and services in other locations may wish to review for their own use. The WATCH tool is currently only available in English and further work may be needed to test translations.

Conclusions

The project achieved the aim of developing a novel patient-centred outcome measure, the WATCH tool, suitable for use with young wheelchair users. In addition to improving the quality of service provided to young wheelchair users and their parents/carers, the tool and the methods used to develop it could inform the design of new PCOM tools in other service areas.

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APPENDICES

Appendix I: Wheelchair Leadership Alliance Wheelchair Charter (2015)

Appendix II: Example quotations for outcomes

Appendix III: WATCH Tool

Appendix IIIa: WATCH information for assessors

Appendix IIIb: WATCH assessment form

Appendix IIIc: WATCH follow-up form

RIGHT CHAIR RIGHT TIME WHEELCHAIR CHARTER



It is estimated that 2% of our population use wheelchairs to get to work, go to school, buy their groceries, look after their children, contribute to our society and achieve their goals. Sadly many of them don't fulfil their aspirations because the current wheelchair services fail to meet their needs.

Currently we see great variation in ability to access assessment and obtain service provision, delays in repairs and equipment, poorly thought through provision plans and patient pathways, confusing information, restrictive and inflexible funding and minimal integration of services.

And throughout all of this are the service users struggling to carve out the kind of lives they would wish to lead.

As a group, the Wheelchair Leadership Alliance has committed to make the kind of changes that will truly improve the lives of these service users and their families. But we cannot do this alone - we need your help.

By signing up to this charter as service users, providers, voluntary sector organisations, commissioners, clinicians and members of the public we will together be able to start the change and commit to better services and an improved quality of life for every wheelchair user.

By signing this charter you are pledging to support the development of an NHS wheelchair service that can really deliver a fair and effective service for all people who need to use it.

We pledge our commitment to:

- 1 A person centred service that works in partnership with service users and their carers and makes the user/carer voice central to any design, innovation and service change.
- 2 Equality of access and provision for all, irrespective of age or postcode and including essential user skills training as standard.
- 3 Entry to service via referral from an appropriately skilled professional. The time from referral to delivery will be at least within the constitutional right of 18 weeks with further substantial improvements by 2016/17 for all people using the service.
- 4 Assessments for all wheelchairs and associated postural support within nationally mandated timescales and priorities taking into account all aspects of individual needs including those of carers.
- 5 Establishing regular reviews with the user/carer according to their individual needs.
- 6 Prescriptions which take into account the current and future needs for all adults and children including those of carers.
- 7 Delivery, maintenance and emergency backup provided to nationally mandated timescales.
- 8 Innovative and flexible budgeting working with key partners to strengthen integration across health, social care, work and education, enabling the accommodation of individual needs, independence health and wellbeing.
- 9 Recruitment of qualified staff in respect of numbers and skills, with support for on-going development and training.
- 10 Supporting clinicians, manufacturers and independent organisations working together to develop innovative, affordable products and solutions.

Signature:

Representing:

Date:



Appendix II: Example quotations for outcomes

Achievement and goals (combination of 'challenges' and 'achieving goals')

"Well, I feel it's important to overcome. Because without her wheelchair, she wouldn't be able to go out and do anything, so everything would be a challenge and a difficulty."

~

"I'm really into photography...I used to go on loads of walks and take loads of photo. Now we can go on walks in the wheelchair and it means I can still go on walks and take photos."

~

"...And you're going to be doing your Duke of Edinburgh so your wheelchair is going to come in very useful for that, for things like the expedition."

Activities and fun (formerly titled 'activities')

"With my wheelchair I am give [sic] an outside life in school holidays to enjoy the sunshine when we have some. As I can't walk far as my legs hurt or I collapse."

~

"I took him to Disneyland Paris...[he] had a wheelchair seat and he was able to stay in the buggy on the Eurostar. Without the buggy, he'd have never managed to go there at all. It would never have been possible."

~

"The chair just enables her to not be stopped from doing things."

Communication (formerly titled 'communicate')

P: It's helped you do more face-to-face things, hasn't it?

C: Yeah, it has.

P: Before, she could only communicate online. But you could communicate, with the wheelchair, face-to-face."

~

"We'd only been here two or three days and he went outside in his electric wheelchair, he went down to the bottom, there, and started talking to the neighbour next-door, went over right to the fence ... So it's great because he can just go and do those things."

Education

"I definitely wanted to go to college in a wheelchair...And I wanted as much independence as I possibly could get out from it."

~

"I find it hard to walk long distances. So I tend to use it at school...Because it's a two-site school and after lessons, I have to walk a lot through the day, and it gets more painful. So I tend to use it for that."

Energy and fatigue

“She knows that she can just go in the wheelchair and it’s not going to cause this horrible fatigue. You could just see the weariness on her face, that: ‘It’s too much for me and I can’t do it.’ We don’t get half of that now. It’s just, it’s so much better.”

~

“He self-propels himself and he’s got quite significant heart defects, so he gets tired really quickly. He can do it for three, four strides, then that’s too much.”

Feeling included (formerly titled ‘society’)

“The whole school do the Race for Life at the end of July so [he] does his in his wheelchair... so it means that he is no different to the rest of his peer group.”

~

“Parent [P]: [She] has had issues with people saying she’s faking it, because they don’t understand the condition that one minute she could be ok, the next minute she can be really quite poorly with it.

C: And students thinking that our family as a whole or anyone with our condition is faking it.”

Happiness

“She was very pleased. She came out beaming, smiling...It was more grown up for her...She was smiling all the way out of the building really.”

~

Researcher [R]: Thinking back to before getting a wheelchair, how would you rate feeling happy?

Child/young person [C]: Probably about a four.

R: And now?

C: About ten.”

Independence

“[Before having a wheelchair] I didn’t really have any independence because [parent] just moved me everywhere, really.”

~

“I’ve got Lupus and I can’t push her very far unless it’s on flat. The idea was, she had independence, she could maybe go to college. But she hasn’t got any independence at all.”

Managing your condition (formerly titled 'health')

"We've done loads of different trips...There's no way I would be able to take him anywhere without a pushchair. Plus, when he's in a PEG feed, he needs to be strapped in so that I can do a PEG feed."

~

"The discomfort comes with the breathing, doesn't it? Not being able to breathe and the tiredness. She's got problems with her back, now, which we need to go to the doctors about today. So, having the wheelchair helps with that."

Moving around (formerly titled 'getting around')

"He can't get around without [wheelchair]."

~

"[I] couldn't get around the house properly. Now I could go and sit by the back door. So it helps in the house and out."

~

"She wouldn't do half of what she does without that wheelchair. She would basically be housebound a lot of the time."

Pain and discomfort (formerly titled 'pain')

"Without it, at some point, I wouldn't have been able to go out with the family, really, because I'd just be in constant pain with my ribs and my hips. And my knees. It's all the knock-on effect, isn't it?"

~

"She had a plastic back brace fitted which pushed her forward. So to me, she wasn't sitting as comfortably in it as she could have been, until it was adjusted. That's my biggest bugbear is when you need an appointment, you need it pretty quickly and you shouldn't have to be waiting."

Parent or carer wellbeing

"Not hurt mummy/daddy's backs to carry me"

~

"P: If I'm having a bad day, we have to stay in the house because I can't take the weight of your wheelchair.

C: Yeah, because it's a lot. It's heavy."

~

"The handles are in the wrong place...Pushing a pushchair, the handles are usually flat or angled, whereas a wheelchair...It's an unnatural position. To be pushing her up hills, because she's quite a weight now, it's very uncomfortable."

Safety

"[What] he has done is tipped it over backwards. That's been a bit of a problem."

~

"And on one particular occasion, [her] gentleman who used to bring her home, he didn't quite do it properly...And it went back and [she] hit her head on the concrete and we had a little trip to A&E. Luckily, it was just a cut. "

~

"I use it mainly in busy areas, where there's risk with traffic. Because he hasn't got any sense of danger so he would run into the road and things like that."

Self-care

"Helping you to look after yourself, for example, get washed...That's not relevant because I clean him."

~

"If he's in his chair, he can get to the toilet...Which makes things easier."

Self-esteem and confidence

"He'd had a few comments from his friends and as soon as that happened, [he] wasn't coming to school and that had a knock-on effect to his health. So, how the wheelchair looks is a big deal."

~

"When I'm out with my friends...There would be a point where I would get too tired...And they'd have to push me and I just don't really want that. I'd just rather be able to just go out with them...Would be a different story if I was able to push myself the whole time."

Social life (formerly titled 'social')

"I was very, very pleased because with the manual [wheelchair]... I didn't have much of a good relationship with my friends."

~

"There is an indirect benefit to her social life, in that if she uses the wheelchair to do certain activities, she's not too tired, then, to be able to meet up with her friends. Whilst she doesn't use it directly with her friends, she doesn't waste her energy doing other things."

WATCh

(Wheelchair outcomes Assessment Tool for Children)

Information for assessors and clinical staff

The aim of this form is to find out the aspects of life most important to the child or young adult who is receiving a wheelchair.

It should be completed at the assessment visit and the results kept with the patient records. It is intended that the user will be contacted again three to six months after receiving their chair, and asked to complete Part C (a follow-up survey) to see if the patient has experienced any positive or negative changes to their life.

This process should help us improve our services by making sure we focus on users' key needs.

The form should be completed as far as possible by the child or young adult themselves, but in some circumstances they may need assistance from their parent/carer or yourself. Parents/carers are also allowed to complete this form on behalf of their child when the child is unable to do it themselves. We would suggest that you talk through the items in Part A with the user, and encourage them to describe what they want to achieve in Part B.

When sending out the Part C follow-up survey to a patient please ensure that the patient's previous 'top 5' from Part A/Part B have been transferred on to Part C.

An example of how the form should be filled out is presented on the next page.

Example of how to complete Part A

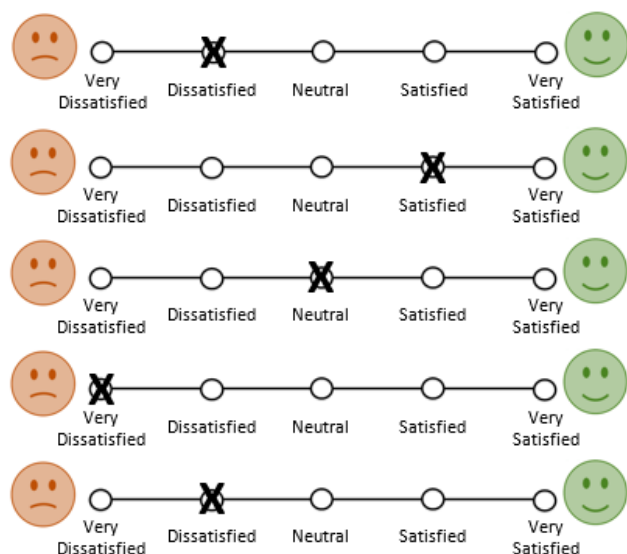
Area of your life	How your wheelchair could help	Top 5
1. Activities and fun	Help you to take part in activities and fun	✓
2. Independence	Help you to do more without help from other people	
3. Social life	Help you to spend time with your friends and family	
4. Moving around	Help you to get around inside and outside of the house	✓
5. Pain and discomfort	Help to reduce your pain or discomfort related to posture	
6. Self-care	Help you to wash and dress yourself	
7. Feeling included	Help you to feel part of wider society	
8. Managing your condition	Help to manage your condition and avoid health problems	✓
9. Communication	Help you to communicate and interact with others	
10. Education	Help you to go to school and learn	
11. Happiness	Help you to feel happy and free from worry	✓
12. Safety	Help you to feel safe and secure	
13. Parent or carer wellbeing	Help your parent or carer to stay happy and healthy	
14. Self-esteem and confidence	Help you to feel more self-confident	
15. Energy and fatigue	Help you to feel more energetic and less tired	✓
16. Achievement and goals	Help you to achieve the things that are important to you	

Patient ticks their top FIVE areas

Example of how to complete Part B/Part C

Top 5 (in order)	Area	What you want to achieve or feel
1 (most important)	Energy and fatigue (no.15)	Feel less tired when using my wheelchair
2	Moving around (no.4)	Be able to move around school by myself
3	Happiness (no.11)	Feel less worried and upset
4	Activities and fun (no.1)	Be able to go to the shops with friends
5 (less important)	Pain and discomfort (no.8)	Improve my posture and reduce pain

How satisfied or happy you are with this area of your life



Answers transferred from Part A

WATCH Assessment Form

(Wheelchair outcomes Assessment Tool for Children)

Information for wheelchair users and parents/carers

We are using this form as part of your assessment, to help us to find out what goals you have in relation to your new wheelchair. The form has two parts:

- Part A lists some areas of your life which your wheelchair might be able to help you with. Please decide which are the **FIVE** most important areas to you
- Part B then asks you to score how satisfied or happy you are now with each of the top **FIVE** areas you chose in Part A

Once you've had your new wheelchair for a few months, we will ask you to score your top five list again to see if there has been any improvements. If you have any questions about the form, or problems filling it in, please let the person doing your assessment know. See below for an example of how to complete this form.

Example of how to complete Part A

Area of your life	How your wheelchair could help	Top 5
1. Activities and fun	Help you to take part in activities and fun	<input checked="" type="checkbox"/>
2. Independence	Help you to do more without help from other people	<input type="checkbox"/>
3. Social life	Help you to spend time with your friends and family	<input type="checkbox"/>
4. Moving around	Help you to get around inside and outside of the house	<input checked="" type="checkbox"/>
5. Pain and discomfort	Help to reduce your pain or discomfort related to posture	<input type="checkbox"/>
6. Self-care	Help you to wash and dress yourself	<input type="checkbox"/>
7. Feeling included	Help you to feel part of wider society	<input type="checkbox"/>
8. Managing your condition	Help to manage your condition and avoid health problems	<input checked="" type="checkbox"/>

Tick your top FIVE areas

Example of how to complete Part B

Top 5 (in order)	Area	What you want to achieve or feel	How satisfied or happy you are with this area of your life
1 (most important)	Energy and fatigue (no.15)	Feel less tired when using my wheelchair	
2	Moving around (no.4)	Be able to move around school by myself	
3	Happiness (no.11)	Feel less worried and upset	
4	Activities and fun (no.1)	Be able to go to the shops with friends	
5	Pain and discomfort (no.8)	Improve my posture and reduce pain	

Transfer answers from Part A

Patient name: _____ DOB: ____ / ____ / ____ NHS No.: _____

Assessor: _____ Date: ____ / ____ / ____

Completed by: (please tick) Patient Parent/Carer Assessor

PART A

Below are a list of different areas of your life which your new wheelchair could make a difference to. Please look at this list and place a tick in the box next to the top 5 most important areas for you. Please make sure you only chose FIVE areas. If there's something missing from the list, you can write it in the space at the bottom.

Area of your life	How your wheelchair could help	Top 5
1. Activities and fun	Help you to take part in activities and fun	
2. Independence	Help you to do more without help from other people	
3. Social life	Help you to spend time with your friends and family	
4. Moving around	Help you to get around inside and outside of the house	
5. Pain and discomfort	Help to reduce your pain or discomfort related to posture	
6. Self-care	Help you to wash and dress yourself	
7. Feeling included	Help you to feel part of wider society	
8. Managing your condition	Help to manage your condition and avoid health problems	
9. Communication	Help you to communicate and interact with others	
10. Education	Help you to go to school and learn	
11. Happiness	Help you to feel happy and free from worry	
12. Safety	Help you to feel safe and secure	
13. Parent or carer wellbeing	Help your parent or carer to stay happy and healthy	
14. Self-esteem and confidence	Help you to feel more self-confident	
15. Energy and fatigue	Help you to feel more energetic and less tired	
16. Achievement and goals	Help you to achieve the things that are important to you	
17. Anything else? Please tell us here:		

Patient name: _____ DOB: ____/____/____ NHS No.: _____

Assessor: _____ Date: ____/____/____

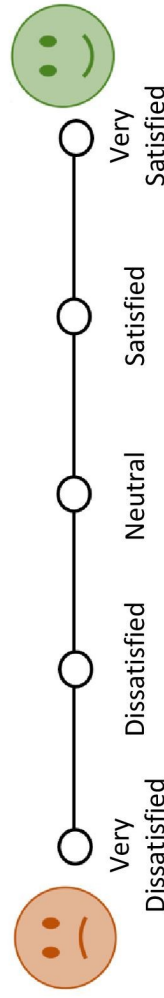
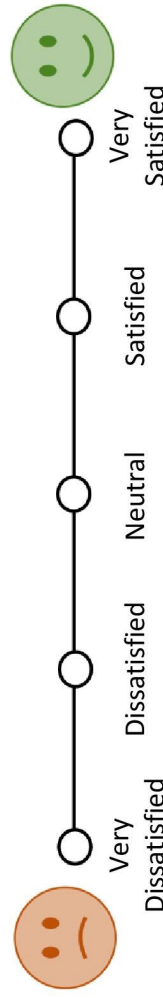
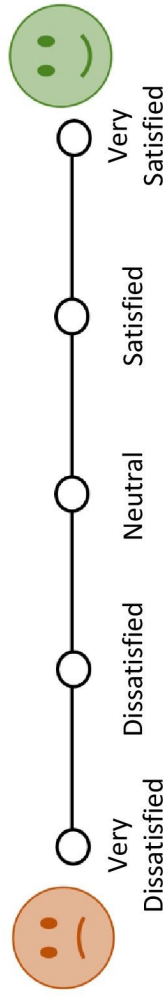
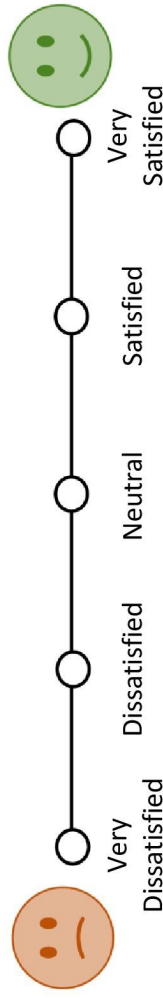
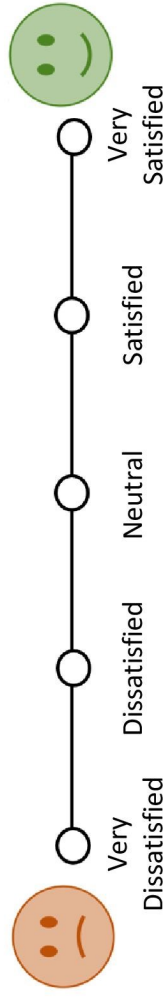
PART B

In the boxes below, please write your top 5 areas from Part A in the order of their importance. You can also add a bit more information about what you want to achieve. So, if you chose 'activities and fun' in your top 5, you could say what you want to achieve, like starting a new sport or hobby.

Please then rate how satisfied or happy you are now with your experience of the 5 areas, on a scale from 'very dissatisfied' to 'very satisfied'. For instance, if you aren't happy with how much pain you have at the moment, you might tick 'dissatisfied'.

Top 5 (in order)	Area	What you want to achieve or feel
1 (most important)		
2		
3		
4		
5		

How satisfied or happy you are with this area of your life



WATCh Follow-up Form

(Wheelchair outcomes Assessment Tool for Children)

Information for wheelchair users and parents/carers

You may remember that we gave you a form to complete before you got your new wheelchair, to help us find out what goals you had in relation to your new wheelchair.

In Part B of the form we asked you to tell us a bit more about the 'Top 5' most important areas of your life and to score how satisfied or happy you were with them before getting your new wheelchair.

Now you have had your wheelchair for a little while, we would like you to score these 'Top 5' again to see if your new wheelchair has helped.

If you have any questions about the questionnaire, or need help filling it in, please speak to your therapist or clinical team.

Patient name: _____ DOB: _____ / _____ / _____ NHS No.: _____

Assessor: _____ Date: _____ / _____ / _____

PART C Follow up

Below are the top 5 areas you chose when you filled in the questionnaire at your assessment. Now that you have had your wheelchair for a little while, please rate how satisfied or happy you are now with these 5 areas, on a scale from 'very dissatisfied' to 'very satisfied'. For instance, if you aren't happy with how much pain you have at the moment, you might tick 'dissatisfied'.

Top 5 (in order)	Area	What you wanted to achieve or feel
1 (most important)		
2		
3		
4		
5		

How satisfied or happy you are with this area of your life

Five horizontal Likert scales are provided, each with five tick marks and corresponding labels: 'Very Dissatisfied', 'Dissatisfied', 'Neutral', 'Satisfied', and 'Very Satisfied'. The scales are accompanied by sad face icons on the left and happy face icons on the right.

About the authors

Dr Nathan Bray

Nathan is a Research Officer for Bangor University's Centre for Health Economics and Medicines Evaluation. He studied Psychology at the University of Liverpool and has a Masters degree in Public Health and Health Promotion from Bangor University. In 2015 Nathan completed a NISCHR funded PhD Studentship in Health Economics. His Doctoral research applied methods of economic evaluation to assistive mobility technologies for children with disabilities. His current research primarily focuses on applying methods of economic evaluation to disability and assistive technology. In 2016 he was awarded a post-doctoral fellowship by Health and Care Research Wales. Nathan's fellowship research project, called MobQoL, will use qualitative and quantitative research methods to develop a new preference-based instrument for measuring the quality of life of people who use wheelchairs and mobility aids. Nathan is also leading an NIHR funded evidence synthesis project to examine the cost-effectiveness of powered mobility provision for very young children.

Dr Lorna Tuersley

Lorna is a Research Officer in Health Economics at the Centre for Health Economics and Medicines Evaluation at Bangor University. Her particular fields of interest are patient preference and healthcare information communication. A pharmacist, Lorna gained her BPharm at Cardiff University, with experience in hospital pharmacy followed by medical/marketing research roles in the pharmaceutical industry. She undertook a PhD in healthcare information seeking for self-care from the University of Manchester, where she subsequently coordinated input to the PINCER trial of pharmacist-led intervention to reduce prescribing errors. She joined CHEME in 2014 working on projects relating to prescribing practice and medicines adherence, and is currently working with Professor Rhiannon Tudor Edwards and Dr Nathan Bray on projects assessing patient-centred outcome measures and quality of life among wheelchair users.

Professor Rhiannon Tudor Edwards

Rhiannon is Professor of Health Economics and Co-Director of the Centre for Health Economics and Medicines Evaluation at Bangor University. She is a graduate of the University of Wales, Aberystwyth; University of Calgary, Canada; and the University of York. Rhiannon was a Commonwealth Fund Harkness Fellow in Health Policy, visiting the United States in 2004-2005. She is a Health and Care Research Wales Senior Investigator, Fellow of the Learned Society of Wales and Honorary Member of the Faculty of Public Health. Rhiannon is Director of the Welsh Health Economics Support Service (WHESS), integral to health and social care research in Wales. She has a particular interest in the methodology of economic evaluation alongside trials of public health and psychosocial interventions.



Canolfan Economeg Iechyd a Gwerthuso Meddyginiaethau

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