Testing the Reliability and Validity of the Therapy Outcome Measure for AAC

Funded by NHS Education for Scotland

Final Report

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NHS Education for Scotland: Report Introduction

In June 2012 the Scottish Government published "A Right to Speak: Supporting Individuals who use Augmentative and Alternative Communication". This report outlined a vision for Scotland as a place where:

"Individuals who use augmentative and alternative communication (AAC) are included, free from discrimination, and live in an environment that recognises their needs and adapts accordingly" (Scottish Government, 2012: 10)

In order to achieve this vision eight recommendations were made, each of which is about something that needs to happen to help make sure that people who use AAC can:

· Be fully included in society
· Have equal access to AAC services
· Get access to AAC equipment when they need it

NHS Education for Scotland (NES) was identified as a key partner in facilitating the delivery of the education, training and development aspects of the report. As such, NES was responsible for commissioning a range of projects which contribute to the delivery of the recommendations contained in the report. In 2012-13 NES commissioned four projects – one of which focussed on outcome measurement. Building on the results of this work, the project described in this document (which was commissioned across 2013-14 and 2014-15) sought to establish the validity and reliability of a specific resource – the AAC TOM.

In this, the final year of the project (2014-15) NES will work to support practitioners with translating the results of this project into their practice.

October 2014

Executive Summary

Background:
In June 2012 the Scottish Government published "A Right to Speak" (Scottish Government 2012), which provided guidance for people who use Augmentative and Alternative Communication (AAC). The guidance included eight recommendations. The first two are relevant to this project:

- *AAC services to demonstrate the effectiveness of AAC interventions by promoting the implementation of AAC research on specific, targeted and universal AAC interventions.*
- *National statistics on AAC to be gathered by relevant agencies to support future gathering of cost effectiveness data on AAC to ensure that AAC funding is sustained in the longer term.*

In response to the guidance, NHS Education for Scotland (NES) commissioned a project to critically appraise existing methods of measuring outcomes for use in AAC (NES 2013). The results of this project showed that no standardised outcome measure exists for use with people who use AAC and it was recommended that the use of an adapted version of Therapy Outcome Measure (TOM), a standardised, well respected Outcome Measure, (Enderby et al 2006) should be investigated.

Aim:
This project, funded by NES, tested the validity and reliability 'Therapy Outcome Measure for AAC' (TOM AAC).

Methods:

- Training of AAC professionals in use of TOM AAC
- Questionnaire identifying issues of importance for establishing validity for this population
- Focus groups to refine descriptors
- Development of case histories
- Reliability trial
- Analysis of results using Intraclass Correlation Coefficient (ICC)

Results:
Questionnaire:

- the descriptors were appropriate and relevant
- there was a good understanding of the domains of impairment, activity, participation and well-being
- the measure was quick and easy to use

Focus groups:

- Strong agreement that this was a useful measure
- Issues around wording of the impairment section led to redrafting the impairment (communication) domain

Reliability:

- Agreement was highest for physical impairment (0.887), comprehension (0.831) and wellbeing (0.816) and lowest for expression (0.486)

Conclusion
TOM-AAC is valid, reliable and appropriate for capturing information on outcomes associated with AAC services. One section has been amended and retested to improve reliability.

Background

In June 2012 the Scottish Government published "A Right to Speak" (Scottish Government 2012), a document which provides guidance for people who use Augmentative and Alternative Communication (AAC), which refers to methods which people use to support or replace spoken communication: ISAAC https://www.isaac-online.org/english/what-is-aac/).The guidance, which is aimed at service users, carers and professionals, includes eight recommendations. The first two are relevant to this project:

1. AAC services to demonstrate the effectiveness of AAC interventions by promoting the implementation of AAC research on specific, targeted and universal AAC interventions.

2. National statistics on AAC to be gathered by relevant agencies to support future gathering of cost effectiveness data on AAC to ensure that AAC funding is sustained in the longer term.

In response to the guidance, NHS Education for Scotland (NES) commissioned a project to critically appraise existing methods of measuring outcomes for use in AAC (NES 2013). The results of this project showed that currently, no standardised outcome measure exists for use with people who use AAC and it was recommended that the use of an adapted version of Professor Pam Enderby's Therapy Outcome Measure (TOM), a standardised, well respected Outcome Measure, (Enderby et al 2006) should be investigated. Prior to this project, the necessary adaptation to TOMs for AAC had not been finalised or tested for validity and reliability. NES commissioned Talking Mats and Professor Pam Enderby to undertake a project to test the reliability and validity of TOM AAC.

Description of TOM AAC

TOM is an outcome measure used by many rehabilitation professionals to measure the impact of their interventions. It is based on the World Health Organisation's International Classification of Functioning, Disability and Health (WHO ICF, 2001). TOMs is administered following assessment/intervention of an individual by a professional. They rate individuals using an 11 point ordinal scale with 6 defined points. People are rated in relation to four descriptors: Impairment, Activity, Participation and Well-being. Prior to this project, Professor Enderby had drafted descriptors for use with an adults and children who use AAC. These draft descriptors were the starting point for this project (Appendix 1).

Aims:

This was a two stage project which aimed to:

1. Test TOM AAC for face validity with a group of AAC professionals
2. Test TOM AAC for inter rater reliability between AAC professionals

We report on the methods and findings for each stage and then discuss implications for practice and future use of TOM AAC.

Recruitment

In order to test TOM AAC for validity and reliability, a multidisciplinary group of AAC professionals was recruited. We initially aimed to recruit 18 AAC professionals, representing the geography and range of AAC professionals in Scotland. We had an overwhelming response from a range of

professionals (n= 29) to our initial invitation to participate in this project. We offered them all initial training in TOM for AAC. This was held in Stirling in January 2014, facilitated by Professor Pam Enderby from the University of Sheffield (see Tables 1 and 2 for details of participants).

Table 1 Professional groups (n = 29)

Profession	Numbers
Speech and Language Therapist	16
Teacher	7
Rehab engineer/technologist	2
Social work	1
Occupational Therapist	1
Physiotherapist	1
Nurse	1

Table 2 NHS areas represented

NHS area	Numbers
Lothian	2
Forth Valley	3
Greater Glasgow and Clyde	2
Fife	4
Tayside	6
Grampian	2
Highland	1
Ayrshire and Arran	2
SCTCI	2
CALL Scotland	2
Capability Scotland	3

Professor Enderby's training was well-received and people developed a clear understanding of why outcome measurement was important, as well as how it differed from assessment. People had the opportunity to practice scoring case histories using the TOM AAC. This activity helped people see how quickly they became familiar with the different scales (impairment, activity, participation and well-being). There appeared to be good agreement between individuals in relation to scoring.

Feedback from individuals was that this was a useful day and that they were keen to try using TOM AAC in practice.

R & D Approval

We sought advice from NHS South East Scotland Research Ethics Service who stated that as there was no identifiable data involved, and outcome measurement is part of routine practice, there was no need for ethical approval for this project. We contacted the relevant Research and Development (R & D) Officers in each health board area as well as local authority Quality Improvement officers in each local authority to tell them about the project and to seek their approval to proceed.

Stage 1 – Validity testing

Methods

Following attendance at the TOM training, each AAC professional was asked to use the TOM AAC rating scale on up to 10 clients. The TOM AAC is an outcome measure that is administered following assessment/intervention by a professional, not face to face, so their care was not directly affected during this process. Once professionals had tried rating a maximum of ten clients using the AAC TOM, they were asked to complete a questionnaire which was distributed via Survey Monkey (Appendix 2). Participants were also invited to attend a half day focus group where more in-depth discussion took place about the face validity of the measure. The purpose of the questionnaire and focus groups were to gain AAC professionals' views on the face validity of TOM AAC.

Findings from the questionnaire

Eighteen people responded to the questionnaire. Questions were divided into two broad categories: a) Coherence and relevance of the descriptors and b) Usability of the measure in practice.

<u>Coherence and relevance of the descriptors</u>

Respondents were asked several questions relating to whether or not the TOM AAC 'made sense' to them and captured aspects of their work which they felt were important (Figures 1 – 4)

Figure 1

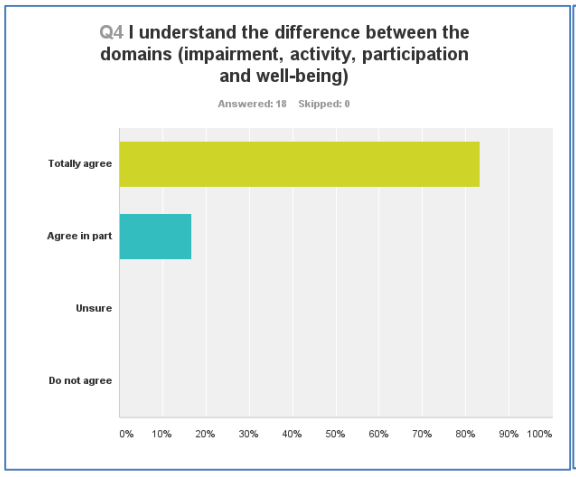


Figure 2

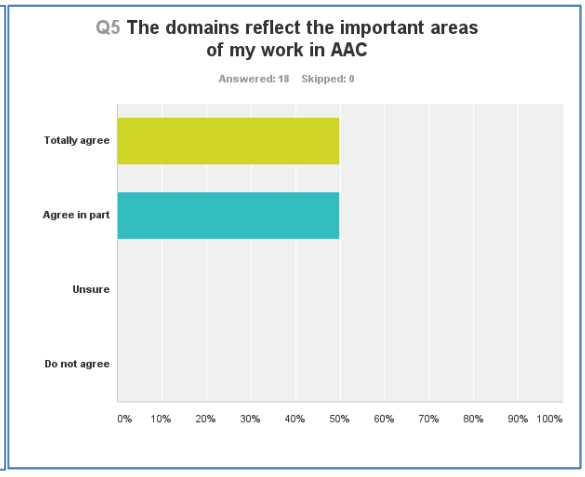


Figure 3

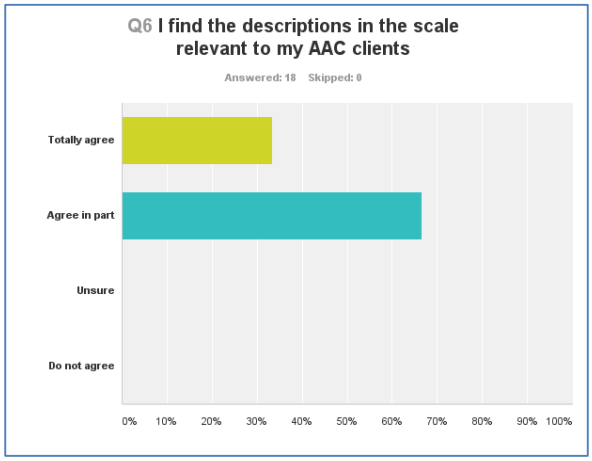
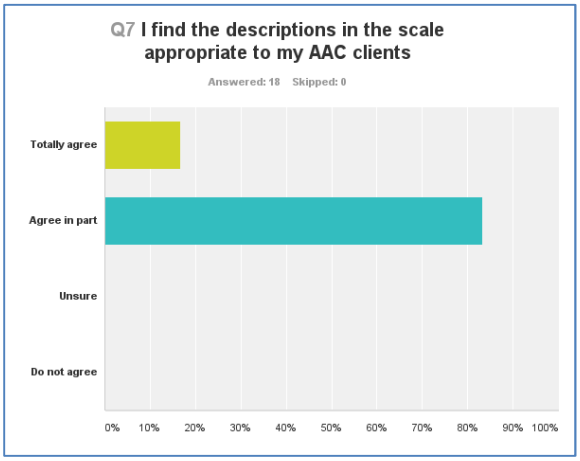


Figure 4



There was agreement between respondents that the descriptors in TOM AAC were appropriate and relevant for use with an AAC population. Respondents also reported that they had a good understanding of the difference between impairment, activity, participation and well-being.

Usability of the measure in practice

Respondents were asked to comment on the usability of the measure with an AAC population. Some respondents felt that the scales required further expansion (Figure 5). This issue was discussed in more detail during the focus groups, and is reported on in the next section.

Figure 5

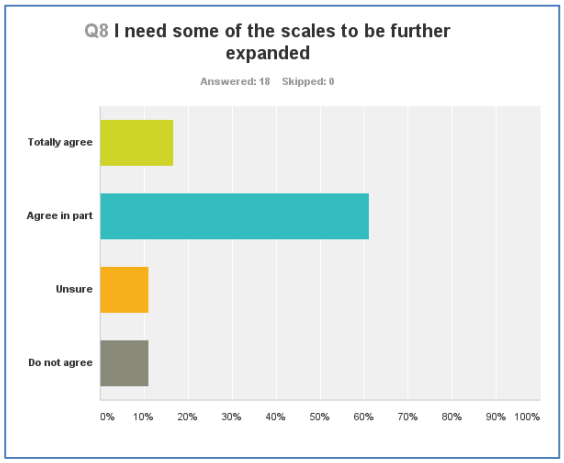


Figure 6

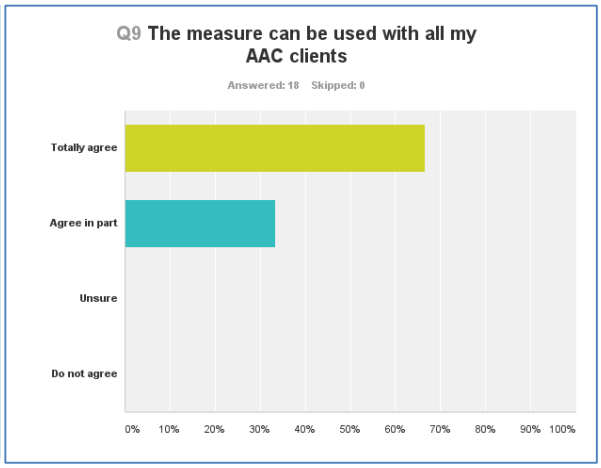


Figure 7

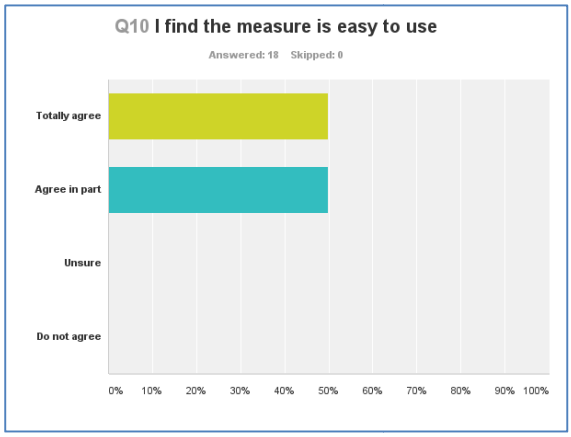
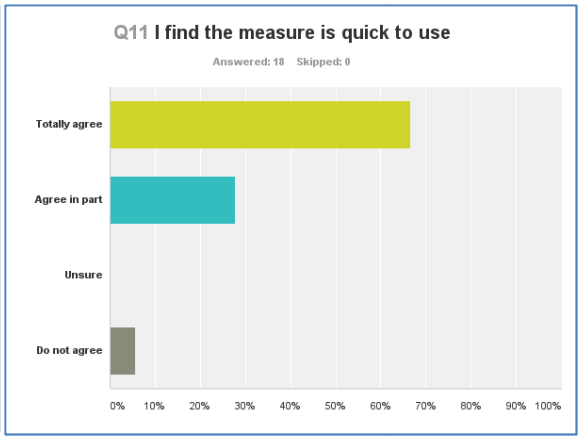


Figure 8



Most people agreed that the measure was quick and easy to use and felt that the training had equipped them to use the measure in practice. Most also agreed that the TOM AAC would help them to report on outcomes on their work with individuals who use AAC.

Figure 9

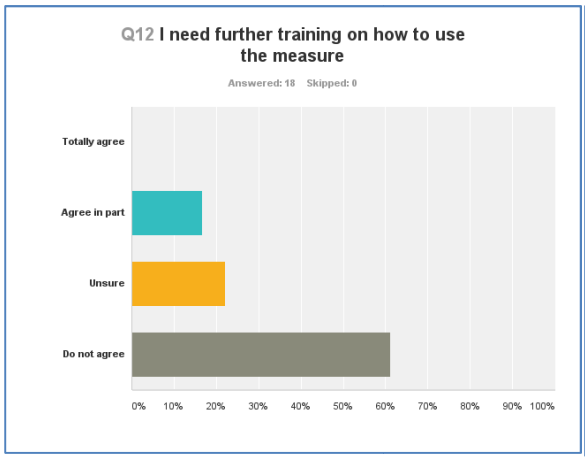
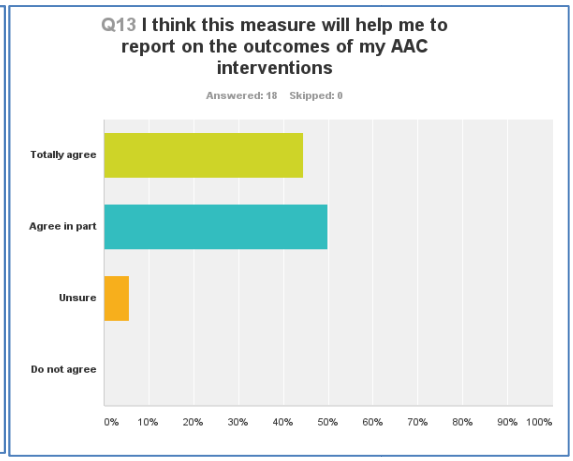


Figure 10



Some respondents also added comments in the free text at the end of the questionnaire. The quote below is representative of the comments we received:

> *"I have found the TOMs AAC easy and quick to use. I think it will give me a really worthwhile way of measuring outcomes and a good tool for sharing this information with stake holders. I am reassured that different professions working together can reach such similar conclusions about clients they share."*

Findings from questionnaire data suggest that TOM AAC has strong face validity for AAC professionals. The focus group discussions allowed us to explore practical issues in more detail and gave us insight into how descriptors might be changed to further improve face validity.

Findings from the focus groups

Participating AAC professionals were invited to attend one of three focus groups where discussion took place about their experiences of using TOM AAC. A total of 16 people attended. During each focus group, participants were asked to comment on each section of TOM AAC (i.e. impairment, activity, participation and well-being sections). They were also invited to make more general comments about the usefulness (or otherwise) of this version of TOM AAC.

Each focus group was digitally recorded and later listened to and relevant quotes were transcribed. Similar themes arose from each focus group and are summarised (under the headings from the different sections of TOM AAC) below.

A. General comments:

Participants agreed that TOM AAC was straight forward to use and that it would be useful in practice, particularly when used with other members of the team:

> *'As a teacher – well, I'm a teacher and I's in social work, it's kind of new to me……I think the more you do it, the better it is – the easier it is and the quicker you become. And once you've kind of got it, it does make much more sense…….I think it's really useful. I think it's a really quick, useful tool.' (Participant from focus group 3)*

Some participants who worked with children felt that the descriptors did not adequately reflect different developmental stages:

> *'it didn't feel terribly well-geared towards children.' (Participant from focus group 2)*

However, there was agreement that the TOM AAC would provide a useful outcome measure which could be used to show the impact (or otherwise) of AAC interventions.

B. Impairment:

Participants had specific comments about the wording in the 'impairment' section. For example, some suggested that in the physical descriptors, the words should be changed from 'tone' to 'control/tone/movement'. The majority of discussion around impairment during focus groups centred on the 'speech' and 'language' descriptors which were separate in this first version of TOM AAC. There was agreement that there should be a distinction between 'expression' and 'comprehension' rather than a distinction between 'speech' and 'language' as many AAC users have limited expressive skills but good comprehension:

> *'because a classic AAC user……you'd be seeing a high comprehension score and a zero expressive score. This is just a fudged mixture. If it doesn't even fit the classic AAC user, it's not going to fit all your kind of degrees…..so I definitely felt that you needed to be able to untangle to comprehension and expression' (Participant from focus group 2)*

Other comments about impairment related to consistency of wording and ensuring that when scoring the sensory impairment section, people were clear that they were scored with their glasses or hearing aids.

C. Activity:

In this section, participants had been asked to try rating AAC users twice – both with AAC and without AAC. This prompted lots of discussion within the focus groups because people were unclear about the definition of AAC and which methods people might be using. It was agreed that this would need to be described clearly in the descriptors and that teams would need to agree exactly what they meant by 'with' or 'without' AAC.

Participants felt that being able to say 'yes/no' was a fundamental part of communication and should be moved from point '2' to '1' in the descriptors.

D. Participation:

Participants had some general comments about the consistency of language used within this section and felt that the definition of autonomy needed some clarification. They also were in agreement that people should be rated both with and without AAC in this section as well as in the 'activity' section.

E. Well-being:

People reported that they found it very difficult to score a person's well-being because it was hard to gauge whether or not people were appropriate to their situation or not:

> *'Difficult to know how you score. I had the same chap that said yes and no – he's in his early 30's – has had a major stroke – physically very well. Communication is very poor and he's happy as Larry.' (Participant from focus group 3)*

However, participants agreed that it was important to measure this domain, as provision of AAC may well have an impact on a person or their family's well-being, so there would be value in measuring this.

Amendments made to improve face validity of TOM AAC

Findings from the questionnaire and the focus group suggest that TOM AAC has strong face validity for AAC professionals who have been trained to use the measure. Qualitative data from the focus groups pointed to specific changes which could be made to increase the face validity and usability of TOM AAC. These were discussed with Professor Enderby who made a number of changes to the descriptors as a result (Appendix 3). In particular, the wording was changed to ensure consistency across the descriptors. Within the impairment section, distinction was made between 'expression' and 'comprehension' rather than 'speech' and 'language'. More detailed explanation was also provided for each descriptor to increase the clarity of meaning for each section. Rewording of this version of TOM AAC involved an iterative process between us and Professor Enderby. Once we were happy with the final draft, we moved on to the reliability testing phase of the project.

Stage 2 - Testing TOM AAC for reliability

Inter-rater reliability of the original TOM was carried out between 1993 and 2000 and eleven published trials are summarised in Enderby et al (2006:26). The numbers of therapists recruited to different studies ranged from 2 to 21. The median number of patients in these studies was ten. In this project we have tested the inter-rater reliability of TOM AAC between 17 different AAC professionals on ten case histories, leading to 170 data points. This is in line with other studies which have been carried out to test the reliability of other sub sections of TOM.

Inter-rater reliability is important because it provides assurance that the scale can be used consistently by different professionals (i.e. the same score is given regardless of the person doing the scoring, Clark-Carter 2010). In order to do this, we devised ten case histories (which included children and adult AAC users). Most of the case studies were provided in written form, but three of these were augmented with video clips (case histories 8, 9 and 10). Case histories one to seven were anonymised composite case studies (pseudonyms were used) created from clinical experience of the project team. These were devised to represent people with a broad range of impairments and disabilities who might benefit from AAC (see Table 3). In addition to this, three adults with appropriate mental capacity, who volunteer for the Talking Mats organisation and use AAC, agreed to participate in the project. They all agreed to be filmed and share their case history. They reviewed their videos and were happy for their information to be used. They fully understood the purpose of the project and completed signed consent forms.

We asked each AAC professional to rate each case history using TOM AAC. In previous reliability testing of TOM, the limitations of testing inter-rater reliability using case histories have been highlighted because information *'can be either inadequate or reveal information in such a way as to prime judges'* (Enderby et al 2006: 26). Case histories are known to have difficulties in inter-rater reliability trials. However, they are resource efficient and allow presentation of data testing the full range of severities of conditions to test scoring systems. In preparing the case histories, we endeavoured to give as much information as we could without over burdening participants who were all practicing clinicians giving their time voluntarily. Furthermore, published studies (John and Enderby 2000) with other professions and client groups using the TOM have all reported that using the TOM with their own patients in real life situations where they can explore the patient's experiences which would assist them in choosing the appropriate score, is easier than rating from case histories. Therefore, it is likely that reliability in the clinic will be better than in a trial.

Table 3

	Pre-school child	Primary aged child	Secondary aged child	Adult
Learning disability	✓	✓	✓	✓
Physical disability	✓	✓	✓	✓
Acquired disability				✓
Degenerative disability				✓

Each professional was sent the 10 case histories (Appendix 4) and a set of instructions (Appendix 5) and asked to rate them independently.

Findings

Seventeen professionals rated the ten case histories. Scores were collated onto an excel spreadsheet and then analysed for agreement by a statistician. Agreement was quantified for each of the eight domains using the intraclass correlation coefficient (ICC). The ICC is the ratio of between-case variation (the degree to which different case histories vary) as a proportion of the total variation in scores, and lies between 0 and 1; larger ICCs indicate greater agreement. ICCs were calculated as described by Shrout and Fleiss (1979) using definition 2 (case histories are rated by a random group of raters, drawn from a wider potential population).

Alongside the ICC, the minimum and maximum rating for each of the ten case histories is reported. For TOM, a clinically important disagreement is defined as 1 unit in either direction; therefore, if any pair of raters disagree by more than 2 units this would indicate poor agreement.

Each of ten case histories was judged by either 16 or 17 different raters: one rater did not rate three of the ten case histories. The ICCs and case history ranges are presented in table 4. Agreement was generally acceptable, and was highest for physical impairment (0.887), comprehension (0.831) and wellbeing (0.816); the lowest was for expression (0.486).

Table 5 gives more information on the individual case histories. For physical impairment, three of the case histories (#1,3, and 6) demonstrated complete agreement: every assessor gave a score of 5 to each history. Similarly, sensory impairment agreed completely for 2 case histories (#2 and 4); again, all 17 raters assigned scores of 5. Agreement was generally within +/-1 unit (i.e. the difference between highest and lowest was no more than 2 units) but activity, expression and participation showed some important disagreements.

Table 4 ICCs by domain

TOM domain	**ICC**	**Range (difference between lowest and highest rating)**			
		0 (Complete agreement)	<=1	<=2	>2
Physical Impairment	0.887	3	5	2	0
Cognitive Impairment	0.726	0	4	4	2
Sensory Impairment	0.605	2	6	1	1
Expression	0.486	0	2	3	5

Comprehension	0.831	0	3	6	1
Activity	0.622	0	2	4	4
Participation	0.703	0	1	4	5
Wellbeing	0.816	0	5	3	2

Case histories 1-7 are rated by 17 raters, 8-10 rated by 16 raters.

The figure shows the average rating for the 17 raters on each of the 8 domains. There was variability among the raters, and although there are no raters who are consistently lower or higher than average, it is hard to judge. Some of the domains are negatively correlated, for example physical impairment and cognitive impairment (i.e. a rater who rated one higher would tend to rate the other lower). Although not the primary interest, this could be the focus of more work.

Table 5 range of agreement of individual case histories

		Minimum - Maximum by case history									
TOM domain	**ICC**	1	2	3	4	5	6	7	8	9	10
Physical Impairment	0.887	5.0-5.0	1.0-2.0	3.5-4.5	5.0-5.0	1.0-3.0	5.0-5.0	4.0-5.0	1.0-3.0	1.0-2.0	2.0-3.0
Cognitive Impairment	0.726	1.0-4.0**	3.5-5.0	3.0-5.0	0.5-2.0	4.0-5.0	4.0-5.0	1.0-3.5*	4.0-5.0	4.5-5.0	2.0-4.0
Sensory Impairment	0.605	2.0-4.5*	5.0-5.0	4.0-5.0	5.0-5.0	2.0-3.5	4.0-5.0	4.0-5.0	4.0-5.0	4.0-5.0	4.0-5.0
Expression	0.486	1.0-2.0	0.0-3.0*	0.0-4.0**	0.0-1.5	0.0-4.0**	2.0-5.0**	1.5-2.5	2.5-5.0*	2.0-4.0	1.0-3.0
Comprehension	0.831	1.0-3.0	4.0-5.0	3.5-5.0	0.0-1.5	4.0-5.0	3.0-5.0	1.0-3.0	3.5-5.0	4.0-5.0	1.0-3.5*
Activity	0.622	1.0-2.5	1.0-3.0	3.0-4.5	0.5-1.5	1.0-4.5**	2.0-5.0**	1.5-2.5	1.0-5.0*	2.5-5.0**	1.0-3.0
Participation	0.703	1.0-2.5	2.0-4.5**	3.0-5.0	0.0-1.5	1.0-4.5**	2.0-4.5*	1.0-2.0	3.5-5.0	2.5-5.0*	1.0-3.5*
Wellbeing	0.816	1.0-4.0	4.0-5.0	4.0-5.0	0.0-2.0	1.5-4.5**	3.0-4.5	2.0-4.0	4.5-5.0	4.0-5.0	4.0-5.0

Case histories 1-7 are rated by 17 raters, 8-10 rated by 16 raters. Case histories/domains with disagreement of >2 categories are highlighted: * due to a single rater ** 2 or more raters

Mean ratings by outcome and rater

The results show generally good inter-rater reliability between professionals who used TOM AAC on the ten case histories. Surprisingly, the provision of DVDs did not appear to have any demonstrable effect on inter-rater reliability. We may not have provided sufficient information in case histories five and six, as ratings for these case histories gave the largest range between individuals. The domain of 'expression' appeared to produce the most variation between raters. This may be because the indicators in this domain need to be more clearly defined and the scoring both with and without AAC needs to be explicit. As this domain is particularly relevant for AAC this requires further investigation.

Dissemination:

This project was presented at the International Society for Augmentative and Alternative Communication in Lisbon July 2014. It was warmly received and has stimulated contact and expressions of interest in using TOM AAC in other countries. Two further submissions have been accepted at Communication Matters annual conference and RCSLT triennial conference in September.

A stakeholders day is planned for December 2014 where findings will be presented.

A book chapter in the third edition of TOMs has been accepted. Two publications for peer review journals are planned.

Recommendations

1. The 'expression' section needs clarification and further testing. This has been reworded and sent out to participants for re-rating. Further analysis will be carried out.
2. Dissemination of TOM AAC to the participants and broader audience including presentations and publications.
3. The use of TOM AAC should be encouraged for all AAC Centres in Scotland.
4. Benchmarking of services using TOM AAC in order to identify best practice.
5. Use of TOM AAC to explore variation in service provision.
6. Ongoing data collection to explore changes over time and impacts of funding and policy on services.

Summary

This first iteration of TOM AAC has been tested for face validity and inter-rater reliability between AAC professionals. Initial findings suggest that the scale has strong face validity and there was good inter-rater reliability for eight of the nine domains. All the stakeholders feel positively towards this measure and realise the importance of collecting reliable data appropriate for their services in order to inform commissioning and service improvement. Once the reliability of the communication-expression domain has been established, then TOM AAC will be available for use by the end of 2014 and recommend its adoption for AAC services in Scotland.

References

Clark-Carter, D. Quantitative Research Methods: Gathering and Making Sense of Numbers. In: P. Roberts and H. Priest, Eds, *Healthcare Research A textbook for Students and Practitioners* Chichester Wiley-Blackwell, pp. 130-149.

Enderby et al 2006 *Therapy Outcome Measures for Rehabilitation Professionals (Second Edition*) England: Wiley and sons

John, A. & Enderby, P. (2000) Reliability of Speech and Language Therapists using Therapy Outcome Measures. *International Journal of Language Disorders,* 35, 287-302

NHS Education for Scotland 2013 *A critical appraisal of existing methods of measuring outcomes in relation to Augmentative and Alternative Communication: Final Report*

Scottish Government (2012*) 'A Right to Speak'*
http://www.scotland.gov.uk/Publications/2012/06/8416/0

Shrout, PE, Fleiss, JL. Intraclass correlations: Uses in assessing rater reliability. Psychological Bulletin 1979; 86(2): 420-428

World Health Organisation, 2001. *WHO-ICF: International Classification of Functioning, Disability and Health.* Geneva: World Health Organisation.

Appendix 1 TOM AAC

Therapy Outcome Measure adapted for AAC

Identify the descriptor that is 'best fit'. The person rated does not need to have each feature mentioned.

Use .5 to indicate if patient/client is likely to be better or worse than the descriptor. You may choose to give a carer 'well-being' score if that is appropriate to your care plan.

Impairment- Physical

0	severe abnormality of tone-total body involvement. No voluntary control over movement.
1	severe abnormality of tone with total body involvement. Minimal voluntary movement.
2	moderate abnormality of tone with total-body involvement or the involvement of two limbs. Some gross voluntary control.
3	moderate abnormality of tone with partial involvement or severe single limb involvement. Impaired voluntary control/movement.
4	mild abnormality of tone with mild impairment in voluntary movement and control.
5	no physical impairment

Impairment-Cognitive

0	Unresponsive to stimuli
1	Non-purposeful random and fragmented responses. Occasionally response to some simple commands; responses may be severely delayed or inappropriate. Recognises familiar people and routine tasks in context. Co-operates occasionally. Shows little sign of recall /memory. Attempts to learn simplest routines with maximal assistance.
2	Inconsistent reactions directly related to type of stimulus presented. Occasionally responds appropriately. Can attend but is highly distractible unable to focus on individual task. Memory may be severely impaired; may perform previously learned tasked with structure.
3	Recognises familiar people and tasks in most contexts, able to retain small amounts of information consistently. Responds appropriately with some consistency, appears orientated to setting. Insight, judgement and problem-solving are poor. Some memory but unreliable.
4	Alert and able to learn but needs occasional prompting and assistance, responds well in most situations. Able to recall and integrate past and recent events; shows carryover for new learning and needs no supervision when activities are learned, may have problems with abstract reasoning and judgement in unusual circumstances. Occasional memory problem.
5	No cognitive impairment, responds appropriately is alert and able to learn.

Impairment –sensory

0	Severe hearing and visual impairment.
1	Severe hearing or visual impairment. Can perceive very restricted range of environmental sights or sounds. Limited benefit from hearing aid/glasses
2	Severe/moderate hearing or visual impairment requires attention to perceive a limited range of sights and/or sounds. Benefits from hearing aid/glasses
3	Moderate hearing or visual impairment. Can hear/see a range of environmental sounds and sights. Benefits greatly from hearing aid/glasses.
4	Mild hearing or visual impairment
5	No hearing or visual impairment

Impairment –Speech

0	Profound speech impairment: profound problems are evident in all areas, inability to produce any distinguishable sounds. No oral motor control. No respiratory support for speech.
1	Severe speech impairment: severe and inconsistent articulatory and prosodic impairment. Mostly open vowel sounds with some consonant approximations. Effortful and slow speech with severe restriction of respiratory support and limited motor control.
2	Severe/moderate speech impairment: most consonants attempted but poorly represented acoustically, prosodic impairment and difficulty controlling speed of speech either slow or increasing in speed. Breath support consistent but weak. Limitation of oral motor control.
3	Moderate speech impairment: consistent omission or distortion of articulation of consonants variability of speed some limitation of oral motor control and prosodic abnormalities.
4	Mild speech impairment: slight or occasional omission or mispronunciation of consonants, slight occasional difficulty with oral motor control, prosody or respiratory support.
5	No speech impairment.

Impairment Language

0	Profound language impairment: profound problems limiting comprehension and expression.
1	Severe language impairment: usually involving comprehension and expression comprehension may be at one keyword level. May express negative and affirmative.
2	Severe/moderate language impairment: comprehension may be consistent at a minimum of two or three keyword level some limited verbal gestural expression used appropriately and purposefully.
3	Moderate language impairment: consistent use of language at a basic level, some butter inconsistent comprehension and use of more complex language structure and vocabulary.
4	Mild language impairment: occasional difficulties with more complex or expanded use of language and comprehension. Simplistic structures preferred.
5	No language impairment.

Activity/communication ability

0	No consistent functional communication-- functioning at pre-intentional level.
1	Limited functional communication. Using some purposeful responses to indicate limited needs or feelings with informed/familiar communication partners.
2	Communicates basic needs and information to informed /familiar communication partners. Can reliably communicate 'yes' and 'no'. Consistent attempts at purposeful communication.
3	Consistent level of communication relating to subjects outside the immediate context. Can transfer more complex messages. Maybe limited in output relating to restricted access to symbol set or other barriers to vocabulary. Some inconsistency. Communicates beyond here and now familiar persons and in some contexts.
4	Functional communication available to the individual in most circumstances. Only occasional difficulty. Access to extensive vocabulary which meets needs. May have difficulty reticence in some environments.
5	Able to communicate with anyone in any circumstance using broad range of communication modes.

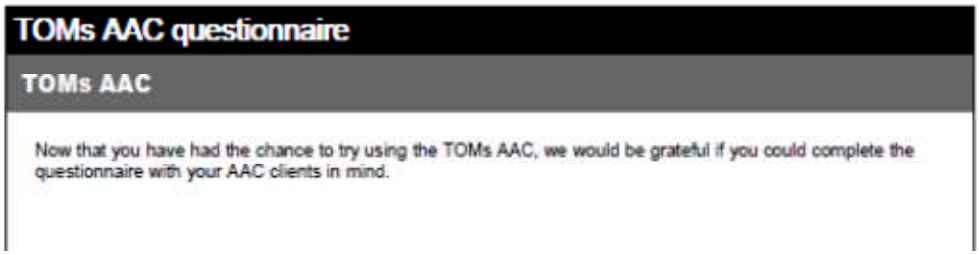
Participation

0	Unable to fulfil any social/occupational/family role. No autonomy. No control and the environment. No social integration.
1	Low self-confidence /poor self-esteem /limited social integration /socially isolated .Unable to fulfil any educational/occupational role. No friends/acquaintances outside family/carers. Only able to engage in social activities with large amounts of support from carers.
2	Some degree of self-confidence and social integration beyond immediate family and carers. Fulfilling some social occupational education or family role with support. Able to effect some decisions/ control in familiar situations. Social life will be very limited.
3	Makes decisions and has control over some aspects of life. Able to engage with family /occupation /recreation/ education system to some extent with appropriate adjustment and support. Has a few friends/acquaintances. Has some autonomy and control over life. Needs encouragement to achieve potential.
4	Autonomous in most or all activities. May have occasional difficulties integrating or in fulfilling social/role activity. May have difficulty in achieving potential in some situations on some occasions. May have restricted interests/pastimes.
5	Autonomous in all activities. Able to fulfil social, occupational and family role.

Well-being

0	High and constant levels of distress and problematic emotions, like frustration/ elation / anger etc. May have severe depression and/or severe anxiety. May have severe apathy/social withdrawal. Likely to be unable to express or control emotions appropriately.
1	Severe levels of distress and problematic emotions. These are present all or nearly all of the time. Becomes distressed easily, requires constant reassurance / support, needs clear / tight limits and structure, loses emotional control easily.
2	Moderate to severe levels of distress and problematic emotions. Present most of the time. Frequent emotional support required.
3	Moderate levels of distress and problematic emotions. Occur frequently, more likely to occur in novel situations/changes in routine. Controls emotions with assistance, emotionally dependent on some occasions, but can use strategies to assist emotional control.
4	Mild levels of distress and problematic emotions. Not present all the time, likely only associated with novel situations or changes of routine. Able to control feelings in most situations, generally well adjusted / stable (most of the time / most situations), occasional emotional support needed.
5	Well adjusted, stable and able to cope emotionally with most situations, good insight, accepts and understands own limitations.

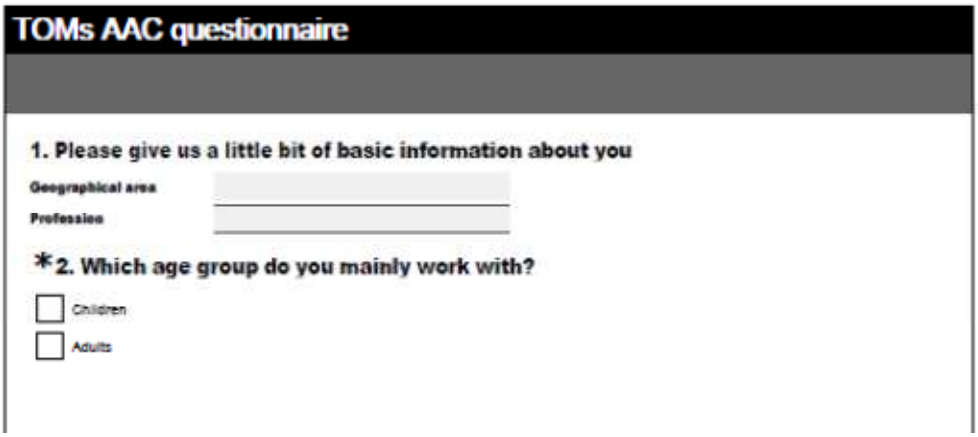
Appendix 2 – Questionnaire for AAC professionals



TOMs AAC questionnaire

TOMs AAC

Now that you have had the chance to try using the TOMs AAC, we would be grateful if you could complete the questionnaire with your AAC clients in mind.



TOMs AAC questionnaire

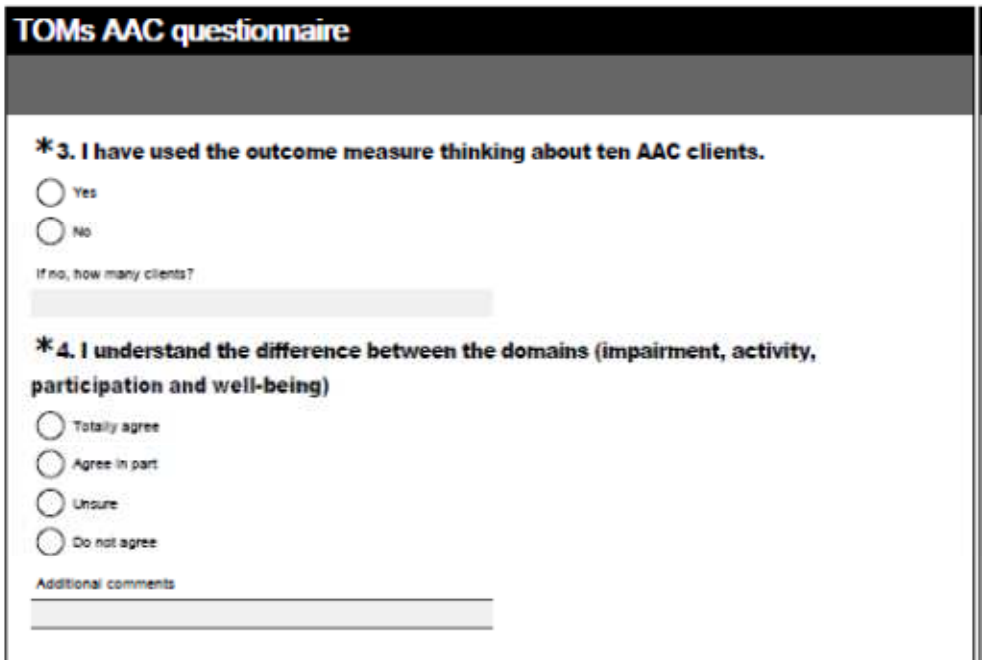
1. Please give us a little bit of basic information about you

Geographical area

Profession

*2. Which age group do you mainly work with?

- [ ] Children
- [ ] Adults



TOMs AAC questionnaire

*3. I have used the outcome measure thinking about ten AAC clients.

- ◯ Yes
- ◯ No

If no, how many clients?

*4. I understand the difference between the domains (impairment, activity, participation and well-being)

- ◯ Totally agree
- ◯ Agree in part
- ◯ Unsure
- ◯ Do not agree

Additional comments

TOMs AAC questionnaire

Copy of page:

***5. The domains reflect the important areas of my work in AAC**

- ◯ Totally agree
- ◯ Agree in part
- ◯ Unsure
- ◯ Do not agree

Additional comments

***6. I find the descriptions in the scale relevant to my AAC clients**

- ◯ Totally agree
- ◯ Agree in part
- ◯ Unsure
- ◯ Do not agree

Additional comments

***7. I find the descriptions in the scale appropriate to my AAC clients**

- ◯ Totally agree
- ◯ Agree in part
- ◯ Unsure
- ◯ Do not agree

Additional comments

***8. I need some of the scales to be further expanded**

- ◯ Totally agree
- ◯ Agree in part
- ◯ Unsure
- ◯ Do not agree

If you think they need to be expanded, please give details

TOMs AAC questionnaire

***9. The measure can be used with all my AAC clients**

- ◯ Totally agree
- ◯ Agree in part
- ◯ Unsure
- ◯ Do not agree

Additional comments

***10. I find the measure is easy to use**

- ◯ Totally agree
- ◯ Agree in part
- ◯ Unsure
- ◯ Do not agree

Additional comments

***11. I find the measure is quick to use**

- ◯ Totally agree
- ◯ Agree in part
- ◯ Unsure
- ◯ Do not agree

Additional comments

***12. I need further training on how to use the measure**

- ◯ Totally agree
- ◯ Agree in part
- ◯ Unsure
- ◯ Do not agree

If you feel you need further training, please give details

TOMs AAC questionnaire

***13. I think this measure will help me to report on the outcomes of my AAC interventions**

- ◯ Totally agree
- ◯ Agree in part
- ◯ Unsure
- ◯ Do not agree

Additional comments

TOMs AAC questionnaire

14. Please add any other comments about your experience of using the Toms AAC.

Appendix 3 – Updated TOM AAC

Therapy Outcome Measure adapted for AAC

Definition of AAC

People of all ages with severe speech and language impairments use a range of Augmentative and Alternative Communication (AAC) methods to assist them to communicate their views and needs. AAC is the term used to describe methods of communication which can be added to the more usual methods of speech and writing when these are impaired. AAC can help someone understand as well as express themselves and includes unaided systems, such as signing and gesture, and aided systems, ranging from pen and paper to the most sophisticated computer technology currently available. Most people who use AAC employ a combination of unaided and aided methods. Aided methods are usually divided into two groups: low-tech and high-tech AAC systems.

Using the scale:

Identify the descriptor that is 'best fit'. The person rated does not need to have each feature mentioned. Choose the descriptor bearing in mind appropriacy given the age, gender and culture of the individual.

Use 0.5 to indicate if patient/client is likely to be better or worse than the descriptor. You may choose to give a carer a 'well-being' score if that is appropriate to your care plan.

Impairment- Physical

0	Profound abnormality of tone/control/movement- with total body involvement. No voluntary control over any movement
1	Severe abnormality of tone/control/movement- with total body involvement. Minimal voluntary control of movement
2	Moderate abnormality of tone/control/movement- with total-body involvement or the severe involvement of two limbs Some reliable movement or gross voluntary control of movement, which may be uncoordinated, very slow or disrupted
3	Moderate abnormality of tone/control/movement - with partial involvement or severe single limb involvement Impaired voluntary control of movement, which may be inaccurate and slow
4	Mild abnormality of tone/control/movement - with mild impairment in voluntary control of movement and control May have occasional incoordination and inaccuracies
5	No physical impairment

Impairment-Cognitive

0	Unresponsive to stimuli
1	Non-purposeful random and fragmented responses. Occasional response to some simple commands; responses may be severely delayed or inappropriate. Recognises familiar people and routine tasks in context. Co-operates occasionally. Shows little sign of recall/memory. Can learn simple routines/tasks with maximal assistance.
2	Inconsistent reactions directly related to type of stimulus presented. Occasionally responds appropriately. Response may be delayed but appropriate. Recognises familiar people in more settings. Can attend but is highly distractible. Unable to focus on individual tasks. Memory may be severely impaired; may perform previously learned tasks within familiar structure. Insight, judgement, and problem-solving are poor.
3	Recognises familiar people and tasks in most contexts, able to retain small amounts of information consistently. Responds appropriately with some consistency. Appears orientated to setting. Insight, judgement, memory and problem-solving are sometimes unreliable.
4	Alert and able to learn but needs occasional prompting and assistance. Responds well in most situations. Able to recall and integrate past and recent events. Shows carryover for new learning and when activities are learned. Good insight and judgement. May have problems with abstract reasoning in unusual circumstances. Occasional minor memory problem.
5	No cognitive impairment. Good insight, judgement, and problem-solving abilities. Responds appropriately. Is alert and able to learn.

Impairment –sensory - hearing and vision. (Rate the person using glasses and hearing aids if normally used)

0	Profound hearing and visual impairment.
1	Severe hearing or visual impairment. Can perceive restricted range of environmental sights or sounds. Limited benefit from hearing aid/glasses
2	Severe/moderate hearing or visual impairment requires attention to perceive a limited range of sights and/or sounds. Benefits from hearing aid/glasses
3	Moderate hearing or visual impairment. Can hear/see a broad range of environmental sounds and sights. Benefits greatly from hearing aid/glasses.
4	Mild hearing or visual impairment. Occasional difficulty with hearing in some environments or seeing in some lights. Benefits greatly from hearing aid/glasses
5	No hearing or visual impairment

Communication Impairment: Expression

0	Profound difficulty with expressing self in speech, AAC or gesture. Not understood by familiar or non-familiar listeners.
1	Very severe problems with expression limited to a few recognisable words or gestures. Only basic messages e.g. positive and negative, understood by familiar family and friends and only with help of context, hand signals/gestures/facial expression.
2	Severe difficulty expressing self. Can produce some recognisable expression (speech, AAC or gesture) but difficulty communicating anything out of context. Familiar topics of conversation can usually be understood by familiar friends and family but strangers only able to understand occasional expression.
3	Moderate difficulty in being understood. Can be understood by familiar family and friends in most circumstances but not understood consistently by non-familiar listeners, and this may be limited to topics in context.
4	Occasional difficulty in being understood. Maybe less intelligible in some contexts. Generally good expression but some maybe less well understood.
5	No difficulty in being understood. Normal expressive ability.

Communication Impairment: Comprehension

0	Profound difficulty: comprehension inconsistent even at one keyword level in context.
1	Very severe difficulty: understanding limited to few recognisable words in context or accompanied by visual clues, context etc.
2	Severe comprehension difficulty. Can comprehend in familiar context, but inconsistency in ability. Familiar topics of conversation, e.g. Familiar names/ greetings/basic instructions in context can usually be understood.
3	Moderate comprehension difficulty: Can understand simple sentences and structures, but has difficulty with quick changes of subject, more complex topics or understanding in some contexts when there may be distraction/noise.
4	Mild/occasional difficulty in comprehension: generally understands most conversation but has difficulty understanding occasionally e.g. when tired/stressed
5	No difficulty in comprehending. Normal receptive ability.

Activity (In relation to AAC)

Firstly, rate this to reflect the individual without any AAC i.e. not using signing systems or technology. Then rate again when the person is using current AAC i.e. signing system or additional technology.

0	No consistent functional communication-- functioning at pre-intentional level.
1	Limited functional communication. Using some purposeful responses to indicate limited needs or feelings with informed/familiar communication partners within limited contexts. Can reliably communicate 'yes' and 'no'. Limited communicative intent.
2	Communicates basic needs and information to informed /familiar communication partners. Consistent attempts at purposeful communication in limited contexts. Some communicative intent.
3	Consistent level of communication relating to subjects outside the immediate context. Can transfer more complex messages. Maybe limited in output relating to restricted access to symbol set or other barriers to vocabulary. Some inconsistency. Communicates beyond here and now with familiar persons and in some contexts. Consistent communicative intent
4	Functional communication available to the individual in most circumstances and with broad range of individuals. Only occasional difficulty. Access to extensive vocabulary which meets needs. May have difficulty reticence in some environments. Consistent communicative intent
5	Able to communicate with anyone in any circumstance using broad range of communication modes.

Participation

Firstly, rate this to reflect the individual without any AAC i.e. not using signing systems or technology. Then rate again when the person is using current AAC i.e. signing system or additional technology. Consider how the person participates socially/can perform their role without AAC and then with it.

(Autonomy/ self-sufficiency/self-reliance = able to determine and have control over one's own viewpoint and not have decisions made by others)

0	Unable to fulfil any social/educational /occupational/recreational /family role. Unable to participate in any situation, even with high-level support. No control and the environment. No social integration.
1	Low self-confidence /poor self-esteem /limited social integration /socially isolated .Unable to fulfil any social /educational/occupational/recreational/or family role. No friends/acquaintances outside family/carers. Only able to engage in social activities with large amount of support from carers.
2	Some degree of self-sufficiency and social integration beyond immediate family and carers. Fulfilling some social occupational /education/recreational or family role with support. Able to personally effect some decisions/ control in familiar situations. Social life is very limited and requires involvement of support from carers.
3	Makes decisions and has control over some aspects of life. Able to engage with family /occupation /recreational/ education system to some extent with appropriate adjustment and support. Has a few friends/acquaintances. Has some self-sufficiency and control over life. Needs encouragement by others to achieve potential.
4	Can indicate preferences and views in most or all activities. Has broader range of friends. Has only occasional difficulties integrating or in fulfilling social/role activity. May have difficulty in achieving potential in some situations on some occasions. May have restricted interests/pastimes.
5	Can indicate preferences and views in all activities. Able to fulfil social, recreational, occupational educational and family role.

Well-being

Firstly, rate this to reflect the individual without any AAC i.e. not using signing systems or technology. Then rate again when the person is using current AAC i.e. signing system or additional technology.

(E.g. are they more upset/distressed/frustrated without access to available AAC-- or does this make little difference and they have the same emotional status with or without?)

Do not forget that you can rate the relative or carer on this scale as well.

Some carers may find that it is more upsetting/frustrating/anxiety producing when the individual is using technology-- others may find the opposite!

0	High and constant levels of distress and problematic emotions, like frustration/ elation / anger etc. May have severe depression and/or severe anxiety. May have severe apathy/social withdrawal. Likely to be unable to express or control emotions appropriately.
1	Severe levels of distress and problematic emotions. These are present all or nearly all of the time. Becomes distressed easily, requires constant reassurance / support, needs clear / tight limits and structure/ loses emotional control easily.
2	Moderate to severe levels of distress and problematic emotions. Present most of the time. Frequent emotional support required.
3	Moderate levels of distress and problematic emotions which occur frequently. More likely to occur in unfamiliar situations/changes in routine. Controls emotions with assistance, emotionally dependent on some occasions but can use strategies to assist emotional control.
4	Mild levels of distress and problematic emotions. Not present all the time, likely to only be associated with unfamiliar situations or changes of routine. Able to control feelings in most situations, generally well-adjusted/ stable (most of the time / most situations). Occasional emotional support needed.
5	Well adjusted, stable and able to cope emotionally with most situations, good insight, accepts and understands own limitations.

Appendix 4 – Case histories

Case study 1

Name	Susie
Age	3 and a half
Diagnosis	Foetal alcohol syndrome
Context	Lives with foster family

Susie is physically able. She plays a lot with Duplo and loves playing in the park. Susie's development is delayed but she does understand simple commands. She has poor vision and needs glasses but they keep getting broken.

Susie has very limited use of single words which are largely unintelligible. Her speech and language therapist has started introducing MAKATON which her foster Mum is keen to use at home. She also has a iPad with a Scene and Heard app which her therapist has recently introduced in the nursery for story-telling.

Susie's understanding is limited to 2 information carrying words. She tends to communicate by pulling people to where she wants them to go and gets frustrated when people don't understand her.

She goes to a local play facility run by the council and tends to spend most of her time there wandering from one activity to another but doesn't interact with other children. She really loves it when there's a music session.

Susie gets frustrated and is prone to temper tantrums

Susie's foster mum is very patient and accepting. She has fostered many children with ASN.

Case study 2

Name	Angus
Age	4
Diagnosis	Athetoid cerebral palsy
Context	Lives at home with his Mum, Dad, older sister and dog. He lives in a small village in the Highlands.

Angus has severe athetoid movements in all limbs. He is able to point using his fist. He uses a wheelchair with specialist seating, including head support. He responds to jokes and follows family conversations. He loves watching animal programmes. His vision and hearing are within normal limits.

Angus vocalises but has no intelligible speech. Angus's comprehension appears to be within normal limits. He has a PODD communication book which he accesses through gross pointing and listener scanning. He has just started using an eye gaze system using The Grid 2 with PCS symbols, based on his communication book layout. He has a reliable yes no (looking up for yes and down for no)

Angus attends the local nursery every morning where he has a support worker. His grandpa lives on a farm and takes him out for walks when the weather is good. He really loves seeing all the animals. Angus tries to join in with all the activities at nursery and is very popular. At home he makes sure everyone knows that he wants to be included. His big sister involves him when her friends come round to play.

Case study 3

Name	Hannah
Age	8
Diagnosis	Hannah had Meningitis when she was 2 and now has severe oral dyspraxia and mild learning disability.
Context	Lives at home with Mum and Dad. Attends local primary school which has a unit for children with Additional Support Needs.

Hannah is mobile. She has mild limb dyspraxia which makes fine motor movements difficult. She wears glasses for reading and her hearing is within normal limits.

Hannah can vocalise but has no intelligible speech. She has a small communication book and uses some gestures which only familiar people can understand. She also uses an iPod with Proloquo2go. She can link pieces of information and create complex messages using this. She follows most conversations easily. She can read simple text.

She attends some mainstream classes with help from her support worker. She uses her iPod to answer questions and tries to ask questions in class. She goes to Brownies and enjoys swimming.

Hannah has several friends at Brownies and is popular at school. Her parents make sure that they invite friends over and encourage Hannah to participate in lots of activities.

Case study 4

Name	Jenna
Age	8
Diagnosis	Autistic Spectrum Disorder
Context	Attends a local mainstream Primary school with a specialist Autism facility. She lives at home with her mum and dad and sister.

Jenna was diagnosed with ASD when she was 2 years old. She has no physical difficulties but has severe autism with very challenging behaviour. Her hearing and vision appear to be within normal limits.

She is not toilet trained and wears nappies. Her sleep pattern is very erratic - often waking up in the middle of the night. She has no speech - she kicks and screams and tries to eat anything that interests her. Recently, teachers have implemented a PECS approach with some success in phase 1 – she can select a picture of a ”highly preferred item” and hand it to her teacher who gives her an open hand cue. On receiving the picture the teacher then gives her the requested item.

She is obsessed with “My little pony” and will replay her DVDs constantly at home. Her parents keep cupboards and doors locked to limit destruction in the house. The family is under strain and are finding the combination of managing Jenna’s behaviour and dealing with professional input challenging. All involved are trying to establish a link between functional activities, communication training and reducing unwanted behaviour.

Case study 5

Name	Claire
Age	12
Diagnosis	Head injury following a road traffic accident aged 5
Context	Lives with Mum and older brother. Attends special school for children with physical disabilities.

Claire has a severe right hemiplegia and limited control of her left hand. She uses a wheelchair with special seating and is totally dependent on others for all ADLs. Her cognitive ability appears to be within normal limits but at times she is unrealistic about what she can and cannot do. She is doing well at a school for children with physical disabilities and enjoys reading and maths. Claire has visual problems she can only see out of her left eye. She wears glasses but requires text to be enlarged and positioned carefully for her to see it. Her hearing is within normal limits.

Claire has no useful speech. She vocalises when distressed or happy. She looks up for yes and down for no. She uses a Lightwriter with auditory feedback and her Speech and Language Therapist is exploring the use of an iPad. She can spell out sentences but this is very slow. She also uses idiosyncratic sign language which her family and carers understand. She appears to understand well and gets distressed when people talk over her.

Going to school exhausts her so she rarely does anything in the evening except watch TV. She has some friends at school but as they live far away she never sees them outside school. At times she gets very frustrated and angry. Her mother is very stressed – she is still going through legal processes re compensation.

Case study 6

Name	Akil
Age	16
Diagnosis	Autistic Spectrum Disorder
Context	Lives with parents, grandparents and 3 sisters

Akil attends a mainstream local school where he excels at maths. His comprehension is within normal limits for his age. He can speak but finds face to face interaction very difficult. He has some speech but prefers to use alternative methods of communication. He uses limited speech with his family but prefers to communicate using his iPad with Predictable in other situations. Using his Ipad he can communicate complex ideas but without it he struggles to express himself. His non-verbal communication (particularly eye contact) is poor. He has no difficulties with mobility or hand control. He has some sensory sensitivity to loud noises.

Akil is in the local cricket team. He goes regularly to the Hindu temple with his father. Most of Akil's social life revolves around his family and the Hindu temple. At school he keeps very much to himself but studies hard and is popular with his teachers.

He is generally content and happy to communicate with his iPad when required outside the family. He can get distressed at times when put under pressure to communicate. His family accept Akil well and are proud that he is doing well at school.

Case study 7

Name	Harry
Age	24
Diagnosis	Down's Syndrome
Context	Harry lives in a group home with 24 hour support. He has two flat mates who also have a learning disability. He attends a day centre 5 days a week. His parents live nearby and take him out every weekend.

Harry walks independently. He's a bit clumsy, particularly for fine motor coordination. He has a 'moderate learning disability'. Harry wears glasses for long distance vision. His hearing is within normal limits.

He understands simple ideas, mostly in the 'here and now'. He has difficulty making complex decisions about his life (e.g. employing his own carers).

Harry's speech is very dysarthric and very difficult to understand, although familiar listeners can tune in. Harry has a small communication book with PCS symbols organised into topic pages. He has been taught MAKATON but only uses one or two idiosyncratic signs. He often gets frustrated when people don't understand him and often 'loses' his communication book. Harry understands short sentences if they're supplemented with MAKATON signs. He communicates mainly in single words and by pointing. He needs to be encouraged to use his communication book.

Harry attends the day centre where he takes part in various groups, including Bingo, cookery and painting. In the evenings he watches TV and particularly likes football. At the weekends his parents take him to garden centres and the shops.

Harry is a loner and rarely joins in, either at the day centre or in his flat. He is very much loved by his parents, but he rarely sees his brother or his nephews who live nearby. Harry is prone to unpredictable outbursts, which staff find difficult to deal with.

Harry's family worry about his behaviour and what will happen in the future.

Case study 8

Name	Greig (see DVD)
Age	34
Diagnosis	Cerebral Palsy
Context	Lives at home with his Mum and Dad. He attends a day centre 4 days a week.

Greig has spastic quadriplegia and uses a wheelchair. He is dependent on others for all his ADLs. He has no hearing loss and wears glasses when using the computer. He has no intelligible speech and uses an Eco2 communication aid with LLL. He also communicates through gestures, vocalisations and facial expression. He uses his high-tech system at the day centre but not at home.

His comprehension is good and he has a good sense of humour. He is very involved in all aspects of day centre life.

He is always cheerful and appears well adjusted.

Case study 9

Name	Anne (see DVD)
Age	59
Diagnosis	MND
Context	Lives at home with husband. Her son and daughter live nearby and help with her care.

Anne was diagnosed with MND 10 years ago. She is physically totally dependent and needs support for all ADLs. She can use a switch with one knuckle to operate her lap top which has The Grid2 software. She has an environmental control system which she operates with a foot switch to control her TV.

She wears glasses and her hearing is within normal limits.

Anne's speech is severely dysarthric and only familiar people can understand her. She relies on family members to interpret for her. She uses her computer daily for emails, internet shopping, Facebook and Skype. She is very involved in all aspects of family life.

She goes on holiday with her son twice a year and she and her husband look after their grandchild 2 days a week. She goes out shopping with friends at the weekends and has lots of visitors to the house.

Case study 10

Name	Matthew (see DVD)
Age	64
Diagnosis	Stroke
Context	Lives at home with wife

Matthew had a severe stroke in 2007. He has a right hemiplegia and finds walking on rough terrain difficult. He wears glasses and his hearing is within normal limits. He has severe word finding difficulties and has both limb and oral dyspraxia. His yes and no responses are inconsistent and he has difficulty following conversation without support. His social skills are good and he often covers up his lack of understanding.

He uses a small communication book with symbols arranged in themes. He can say and write occasional words but these are inconsistent. He also uses his phone to take photos which he shows to his wife to let her know what he has been doing. He has a Springboard Lite which he rarely uses now.

Matthew has carers 2 days a week and attends a day centre 2 days a week (which he enjoys) and is at home on his own for 1 day. He is with his wife at weekends. He enjoys pottering in the garden, feeding the birds and going for a walk. He likes to be involved in planning holidays.

He is always cheerful and appears to be contented despite his severe communication difficulties. His wife finds their situation more difficult to deal with.

Appendix 5 Instructions and scoring sheet

Therapy Outcome Measure instructions and scoring sheet

You have been provided with 10 case studies to rate using the TOMs AAC. Three of the case studies (8, 9 and 10) are accompanied by a DVD which you should watch before you rate them. Please refer to the descriptors when rating the case studies. Although in the final version of TOMs AAC, you have the option to rate people with and without AAC, for the purposes of this exercise we would like you to rate them once, either as they are described or as you see them on the DVD clips.

Thank you!

Case study	Impairment-Physical	Impairment-Cognitive	Impairment – sensory - hearing and vision	Communication Impairment: Expression	Communication Impairment: Comprehension	Activity	Participation	Well-being
1 (Susie)								
2 (Angus)								
3 (Hannah)								
4 (Jenna)								
5 (Claire)								
6 (Akil)								
7 (Harry)								
8 (Greig)								
9 Anne)								
10 (Matthew)								