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Communication Matters Research Matters:
an AAC Evidence Base research project – final report

Shining a light on Augmentative and Alternative Communication

Manchester Metropolitan University
The University Of Sheffield.
Barnsley Hospital NHS
NHS Foundation Trust
BIG LOTTERY FUND
LOTTERY FUNDED

Front cover

The late Alan Martin, a user of a communication aid and a Co-researcher in the project at Manchester Metropolitan University, creating one of his light art pictures, by dancing in his wheelchair whilst holding various light sources.

Picture courtesy of photographer Ian Hobson and Alan Martin's family.

Acknowledgements

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Communication Matters would like to thank our collaborators who have worked so hard to ensure that this research resulted in knowledge that could benefit people who use Augmentative and Alternative Communication, specifically: Professor Pam Enderby, Dr Sarah Creer, Dr Alex John and Dr Susan Baxter of the University of Sheffield; Dr Janice Murray, Michelle Beech and Alan Martin from Manchester Metropolitan University and Simon Judge from Barnsley Hospital NHS Foundation Trust.

We would also like to thank the many hundreds of people across the UK who have been involved in the AAC Evidence Base research project, including people who use Augmentative and Alternative Communication, family members and carers of people who use AAC, speech and language therapists, occupational therapists and other professionals, education staff, academics, companies and charities. Without your contributions this research would not have been possible.

Our thanks go to the members of the Independent Research Panel who continue to provide oversight, support and advice for Communication Matters' research activities; and to Liz Moulam who saw the research through from idea to grant application and got the project off the ground in its first months.

A final thank you to Katie Holmes, Research Manager, who has managed the day to day operations of the project for its entirety; David Morgan, who acted as Research Lead; Mike Clarke who was the Trustee with lead responsibility for the project; and Tom Griffiths for acting as liaison with the trustees over the final report.

We would like to dedicate this report to the late Alan Martin, Co-researcher at Manchester Metropolitan University, for his support and insight throughout this project.

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1 Introduction

What is Augmentative and Alternative Communication?

The term Augmentative and Alternative Communication (AAC) covers a huge range of techniques which support or replace spoken communication. These include gesture, signing, symbols, communication boards and books, as well as powered and computerised devices such as voice output communication aids (VOCAs).

The idea behind AAC is to use the person's abilities, whatever they are, to compensate for their difficulties and to make communication as quick, simple and effective as possible when speech is impaired.

Enabling people to communicate improves their quality of life. It offers people new opportunities in their education, social life and friendships, and helps to increase their independence.

Who uses AAC?

Some children and adults find communication difficult because they have little or no clear speech. There are many reasons why this might be the case including a congenital disability such as cerebral palsy, or an acquired disability such as Parkinson's disease, stroke or brain damage following an injury.

Communication Matters

Communication Matters is a UK charity that helps people of all ages and ability who need to use AAC. One of the charity's core strengths is its diverse membership which reflects the wider community of people who have an interest in AAC. Members include people who use AAC, family members and carers, professionals, academics, special schools, charities, and commercial suppliers of AAC equipment and services.

This stakeholder base is an important underpinning theme in the AAC Evidence Base research project and all stakeholders were involved in determining the research priorities and in shaping the research work. Communication Matters aimed to commission research that would deliver benefit for people who use AAC and their families as well as professionals and researchers.

AAC definitions developed during the research

Augmentative and Alternative Communication (AAC)	AAC covers a range of strategies, equipment, systems, methods and techniques used by people who have impairments of speech, language or communication. These approaches may be unaided or aided and used to augment or provide alternative approaches that utilise visual, spoken and written mediums. It can include use of eyes, facial expression, gesture, signing, symbols, communication boards or books and technology-based systems such as voice output communication aids. AAC may incorporate the integration of different systems.
Unaided communication	Unaided communication is a subset of AAC which refers to those methods of communication which do not involve additional equipment, such as signing, body language, eye pointing, facial expression and gesturing.
Aided communication	Aided communication is a subset of AAC which refers to those methods of communication which involve using additional equipment, such as picture, symbol, letter or word boards or books and technology-based systems such as voice output communication aids. This may be used alongside speech and unaided communication.
Low-tech aided communication	These systems are those which do not require power to function such as picture, photo/symbol, letter or word boards or books. It can also include objects of reference, or the use of everyday objects that support communication.
High-tech (powered) aided communication	These technology-based systems are those which require some power to function, ranging from systems such as single recorded message output devices to more complex systems which take text or symbol input and produce a speech output.
Communication aid	A communication aid is a piece of equipment which helps a person to communicate. These aids range from letter, word, symbol or picture boards to any technology-based system such as a voice output communication aid.

The terms ‘powered aided communication’ and ‘powered communication aids’ are used in this report in preference to ‘high-tech’.

Why was this research needed?

> ‘Without communication no-one can ever really know you[1].’

Communication is an essential life skill, central to interaction and vital for development, helping to reduce social isolation.
Communication is a universally recognised human right. The UN Convention on the Rights of Persons with Disabilities[2] recognises AAC as a method of communication and includes an obligation to promote the availability and use of new technologies including AAC.

Despite this people with severe communication impairment are often denied the resources and support that could enable them to communicate more with the people around them. Their needs may not be understood or even acknowledged, and there is a lack of knowledge about how best to meet needs.

> ‘Communication is crucial. Recognising that is right in terms of equity for those in need and right in the national interest as we all wish to cut the costs of failure and to increase the productiveness of our country.’
>
> Bercow, 2008[3]

In order to improve services it is important to gather basic information to assist those commissioning services and providing services to determine what is needed and how provision could be improved.

> ‘A consistent recommendation from the studies, literature reviews and sector analysis that has been undertaken is the requirement for better data collection to create a robust evidence base to inform good practice and good commissioning of services.’
>
> Office of Communication Champion, 2011[4]

The research undertaken by the University of Sheffield in collaboration with Barnsley Hospital aimed to provide robust evidence of how many people in the UK could benefit from AAC and to provide for the first time a picture of current AAC service provision in the UK.
In order to improve understanding of the needs of people who could benefit from AAC and of how best to meet those needs, best practice, knowledge and evidence should be shared.

The research undertaken by Manchester Metropolitan University aimed to develop a website that would make knowledge and evidence about AAC accessible to a wide audience, enabling professionals to improve their practice and empowering individuals to make more informed choices.

In order to advance knowledge in the field of AAC Manchester Metropolitan University was commissioned to create a template for gathering case study data, which would capture evidence of best practice and make group data available to researchers.

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[1] Martin Pistorius, ‘Communication: An AAC User’s Perspective’, Communication Matters Conference 2011

[2] http://www.un.org/disabilities/

[3] The Bercow Report: A Review of Services for Children and Young People (0 – 19) with Speech, Language and Communication Needs, 2008

[4] Specialised AAC provision, Commissioning national services, Office of the Communication Champion and Council, November 2011

The UK policy context

This research is part of a wider wave of campaigning activity which has built up over the past 10 years and has involved many organisations, including Communication Matters, pressing for changes to improve AAC services across the UK. This tide of change has contributed to significant developments in Government policy during the project.

The publication of this research is particularly timely as it delivers essential, hitherto unknown, evidence needed to underpin campaigning, policy development and the commissioning of services.

In 2007 the Government commissioned John Bercow MP to conduct a review of services to support children and young people (0-19) with speech, language and communication needs in England. His report, published in 2008[5], made forty recommendations, including the development of a centrally coordinated 'hub and spoke' model of regional AAC provision. The Labour government adopted most of these recommendations when it published its Better Communication Action Plan[6].

Bercow's report and the subsequent work of the Communication Champion, Jean Gross CBE, identified that there was no consistent system for ensuring that those who need communication aids received them. Although there were examples of good practice many local areas failed to make effective provision.

During the AAC Evidence Base project the Government proposed and passed into law a significant reorganisation of the NHS which included fundamental changes to the commissioning of all NHS services (the Health and Social Care Act 2012).

The Communication Champion recommended that in England the new NHS Commissioning Board should commission regional AAC 'hubs' to act as centres for specialist provision of AAC and assistive technology. The hubs would provide 10% of services and provision and local AAC services (the 'spokes') commissioned by Clinical Commissioning Groups would provide the remaining 90% of services and provision. Subsequently the Manual for prescribed specialised services published by the NHS Commissioning Board[7] specified that the Board would commission services for patients that require specialist assessment for AAC aids. In June 2012 the Department for Education commissioned four regional groups to work to support the transition to the new commissioning model in England.

The Welsh Government commissioned a review of communication aids services that was published in 2011. It recommended the implementation of an expert 'hub' service supporting local services across Wales. This was subsequently scrutinised by an expert panel drawn from Health, Education and Social Services which upheld the findings of the review. The Scottish Government commissioned a review of AAC services and in 2012 it announced the roll-out of new guidance to improve services for people who need AAC, supported by £4m of funding to health boards.

The wider context – a period of change

This project took place during a period of significant change in health and social care which presented the researchers with several challenges. For example it was difficult to undertake a large-scale data collection in England in the midst of a major reorganisation of the NHS. However, change also presented us with opportunities. The project has been able to access data from the Scottish and Welsh reviews and to share research data and methods, having a direct impact on the development of new commissioning models. We have also been able to use links to other projects to broaden the reach of our dissemination activities.

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[5] The Bercow Report, A Review of Services for Children and Young People (0 – 19) with Speech, Language and Communication Needs, 2008

[6] Better Communication, An action plan to improve services for children and young people with speech, language and communication needs, 2008

[7] Manual for prescribed specialised services, November 2012

2002	• Communication Aids Project started and ran for 4 years, providing communication equipment for more than 4,100 children in England
2007	• Start of campaign to improve the provision of AAC services in Scotland led by Royal College of Speech and Language Therapists, Capability Scotland and AAC in Practice
2008	• Scope No Voice, No Choice campaign • Publication of Bercow Review of Services for Children and Young People (0 – 19) with Speech, Language and Communication Needs • In response to the Bercow Review the Government publishes its 'Better Comunication Action Plan'
2010	• Jean Gross starts work as Communication Champion for children (England)
2011	• National year for communication in England – the Hello campaign • Office of the Communication Champion and Council publishes a report on specialised AAC provision and a model service specification, proposing the implementation of a 'hub and spoke' model for commissioning • Welsh review published: 'A review of Current Service Provision: Communication Aids'
2012	• AAC is included in the 'Manual for prescribed specialised services' published by the NHS Commissioning Board • Scottish Government publishes 'A Right to Speak – Supporting Individuals who use AAC' and makes funding available to support the implementation of its recommendations

2 Executive summary

The outcomes agreed with the Big Lottery Fund for this research project were:

- Increased awareness in the UK relating to prevalence of need for AAC
- Increased understanding of the current provision of AAC in the UK
- Improved access to best practice evidence to support early identification and intervention for people of all ages who need AAC

Furthermore the Big Lottery Fund's Research Grant Programme aims to improve the research capacity and expertise of voluntary and community organisations, enabling them to influence the research agenda and engage in further research in partnership with others.

The prevalence of need for AAC in the UK

This research was carried out by the University of Sheffield in collaboration with an honorary researcher from Barnsley Hospital NHS Foundation Trust.

The overall potential need for AAC and powered aided communication was estimated through epidemiological investigation – making estimates of the need for AAC based on figures from the literature and consultation with experts working in the field.

We estimate that just over 0.5% of the UK population could benefit from some type of AAC. This equates to 529 people per hundred thousand population. The population of potential AAC users has a broad range of often complex conditions (where an individual has more than one impairment or difficulty) with different underlying medical diagnoses.

We estimate that approximately 0.05% of the UK population could benefit from powered communication aids. This is likely to be a low estimate given the rapid advances in technology and changing demography.

Our survey of AAC services suggests that the number of people who have access to powered aided communication services is much lower than the 0.05% estimate of need.

Nine conditions account for 97.5% of the total number of people who could benefit from AAC (in order): Alzheimer's/Dementia; Parkinson's; Autistic Spectrum Disorder; learning disabilities; stroke; cerebral palsy; head/brain injury; Profound and Multiple Learning Disabilities; motor neurone disease. Two of these conditions, Alzheimer's/Dementia and Parkinson's, account for nearly half of the total (45.9%).

Current AAC service provision in the UK

This research was carried out by the University of Sheffield in collaboration with an honorary researcher from Barnsley Hospital NHS Foundation Trust.

It provides, for the first time, a picture of current AAC service provision in the United Kingdom. It is based on the analysis of data returned from a wide-ranging survey of UK services. The survey methodology has been developed into a tool that can be used to map and audit services in future. The research found that there is little consistency in the elements or components of service provision of any of the teams delivering AAC in the UK, each having their strengths and weaknesses.

In addition, the research has generated a framework of the components that make up an AAC service, including the provision of powered aided communication. This is based on both quantitative and qualitative research involving people who use AAC, their family members and carers, and the professionals who work with them. As a result, the components reflect not just what professionals regard as important but also what is valued by the people who are using the services. These stakeholder groups were also involved in agreeing definitions for each of the service components and for common AAC terminology. This is a significant contribution to the field as it will allow service providers and commissioners to describe, stipulate and monitor local and specialist provision.

There was consensus between professionals, people who use AAC and their communication partners that all service components were required to facilitate effective assessment of need, and provision and use of AAC.

The qualitative research data provides a 'snapshot' of people's experiences of accessing AAC services and their perceptions of what should be provided. Funding arrangements for services and equipment was the issue of concern most commonly raised by people who use AAC, communication partners and professionals.

Improved access to best practice evidence – the AAC Evidence Base website

This part of the research was carried out by Manchester Metropolitan University. The AAC Evidence Base website (www.AACknowledge.org.uk) brings together knowledge and research evidence about AAC in one place and aims to make it accessible to a wide audience.

Manchester Metropolitan University used a participatory action research approach to develop the AAC Evidence Base website. Participatory Action Research is an approach to research which enables participants to drive the content and development of the research. A wide range of stakeholders (over 80) were involved in shaping the design and content of the website and in reviewing prototype versions of the site as it was developed. The use of focus groups enabled stakeholders to consider others' perspectives, and led to a wider range of evidence and content being considered for the AAC Evidence Base website. A key theme which emerged was that the content should offer something to those unfamiliar with AAC as well as those with much greater knowledge and experience.

It proved challenging to define 'evidence' as it meant different things to different stakeholders. However it was important to agree a shared understanding of the term before constructing the shape and content of the website.

The AAC Evidence Base website went live on 10th December 2012. In order to meet the needs of a wide audience it provides different ways of finding out more about AAC. The website features:

- A bibliography of published research into AAC
- Plain English summaries of research articles
- Case stories
- Factsheets
- Frequently asked questions
- Glossary
- Links to many other sources of information

Improved access to best practice evidence – the case study template

This part of the research was carried out by Manchester Metropolitan University.

Currently the majority of AAC research evidence is based around single case studies or studies with small groups of participants. This level of evidence is viewed as much lower than the other levels with the highest being the systematic reviews of randomised controlled trials. A higher level of evidence is required to support funding for research, the implementation of policy, and the commissioning of services.

Case studies do offer rich and individualised information for practitioners, researchers and system developers, however findings from single case studies are limited in terms of generalising to a whole population.

The case study template research was proposed by Manchester Metropolitan University as a way of developing a tool that could be used to collect case study data in a consistent way. The collection of comprehensive data in a consistent way would enable researchers to compare data across case studies and contribute to more research being published at higher evidence levels. The template was developed through an iterative series of prototypes which were tested and reviewed by people drawn from the key stakeholder groups. This inclusive process has resulted in a template that does more than address the priorities of researchers; it also addresses the diverse perspectives of the other stakeholder groups. This is reflected both in the language and construction of the template and in the nature of the data collected.

The case study template may provide a model for data collection in other fields of research.

The data collected using the case study template is stored in a database managed by Communication Matters. Data will be made available to researchers whose requests have been approved by Communication Matters.

As more case studies are collected it will be possible to collate data across case studies to provide group data, which in the long term will contribute to an increase in robust findings generalised across the use of AAC.

Impact

Although Communication Matters is a small charity it is highly respected and influential within its field. During this project the trustees have led and facilitated a number of initiatives aimed at improving AAC services, working in partnership with other organisations. Our position as a leading voice in the field of AAC has enabled us to establish many links between the research project and other initiatives, including documents published by Communication Matters defining standards for assessment centres and suggested outcome measures. The systematic literature review conducted by the University of Sheffield was referred to in the Office of Communication Champion report into specialised AAC service provision. The audit tool developed by the University of Sheffield was used by a separately funded Department for Education project to map provision of AAC delivered through local services. Emerging findings have been shared with policy makers. These examples demonstrate how the research has influenced and informed the development of AAC services, even before publication of the findings.

A series of dissemination events have been arranged in partnership with lead organisations in England, Wales, Scotland and Northern Ireland and these events will reach key decision makers and service providers.

The AACknowledge website developed by Manchester Metropolitan University has been favourably received and has had good coverage in the media. Our aim was to create something of lasting value and usefulness for the AAC community and Communication Matters will maintain the website and add new content over time.

The project has created two services that will support and encourage further research into AAC: the case study database (developed by Manchester Metropolitan University) and the Research Involvement Network (set up by Communication Matters) which will help researchers to find participants.

The funding from the National Lottery through Big Lottery Fund enabled Communication Matters to take on the management of a high-value complex research project. It enabled us to put the right governance and management structures in place to successfully lead the project. The benefits to Communication Matters as an organisation have included: working with highly respected research partners; gaining experience of managing research and working in partnership with researchers; increased capacity to respond to requests to support research; improved knowledge of the voluntary sector; the creation of new services; and a higher profile and increased media coverage.

We expect this research to continue to deliver positive benefits both for our organisation and for people who use AAC and their families long after the end of the grant funding.

3 Examining the need for and provision of AAC in the United Kingdom

This is a summary of the research carried out by the University of Sheffield in collaboration with Barnsley Hospital for Communication Matters. Readers should refer to the full report[8] for full details of the methods, data collection and detailed results.

3.1 Background

3.1.1 Objectives of this research

- To investigate evidence of need for Augmentative and Alternative Communication (AAC) i.e. how many people could benefit?
- To identify the numbers and types of AAC services in the UK, their funding arrangements and types of service provision. To map the provision and use of services for AAC and powered aided communication

3.1.2 Why these objectives are important

There appears to be an increase in the number of individuals with communication difficulties who could have improved lives with appropriate AAC and there are many anecdotes suggesting fragmented provision. In order to improve services it is important to gather basic information to assist those commissioning and providing services to determine what is needed and how provision could be improved.

Studies identified in the course of this project suggested that AAC can:

- improve quality of communication
- improve the effectiveness of communication
- reduce challenging behaviour
- increase assertiveness

Which can lead to:

- increased educational opportunities
- increased social opportunities
- improvements in quality of life and independence

3.1.3 Research overview

The research examined national provision of AAC with a focus on the provision of powered aided communication – this area having been previously identified by Government and in other reports as having the most significant service delivery problems. The data collected during this project is summarised here and described in detail in the full report. The results are structured by the over-arching themes and research questions related to the need, service provision and use of AAC.

The overall potential need for AAC and powered aided communication has been estimated through epidemiological investigation – making estimates of the need for AAC based on figures from the literature and consultation with experts working in the field.

Existing service provision has been investigated through an analysis of the qualitative data gathered from over 150 participants. This work generated a framework of AAC service components representing the range of possible activities associated with the provision of AAC and aided communication services. Each component has been identified using a Delphi methodology to reach consensus and qualitative analysis of the data has generated a comprehensive picture of the perceptions of all those involved in this field.

The picture of current UK AAC service provision is reported through analysis of data returned from a wide-ranging survey of UK services. This analysis allows identification of variance in service provision and models in the UK.

Data on the current level of use of AAC and, in particular aided communication, is provided through analysis of quantitative data returned from AAC services in the UK.

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[8] Examining the Need for and Provision of AAC in the UK, available from www.communicationmatters.org.uk/research

3.1.4 Literature review

All aspects of the study were informed by a broad-ranging systematic literature review. This review, published in 2012[9/10], was undertaken to review powered aided communication provision. The aim of the review was to establish the current best evidence for researchers, people who use AAC, service commissioners and service providers. The review investigated:

- the technologies in use
- the populations described as benefiting
- the outcomes reported following provision
- the barriers and facilitators to use

Eight databases were reviewed and initially 2883 papers from peer-reviewed journals were identified. The abstracts of these papers were then screened for relevance and quality of the methodology; this resulted in 299 papers being fully accessed and scrutinised. 141 papers were found to be relevant to this study and included in the review.

Briefly summarised the literature review found that:

- There is a lack of large studies in the field of AAC: only three studies included more than ten individuals
- There are many references in the literature related to funding difficulties for the provision of powered communication aids
- The range of powered communication aids available and used by persons with language rather than motor speech disorders appears to be increasing
- There are few research studies examining the benefits that AAC may bring to users however those undertaken demonstrate measurable benefit
- Outcomes are not consistently reported making the pooling of data difficult
- The evidence of the impact of AAC is mostly limited to low-tech devices and provides little information which would facilitate generalisation or knowledge or maintenance of use
- More evidence is required to underpin recommendations by practitioners regarding choices between devices or features of AAC devices
- Case and group studies indicate that AAC interventions have been found to be useful in expanding the communication of many individuals with a broad range of underlying conditions affecting their communication potential
- The complexity of the multi-factorial impairments and frequently associated cognitive, sensory and environmental situations has an impact on study design and limits the wider application of the findings
- The majority of studies have indicated the importance of identifying the right AAC approach within the context of a service offering a programme of support and teaching for people who use AAC and carers to maximise usage
- There is little existing evidence around the efficacy of different service models

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[9] Baxter S, Enderby P, Evans P, Judge S. Interventions using high-technology communication devices: a state of the art review. Folia Phoniatr Logop 64(3):137 – 144 2012

[10] Baxter, S., Enderby, P., Evans, P., Judge, S., Mar. 2012. Barriers and facilitators to the use of high-technology augmentative and alternative communication devices: a systematic review and qualitative synthesis. International Journal of Language and Communication Disorders 47 (2), 115 – 129.

3.2 Objective 1: Investigate evidence of need

The systematic literature review established the current evidence of the level of need for AAC and confirmed the requirement to establish the level of need within the UK population.

The systematic literature review found that none of the papers reporting an indication of the level of need were relevant to estimating the need within the UK population. Also the few papers reporting demographic information relating to AAC provided different figures suggesting variation in access to services.

3.2.1 Epidemiology

Having an estimate of the number of individuals requiring AAC is necessary for the development and commissioning of relevant services. These numbers will also assist in identifying unmet need and the benchmarking of provision.

The context to attempting to quantify the need for AAC is complex:

- the population of individuals who require or could benefit from AAC is heterogeneous and changing
- medical successes have led to a larger proportion of children with severe disabilities surviving for longer
- people with acquired injuries such as head injury are also surviving for longer
- the UK population is becoming older with an associated increase in complex conditions (where the individual has more than one impairment or difficulty) and acquired neurological conditions, e.g. Parkinson's disease
- the increased sophistication of AAC strategies and aids means they can be accessed by people with a greater range of difficulties

Furthermore, the expectations of individuals and their families along with greater realisation of untapped potential may contribute towards an increased demand on services and uptake of AAC.

In this study, the need for AAC was estimated using a combination of three methods: deducing the prevalence from existing literature; inspecting existing data sets for information; and consulting experts through survey and other methods.

Aetiological conditions

The first part of the process of estimating need was a comprehensive process of identifying the aetiological conditions that may lead to a need for AAC (summarised in table 1). These conditions were identified from the literature, initial data from services and consultation with AAC professionals

Child group	Adult group
Acquired neurological e.g.: • Stroke • Head injury	Acquired neurological e.g.: • Stroke • Head injury
Progressive neuromuscular e.g.: • Friedreich's Ataxia • Muscular Dystrophy • Myasthenia gravis	Progressive neurological eg: • Multiple Sclerosis • Motor Neurone Disease • Parkinson's Disease • Muscular Dystrophy • Dementia Changes to laryngeal and oral pathology e.g.: • Head and Neck Cancer
Congenital conditions e.g.: • Cerebral Palsy • Cleft Palate and craniofacial malformations • Syndromic conditions • Profound and Multiple Learning Difficulties • Learning Disabilities • Autistic Spectrum • Developmental delay	Congenital conditions e.g.: • Cerebral Palsy • Cleft Palate and craniofacial malformations • Syndromic conditions • Profound and Multiple Learning Difficulties • Learning Disabilities • Autistic Spectrum • Developmental delay

Table 1: Examples of aetiological conditions that may lead to a need for AAC for both adults and children as mentioned in the literature

Existing data sets

The second step of the process was to identify any existing potential data sources. Two data sets were identified: the General Practice Research Database (GPRD) and English Health Survey. These sources were searched to provide information about statistics relevant to the need for AAC.

The GPRD is taken from UK primary care data, covering approximately 8.32% of the population and containing data from over 600 practices. The database provides research standard information on 11.39 million patients, of which 5.14 million are currently active (July 2011).

The English Health Survey is a series of annual surveys commissioned by the Department for Health. The survey is addressed to approximately 16,000 adults and 4,000 children (1995) although this is variable dependent on the year. The English Health Survey data suggests that 0.4% of the population have both difficulty speaking and a severe communication disability.

Key point

Existing data stored in the UK regarding the need for AAC is limited.

Construction of estimate of need

The literature and UK data sources were searched to provide a figure for the prevalence of each condition that had been identified. The literature was then searched for figures relating to the prevalence of speech, language and communication needs. Finally professionals involved in the treatment of people with the conditions on the list were consulted to assist with providing estimates of percentages of people with speech, language and communication needs; those who could benefit from AAC; and those who could benefit from powered communication aids. These figures were then compiled into a total population estimate for those who may need some type of AAC and additionally those who may need powered communication aids.

Key point

We estimate that 0.5% of the UK population require some type of AAC. This equates to 529 people per hundred thousand population. The population of potential AAC users has a broad range of complex conditions with different underlying medical diagnoses.

Key point

We estimate that approximately 0.05% of the UK population require powered communication aids.

The graph (figure 1) depicts the percentage of the total number of people who could benefit from some type of AAC in terms of the individual conditions.

Key point

Nine conditions account for 97.5% of the total number of people who could benefit from AAC (see figure 1). Just two of these conditions, Alzheimer's/Dementia and Parkinson's, account for nearly half of the total (45.9%).

Figure 1: The percentage of the total number of people who could benefit from AAC in terms of the individual conditions.

●	Alzheimer's/dementia	23.2%
●	Parkinson's disease	22.7%
●	Autistic spectrum disorder	18.9%
●	Learning disabilities	13.3%
●	Stroke/CVA	9.9%
●	Cerebral Palsy	4.5%
●	Head/brain injury	2%
●	PMLD	2%
●	MND	1%
●	Other[11]	2.5%

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[11] Conditions comprising 'other' are: Prader-Willi, Huntington's disease, Williams syndrome, Head and neck cancer, Cleft palate, Multiple Sclerosis, Locked-in syndrome, Muscular Dystrophy, Angelman syndrome, Myasthenia Gravis, Rett syndrome, Craniofacial abnormalities, Friedreich's ataxia.

Validation exercise

The data relating to the groups of people who may benefit from AAC was subject to a validation exercise with participants who were knowledgeable about AAC ranking the most common aetiologies that they considered required AAC services.

The validation exercise showed that there was some difference between the perception of AAC use and the estimated need calculated from conditions. Of particular note is the discrepancy relating to Alzheimer's and Parkinson's. This may be a result of technologies relevant to this population being available but distribution, practice and use lagging behind. This discrepancy warrants further investigation.

Key point

There may be a large unmet need for AAC within the population of people with Dementia and Parkinson's. This discrepancy warrants further investigation.

3.2.2 Current level of use of powered communication aids

To establish the number of people who use AAC in the UK, the practitioners' survey (see 4.3) asked AAC services to provide information about: how many people on their current caseload used powered aided communication; and how many people who used powered aided communication were known to the service. These numbers were then calculated as a percentage of the population covered by the service.

The percentages across the services ranged from 0.000% to 0.081% with an average of 0.014%. This data indicated that whilst known use of powered aided communication is low in some areas, in other areas up to 0.08% of the population may currently use powered aided communication. This suggests that the estimate of 0.05% made from the prevalence data is within a reasonable order of magnitude. As the average known use was 0.014% of the population the data also suggests that fewer than half of those who could benefit from powered aided communication have access to it.

3.3 Objective 2: Identifying and mapping AAC service provision

The aim of this part of the research was to identify the numbers of AAC services in the UK, their funding arrangements and types of service provision; and to map the provision and use of services for AAC and powered aided communication.

Surveys and interviews with people who use AAC and communication partners[12] explored their experience of provision. Respondents to the survey were made up of:

- 35 people who use AAC: the respondents were almost entirely adults with a broad range of communication strategies and experience of communication aid use
- 27 communication partners: the respondents were mostly family members and all but one had English as their first language

Surveys, interviews, site visits and focus groups were used to capture the views of practitioners and associated professionals. The participants in these were:

- 123 professionals working in the field of AAC. Most professionals involved were Speech and Language Therapists or specialist Speech and Language Therapists with other professions including: occupational therapists, teachers, clinical scientists, and managers
- 92 services responded to the practitioners' survey
- 4 freedom of information requests were made to obtain data on AAC service provision

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[12] A communication partner is a person who knows the individual who uses AAC well and is familiar with the ways in which he or she communicates.

3.3.1 Service components

A framework of 'components' involved in AAC provision with a focus on powered aided communication service delivery was developed through a qualitative analysis of data from interviews, focus groups and email surveys. The results are presented in figure 2.

To ensure a common language for terms relating to AAC provision, definitions were developed for the components of powered aided communication service provision. These definitions were derived from existing definitions within the literature and from analysis of the descriptions of activity provided by participants in the study. The definitions were validated through a Delphi technique using those with experience of using AAC and powered communication aids as the 'expert' panel.

The Delphi method is aimed at a consensus by iteration and stops when the highest level of consensus is reached by the 'expert' panel. The Delphi was conducted over three rounds through use of questionnaires and the 'expert' research panel. The definitions were validated by people with experience of AAC, academics, people who used AAC, communication partners and practitioners.

The full research report contains the agreed definitions for each service component.

Figure 2: Components required for AAC service provision (including powered aided communication)

Provision

- Assessment
- Funding
- Training
- Customisation
- Positioning and mounting
- Maintenance
- Repair
- Review
- Support
- Research and development
- Custom manufacturer
- Information, advice and education
- Loans
- Integration

Key point

There was consensus between professionals, people who use AAC, and communication partners that all service components were required to facilitate an effective system of identification, provision and use of AAC.

Each component consists of a set of elements. The component discussed at most length was 'Assessment' and this, for example, incorporates the following elements: formal and informal assessment of physical and cognitive abilities; access requirements; needs and wishes of the individual and their carers; environmental facilitators and barriers; identification of communication partners and their needs; training and support requirements; matching the device to the person.

Analysis of the qualitative data was carried out against the framework of components identified. Through this analysis a comprehensive picture of people's perceptions of the effectiveness and role of the various components of AAC service delivery was generated. A summary of the key findings follows.

- The potential of persons with communication difficulties who could benefit from AAC needs to be recognised by people within their environment as well as health, education and social care staff
- Assessment for AAC requires consideration of a broad range of factors including an individual's abilities (physical, sensory and cognitive); communication potential and requirements; environmental constraints; needs and aspirations of the individual and their family; and resourcing
- Professionals involved in assessment for AAC need a broad range of knowledge, skills and abilities. Furthermore they need to be able to access those with extended specialist skills
- The term 'Assessment of AAC' is used to mean all or some of a wide range of activities including: powered aided communication assessment; evaluation; matching and physical access assessment

- Loaning equipment for a trial phase is considered essential to establish whether it is appropriate and acceptable. Individuals often need on-going training and support during this trial phase
- Correct positioning and mounting of AAC devices requires careful consideration if the person is to be successful in accessing their communication device without restricting other activities. There is a need for close collaboration between those involved in AAC provision and wheelchair services
- As technology becomes more sophisticated there is a greater requirement for more technical support to allow better integration of systems and support for integrated technology. It was reported that frequently this level of expertise was not available
- Customising and personalising vocabularies on unpowered and powered AAC was seen to be key to successful use however it requires specialist knowledge and time
- Administrative tasks associated with AAC services such as logging equipment are often carried out by therapists; diverting them from their core duties
- Arrangements for maintenance, repairs and replacement have been locally determined and there are many different approaches. There is no consistent approach to ensuring that a user of a communication aid is not left without a voice
- Whilst many people who use AAC and their communication partners commented that they received sufficient support and training in using a communication aid, this was not the experience of all with some expressing significant dissatisfaction
- Training is regarded as key to supporting the use and identification of AAC and powered aided communication. Training takes place at all stages from training of specialist practitioners to training practitioners to implement supportive communication environments
- Many services have developed innovative methods to identify, assess and provide on-going support to people who use AAC, communication partners and other relevant staff. For example, one service reported the value of on-going social group activities for people who use AAC and their communication partners
- Continuing support for developing communication skills through the use of AAC was recognised as being essential. However this provision varied greatly and concern was expressed about the lack of on-going support, particularly for adults

3.3.2 Service models

The provision of aided AAC services rests with different providers including: health services, local authorities, educational authorities, charitable organisations, and personal accounts. This study investigated the configuration of UK AAC services through gathering quantitative data from services. The study found a number of different models and types of provision, with differences identified in the funding routes, staff skill mix, facilities and equipment.

AAC services are commonly delivered in the individuals' own setting e.g. at home or school. This may reflect practitioners' belief in the efficacy of AAC being assessed and used in context.

Charities are minimally involved in providing AAC, but contribute to providing information and funding or loans of equipment. Companies are involved in some areas of service provision, particularly around assessment, loan, replacement, maintenance and repair.

The numbers of staff, skill mix and methods of working are unique to each AAC service. This applies to both local and specialist services.

Key point

There is little consistency in the elements or components of service provision of any of the teams delivering AAC in the UK.

Many participants, both professionals and people who use AAC, described spending significant effort in arguing for funding of communication aids for individuals. Professionals described this as being highly disruptive to their ability to deliver a good service.

Key point

Funding arrangements for services and equipment was the issue of concern most commonly raised by people who use AAC, communication partners and professionals.

3.3.3 Mapping of services

Mapping of services was achieved through collecting survey data from AAC services. This data allowed comparisons of service delivery across the UK and for services to be categorised.

Up to 70% of the 92 AAC services that responded received some or all of their funding from health. 66% were solely health funded. Less than 5% of services responding to the survey reported joint service funding arrangements.

42% of services who assess for AAC refer clients onwards to other services for assessment (presumably more specialised services).

The majority of services responding cover an area equivalent to a local authority or NHS trust/board area with less than 20% of those surveyed covering a wider area.

A broad range of eligibility criteria are used by different services resulting in variable access to services. The criteria used related to any combination of: age; condition; geography; funding; equipment use; procedure; and individuals' abilities. Criteria relating to funding of equipment were equally diverse and complex.

Only 33.7% of services responding were accessible to both children and adults.

46% of services reported that some communication aids were purchased using private funding and 51% of services reported some aids were funded by charities.

The survey tool used to collect this data was developed into a proposed service audit and mapping tool as an outcome of the project. This development was completed through analysis of the data collected and further consultation with professionals and comparison to published standards. During the life of this project the audit tool was used by a separately funded Department for Education project to map provision of AAC delivered through local services.

3.3.4 Experience of services

People who use AAC, their family members and carers provided information through interviews and surveys regarding their experience of services.

Whilst many people who use AAC and carers expressed satisfaction more reported frustration with all or some part of the service they experienced. Frustration was expressed relating to time taken to identify that they would benefit from AAC; funding difficulties in provision of communication aids; and a lack of support. It was noted that there were many negative comments relating to the knowledge and skills of speech and language therapists relating to AAC technology.

People who use AAC reported varying levels of satisfaction with different aspects of AAC provision and were conscious that the level of service provision varied across the country.

3.3.5 Service categorisation

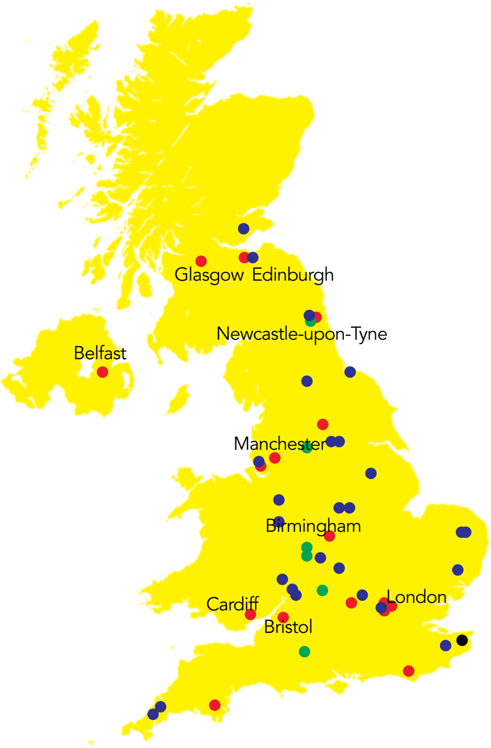
During the project, the Draft Specification for Specialised AAC Services was drawn up as part of the 'Liberating the NHS' reforms. The research team used the specification to create a definition that could be applied to the data collected by the project in order to categorise and map service provision across the UK.

The definition determined that a specialised service should deliver services across a wide geographical region, provide a wide ranging loan bank of technologies for assessment and trial and provide a set of service components including: assessment; loan for trial; provision of powered aids; maintenance; customisation of equipment (particularly hardware); and training for professionals. Additionally, the definition required an interdisciplinary team with competencies in:

- electronic assistive technology (clinical scientists, clinical technologists, rehabilitation engineers, assistive technologists or equivalent)
- speech and language therapy with specialism in AAC
- learning and educational development for those clients in education (teacher)
- seating, positioning, mounting of equipment and access and control methods (physiotherapist or occupational therapist)

An algorithm was developed in order to apply this definition to the data collected in the study. The algorithm was also expanded to allow classification of other types of services identified in the data.

Figure 3: distribution of different categories of the services across the UK[13].



●	A	Specialised service
●	B1 B2	Tertiary Specialist with custom manufacture Tertiary Specialist without custom manufacture
●	C	Local Specialist
●	D	Local service

Only 1 service responding to the survey could be classified as a specialised service using the full definition within the specialised services definition set.

3.3.6 Current level of use of powered communication aids

The practitioners' survey asked AAC services to provide information about the current level of use of powered communication aids. See 3.2.2 for the findings related to the prevalence of need for AAC. Other findings from the data were:

- People with cerebral palsy appear to make up the largest single user group of powered aided communication (32% of the users reported within the service data)
- The market size for powered communication aids in the UK may be around £10 million per annum

3.4 Recommendations

For commissioners

For AAC services to be fully commissioned the arguments for provision must be made nationally, commissioning responsibilities must be clear and commissioners adequately resourced to carry out recommendations.

- Identify provision of services available to AAC users and potential users
- Ensure that all the components of service delivery identified are available within the population being commissioned
- Ensure that criteria for access are clear and equitable across all groups
- Facilitate and require collection of consistent data reflecting service provision and patient outcomes

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[13] The map has been generated using ArcGIS online (Map attribute: National Geographic, Esri, DeLorme, NAVTEQ, UNEP-WCMC, USGS, NASA, ESA, METI, NRCAN, GEBCO, NOAA, iPC).

For service providers

To be able to make informed decisions about AAC and powered aided communication provision, appropriate data needs to be collected by services and made publicly available. There is a requirement for a knowledgeable and skilled workforce to exploit the potential of new technologies.

- Identify the components of service provision available for all potential AAC users within your population
- Calculate the potential population of AAC users (0.5% of your population) and estimate the level of unmet need by comparing this against your caseload
- Collect consistent data on provision of and outcomes from AAC service delivery. Ensure an infrastructure exists to allow this data to be interrogated
- Identify which AAC service components potential AAC users and powered communication aid users are able to access within the area, and make the pathways explicit to users and commissioners
- Highlight any missing components of effective and acceptable AAC service provision to commissioners
- Consideration should be given to the processes of ensuring an AAC user is not left without a voice when their device is removed for repair
- Establish clear routes for reporting issues associated with unmet need and difficulties with funding to service managers and commissioners
- Ensure service users are able to make their views known on all elements of service provision and outcomes of provision
- Ensure continuing professional development is provided that will enable local and specialist practitioners to be kept informed of technological and service provision developments
- Facilitate collaboration with all professionals involved in the care of AAC users across sectors

For higher education institutions

In order to allow appropriate identification of the need for AAC and appropriate intervention, qualifying healthcare professionals, particularly speech and language therapists, need to be equipped with knowledge related to AAC, technological developments, methods of assessment appropriate for this population, and methods of facilitating AAC usage.

For researchers

To be able to demonstrate the effect of different AAC interventions researchers need to improve their measurement of outcomes and better investigate factors that are associated with successful use.

- Where possible use outcome measures reflecting the broad impact of AAC provision. Report outcomes of interventions consistently
- Consider research reflecting long-term usage and follow-up
- Consider using the research case study template developed by the AAC Evidence Base research project to allow consistent reporting of single case studies
- Determine the factors and processes associated with positive outcomes of AAC use

3.5 Conclusion

The objectives of this research were to identify the numbers of individuals who could potentially benefit from AAC and to identify current service provision with a particular focus on powered communication aid provision. Both objectives have been challenging given that the population can be described in many different ways and data related to the epidemiology is collected indirectly, the population is heterogeneous, those using AAC frequently have complex conditions, the technologies range from unique and specialist to off-the-shelf and easily available, and no two areas provide the same range of services to the same group of clients.

In order to address these objectives a broad range of research designs were used including literature reviews, quantitative data collection through surveys, face-to-face and telephone interviews, focus groups and questionnaires. Those who have participated in the research include people who use AAC, people who have not succeeded in using AAC, communication partners and a broad range of professionals including those from health, education and the third sector.

Our conclusion that the best estimate of need for AAC is 0.5% of the population is, surprisingly, the same as estimate previously published by the Communication Champion. The changing prevalence of disability in the community associated with survival and longevity along with the changing nature of technology and its accessibility are likely to result in the need to review figures of need on a regular basis. Even our estimate, which is likely to be on the low side, should give cause for concern as it appears that there are many who would benefit from AAC who are not accessing services or benefiting from the new technologies. The gap between what AAC interventions can achieve and the benefits they can bring, and the use of AAC that we observed is becoming greater. We would suggest that this is due to the historical patterns of service delivery, funding arrangements and the knowledge and expectations of the professionals involved.

It is likely that those responding to our invitations to be interviewed or who have completed questionnaires and surveys are those who are familiar with AAC services or have benefited from them. It is hard to make contact with those who may need such services but are unaware of them! Thus, it is possible that our data is biased in a positive direction. Despite this there are many direct quotations in our full report reflecting inequity, frustration and disappointment which has led to individuals having difficulty in achieving their potential. Of particular note is the marked variation in approaches to funding services and the provision of equipment. Many services reported taking considerable time to seek funding from different sources or being dependent upon the fortunes of ‘end of year monies’. Service commissioning and funding arrangements are often inconsistent and dependent upon in year savings from other budgets making it difficult for services to plan strategically and to ensure maintenance and replacement are built into continuing care plans.

This research provides detailed descriptions of the service components required to deliver effective AAC provision. This is a significant contribution to the field as it is supported by agreed definitions and will allow service providers and commissioners to stipulate and monitor local and specialist provision. It also underpins another major contribution which is an explicit algorithm leading to a typology of AAC services which has facilitated the mapping of the services available in the UK. Our map demonstrates the disparity in provision. This disparity is reinforced by the wide variation in eligibility criteria applied to services with criteria being applied related to any combination of: age; condition; geography; funding; equipment use; procedure; and individuals’ abilities.

Thus we have been able to define the characteristics and domains of an acceptable service which we would suggest needs to be available to all using AAC and powered communication aids and we have clarified the different levels of local provision. This explicitly details the requirements of local services and the support needed to access dedicated facilities needed by a proportion of people who use AAC.

The rapid increase in mobile technologies offers exciting opportunities for many people with severe disabilities. But they also introduce challenges to service providers who may not have the knowledge and skills to support and exploit their use. These new technologies will be able to assist individuals who are at present not well served but practical issues such as mounting and positioning this equipment, teaching its use and extending communication skills through the technology will need constant development by service providers. Of concern are the limited learning opportunities in AAC of undergraduate and postgraduate healthcare professionals, particularly speech and language therapists. It is a challenge for therapists to keep up-to-date with the rapidly changing technologies, programming, mounting systems, facilitative strategies etc. in this specialist area. This can lead to frustration and disappointment for service users and their families and can be a major cause of the disparity in provision.

This data provides a 'snapshot' of service provision before what has been termed as the largest reorganisation of the National Health Service. This reorganisation is anticipated to have a major impact on provision of AAC and specialised AAC services. The research suggests that local and specialised services following this model may be able to improve the equity of access and reduce the frustration and struggle of many families who find it difficult to get the right advice, assessment, access to equipment, training and continued support. If the proposed model is successfully implemented a repeat of this research in 2023 should not highlight the same level of disparity, inequity and frustration.

Our hope is that this report will improve the identification of those who would benefit from AAC, will clarify what is required for effective AAC provision and reduce inequity and variation in practice.

Our estimate is that 0.5% of the population would benefit from AAC generally and 0.05% could benefit from powered communication aids. But we conclude that this is a low estimate considering the rapid advances in technology and changing demography. It is disappointing that in most areas less than half of those who could benefit have access and use of these technologies. The need is there. The technologies are there. But commissioning of services, funding arrangements and the underpinning knowledge and expertise of healthcare professionals have not risen to the challenge.

4 Improved access to evidence and knowledge – the AAC evidence base website

This is a summary of the research carried out by Manchester Metropolitan University for Communication Matters. Readers should refer to the full report[14] for further details of the research methods.

4.1 Background

Why was it needed?

The field of AAC is a relatively new academic and practice-based phenomenon. The impetus for the development of the AAC evidence base website was the recognition that many activities within AAC were not being readily captured and shared in published or accessible formats. There are numerous sources of information on AAC, including several informative websites. Many of these websites are supplier-biased or profession-specific or academically focussed and this may make them inaccessible to a wider audience. Alternatively they tend to be practically focussed with no evidence base for the claims made.

Information that may be placed on a website falls into two broad categories: (i) theory-driven publications, and (ii) practice-based interventions.

(i) Theory-driven publications may include a wide range of evidence from academic journal publications to practice-driven assessment and intervention packages. They tend to be accessible to specific groups of people within the field of AAC.

(ii) Practice-based interventions are likely to include single case study information about what worked best for a particular individual, and are unlikely to have been published but may have been the subject of a conference presentation.

The first element of the project was to identify how different AAC stakeholder groups were affected by the lack of access to evidence. The second element was to identify the range and scope of evidence that stakeholder groups would find useful in an evidence-based website. If this could be achieved it would support one of Communication Matters' main aims of increasing accessibility for all to AAC evidence and information.

Key point

Making AAC evidence available to all stakeholders was challenging before the development of the AAC evidence base website.

Who should it be for?

This project aimed to establish an accessible and informative AAC evidence base website offering all relevant parties, e.g. parents, professionals, people who use AAC, something for their own development. This was a challenging task, not least because of the diverse interests and needs of those involved in the AAC field.

What should it include?

The aim of the AAC evidence base website was to enhance access to knowledge and skills. AAC activity is documented in a range of ways, for example, academic journals, specialist magazines, books, websites, information leaflets, published activity packs, case notes, reports, journal clubs, activity weekends, discussion forums. These sources of information are not readily accessible to all members of the AAC community. What was unknown at the outset of the project was the way in which stakeholder groups would prioritise their need to access such sources of information and evidence. Identification of stakeholders' priorities for information formed a key aspect of the project methodology.

How should it be developed?

Whilst it would have been possible to develop an evidence-based website without stakeholder consultation, such an approach may have developed something that was not fit for purpose. The key drivers for this development were collaboration and consultation; and the collection of relevant sources of AAC evidence prioritised by stakeholder groups. These principles guided the choice of research methodology and the website construction.

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[14] The full Manchester Metropolitan University report is available from www.communicationmatters.org.uk/research

Another influence within the project design was the desire to increase the accountability of published information by taking an Evidence Based Practice (EBP) perspective. EBP was described by Sackett et al (1997) as the integration of best research evidence with clinical expertise and patient values. Dollaghan (2007) defined EBP as 'the conscientious, explicit and judicious integration of (1) the best available external evidence from systematic research, (2) the best available evidence internal to clinical practice, and (3) the best available evidence concerning the preferences of a fully informed patient' (p. 2).

This quotation implies that the perspectives of professionals, families and people who use AAC are likely to reflect differing needs and experiences, whilst each strives for valid sources of knowledge to inform their practice, skill development, and research or life choices.

Dollaghan (2007) summarised the intentions behind the AAC Evidence Base beautifully by suggesting that 'facts known only by practitioners need to be anchored by values known only by patients' (p. 2).

4.2 Overview of the Participatory Action Research methodology

What is Participatory Action Research?

Participatory Action Research (PAR) enables participants to be part of a reflective cycle of collecting and analysing data to determine what actions or choices best serve the community involved. It reflects questioning about knowledge and how knowledge can often be perceived to best represent the powerful of a community and maintain their position in society. PAR challenges knowledge and experience on the basis that all experiences have validity but that they bring with them a range of perspectives and interpretations of the knowledge associated with those experiences.

PAR differs from conventional research in that its aim is to enable action. The action is achieved by the cycle of reflection through data collection and analysis, with the range of actions identified and delivered. This is an iterative cycle, requiring repeated reflection and modification of the actions. Another key characteristic of PAR is the way it addresses the power relationships between researchers and participants. It advocates a blurring of the lines between researchers and researched, so that eventually the researched become the researchers. It suggests moving from being objects of interest to a position of equality. PAR is complex and time-consuming, requiring researchers to work with a range of stakeholders in a way that accommodates differing demands, needs and expectations.

Why was it appropriate for this research?

PAR was most appropriate because the research aimed to open up access to information, enabling a wider audience to gain access to knowledge that was previously perceived as the domain of the more powerful in the AAC community, e.g. researchers, academics and practitioners. As an approach it requires recognition and illumination of perspectives, with an expectation of accommodation of a range of perspectives. Finally, it is a methodology that fits with the project aim of action, i.e. developing an AAC evidence base in the form of a website.

How was it implemented?

PAR informed the construction of a number of methodological processes and procedures including: (i) setting up the research team; (ii) the initial literature review; (iii) the data collection phases; (iv) the data analysis processes; (v) the data review and its influence on website construction; (vi) website content and its review. These elements are discussed in more detail below.

Key point

Participatory Action Research is an approach to research which enables participants to drive the content and development of the research. This works particularly well in an AAC context.

4.3 The research team and the role of the Co-researcher

Having adopted a PAR approach, it was important to set up a diverse research team. The team included a Principal Investigator, who was a part-time research speech and language therapist with three decades of clinical, educational and research experience in the field of AAC. The Principal Investigator's role was to manage all elements of the Manchester Metropolitan University work. This person also developed some parts of the website content and led the case study protocol development.

The team also included a full time Research Assistant with a background in information and communication technology. This person was responsible for the organisation and evaluation of data collection sessions; and the technical development of the website and the case study database. Additionally this person developed much of the website content.

The team further included a part time Co-Researcher who was an adult with a lifelong experience of communication difficulties and of using AAC. This person joined the project as a consultant to support the construction of the research questions; to attend data collection sessions; to review the data analysis; and to revisit the data findings with stakeholder participant groups. These contributions offered a unique perspective on the research design and delivery that could not have been achieved by any other means.

Key point

Research teams should include key stakeholders as core members of the team.

4.4 How the methodology was implemented

4.4.1 The research questions

The initial research questions were formulated as:

- What type of information is required in the evidence database?
- In what formats should information be available to support wider access?

4.4.2 Defining the challenge

Prior to contemplating what data to try to collect or the procedure to be used in data collection, it was important to complete an initial literature review contextualising the following questions:

- How do we define evidence?
- Where do we find evidence?
- How do we quantify evidence?
- What types of evidence exist within the AAC literature?
- The answers to these questions would inform the structure and access features of the website

How do we define evidence?

As already stated evidence based practice is an important driver for practitioners, researchers and funding agencies.

Schlosser (2003) led the debate on evidence based practice and AAC, intimating that having a growing evidence base helps meet the ever increasing demand for accountability; fills the research-practice gap; provides the best possible assessments and interventions for clients; improves critical thinking and research skills and promotes life-long learning; provides a common language for use among multi-agency teams; and promotes transparency for service users.

Many of these points resonate with Communication Matters' mission to increase knowledge and awareness of AAC.

Where do we find evidence?

As there are many routes to finding information and evidence on AAC topics, accessing relevant and robust evidence on AAC remained a challenge throughout the life of the project. The research team examined a range of sources and incorporated them into the prototypes of the website. These included many well-known repositories of evidence that offer the researcher some certainty of pre-filtered content.

The approach adopted included searching through the following electronic resources: systematic reviews (Pennington, Goldbart & Marshall, 2003; Schlosser & Lee, 2000); specialised databases, e.g. DARE, Cochrane; practice guidelines (as yet, this continues to be a limited resource in relation to AAC); general databases, e.g. Medline, CINAHL; Pro-Quest digital dissertations which offers access to doctoral theses that may not be published elsewhere; and general search engines. Quality control of the latter is a concern and so the five criteria generally applied to web-based sources were adopted: accuracy, authority, objectivity, currency and coverage (Kapoun, 1998).

How do we quantify evidence?

Levels of Evidence

Typically research evidence is described in terms of levels, with the large scale studies described at levels 1 and 2 (see Table 1 below) being perceived as the most highly valued. However there are very few large scale AAC studies because the needs of people who use AAC are particularly individualised. It has proved difficult to conduct research involving large numbers of participants because it is hard to find participants with sufficiently similar characteristics. This means that practitioners usually consult studies in levels 3, 4 and 5 for evidence to inform practice.

Level	**Type of evidence**
1a	Systematic Review or Meta-Analysis of Randomized Controlled Trials
1b	A single Randomized Controlled Trial
2a	Systematic Review of Cohort Studies
2b	A single Cohort Study
3a	Systematic Review of Case Control studies or quasi experimental studies
3b	Single Case Control studies
4	Non experimental descriptive studies e.g. correlation studies and single case studies
5	Expert opinion, textbooks, 'first principles' research

Table1: Levels of research evidence (Robey and Schultz, 1998)

Research methods are not generally understood by people outside the research community. As well as making research evidence more widely available this project aimed to increase understanding of research methods and of how evidence can be evaluated. A number of resources exist to evaluate evidence in terms of the appropriateness of the research question, the chosen methodology and the claims made from the results. These are described in detail in the full report.

Key point

Defining evidence is challenging, since it means different things to different stakeholders.

What types of evidence exist within the AAC literature?

The research team had to decide whether to approach evidence from the perspective of research methodologies and levels of evidence, e.g. case control studies, descriptive studies; or, from a practitioner perspective, e.g. assessment, intervention, product development.

Prior to data collection, topic-based searches were completed to compare with reviews based purely on methodological approaches. These informed the evidence collection processes that we cited during data collection phases of the project, e.g. during focus group debates on types and levels of evidence.

This review of existing approaches to evidence led to the development of more specific questions which formed the basis of a semi-structured debate in the focus groups conducted during the data collection phase. These questions were:

- What does the term 'evidence' mean to you in relation to AAC?
- What do you do/ use now to get evidence?
- What are the advantages and disadvantages about how you get that evidence now?
- Who would you envisage could make use of an accessible AAC evidence website?
- What access and navigational features would support your use of the website?
- What would you want to use the website content for?
- How should Communication Matters market the website and which stakeholders should be the priority?

Key point

It was important to agree a shared understanding of the term evidence before constructing the shape and content of the AACknowledge website.

4.4.3 Ethics

Manchester Metropolitan University's project plan was the subject of two ethical reviews: (i) a Manchester Metropolitan University internal ethics evaluation committee; (ii) an independent NHS evaluations committee (MREC/LREC). In both instances the project plan was approved as being ethically sound and sensitive.

4.4.4 The research participants

Nine focus groups were convened which included participants from a range of perspectives: a family member group and a professional group; and thereafter seven mixed groups made up of family members, people who use AAC, professionals, researchers and developers/ suppliers. About half the contributors were not members of Communication Matters, offering the data collection process and analysis a broader perspective.

4.4.5 The data collection procedures

Data collection incorporated two phases: (i) focus group discussion; (ii) prototype reviews.

Initial data collection was primarily through Focus Groups (Pope & Mays, 2006), with individual follow-up for clarification purposes. Focus groups worked well in this context as participants had the opportunity to contribute but also to reflect on the contributions of others and add further comments of their own, resulting in a more holistic perspective of the issues being debated and considered.

The prototype reviews involved both focus group participants and naïve participants in reviews of the prototype design and the content of the evidence base website. There were a total of four iterations and reviews prior to the website going live. These iteration reviews involved different stakeholders and added strength to the evaluations: i.e. did the website meet the expectations of the focus group participants and how well did it meet the needs of naïve visitors to the site? This fitted very neatly with a PAR approach to research design and evaluation.

Key point

Using focus groups enabled stakeholders to consider others' perspectives, enabling a wider range of evidence and content to be considered for the AACknowledge website.

4.5 The data analysis procedures – how data analysis influenced the design of the website

4.5.1 Analysis of raw data

Each focus group was recorded and translated into a verbatim transcript. Each transcript underwent a qualitative analysis process of coding, reviewing and re-coding, resulting in a thematic map of key components to be considered in the construction, navigation and content aspects of the website development (Denzin & Lincoln, 2000). The use of thematic Framework Analysis enabled the researchers to test the topics raised by participants against the framework they had derived from the academic literature and their own experiential biases. This resulted in a thematic network (Denzin & Lincoln, 2000) with themes arranged into global, contextualizing and basic themes.

4.5.2 Interpretation

The data distilled into several key components summarised under the following global themes: Construction, Navigation, and Content.

Global Theme 1 – Construction: key components were identified and these were factored into how the website was constructed. These components included:

- Information should not be organised as routes through the site for ‘parents’ or for ‘professionals’ but in terms of introductory level through to specialist level which any visitor to the website can access
- Searching should be as easy as possible offering users of the website various ways of getting to the same information

Global Theme 2 – Navigation: the key components were valued by all stakeholder groups. These components included:

- Plain English/language: AAC jargon should only be used when required for specific content; and plain language descriptors should be provided wherever possible
- To support those with difficulty generating search terms, symbolisation should provide a key to how information has been clustered, e.g. child symbol, family symbol, adult symbol, AAC device symbol

Global Theme 3 – Content: the key components described the type of content to be included in the website and some considerations about the way content should be displayed to improve accessibility.

- Content should offer something to those unfamiliar with AAC as well as those with much greater knowledge and experience
- Symbolisation should be available at the navigational level, rather than content level, on the basis that most users would have access to a screen reader, if required
- Video material and instructional video material was highly valued
- The range of best evidence that people wanted emerged from the data as:
  - A glossary of terms, including some definitions and condition specific information
  - Experiences in the form of case stories (this should include stories from the perspectives of people who use AAC, professionals, and family members)
  - Technical specifications of AAC systems and devices, with reviews from stakeholder groups
  - Decision-making studies: specifically assessment and intervention studies (ranging from peer-reviewed journals to anecdotal experiences)
  - Service provision, funding and policy studies (ranging from peer-reviewed journals to anecdotal experiences)
  - Published case stories (specifically with an assessment, intervention and training focus)
  - Fact sheets
  - Discussion forums

Key point

Thematic analysis of data enabled all key elements of content, organisation and structure to be defined by stakeholders.

4.5.3 Website construction

These key components informed the development of the prototype website. The site was constructed using Drupal, and was developed in consultation with Communication Matters.

4.5.4 Prototype reviews and website modifications

Feedback from the prototype reviews (see 5.4.4) resulted in changes to organisational, navigational and content elements. The reviewers also identified desired elements that were outside the scope of the initial website development.

4.5.5 Going live

The AAC evidence base site (www.AACknowledge.org.uk) went live on 10th December, 2012.

4.6 Reflection on the effectiveness of Participatory Action Research methodology

The PAR approach proved appropriate and highly valuable in ensuring the development of a product that was fit for purpose. Two examples sum this up.

Firstly, stakeholders were very clear that the website should not be divisive by tagging sections for specific groups of users, e.g. families or professionals. There was a keen desire to ensure that any information on the site should be available to all. However, stakeholders recognised that some organisation of the content was required. As a consequence the website was designed with two key navigational routes: one for the novice and another for those with knowledge of AAC. However, both routes enable access to all information in some way or another.

Secondly, the use of language and terminology exercised the minds of many stakeholders during discussions. One clear message emerged that terminology is often confusing and exclusive. For example ‘evidence’ does not have a unitary meaning across stakeholders. It may have particular meaning to professionals and researchers but it held negative, legal and medical model connotations for many people who use AAC and their families. Recognition of this was critical to the development of organisational and content features of the website.

4.7 Maintenance of the website and hand over to Communication Matters

The maintenance and ownership of the AAC evidence base website was transferred to Communication Matters in the final phase of the project. Manchester Metropolitan University and Communication Matters worked closely together at all stages of construction and content development. This proved to be an effective and valuable collaboration, resulting in a user-led product development.

Key point

Using a participatory approach made the website development a longer process but ensured the final outcome was an inclusive and ‘fit for purpose’ product.

Full references can be found in Appendix 2.

5 Improved access to evidence and knowledge – The case study template

This research was carried out by Manchester Metropolitan University for Communication Matters.

5.1 Background

Research evidence that is accessible and meaningful is in limited supply to those who make service provision decisions (Schlosser, 2003). Research evidence cited across the AAC literature suggests that the majority of these accounts are non-experimental single case studies. Case studies are descriptive in nature and there is no consistency in which features are included in the description. For example, in Pennington et al's systematic review (2003) of 307 peer reviewed papers on AAC interventions, only 125 met the inclusion criteria regarding experimental control: the majority were single case experimental control or single case experimental designs.

Case studies do offer rich and individualised information for the practitioner, researcher and system developer in terms of ideas for intervention, developing research questions, or developing new technologies to support communication. However, methodologically, findings from such non-experimental case studies offer a limited application in terms of generalising to a whole population. The capacity to produce research data that can offer the commissioner or research funding agency a way of interpreting and understanding need is critical to the advancement of the field of AAC. The impetus for the development of the case study template was the desire to facilitate the collection of consistent data within a single case study format.

Key point

The research field of AAC is in its infancy. Most of the currently available research findings are descriptive and do not support generalised evaluations and conclusions. This limits the findings in terms of supporting service development and management strategies.

5.2 The objective

The objective of the study was to facilitate the collection of single case experimental data over the long term within the field of AAC, with a view to offering this data to researchers and practitioners, thus increasing the publication of evidence. This objective would be realised through the use of the template to collect case studies that would be stored in a database managed by Communication Matters.

This required considerable thought to be given to what information should be sought and how that information could most easily be collected. The inspiration for the study came from the work of Pennington et al (2007). They had developed an AAC template for the collection of single case data. Their template was designed for use by traditional researchers. This was helpful but did not meet the aim of involving all stakeholders in supporting research development across the field of AAC, as many of the elements and terms used might not be readily understood by all. The structure and content of the Pennington et al guidelines formed the basis for the methodology used in this research. The process and procedures are considered below.

5.3 The research question

What data would it be useful to capture when collecting information about people who use AAC? The methodology aimed to support the development of a template that would inform more systematic data collection within a research, practice or personal context.

Key point

To inform AAC research we need to be consistent in the range and type of data we collect.

5.4 The research team

The research team was led by the Principal Investigator at Manchester Metropolitan University. A specialist reference group of seven people was formed which included the Co-researcher from the team (a person who uses AAC), and researchers, clinicians and a Personal Assistant. They reviewed the comments from participants and supported the construction of each prototype. The final electronic version of the template was constructed by the Principal Investigator and the Research Assistant.

5.5 The research participants

The twenty-two participants in the study reflected the stakeholder groups within AAC: people who use AAC and family members, professionals, commercial developers, clinical and research groups. All participants were experienced in using AAC, seven were adults who use AAC. Of these, two people had acquired communication difficulties; one person had progressive communication difficulties; the remaining four had used AAC throughout their lives. The other fifteen participants included: five researchers, two service commissioners, two AAC suppliers, three speech and language therapists, two teachers, and a Personal Assistant.

5.6 The data collection procedure and ethics approval

The initial template materials were based on the Pennington et al guidelines (2007). The procedure included a cycle of: (i) prototype template developments; (ii) an evaluation of the prototype either through focus group discussions, or individual contributions completed and returned electronically; and (iii) specialist reference group evaluations. The rationale for including both focus group and individual contributions was to ensure that prototype iterations reflected debate, and agreement on key components, as well as individual and independent opinion about what it was crucial to retain.

The study gained appropriate ethical approval through local and regional ethics processes, including university ethical approval, and, where needed, specific NHS ethics committees.

5.7 Template prototypes and modifications

In total the prototype template went through four iteration/evaluation cycles, with the fifth and final version being developed as an electronic template. Prototype 1 had minimal alterations from the original guideline content (Pennington et al, 2007). There were some language and label changes, some reorganisation of elements within sections and the ICF codes (International Classification of Functioning, Disability and Health) were temporarily removed (WHO, 2001). The key sections remained as: biographical; health or medical; emotional; communication; AAC use; communication partners; and environmental factors. The content in this version was reviewed by an interdisciplinary group of participants attending the annual conference of Communication Matters in 2011. The eight contributors included: speech and language therapists; researchers; teachers; suppliers; and commissioners.

Prototype 2 was completed and reviewed by six people all of whom had different reasons for using AAC, for example one person with a progressive illness and another who had lifelong experience of using AAC. These people completed the template individually and independently of each other.

Prototypes 3 and 4 were evaluated by participants from each of the stakeholder groups. Participants contributed to focus group discussion and/or submitted individual written comments. Iterations 3 and 4 included reviewers who had seen all prototype versions plus eight naïve participants coming to the review process with fresh eyes.

The prototype versions were made available in either paper or electronic format. At each iteration all participants could see all elements of content in each prototype (see Appendix 1 for an example of the main elements of prototype 4).

From the second iteration all participants were asked to: (i) submit information in response to the template prompts from a personal perspective, or with a service user in mind; and (ii) critique the tool from a perspective of information they might find valuable in a clinical, personal or research context.

Key point

An iterative process supports the development of a template that is meaningful and one which resonates with the key issues as determined by all stakeholders.

5.8 Analysis and review

The data collected in this study was based on pre-set parameters, as defined by the original guidelines. This facilitated a process of deductions based on adopted principles and a review of participant responses to those principles. In effect, the original guidelines determined a framework from which to debate, determine and construct what the case study template could or should look like. This constructivist approach to data collection and evaluation lends itself well to the use of Framework Analysis (Denzin & Lincoln, 2000; Srivastava & Thomson, 2009), as it allows the distillation of qualitative commentaries into a summary framework from which to reconstruct a case study template. As a consequence, Framework Analysis (op. cit.) was used to capture the key factors for change and modification. Themes generated by this analysis also enabled consideration of the rationale for change to certain aspects of the template. Analysis consisted of a review of participant evaluations of the content areas, the organisation and the accessibility of each prototype.

By using Framework Analysis (op. cit.) during each prototype iteration the debate was distilled into four organising themes: (i) language and terminology; (ii) content areas; (iii) template construction; (iv) potential uses of data collected with the tool (see Murray et al. 2013 for a detailed consideration of the findings that informed the content and structure of the final template).

5.9 Product development

There is a single template but those accessing it have the option of providing a general summary (referred to as the personal stories section), and/or more specific data (referred to as the case study section). The case study section contains considerable detail, with detailed menu options supporting the user to complete the template as comprehensively as possible. It also offers room for quantitative data and qualitative discourse. The ICF codes have been re-introduced for cross referencing. This two tier approach was adopted for two reasons: (i) it may help contributors build up to the more detailed data collection elements required in the case study section; (ii) it may help clarify the differences between non-experimental and experimental case study data collection techniques (Brackenbury et al., 2008).

5.10 The case study database

Aims of database

The case study database was developed to store the case study data collected using the template so that it could be made available to researchers. The information stored in the database may help researchers develop new ideas and provide evidence for service developments; and as a consequence, it may help educators and therapists to work more effectively with people who use AAC.

Key point

The development of a case study database will support researchers and developers access consistent and specific case data. This will in turn inform research findings and product developments.

Construction of database

The database was constructed using Adobe FormsCentral software.

Ethics, due diligence

Communication Matters and Manchester Metropolitan University developed protocols to ensure safe collection and storage of data. Prior to completing a case study template, all contributors are made aware of the ways in which their case study data could be accessed and used. Data always remains anonymous. This procedure received ethical approval from Manchester Metropolitan University's research ethics committee. Anyone requesting access to elements of the database will have to demonstrate they have received relevant ethical approval.

Invitations to contribute case story and case study data

During the project, the Manchester Metropolitan University team approached potential contributors through a number of routes, including: the Communication Matters Research Involvement Network; participants involved in other elements of the larger project; and publicity through Communication Matters' network of contacts. The aim was to collect twenty-three case story or case study contributions. It is anticipated that the number of case studies will continue to grow

Management of database

The management and ownership of case study database was transferred to Communication Matters towards the end of the project. Communication Matters and Manchester Metropolitan University collaborated to ensure that the procedures for managing the case study database were created and documented. Communication Matters will publicise the case study database to encourage contributions of new case studies and to make researchers aware of the opportunity to access the data for research purposes. Requests from researchers to access data will be reviewed by Communication Matters using an agreed procedure.

5.11 General conclusions from the Manchester Metropolitan University research

This project has enabled the development of some complex, innovative and unique contributions to the field of AAC. Specifically, the work resulted in: an evidence-based website; a case study template to support consistent research activity; and a case study database to inform research, practice and product design.

Building research capacity

The development of an open access evidence-based website will enhance knowledge across the field of AAC and support evidence-based research activity.

The case study template design has opened up perspectives on research and enabled inclusivity and stakeholder involvement as never before. The protocols and procedures used within the methodology demonstrate that it is possible to make accommodations for a range of perspectives in data collection and product development. Participatory Action Research is recommended as a useful methodology for AAC research and development.

The language and terminology used within one field (AAC) has been found to be non-inclusive because of the range of stakeholder perspectives involved; however, the final template design has demonstrated that respecting and accommodating perspectives can lead to a comprehensive and useful research tool that can support the aims of Communication Matters.

Improved access to evidence and knowledge

Communication Matters aspired to increase supported access to AAC knowledge. The research has systematically explored and identified the most prized AAC evidence and information through the participatory research methodology that sought the opinions of key stakeholders within the Communication Matters community but also involved stakeholders with a more peripheral interest in AAC, e.g. service commissioners, other charities. This resulted in the identification of, and agreement on, priority information to include in an evidence base website. As far as we are aware this remains a unique approach to website construction.

The website has enabled the development of an infrastructure that will support information dissemination and exchange across stakeholder groups, and will also support the evolution of the website as more ideas and resources stem from it.

Stakeholder involvement

Communication Matters' ethos of involving stakeholders, particularly people who use AAC and their families was at the core of all the Manchester Metropolitan University-led work. This was demonstrated by the inclusion of someone who used AAC as a full member of the research team; and by the involvement of stakeholders at every stage of the product developments.

Key point

Collaboration between third sector organisations, service providers and universities supports a participatory and inclusive approach to research and product development. The final outcomes are richer in flavour and more robust in terms of meeting the multiple needs of all stakeholders involved in AAC.

Full references can be found in Appendix 2.

6 Building research capacity for the future

One of Communication Matters' charitable objectives is 'to promote, undertake, encourage and provide facilities for research'. The funding from the National Lottery through Big Lottery Fund has enabled Communication Matters to set up structures and services that have supported the research work during the project and that will support future research into AAC.

The Independent Research Panel

During the grant application proposal Communication Matters set up an Independent Research Panel to provide advice on its research activities. The Panel is made up of people who represent different interests, including a person who uses AAC; a family member of a person who uses AAC; a representative of a commercial company; a person working in the care field; a commissioner and researchers. Initially the Panel provided advice and guidance via emails and phone calls but once the grant was awarded it was able to meet twice a year and was chaired by the Research Manager. Face to face meetings helped to strengthen the Panel and provided opportunities to explore its role. During the project the Panel provided advice and gave feedback on the progress of the research. It also contributed to the development of the Research Involvement Network. The Panel will continue to operate after the end of the project, providing advice to Communication Matters regarding its research activities and a new Chair has been appointed to facilitate this.

The Research Involvement Network

The idea for the Research Involvement Network grew out of Communication Matters' consultation with stakeholders from the AAC community to determine its research priorities. People who use AAC and their families reported that they were often asked to participate in research projects and this could become a burden. Researchers also reported that it was hard to find people who use AAC to participate in research. The aims of the Research Involvement Network are:

- To support and encourage research into AAC in the UK by building a list of potential participants
- To provide researchers with access to a wider range of participants
- To promote the involvement of people who use AAC in all aspects of research: not just as subjects but also as advisers, steering group members and co-researchers
- To support people who use AAC, their families and carers, and other members of the AAC community in becoming participants in research
- To build a network that reflects the broad population of people who use AAC

The Communication Matters Research Manager investigated models of involvement used by other charities and drew up procedures and documentation which were reviewed by the Independent Research Panel. The Research Involvement Network was launched at the Communication Matters conference in September 2011 and the first hundred members have been recruited. The first request from a research project has been reviewed and approved, and publicised to the relevant members of the Network. Communication Matters will continue to recruit members to the Network. We envisage this will be a valuable resource for researchers in future.

Capturing and sharing knowledge

The AAC Evidence Base website will establish Communication Matters as the key source of information and research evidence about AAC in the UK. Communication Matters will manage the website, adding further content. We will monitor use of the website and evaluate feedback and use this information to help us decide the priorities for content development.

By collating data using the case study template Communication Matters will build a bank of data that will be a valuable resource for researchers into AAC. The case study template is also a useful tool that researchers can use for data collection.

As a result of the research project Communication Matters would like to specifically encourage and support:

- The sharing of best practice, knowledge and evidence
- The on-going collection of consistent data on service provision and outcomes
- The establishment of appropriate methods to identify potential AAC users

The Research Manager's contract will end at the end of the project. Communication Matters started planning the handover of research responsibilities more than a year in advance, in order to minimise the risk of losing invaluable research knowledge and expertise. There are currently two trustees with research experience on the Board and Communication Matters is undertaking a reflective evaluation of the project to ensure that the lessons learned are recorded.

Appendix 1: Case study template

This prototype (version 4) sets out the concept of drop-down options and free text space. The language used had moved considerably from the original Pennington et al (2007) guideline. ICF codes had not been reintroduced at this point.

	Drop down choices throughout, with dialogue box for free text (as many choices as relevant may be selected)
How would you describe the different ways you communicate?	• e.g. symbol book, sign language, gesture, sounds and vocalisations, body language, high tech aid, etc • Contexts: used only at school, etc • Do you use your communication to: ask questions, comment on something, make a joke, reject something, etc • Dialogue box
What communication aids and equipment have you used/ **What communication aid/s do you use now?**	• Previous: Choices: range included + when • Current: Choices: range included • Dialogue box
How do you access to your communication aid?	• Choices: e.g. knuckle pointing, eye gaze, 2 switch block scanning • Dialogue box
Do you need some support with seating and the positioning of your communication system?	• Choices: Describe typical positioning options in terms of best location of AAC system, switches, mountings, and specialised seating characteristics • Dialogue box
What things affect your use of your communication system?	• Choices: battery life, the weather, changing muscle tone, fatigue etc • Dialogue box
When are you most likely to use your communication system?	• Choices: with family, with friends, with employees • Choices: at home, at work, out and about, college • Dialogue box

When are you least likely to use your communication system?	• Choices: with family, with friends, with employees • Choices: at home, at work, out and about, college • Dialogue box
Who is best at communicating with you?	• Choices: family, friends, PAs etc • Choices: Why: familiarity, good at listening etc • Choices: have they had AAC training? Options • Choices: how long have you known them? options
Have you ever had a specialist AAC assessment?	• Choices: Never, Once • Choices: where: at home, specialist centre, supplier assessment • Choices: who involved: SALT, OT, CS, Supplier, don't know • Choices: What was recommended? • Choices: How was the aid funded? • Choices: How long did it take from assessment recommendation to receiving your aid?
Please read	**The following sections ask for some information that may be available to some people. It is helpful information as it gives background to why certain types of communication systems may have been recommended. Please complete as much as you are able to, or you may have access to someone who can help you complete these sections, e.g. SALT. This sort of information will help us to understand the types of assessment processes being used.**
Do you know if you have a specific speech and language diagnosis?	• Choices: Not known, primary progressive aphasia, specific language impairment, severe dysarthria etc • or if not known • Choices: my speech is slurred, I find it difficult to understand what people say, I can't find the word in my head but pictures help • Choices: people find me difficult to understand (intelligibility rating descriptors) • Choices: I use my tone of voice to add meaning: people know when I am surprised, happy, sad through the use of my voice (prosody measure) • Choices: I do use my speech but I sometimes get stuck on a word (fluency ratings)

Have you ever had your language and communication skills assessed by a SALT?	• Choices: Yes, no, don't know • Choices: They assessed my ability to understand sentences using: pictures, spoken words, written words etc • Choices: I have some test results: options and dialogue box • Choices: They assessed my ability to understand single words using: pictures, spoken words, written words etc • Choices: I have some test results: options and dialogue box • Choices: they assessed my ability to get my message across using: sign, gesture, sounds and vocalisations, pictures, symbols, written word • Choices: these assessments represented my communication skills: good, ok, poorly etc • Dialogue box
Background information	**Now for some more specific things about you. We are asking these questions as they tell us about things that may influence which communication system are best for you and will help readers understand why things may have worked for you, or may have been more challenging. Some of the questions may feel medical. They may be things you just get on with and don't notice but they may be relevant for developers and therapists to consider when making things work as easily as possible for others with similar characteristics to you. Not all questions will be relevant to you.**
Age	• In years and months
Gender	• M/F
Country of birth	• Choices
Country of residence	• Choices • Choices: languages used at home • Choices: languages understood
How would you describe your schooling and educational experiences?	• Choices: type of school/s, colleges, or university attended, and list any qualifications achieved • Dialogue box: comments about educational experiences

One key skill that is given attention in school and through life is literacy. How would you describe your reading and spelling skills?	• Choices: Would you describe yourself as someone who (i) enjoys reading and has no difficulty with any text, or (ii) someone who has difficulty with reading but didn't used to, or (iii) someone who has always had difficulty reading • Dialogue box:
What employment experiences have you had?	• Choices: employed(full time or part time), voluntary work, none • Dialogue box
How would you describe where you live?	• Choices: e.g. home, school, college, supported accommodation • Choices: does this location have any adaptations that aid your independence? E.g.
	The following section includes things that do inform the types of services people get access to, as well as the range of AAC systems that may be most useful. If you provide this type of information we would be able to see if the same decisions are being made for people with medical, rather than personal and social characteristics. These sections will not be relevant to everyone.
Do you know if you have a specific medical diagnosis?	• Choices: e.g. cerebral palsy, CVA, MND, ASD • Or these descriptions may fit you • Choices: I have had a stroke, I was in an accident, I have always had a physical difficulty, I use a wheelchair
Was there a specific time your communication abilities changed?	• Choices: as above really but attempting to get at from birth or acquired
How would you describe your general well being?	• Choices: e.g. generally keeps well, recurring chest infections
Do you have to take regular medications that impact on your communication?	• Choices: Describe current medications as these may have an impact on other functions, e.g. drowsiness, muscle tone
Do you have any visual difficulties?	• Choices: provide descriptions for either visual acuity and/or perceptual difficulties for people to choose
Do you have any hearing difficulties?	• Choices: e.g. state known hearing loss in dB; state if measurement is not possible, or provide a description of potential impact

Quite often people who have mobility difficulties experience considerable pain. This can affect how an AAC system is used. Would you describe yourself as coping with regular pain?	• Choices: e.g. location, frequency and severity • Choices: Does this affect movement in terms of: using your arms, hands, head (GMFS), lifting and carrying, pointing • Choices: joints, muscle power, involuntary movements, control of voluntary movements
	In this section it is helpful to understand what things make it easier for you to concentrate and learn new things.
Do you find it easy to learn new things?	• Choices: no measure available give a description of general levels. Eg age equivalent/ strengths and weaknesses
Do you find it easy to direct your attention to specific things or do you get easily distracted?	• Choices: I need quiet to be able to concentrate, I can cope with lots of background noise, I find it hard to stay on one activity for very long, I get tired, I get bored
Do you have a good memory for different sorts of things?	• Choices: I am good at remembering faces, names, new words, symbol sequences, spellings, events
Do you find it easy to keep control of your emotions?	• Choices: I find that I can laugh and cry very easily, without knowing why. I can find this embarrassing,
	The following sections will only be relevant to some people. You will know instantly if they do not apply and can move on to the next box
Some people are able to communicate using body movements, rather than any other AAC system. Do the following seem relevant to you?	Choices: e.g. whole body stiffens taken to indicate discomfort

Appendix 2:
References to sections 5 and 6

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