

# A critical appraisal of existing methods of measuring outcomes in relation to Augmentative and Alternative Communication

**Final Report** 

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# Disclaimer:

# 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 research projects which contribute to the delivery of the recommendations contained in the report. This document relates to one of the four research projects NES commissioned in the financial year 2012-2013. Together these research projects contributed to the delivery of action 1.1 of the report which is "Develop a National AAC Research Strategy" (Scottish Government, 2012: 3).

Over the next two years of the project NES will be funding further research as part of its work to improve provision for individuals who use AAC in Scotland. NES intends to use the findings of this and the other three research projects commissioned in 2012-2013 to inform and define future research needs through the identification of the most urgent research questions around AAC and its effectiveness

# August 2013

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# 1. 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). The guidance, which is aimed at service users, carers and professionals, includes 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.
- 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 research to critically appraise existing methods of measuring outcomes for use in AAC. In this report we provide a summary of this piece of work, outlining the methods used, results and recommendations for future research and development.

#### 2. Aims:

- To identify, explain and critically appraise a range of existing methods of measuring outcomes.
- To explain and critically appraise the application of these methods to AAC.
- To explain and critically appraise how the outcomes of AAC interventions are currently measured - within Scotland, the UK and internationally.
- To provide recommendations about how the outcomes of AAC interventions can best be measured and on any systems/processes which would be needed to implement/facilitate this.

#### 3. Methods:

This project is divided into four stages which are summarised in Figure 1.

Overview of Appraising methods of measuring outcomes in AAC 2. Synthesise findings 3. On-line survey for with CM outcome AAC practitioners (on measurement report outcome and Framework for measurements Measuring Impact currently in use) 4. Expert panel days 1. Carry out search for AAC practitioners and appraisal of (Feedback on findings published and grey Critical appraisal from literature review literature of methods of and survey). measuring outcomes in AAC -Final report and recommendations

Figure 1 Overview of the project

We will describe the methods used and results for each stage before summarising the findings and implications for future work.

# 3.1 Stage 1- Rapid review of the literature

We used rapid review procedures (Khangura et al 2012) to search and appraise the literature. This provided us with a systematic but targeted method of searching and identifying the literature. The questions for the review were:

- 1. Which Outcome Measures are used in Health, Education and Social Services?
- 2. What are the purposes of the measures?
- 3. How do these relate to AAC?
- 4. Are there any gaps in the literature?

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Searches were carried out on Google scholar, ASSIA and Cochrane reviews data bases
Google scholar, ASSIA and Cochrane reviews to identify which formal Outcome Measures
(OM) are used in Health, Education and Social Services. The following search terms were
used:



Following initial searches, inclusion and exclusion criteria were refined (see Table 1)

**Table 1 Inclusion and Exclusion criteria** 

Inclusion criteria	Exclusion criteria
Published between 1985 (1st AAC journal)	No formal Outcome Measures are discussed
and 2013	
Written in English	Outcome Measures relating solely to mental
	health
Peer reviewed	Relating to assessment or diagnosis rather
	than Outcome Measures
Formal Outcome Measures are discussed	
(we used the definition used in the	
Communication Matters report: 'tools used	
to assess change in a person over time. The	
type of measure would measure change in a	
specific aspect or aspects of a person's life'	
(CM 2012:4)	

# 3.1.1 Results

A total of 5121 papers were retrieved from the searches. Titles and abstracts were screened and obviously irrelevant papers and duplicates were deleted, leaving 141 papers. These were read in full and the following data was extracted:

#### Disclaimer:

Table 2 Data extraction of full papers

Author, Year	Country	Population	Outcome Measures

A categorisation framework was drawn up, guided by the framework for measuring impact website (<a href="http://www.measuringimpact.org/">http://www.measuringimpact.org/</a>) which suggests that outcome measures can be categorised according to their purpose and target audience. The process of categorisation proved to be challenging and there were several iterations before we were happy with our framework. The final version is outlined in Table 3.

Table 3 Categorisation of outcome measures identified in papers

Outcome	Purpose			Client	Generic?	Validated?	Useful
Measure				Specific?			in AAC?
	Client	Effectiveness	Efficiency				
	experience	Professional	Service				

A total of 72 different Outcome Measures were identified from the full papers. Of these, eight were global measures which could be used across different client groups. The remaining 64 measures were specific to particular client groups, either because they were designed for use with a specific disease or age group or because they were aimed at measuring particular patient or carer experiences. No specific measures for use with people who use AAC were identified. However, some of the global outcome measures had potential to be applied to AAC populations. The eight global outcome measures which we identified are summarised in Table 4, along with their applicability to AAC.

Table 4 Applicability of global Outcome Measures to AAC

Outcome measure	Purpose	Applicability to AAC	Limitations
AUSTOMS (Australian	Measures outcome in	Yes	Validated with an
Therapy outcome	terms of functioning		Australian
measure)	and participation		population
COPM (Canadian	Goal focused.	Yes	OT based outcome
Occupational	Measures perceived		measure. Language
Performance Measure)	change from client's		used may be
	perspective		inaccessible to
			other professionals
EQ5D	Non-disease-specific	Possibly	Very general
	instrument for		measure of health
	describing and valuing		and well being
	health.		
FIM/FAM	General measures of	No	Does not include
	functioning		communication
GAS (Goal Attainment	Goal focused outcome	Yes	Outcomes based on
Scaling)	measure		patient's perception
			of goal
			achievement.
Nottingham Health	Measure provides a	No	Does not include
Profile	brief indication of a		communication
	patient's perceived		
	emotional, social and		
	physical health		
	problems.		
TOMs (Therapy	Measures outcome in	Yes	Does not currently
Outcome Measure	terms of functioning		have questions
	and participation		relating to AAC

Table 4 shows some of the complexities inherent in trying to make comparisons between different Outcome Measures, not only because they are used for different purposes but also Disclaimer:

because they are designed to be used by various professionals. We are aware that from this literature search, we identified measures that are predominantly used by health professionals, and that other disciplines (such as educationalists and social workers) may use other outcome measures and may wish to measure things from different perspectives. This is one of the limitations of this literature review, but by combining our results with the other methods employed in this project we hope that we have gone some way to address this.

In summary, from this rapid review of the literature we found that:

- A wide range of outcome measures exist and the purposes and application of these vary;
- No specific Outcome Measure for AAC exists which can be used across client groups
- Some global Outcome Measures may be applicable to AAC.

Our next step was to synthesise the findings from our literature review with the findings from the Communication Matters Outcome Measures project. This is summarised in Section 3.2.

# 3.2: Synthesis of findings from literature review with Communication Matters Report and Framework for Measuring Impact

In September 2012, Communication Matters (CM) published a report on an Outcome Measures project. The aim of this was to:

"provide information to service providers and users in order to equip them with knowledge about tools that are appropriate to identify change associated with services and an individual's communication skills" (CM 2012:1).

The project was commissioned because it was recognised that AAC services should be measuring outcomes in order to provide feedback to clients, services and commissioners. The project took the form of a working group of AAC experts who met to identify and discuss commonly used outcome measures that were thought to be of use in AAC. In the report, Outcome Measures are identified and categorised according to their focus (what

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they are measuring), psychometric properties, the framework upon which they are based and whether or not they can be used in AAC.

The report highlights the following issues in relation to outcome measures in AAC:

- It is very difficult to distinguish between outcome measures and assessment. The report states that: "some assessments can act as outcome measures, but this is not always the case" (CM 2012: 6).
- Underlying conceptual frameworks can help inform our decision making when choosing outcome measures. Specific frameworks relevant to AAC were the International Classification of Functioning, Disability and Health (ICF) (WHO 2001) and Janice Light's Communicative Competency Framework (Light 1989).
- A total of 23 measures were identified and have been collated onto a table which summarises the purpose of each Outcome Measure and its applicability to AAC.

Although 23 measures were identified, many of them were assessments (such as Blackstone's Social Networks) or approaches to eliciting goals and aims (such as Malcomess' Care Aims) rather than outcome measures. This illustrates that outcome measures and assessments appear to exist on a spectrum and distinguishing between them is not straight forward. The fact that sometimes, assessments can be used as outcome measures further complicates the picture.

The CM report highlights that outcomes should collect data at different levels. These can be aligned according to the Framework for Measuring Impact which helps us identify which measures we need to choose for different purposes (Table 5):

Table 5 Different levels of outcome measures

From CM report	From Framework for Measuring Impact
At the level of the client:	
to inform interventions;	Patient experience measures;
to measure change over time;	Effectiveness measures
to measure impact of interventions	
At the level of the service:	Patient experience measures;
to monitor service delivery	Effectiveness measures
At the level of the purchaser/commissioner:	
to establish benefits of service;	Effectiveness measures

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areas.

The CM report and the results of our literature review provide us with useful information about outcome measures in AAC. Four global outcome measures were identified from the CM report which could be applied to AAC: COPM, GAS, TOMs and AUSTOMs. We identified these as well as an additional measure (EQ5D) in our literature review. The EQ5D is likely to be of limited value in measuring AAC outcomes because it is very general in nature and is therefore unlikely to pick up changes due to AAC interventions.

From the literature review and the CM report it has been possible to identify which Outcome Measures have the potential to be used in AAC. However this did not provide us with information about what AAC practitioners are using in practice. In order to find out about current practice, we conducted a survey, which is outlined in section 3.3.

# 3.3 Online Survey

In order to find out what AAC health, education and social work practitioners do in practice in relation to measuring outcomes in AAC, we designed an online survey. This was sent out to people working in AAC in Scotland, the rest of the UK and internationally. We used our existing networks, including Facebook and Twitter in order to reach as many people as possible. As we were conducting this project within a limited timescale, the survey was 'live' for the period of one week only ( $1^{st} - 8^{th}$  March 2013). The survey questions are included in Appendix 1, but covered the following areas:

**Demographic information:** (Professional background, geographic location, sector); **Knowledge of outcome measures in AAC; use of outcome measures and strengths and limitations of outcome measures in AAC.** 

#### 3.3.1 Results

We sent the survey out by email to over 246 people from the UK and internationally using our own as well as ISAAC networks. We also used social media to publicise the survey. These proved to be effective methods of dissemination as within one week 153 people had completed the survey. Figure 2 shows the range of professionals who took part.

#### Disclaimer:

Please indicate which sector/s you work in

80 %

60 %

40 %

343 %

13.6 %

13.6 %

Health Education Social Work Research Voluntary

Figure 2 Range of professionals taking part

The majority of respondents were from Scotland, but people from the rest of the world, including North America, Scandinavia and China also took part. Over 70% were Speech and Language Therapists which is to be expected as we specifically targeted people working in AAC.

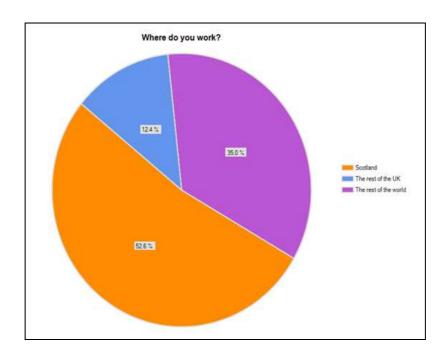


Figure 3 Geographical location

# Disclaimer:

Most respondents were Speech and Language Therapists, which reflects the main professional group who provide AAC services.

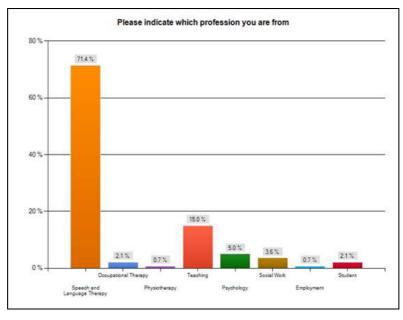


Figure 4 Professional background

Respondents were asked to rate the extent of their knowledge of Outcome Measures in AAC. As Figure 5 shows, most people said that their knowledge was 'not at all extensive', and only 7.2% felt they had very extensive knowledge about this subject.

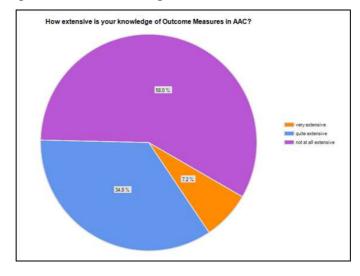
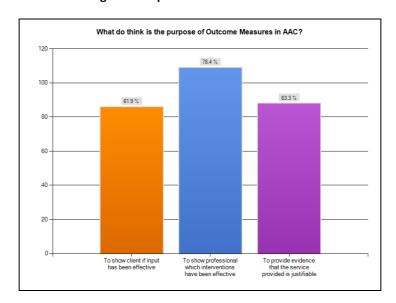


Figure 5 Extent of knowledge about Outcome Measures in AAC

When asked about the purpose of outcome measures, people felt that it could be used for different reasons: to provide feedback to clients, professionals and services. Most people felt that Outcome Measures could be used for at least two of these purposes.

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**Figure 6 Purpose of Outcome Measures** 

Respondents were asked to name which Outcome Measures was most used for AAC in their workplace. 109 people answered this question. Table 6 shows the range of measures that were identified.

**Table 6 Main Outcome Measure used Table in workplace** 

Outcome Measure used	Numbers	Outcome Measure used	Numbers
None used	59	AFROM	1
TOMs	14	Functional communication	1
Care Aims	10	Emotion Talks	1
Talking Mats	7	Subjective impressions	1
GAS	6	East Kent Outcome Scale	1
CODES Framework	4	Sarah Blackstone's social	1
		networks	
Battery of language	3	List of signs	1
assessments			
Goal setting	3	Talking Points	1
In-house assessments	2	Vases	1
EFFC	2	Carer Feedback	1
СОРМ	1	Activity Card sort	1

The responses from this question are of particular interest and suggest that many people are not currently using Outcome Measures when working with people who use AAC. The measures that people did identify indicate that outcome measures is poorly understood. For example, ten people indicated that they use 'Care Aims' as an outcome measure. The Care

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Aims approach was developed by Kate Malcomess

(<a href="http://www.careaims.com/index.php?page=home">http://www.careaims.com/index.php?page=home</a>) as a model to support therapists in their clinical decision making and was not developed as an outcome measure. Many people stated that they used a combination of measures, some of which were based at the level of the patient, involving shared goal or target setting. Others used informal methods, some developed in-house, in combination with more formal, standardised measures. Enderby's Therapy Outcome Measure (TOMs) was the most widely used measure identified. Respondents were asked how frequently they used Outcome Measures. The majority of people who named an outcome measure said that they did not use it with clients who used

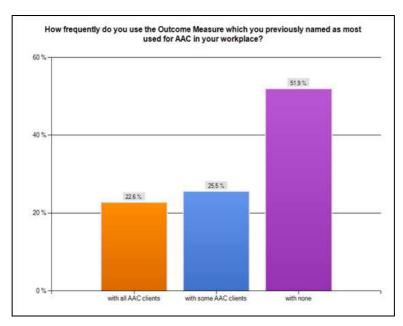


Figure 7 Frequency of use

Although many people said that they did not use Outcome Measures routinely in practice, most people felt that there was value in measuring outcomes for clients, professionals and services. However, there appears to be a discrepancy between what people believe and what they report that they do in practice. People were given the opportunity to tell us more about the strengths and limitations of outcome measures as well as give suggestions for improving how outcome measures are used in practice. We report on comments made by respondents in section 3.3.2.

#### Disclaimer:

AAC (Figure 7).

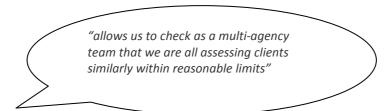
#### 3.3.2 Comments from participants

Respondents made comments in response to the free text questions which are outlined below:

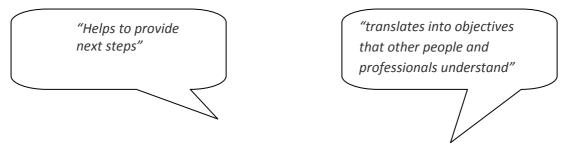
- Please describe the strengths of the Outcome Measure (most used for AAC) in your work place.
- Please describe the limitations of the Outcome Measure (most used for AAC) in your work place.
- Do you have any suggestions for improving how Outcome Measures are used in AAC? People were asked to respond to the questions by relating their answers to the particular outcome measure which they had identified earlier in the survey. We analysed the comments from respondents using Framework analysis (Lacy and Luff 2001) which enabled us to organise the data onto charts which were then indexed and grouped into themes. We report on each question separately, drawing out the main themes and also any particularly relevant exceptions.

# a. Strengths of Outcome Measures used in AAC

People felt that the use of outcome measures helped them to communicate with others in the multidisciplinary team and provided a common language and standard for assessment and therapy:



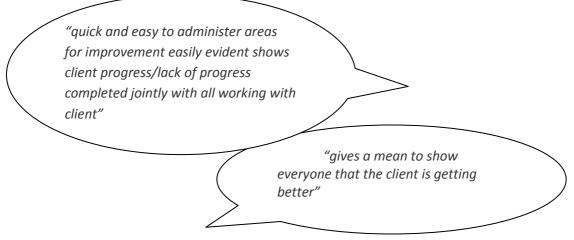
The majority of respondents regarded outcome measures as part of the assessment process, and said that the main benefit of using an outcome measure was to guide therapy, as these comments suggest:



As we have seen from the Outcome Measures named in the survey, it would seem that professionals do not always make a distinction between assessment and outcome Disclaimer:

measures. They appear to regard outcome measures as part of the assessment process which is used to guide decision making and inform therapy rather than to measure change in specific areas of a person's life over time.

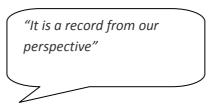
People believed that the main benefit of using Outcome Measures was as a method of providing feedback for therapists, clients, families and services:



However, many of these comments related to the fact that professionals were using client centred goals as a form of outcome measurement, rather than more objective, validated outcome measures.

#### b. Limitations of Outcome Measures used in AAC

Respondents highlighted that some of the measures they used were only meaningful to Speech and Language Therapists and therefore results could be not always be usefully shared with other members of the multidisciplinary team:



Other comments highlighted that it can be difficult to consistently use Outcome Measures across professional groups and settings:

"Others can see the areas needing developed but can be slow to act, relying on SLT for intervention when a holistic approach is required"

"not consistently used in social settings"

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The issue of sensitivity of available Outcome Measures for use in AAC was highlighted as a limitation:

"May not be sensitive enough but it is what we have"

"Quite big jumps between levels- so intervention may look ineffective even though the client has made progress"

Other people appeared frustrated by the subjectivity and lack of standardisation of some the Outcome Measures which they were using, and suggested that this made it difficult to prove that their interventions were effective.

"Not formalised or recognised by employer"

"It doesn't give an actual objective score unless used with another tool"

"Not formally evidence based or standardised. Difficult to prove effectiveness if measured against others"

Although many people used informal goal setting and Goal Attainment Scaling to measure outcomes, they did comment on the limitations and difficulties of using these methods for measuring outcomes. It was also acknowledged that systems such as 'Care Aims' were not developed or intended to be used as outcome measures.

"Observations about risk/impact being lowered are all subjective. System is designed for caseload management not purely a system for outcome measures so this part is limited"

As with all outcome measures, it's mostly a measure of how good you are at setting goals!

"Accuracy/sensitivity is subjective to ability of SLT to write SMART objectives effectively"

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There was an overwhelming belief that existing Outcome Measures were not useful for measuring the impact of AAC interventions.

currently we do not have an outcome measure that would be applicable. "no way of demonstrating outcomes with different types of AAC"

Several people mentioned that Pam Enderby's Therapy Outcome Measure (TOMs) is currently being adapted for use with an AAC population. This was seen as a very positive step, and something that many people welcomed and would like the opportunity to try using in practice.

c. Suggestions for improving how Outcome Measures are used in AAC

Many people felt that the topic of Outcome Measures in AAC was an important one and that there should be a standardisation and sharing of ideas across AAC practitioners regarding best practice. This was something that people were in agreement within the UK and further afield:

"More international networking - a EUproject with focus on developing a webbased structure/a database to be used in European countries" "Sharing practice and tips across the AAC community"

People recognised that their own knowledge and use of Outcome Measures was limited and they identified the need for a framework to guide professionals in their choice of appropriate Outcome Measures.

"Recommendations for more thorough outcome measures would be useful" "A nationally recognised framework developed specifically to record outcomes for all AAC methods to be used by all who use it, including all voluntary organisations"

There was also recognition of the need for clarity about what Outcome Measures are, what they are measuring and who feedback should be aimed at. Although many people expressed frustration that existing Outcome Measures could not be applied to AAC populations, some people felt that global measures *should* be applicable to AAC populations:

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"Develop one specifically for AAC" "They should not be any different to the outcome measures used across other client groups"

Overall there was agreement that the use of Outcome Measures in AAC is at best variable and at worst non-existent. Respondents welcomed this project as a way of helping the AAC community develop its understanding of use of Outcome Measures.

"I think in reality, outcome measures are still sparsely used, and we are in real danger of not demonstrating what we do"

The survey has provided us with useful information regarding current practice and given us an insight into professionals' understanding of Outcome Measures. Our next step was to combine insights from the literature review, the CM report and the survey. We presented our findings to two expert panels so that the issues arising could be discussed in detail. This process and conclusions from the expert panel meetings are discussed in section 3.4.

# 3.4 Expert panel meetings

AAC practitioners from Scotland were invited to attend one of two expert panel meetings. All those who attended were Speech and Language Therapists, highly specialist in AAC. The aim of the meetings were to provide a forum to enable experts in the field of AAC to discuss and reflect on the issue of Outcome Measures in the light of findings from the literature review, the CM report and the survey. Participants were identified through the Link Therapy network at SCTCI (Scottish Centre for Technology for the Communication Impaired) and through the designated AAC leads throughout Scotland.

Six people attended the first meeting and seven the second meeting.

The agenda for both meetings was the same:

- Feedback on the Communication Matters report
- Feedback on progress to date:

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- o Results of the Literature review
- o Results of the Survey
- Why do we need to measure outcomes?
- Which existing measures are useful in AAC?
- Are there particular challenges for measuring outcomes in AAC?
- Where to next?

Both sessions promoted lots of discussion between participants. The emphasis of each meeting was slightly different and discussions are summarised in tables 8 and 9.

Table 7 Summary of discussions from first expert panel meeting

Topic	Main points
Discussion about	A first stepping stone on the way to identifying and agreeing OMs for use in AAC.
CM report	Has shown us the shape and size of the problem.
	The topic of outcome measures is important and needs to be addressed.
	One of the drivers for the CM project was that OMs might be imposed on us.
<b>General comments</b>	There was agreement that we need to embrace some kind of OM in order to demonstrate that what we do is effective. The
about outcome	importance of planning ahead (or 'thinking forward') was emphasised and a fear was expressed that if we don't agree on
measures	useful OMs, we might have them imposed on us.
	It was acknowledged that OM is not just a matter for people working in AAC – it is also an issue in general SLT services plus a
	wide range of other settings. People felt that OMs need to be applicable across agencies, especially in relation to education
	where the Doran report (which is outcome led and will lead to strategic commissioning of services) will have an impact over
	the next 5 years. This led to discussion about terminology (in education, GIRFEC (Getting it Right for Every Child) and
	Curriculum for Excellence language needs to be incorporated into OMs so that other professionals can relate to, understand
	and contribute to OM).
	We need a consistent approach to using OMs.
	OMs are also useful for demonstrating what does and what does not work.
What is an	There was much discussion around this – and broad agreement that an OM should measure a change from point A to point B.
outcome	However, people had concerns about ensuring that contextual factors are taken into account and also ensuring that the OM
measure?	measures are sensitive to showing the effects of AAC interventions.

Topic	Main points
	There is confusion about the difference between assessment and outcome measures.
What do we need	There were some discussions about whether or not we need a specific AAC OM, but again the importance of doing this using
in AAC?	terminology which could be used and understood across agencies was highlighted. Now might be a good opportunity to
	develop something that's fit for purpose.
	It was felt that it would be important to measure the impact of AAC – so an OM that measuring how people
	communicate/function with and without AAC was felt to be useful. This led onto discussion about the TOMs for AAC which is
	currently being developed and piloted.
	We need to be clear why we are using OMs. There was agreement that we might use them for several different reasons.
Potentially useful	CODES framework (Competency, Opportunity, Driving communication forward, Engagement and Skill acquisition) – based on
frameworks	Janice Light's communicative competencies and the Canadian Model of Occupational Performance and Engagement.
	The group felt that this was a possible assessment/measure which might be useful, and certainly helps partnership working
	(but was developed for use with children – so may not be transferrable to other settings). It was agreed that we should
	contact KEYCOMM about CODES and find out more about it and whether or not it can be used as an OM.
	TOMs (AAC version)
	This was discussed at length, and there was agreement that it would be worth finding out if we could pilot it in Scotland.
	There was some concern that the terminology used in the TOMs would not be transferrable to education – the word 'therapy'
	may put teachers/social worker etc. off.
	There was some discussion about the rating scale and whether or not it was sensitive enough to pick up small changes –
	perhaps the pilot will clarify this. It was also felt that it would be important to have worked examples to help people with
	scoring.
	We tried out the AAC TOMs with two imaginary patients (an adult and a child) to see if it worked and it did seem to work.

Topic	Main points
	East Kent Outcome Scales
	This was discussed as a possible Outcome Measure.
Suggestions for	Need to consider how OMs could be used by other agencies.
report	Terminology and definitions – there is confusion about what we mean by outcome measures and how this differs from
	assessment. If we can't agree on what an OM is, we won't be able to agree on the best one to use.
	Also what we mean by communication may not be what other people mean (e.g. in education, communication might be
	interpreted as how schools communicate with parents, etc.).
Action points	Contact University of Sheffield about piloting the AAC TOMs
	Contact KEYCOMM about the CODES framework
	Send conclusion in report to panel members for comments
Future projects	Ask people who are routinely using OMs what their experience is and how useful the measures they use are (possible)
	recommendation for the report?). A starting point could be to contact the Outcomes Google group.

Table 8 Summary of discussions from second expert panel meeting

Topic	Main points		
What is an	There was a lot of discussion about OMs versus assessments and some people felt that assessments could be used as OMs. During the		
outcome	meeting we agreed on eight features that could be used to identify an Outcome Measure. Outcome Measures should		
measure?	<ul> <li>Measure change</li> <li>Are repeated over time</li> <li>Can be used across clients, settings and disciplines</li> <li>Can be used to give feedback to services, professionals, carers and clients (about what works as well as what doesn't)</li> <li>Are robust/standardised/well respected</li> <li>Inform discharge</li> <li>Are short and straightforward to use</li> </ul>		
	Allow for comparison with different types of AAC/No AAC		
What are we	We may be measuring a change in well-being rather than a change in functioning		
measuring?	<ul> <li>Need a measure that takes account of the impact of the environment</li> </ul>		
What do we need in AAC?	Debate about whether we need a specific AAC OM or have an OM that works for all clients		
Partnership working	<ul> <li>Terminology needs to work across disciplines. Need to consider curriculum for excellence and GIRFEC as well as social care terminology</li> </ul>		
Potentially useful frameworks	• <b>CODES</b> – is this an assessment, an OM or both? It provides a detailed account of what the client can do and provides guidance on interventions. Can be repeated.		

Topic	Main points
	TOMs (AAC version)
	It was felt that it would be good to explore this, as it seems to be applicable across different AAC users and is also something
	that could be used with a non-AAC case load. Potential problem is that the language used is health based
	Care Aims (Malcomess) was mentioned many times, but it was agreed that this is not an OM (more of a process).
	The East Kent Outcome Scales were also discussed, but again people felt they were more about process than outcome
	measures.
Action points	Contact University of Sheffield about piloting the AAC TOMs
	Contact KEYCOMM about the CODES framework
	Send conclusion in report to panel members for comments
Future projects	Explore trying the TOMs (AAC) and comparing it with CODES – how feasible are they to use. How satisfied are people with
	them? Is TOMS sufficiently sensitive to pick up changes?
	We need clarity about what an OM is and why we use them

#### 4. Limitations

The project had to be carried out within a very short time scale (28<sup>th</sup> January 2013 – 28<sup>th</sup> March 2013).

This necessitated the literature search being carried out as a rapid review rather than fully comprehensive. The focus was predominantly on Outcome Measures in Health which reached saturation levels but we obtained limited responses in education and social work. This could be an area for future research.

The survey was restricted to responses received within one week. However we were pleased with the number and quality of responses. Several respondents, both in the UK and abroad, indicated that they would be interested in having further discussions and input.

The time scale did not allow a lot of time for expert panel attendees to fit the meetings into their busy diaries. There are other 'experts' whose views we would welcome.

There was not time to examine in depth how Outcome Measures are being used in day-today practice with a range of clients, practitioners and service managers.

The two most favoured Outcome Measures are not fully developed and need to be examined more fully.

# 5. Summary

The project's aims have all been achieved.

#### 5.1 Literature search

The literature search identified that a wide range of outcome measures exist and that the purposes and application of these vary. No specific Outcome Measure for AAC exists which can be used across client groups but there are some global Outcome Measures may be applicable to AAC.

#### **5.2 Communication Matters report**

An examination of the Communication Matters report identified a lack of distinction between outcome measures and assessments. The fact that sometimes, assessments can be used as outcome measures further complicates the picture. The CM report highlights Disclaimer:

that outcomes should collect data at different levels. These can be aligned according to the Framework for Measuring Impact which helps us identify which measures we need to choose for different purpose

From the literature review and the CM report it has been possible to identify which Outcome Measures have the potential to be used in AAC.

# 5.3 On-line survey

Although many people said that they did not use Outcome Measures routinely in practice, most people felt that there was value in measuring outcomes for clients, professionals and services. However, there appears to be a discrepancy between what people believe and what they report that they do in practice. Overall there was agreement that the use of Outcome Measures in AAC is at best variable and at worst non-existent. Respondents welcomed this project as a way of helping the AAC community develop its understanding of use of Outcome Measures.

# 5.4 Expert panel discussions

These were very fruitful and clarified the following:

- The difference between Outcome Measures and assessment.
- What are we measuring and who are Outcome Measures for?
- Which existing measures are useful in AAC?
- Conclusions for report and next stepping stones

# 6. Recommendations

#### 6.1 Definition

There is a need to establish a clear definition of what is meant by 'Outcome Measures'. A preliminary group of features was identified from the panel discussions.

#### Outcome Measures should:

- Measure change
- Are repeated over time
- Can be used across clients, settings and disciplines
- Can be used to give feedback to services, professionals, carers and clients (about what works as well as what doesn't)
- Are robust/standardised/well respected
- Inform discharge
- Are short and straightforward to use
- Allow for comparison with different types of AAC/No AAC

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We propose that these form the basis of future work to establish a useful definition.

#### **6.2 Terminology**

There is a need for terminology that is both consistent and that will be relevant across disciplines, not just for Speech and Language Therapy.

#### 6.3 Most useful Outcome Measures

It was felt that the most useful Outcome Measures appear to be the TOMs –AAC version and CODES. As these are both still in the development phase the panel members suggested that it is both timely and pertinent to contact both Pam Enderby (TOMs) and Debbie Jans (CODES) to discuss their work and share the findings from this project.

Meetings have been arranged with both Pam Enderby and Debbie Jans in April 2013 to take this forward. An appendix to this report will be produced following these meetings

#### 7. Conclusion

Outcome Measures in AAC is an important topic, but poorly understood and defined.

The literature review, online survey and expert panel findings indicate that there is a need to determine a definition of Outcome Measures, examine terminology and look at existing measures (CODES and TOMs for AAC) which offer promise.

All of these are areas for future research.

# 8. References:

- Communication Matters (2012)
   http://www.communicationmatters.org.uk/sites/default/files/downloads/standards/aac
   outcome measurement sept 2012.pdf
- Framework for Measuring Impact <a href="http://www.measuringimpact.org/">http://www.measuringimpact.org/</a>
- Scottish Government (2012) 'A Right to Speak'
   http://www.scotland.gov.uk/Publications/2012/06/8416/0
- Lacey, A. & Luff, D. (2001). Trent focus for research and development in primary health care: An introduction to qualitative analysis. London: Trent Focus.

#### Disclaimer:

- Khangura et al 2012 Evidence summaries: the evolution of a rapid review approach
   <a href="http://www.systematicreviewsjournal.com/content/1/1/10">http://www.systematicreviewsjournal.com/content/1/1/10</a>
- TOMS: Enderby P., John A., & Petheram B. (2006) Therapy Outcome Measures for Rehabilitation Professionals: Speech and Language Therapy, Physiotherapy, Occupational Therapy, Rehabilitation Nursing & Hearing Therapists. Second Edition, John Wiley & Sons Ltd.
- CODES: http://keycomm.weebly.com/codes-framework.html