AAC Data & Evidence- Scoping the Possible

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Contents

1. EXECUTIVE SUMMARY

Purpose: the Scottish Government commissioned the Information Services Division (ISD) of NHS National Services Scotland (NSS) to undertake a scoping exercise exploring how to improve the availability of routine data about people with loss of voice or difficulty speaking and who need communication equipment and support in using that equipment.   This report is the response to that commission.

Background: the Scottish Government recognises that being able to communicate and having freedom of expression is a basic human right. In 2016, legislation was passed by the Scottish Parliament which places a duty on Scottish Ministers to provide or secure the provision of communication equipment, and support in using that equipment, to any person who has lost their voice or has difficulty speaking. This communication equipment and support is often referred to as Augmentative and Alternative Communication (AAC). The legislation commenced on 19 March 2018, with the duty delegated to the NHS Territorial Boards and one Special Health Board.

There is, therefore, now a requirement to collect data about the AAC population, who need and use communication equipment in order to provide evidence of progress towards fulfilling this legal duty, and AAC service provision. Historically, very little AAC service delivery data has been collected and recorded, and earlier studies highlighted that NHS and other services' IT and other data collection systems were not conducive to this. A previous recommendation for the collection of national AAC statistics via a nationally agreed dataset was not implemented. There is, therefore, still no readily available information on the numbers and characteristics of people who need and use AAC in Scotland.

Aim and Objectives: the aim of this scoping report is to explore how the following objectives could be met:

1. Use a public health approach to identify the total population needing AAC but not necessarily known to AAC services.

2. Review existing data sources and systems which capture data about the AAC population receiving or known to services.

3. Assess the feasibility of using these existing data sources and systems to generate routine data reporting for NHS Boards on their progress against the legal duty.

Over-arching findings: this scoping exercise has shown that, currently, NHS and other relevant services' electronic and other data collection systems are unable to generate comprehensive and consistent data about the AAC population and current service users. Therefore, it is not possible to extract data which could enable NHS Boards robustly to assess their progress against the legal duty, and which could be aggregated to show the picture for Scotland.   Key issues include:

- **AAC service provision or relevant underlying diagnostic data is recorded in multiple data systems which do not link to each other**: including potentially NHS (primary care, community services, secondary care); Local Authority (via Community Care Assessments or Education services), third sector contracted service providers.

- **Under-recording of medical conditions associated with AAC.** If such conditions are not recorded by GPs in primary care data systems, a patient's potential to benefit from AAC might not be identified. If that patient is admitted to hospital, and their condition is not relevant to the primary cause of admission, it might not be recorded.

- **AAC population not automatically identified as such in NHS and other records**. There is no automatic method of 'flagging' an individual with a condition associated with AAC, or who

is currently receiving an AAC service, or who has previously received an AAC service but has been discharged.

- **NHS Boards and LAs - data collection and recording**: variation in electronic data recording systems used, and AAC data recorded, between and within Boards and LAs. Extensive use of manual recording systems (e.g. paper records, local spreadsheets), including by Speech and Language Therapists (SLTs) who deliver AAC services.

- **eHealth/ IT resource / capacity**: constraints within NHS Boards and LAs would limit the extent to which IT system and other issues could be addressed.

- **Information governance requirements:** would require considerable local resource to work through what level of personal data would be required to assess progress against the duty (e.g. anonymised or identifiable); and to secure permission to access identifiable data if considered appropriate.

Options / Recommendations: the scoping exercise has identified a number of potential short-term options and longer-term more substantive recommendations which could be pursued, though they would still be subject to the issues and requirements highlighted above, including resource implications.

Short-Term Options: these could be explored by NHS Boards to improve the availability of data to track their progress against fulfilling the duty.

- Confirm the diagnostic information that could be accessed and collated regarding those with conditions associated with AAC who are likely to benefit from AAC. This data could highlight clusters of people with those conditions for strategic consideration of how their AAC needs could be assessed.

- Identify any standardised use of codes within electronic data systems which could act as a means of identifying people who have lost their voice or have difficulty speaking, thereby enabling further analysis of their needs and services received e.g. READ codes in GP practices, ICD codes in acute or outpatient services.

- Capture manual information on a small number of data items on existing users, as a repeat and expanded snapshot of existing service users.

- Consider the feasibility of establishing, where appropriate, national or local registers for conditions that are likely to benefit from AAC, taking into account learning from existing or previous examples e.g. MND Scotland and Cerebral Palsy registers.

- Consider the role of the Scottish Centre of Technology for the Communication Impaired (SCTCI) in delivering information to Boards who refer patients and the potential for informing a Scotland wide picture on the AAC population who have the most complex of needs who cannot be served locally.

Longer-Term Recommendations: these are more substantive recommendations which would require significant time and resource, but they could provide a comprehensive baseline of information about people who need and use communication equipment.

- Re-visit Recommendation 3 from a Right to Speak. "*All AAC service providers should develop and implement a population based approach to the provision of support for people who require to use AAC equipment and services, ensuring that needs are recognised and responded to appropriately within the wider community*".

- This will require the development of a systematic approach to identify people who could benefit from AAC: e.g. promote AAC amongst people in targeted diagnostic groups (those with high potential to benefit from AAC).

- Commission ISD to do an immediate piece of work to establish a minimum dataset (a specified set of data items which would be recorded consistently for each AAC service user), so that what is to be captured is fully defined, taking into account details available from ongoing work, consulted upon and aligns with national codes and values of other datasets used by ISD throughout Scotland.

- Once dataset is published, commission ISD to put in place the appropriate internal mechanisms to allow routine data flow to ISD for analysis and reporting, for example, information governance permissions, build a data repository to hold data (including system security), produce and agree reporting mechanisms (dashboards, publications, etc).

- People who need and use communication equipment continue to have their needs met by SLTs: therefore it is recommended that as a priority SLTs need the facilities to record consistent data including the minimum dataset. The following would also need to be delivered by the Boards for them to report on the dataset;

  ➢ commission system suppliers to embed AAC dataset onto local systems used by SLTs;

  ➢ give all SLTs access to an electronic system;

  ➢ SLTs to adapt work practices so that AAC recording is undertaken on their electronic system;

  ➢ ensure that data can be extracted from the system by local boards information services, validated and sent to ISD.

    All of this would require major Board eHealth resource (infrastructure, procuring system changes and staff for extracting, mapping, validating and sending data) at a time when Health Board eHealth is extremely stretched. SLT resource would also be required in terms of training staff on using systems and embedding new work into their working practices.

- Create a register of those with AAC needs so that over time, a full picture of AAC need could be developed. The feasibility of this would need further consideration and discussion with ISD, to explore in what ways this could link to existing registers, for avoidance of duplication and ensuring optimum integration of information.

2. INTRODUCTION

2.1 Purpose

The Information Services Division (ISD) of NHS National Services Scotland has been commissioned by the Scottish Government's Assisted Communications Team to investigate whether and how existing health, care and other services' data systems can generate routine data which would enable both Boards and the Scottish Government to capture progress on fulfilling the legal duty to provide or secure communication equipment and support in using that equipment (which is one type of Augmentative and Alternative Communication (AAC). The duty (Part 4 of the Health (Tobacco, Nicotine and Care) (Scotland) Act 2016) is exercisable by Health Boards and information is necessary at NHS Board level, that could then be aggregated for Scotland overall.

This step builds on extensive work undertaken by the team, supported by Scottish Government analysts and follows on from a Data and Evidence workshop hosted in December 2018 for NHS Boards who hold the duty. A Data and Evidence short life working group (SLWG) has also been established to advise the National AAC Advisory Group on what can feasibly be done to provide evidence of the fulfilment of the duty.

The Assisted Communications Team commissioned this Scoping Report to consider existing data sources and systems which could be used to identify people with diagnostic conditions associated with AAC, record information about people already identified as AAC service users and assess the feasibility of using these existing data sources and systems to generate routine and regular data reporting which could enable NHS Boards to monitor and report on their progress against the legal duty. This report will provide options and considerations to the SLWG that will feed into recommendations to the designated AAC Executive Leads in each of the boards in Scotland who hold the duty and the National Advisory Group for further advice on AAC.

2.2 Background

The Scottish Government recognises that being able to communicate and having freedom of expression is a basic human right – one which is essential to our physical and mental health and our social wellbeing. This is why legislation - Part 4 of the Health (Tobacco, Nicotine and Care) (Scotland) Act 2016 - was passed in March 2016 and introduced on 19 March 2018 and states the following;

'46A Provision of communication equipment
The Scottish Ministers must, to such extent as they consider necessary to meet all reasonable requirements, provide or secure the provision of—

(a)communication equipment, and

(b)support in using that equipment,

to any person who has lost their voice or has difficulty speaking.'

Whilst the duty is placed on Scottish Ministers in the legislation, there is provision within the National Health Service (Scotland) Act 1978 which allows for the Ministers' functions under the Act to be delivered by Health Boards.

The duty is exercisable by Health Boards and one Special Health Board, the State Hospitals Board for Scotland. Where in the Health Board context, delegated arrangements are in place under the Public Bodies (Joint Working) (Scotland) Act 2014, these delegated arrangements will apply to the new duty. If they are not under the auspices of delegated arrangements then the duty will rest with the Health Board.

This legislation places a legal duty on NHS Boards to provide or secure communication equipment and the support to use it – often referred to as Augmentative and Alternative Communication (AAC).

Health services to people who need communication equipment had been and have continued to be delivered, in the main by Speech and Language Therapists.

In addition to sustained campaigns by third sector and professional groups, a number of reports paved the way for the introduction of this legislation. They also highlighted the need for improvements in the data available about the AAC population. In 2012 the Scottish Government report A Right to Speak included the following recommendation:

"**National statistics** on AAC to be gathered by relevant agencies to support future gathering of cost effectiveness data on AAC to ensure that AAC funding is sustained in the longer term.
Actions
1. All NHS based services to implement the use of **nationally agreed data sets** for AAC
2. All AAC services providers to implement the use of appropriate outcome measures for all clients who use AAC."

It was followed by the report Now Hear Me (NHS Education for Scotland, 2015), which set out a vision for Scotland where people who use AAC are fully included in our society, and reported on the implementation of the recommendations in 'A Right to Speak'. Now Hear Me noted the lack of robust data across the UK in many aspects of AAC service delivery, including prevalence, systems used, support required, cost benefit, outcomes etc. It reported on a study commissioned by NHS Education for Scotland to identify any AAC related data collection and data collection systems in use in Scotland at the time. The study found that although it was evident that some useful information was collected, it was ad hoc, not easily aggregated and frequently incomplete. The study also highlighted that IT support mechanisms for Speech and Language Therapy services, in particular, did not lend themselves to easily collecting reportable data around AAC service delivery. The findings of this study reinforced the need for improved data collection systems to enable services to evidence and improve quality, efficiency and effectiveness, resulting in improved outcomes for service users and their families.

The above shows that historically very little data has been captured in data collection systems regarding AAC services. However, as providing or securing AAC equipment and support is now a legal duty of the Boards, ways to evidence delivery of the duty need to be addressed. This scoping report has been commissioned to explore what can feasibly be done to provide evidence of the fulfilment of the 2018 legal duty and the dataset related Recommendation Two shown above.

3.   DEFINITION

3.1   Aim and Objectives

The aim of this scoping report is to inform the AAC Executive Leads, building on existing population analysis and to progress the work of the Data and Evidence SLWG, about how the following objectives could be met;

➢ Use a public health approach to identify the total population who need AAC: through reviewing existing health, care and other data sources and systems which could be used to identify people with:
- diagnostic conditions associated with AAC
- an AAC need (but not via diagnostic conditions associated with AAC);

➢ Identify and review existing health, care and other data sources and systems which:
- record information about people already identified as AAC service users

➢ Assess the feasibility of using these existing data sources and systems to generate routine and regular data reporting which could enable NHS Boards to monitor and report on their progress against the legal duty. For example:

- can they be accessed by health and other practitioners who provide interventions to people who need and use communication equipment, including SLTs or their administrative support? Whilst the duty lies with Health, there is a need to take into account the multi-agency approach, hence there may also be involvement of staff from health, education and social care.

➢ Make recommendations on any changes to existing data sources or data systems, or any new data capture mechanisms, which would be needed to enable monitoring of progress against the legal duty.

3.2   Approach

This scoping exercise has taken place between 15ᵗʰ April 2019 and 10ᵗʰ May 2019 and has involved working closely with a number of key stakeholders, including system suppliers, Information Services Division staff, managers, practitioners including medical staff, Allied Health Professionals (AHPs), and Scottish Government colleagues, who were all able to share their knowledge and provide useful documentation. Given the constraints of time, engagement with specialist nursing colleagues is not included within the report.

4.   OBJECTIVE 1- USE A PUBLIC HEALTH APPROACH TO IDENTIFY THE TOTAL POPULATION WHO NEED AAC

4.1   Objective

Use a public health approach to identify the total population who need AAC: through reviewing existing health, care and other data sources and systems which could be used to identify people with:
- diagnostic conditions associated with AAC
- an AAC need (but not via diagnostic conditions associated with AAC);

4.2   Findings

Why a Public Health Approach?

Although many individuals who have lost their voice or have difficulty speaking are referred to or seek out and find the support they need in terms of AAC, there will be others who do not know such support exists and / or how to access appropriate services, potentially leading to inequality of access. A public health approach could be used by Health Boards to help address this issue by focusing on the health and needs of the population as a whole rather than on individuals. In terms of AAC, this means that it is necessary to increase our understanding of the whole population who need AAC provision in Scotland (approx. 27,000 – 29,000), and not just of the individuals who are currently receiving services (over 4,000 approx.). To look at this further, this objective looks at using a public health approach to consider AAC need and provision, and seeks to look at data solutions that could identify those with AAC needs but who are not currently known to or receiving services.

Additionally, although not explicitly stated in the legal duty or subsequent key publications, listed below, the need for a public health approach (identification of the whole population who fall into this category) is an implication of the wording of the duty as set out in the above background section, which describes the responsibilities of the Scottish Ministers who have delegated this duty to the Health Boards.

The 2018 AAC National Core Pathway and the Guidance on the Provision of Communication Equipment and Support in Using That Equipment, issued as a support to implementing the legal duty, both discuss the early recognition of need, including early identification of communication difficulties, with the Guidance stating as a desired outcome:

'A person's communication difficulties are recognised at an early stage to enable access to timely assessment of their communication equipment support needs.'

Both documents therefore imply that a population approach could help with identifying people with communication difficulties at an early stage.

AAC Prevalence Data

Research carried out into the estimated prevalence of AAC need in the UK population highlights the disparity between the AAC population known to services and the total AAC population who could benefit from communication equipment and support (and therefore the potential for unmet need). [1,2]

The research found that approximately 0.5% of the UK population could benefit from AAC. Taking an epidemiological approach, it also broke down the prevalence data by condition cohort and highlighted that 97.8% of people who could benefit from AAC have one of nine medical conditions: dementia, Parkinson's disease, autism, learning disability, stroke, cerebral palsy, head injury, multiple sclerosis and motor neurone disease. Other conditions associated with AAC include head and neck cancer, locked in syndrome and syndromes such as Down and Angelmann.

These figures predict potential need for, rather than use of, services, which is required to establish unmet need and therefore identify possible inequity of provision. There is little evidence about current AAC service users in Scotland (beyond two snapshot surveys carried out by NHS Boards for the Assisted Communications Team), but the number of service users reported through these surveys are far below the 0.5% population need predicted by the above mentioned research.
It may be that by identifying these groups of patients and targeting them in terms of promoting AAC, more people with speech difficulties could access and be supported by AAC, reducing unmet need and inequity of access.

Identifying People with Diagnostic Conditions Associated with AAC

There are a number of ways in which Health Boards could identify groups of patients with conditions associated with AAC from existing health, care and other data sources and systems, whilst recognising the potential that these conditions are under-recorded. As follows;

Health Board Data

Health Boards capture and collect a vast amount of data for their own purposes and to feed into national data collections. Nationally consistent data has been captured for over twenty years under the SMR00 (Scottish Morbidity Record) dataset for outpatient data and the SMR01 dataset for general / acute inpatient and day case data. These datasets contain structured data in the form ICD-10 medical classification codes, where diagnoses made at outpatient appointments and on discharge from general and acute hospitals during inpatient episodes and day cases can be captured. Up to six individual ICD-10 codes can be recorded on each SMR recorded (although this is not mandatory for SMR00).; one primary and up to five secondary diagnoses.

The SMR00 and SMR01 datasets contain a CHI number, which allows for the identification of records for an individual and means that hospital Information Services Departments could extract a list of patients with the nine medical conditions associated with AAC described above over a specified period of time. This method should provide a list of those with the associated conditions but will have its limitations as this method relies on comprehensive and accurate coding at source and on the need for the patient to have been to hospital (as an outpatient, inpatient or day case) during the specified time period (although hospital attendance may be quite likely for those with certain medical

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[1] Enderby, Judge et al (2013) Communication Matters - Research Matters: an AAC Evidence Base. Beyond the Anecdote, Examining the Need for, and Provision of, AAC in the UK (2013)
[2] Creer, Enderby et al (2016) Prevalence of people who could benefit from augmentative and alternative communication (AAC) in the UK: determining the need.

conditions). The Board eHealth resource would also need to be available to pull this data and map the data if needed and in a time of resource constraints, this can be an issue.

GP Data

Another option may be to extract diagnosis data from GP systems. All long term conditions or significant medical issues should be appropriately READ coded on GP systems (EMIS PCS & Vision). Once all the READ codes associated with certain conditions are identified then Health Board eHealth departments could extract this data by individual (using CHI) as needed. The consistent recording and accuracy of condition coding is important to make sure conditions are not under reported. GP data can be relatively accurate, especially for common conditions previously captured via the Quality and Outcomes Framework (QOF), part of the old GP contract where GPs were paid according to disease registers. Only two of the conditions associated with AAC were captured under QOF however, so the recording of other associated conditions, may be variable.

Information Services Division Data

If Health Boards did not have the internal resources to extract hospital and GP data, ISD could be commissioned to assist in pulling together this data as needed. The SMR data currently feeds into ISD for national reporting and the GP data could be captured via a SPIRE (Scottish Primary Care Information Resource) request. ISD can link (Information Governance dependant) patient records to other datasets as needed, for example, the CHI number could be used to link records from the NRS register of deaths, to exclude individuals that have died from the final list of those with the conditions associated with AAC.

Third Sector / Party Registers / Databases

There are a small number of third sector registers and databases that may collect details on individuals with certain medical conditions. The data captured in these registers and databases are often held for research purposes and although anonymised general numbers may be released to Health Boards to look at prevalence rates, it may be unlikely that individual details for targeting patients for AAC would be released, as part of governance arrangements.

In addition there is information held by independent service providers on the clients they support, as a routine part of delivering effective services. These too will be varied in format and may not be aggregatable or reportable.

The information held and how useful it may be to identify those with diagnostic conditions associated with AAC will vary greatly. An example of a register that holds a great deal of useful information is the Scottish MND Register, maintained by MND Scotland in partnership with the NHS and University of Edinburgh. Access to information is tightly controlled to protect patient confidentiality.

Neurological Conditions National Action Plan

The challenges being faced in relation to AAC data/information are seen elsewhere, as shown in the consultation on the draft action plan for neurological conditions.[3] This highlights that it is not currently possible to identify how many people in Scotland are living with a neurological condition (some of which are associated with AAC).

Commitment Twelve in the draft action plan states that:
"We will work with NHS Information Services Division and others to:
- understand the gaps in prevalence, and how best to improve the data.
- enhance capture of already routine collected data.

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[3]   https://www.gov.scot/publications/national-action-plan-neurological-conditions-draft-consultation-2019-2024/

- further develop systems and processes that support service planning and workforce development based on this information.
- explore the feasibility of developing a national reporting framework that includes key performance indicators for neurological care and support and measures improvements in care and support.
- explore the feasibility of developing effective measures of experience and outcome of person centred care and support, for people with neurological conditions."

Professional Organisations Supports

- RCSLT -Therapy Outcome Measures – ROOT Tool

Royal College of Speech and Language Therapists (RCSLT) commissioned the online ROOT tool (further information available on line) for their membership, to support evidence gathering on patient outcomes, and to enable benchmarking of services, https://www.rcslt.org/speech-and-language-therapy/guidance-for-delivering-slt-services/outcome-measurement/outcome-tool-overview). Its deliberate focus on outcomes assumes that:

- AAC service users are recorded and easily identifiable in data systems
- process and output data is recorded and accessible

This is currently used in Scotland by one acute SLT service in one health board. It is not clear whether reports could be generated by board, service or individual practitioner.

National Managed Clinical Networks (NMCNs)

The Children with Exceptional healthcare Needs (CEN) is a National Managed Clinical Network with the aim of strengthening specialist services for children with complex and exceptional healthcare needs in Scotland. CEN works collaboratively with staff from health, social work, education and the voluntary sector to share good practice and improve services, supporting identification of CEN across Scotland to drive service improvement and enable joint working between healthcare professionals, CEN and their families.

The CEN NMCN have developed an online database called the Clinical Audit System (CAS) within which information is captured on the children and young people living with exceptional healthcare needs in Scotland. As well as basic demographics, the system captures primary and other conditions, the range of professionals involved in care and the technology being used to support the child. The CEN Clinical Audit System website (https://www.cen.scot.nhs.uk/cen-clinical-audit-system/) states;

'The aim of capturing this information is to

➢ Map the number of children with exceptional healthcare needs in Scotland and use this information to improve services in local health board areas
➢ improve care, co-ordination, planning and services for children and young people with exceptional healthcare needs
➢ to hold information that will help professionals who support you/your child, to do this better'

The Children with Exceptional healthcare Needs NMCN could therefore be another source of information on those with the conditions associated with AAC.

Identifying People with an AAC Need (But Not Via Diagnostic Conditions Associated with AAC)

This section looks at other data capture that may identify individuals as having an AAC need. From most of the methods looked at below, it would be unclear if these individuals already had their AAC

need met by AAC services or not and to ascertain this information those identified would need to be compared against those who access AAC services. This information may also be used to build a historical picture of those who have had access to AAC services in the past.

<u>EMIS Web</u>

There are a number of clinical health systems used throughout Scotland that may capture information on patients who do not currently access SLT services but may use communication equipment (e.g. ad hoc or purchased themselves, etc.) or may have a potential need for such equipment. Due to the time constraints of this scoping report, one of these systems has been looked at here, EMIS Web.

EMIS Web is a digital clinical system that can be used to support healthcare teams across all settings. There are a number of EMIS Web systems, tailored for the following areas;

➢ Clinical Services

➢ Community Care

➢ Hospice Care

➢ Primary Care (also known as EMIS PCS)

➢ Emergency Care

In Scotland, the EMIS systems used are largely for GP Practices and community teams, as follows;

➢ GP Data

Throughout Scotland, just over 52% of GP Practices use EMIS PCS for Primary Care. As mentioned previously, the conditions associated with AAC are often READ coded by the practice, however, there are also a number of READ codes (13o80-13o8F) available for communication support findings.   Both EMIS Web (used in community services) and EMIS PCS (used in GP services) have configurable forms, referred to as "templates" which allows each organisation to build their own local data capture screens. One such illustrative example of how an organisation could build a local template, populated with the necessary AAC code (i.e. 13o87), (from the EMIS web clinical code browser) to collect this information for reporting purposes is shown at. (Appendix A). For example, the code 13o87 'Uses alternative and augmentative communication' is available and could be used to identify patients thought to use AAC by the GP Practice. Further investigation of this would be needed however, as this code may or may not be widely used by GP Practices.

Whilst practitioners and managers advise that GP data systems would be the ideal place to 'flag' someone needing AAC, not all health staff can access an overview of systems, for example, providers of Speech and Language Therapy services.

➢ Community Data

EMIS Web is also used in the community and a number of Community, Children's and Mental Health Teams are rolling out EMIS Web for Community Care (including NHS GG&C, Tayside, Ayrshire & Arran and Borders). This system can allow for the capture [and READ coding (see Appendix A for READ codes)] of communication skills and communication support findings and this coded information could be extracted by Boards to identify patients that may have a need for AAC service input.

Like all systems procured on a Board by Board basis, the capabilities of the system will vary from Board to Board depending on how each Board sets up the system. Additionally, local teams may embed the system into their working practice in very different ways and may only enter data on parts

of the system. For example, some teams may just use it for recording or scanning in notes, whereas others may record a great deal of information on the patient on drop down menus.

For these reasons, although EMIS Web has the capability to capture some AAC information, it may be that it is only used in a very basic, high level way in many areas where communication needs are not captured.

Local Authority Data

Local Authority (LA) data may also hold information on the unmet need for AAC via the Community Care Assessment (and other assessments, for example the Sensory Impairment Assessment). This assessment is a review of an individual's personal circumstances and needs, carried out by a local authority social work department (usually by social worker, occupational therapist or community care assistant). Social work will look at how an individual copes with day-to-day living and then recommend help or equipment that may assist.

There are 32 local authorities throughout Scotland and each will have their own way of conducting and recording the community care assessment. Due to time pressures during this scoping exercise, information on the communication element of the assessment was only received from a small number of LA areas.

One LA records information on spoken communication and asks if there is a communication need and if so, has this need been met. Another LA records preferred methods of communication, related medical conditions and any equipment that had been supplied. Another LA records communication support, needs and contact methods where 'Uses communication device' can be recorded, although often such recording is not mandatory. This information is often recorded on electronic systems (e.g. Corelogic MOSAIC, CareFirst, SWIS), where drop down menus and free text can be used for recording. It may also be the case that paper and local spreadsheet recording takes place.

The information held by LAs could be useful to identify those with an AAC need but the various formats and systems used to record this information would make this extremely challenging and may be more achievable in some areas than others, for example in areas with good recording on electronic systems.

It should also be noted, that in most cases, if an unmet need was identified by the Local Authority, the appropriate course of action would be taken to make sure the individual was referred to SLT services.

Education Data

The SEEMiS Education Management Information System captures Additional Support Needs for all pupils in Scotland, across all 32 local authorities, as part of a national pupil census underpinned by a suite of agreed definitions, on an annual basis. This system currently captures if a pupil has 'Communication Support Needs' but does not record, and is unlikely to record in the near future, if that pupil currently uses any AAC equipment. However, as part of the work of the SLWG on data and evidence, the contribution from the Associate Directors of Education network (ADES) is a local pilot, to test the feasibility of introducing a tab on SEEMiS to help education authorities better understand the AAC needs of this pupil group (by distinguishing AAC from the higher level capture of 'Communication Support Needs'). This has the potential to be shared by Education services, in their collaboration with boards, to support Health Boards in identifying those with a future or emerging developmental AAC need.

Transitions

Transitions, from children's to adult services, from school to further education, from education to the workplace are recognised as complex and even more challenging with the associated additional

changes to the communication support network for people who need and use communication equipment.

Work commissioned by Scottish Government is underway with ARC Scotland (the Association for Real Change, an organisation supporting people with a learning disability) who are developing a draft data plan, recognising the gaps in capturing information and signposting towards sources of existing available information.

<u>In Summary</u>

A great deal of the above relies on a number of factors to produce a meaningful prevalence number or list of those with either the diagnostic conditions associated with AAC or with an AAC need not currently met by an AAC service, for example, accurate coding, good data entry, available and sufficient Board eHealth resources.

Information Governance Requirements

Information Governance permissions would be needed to access the kind of information described above, with the reasons and clear public benefit for data collection considered carefully before such permissions could be sought, to access both anonymised and identifiable data. The potential benefits of Health Boards obtaining such information for the AAC population could inform this case. Even if Health Boards can only access their own NHS data, it could equip them to proactively assess the extent to which they are meeting the needs of their local AAC population. It is likely to be much more difficult to gain permission to obtain identifiable data from non-health areas like third party registers, education, etc.

What Would Health Boards Do With This Data?

What Health Boards would then do with the anonymised or identifiable details of individuals with the medical conditions associated with AAC and those identified with an AAC need is another question and one that will need further consideration beyond this report, although some thoughts are detailed below.

<u>Anonymised Data</u>

If anonymised data was to be obtained from some or all of the various sources detailed above, then groups and areas with a high number of those with potential AAC need could be identified. These groups / areas could then be targeted by health boards and encouraged to seek out AAC services.

This data could also be used to inform AAC prevalence rates and assess improvement in recorded prevalence against said rates.

<u>Identifiable Data</u>

If identifiable data was obtained then all individuals with the conditions associated with AAC and others thought to have an AAC need could be collated and compared against those known to AAC services (depending on Boards being able to identify those known to services-objective 2 & 3). The purpose and benefit of accessing identifiable data would be to ensure that the population of those with communication equipment needs are offered an AAC assessment.

<u>General</u>

There are many benefits to Boards obtaining such data but there are a number of further challenges in obtaining such data, including;

- the duty implies a public health approach but does not explicitly state that such work needs to be undertaken and it may be unlikely that Boards would undertake such work unless explicitly asked to do so;

- the resource to undertake this piece of work would be vast in terms of cost and time and funding would need to be identified for this (Board eHealth to pull data, administration (for any Information Governance requests) & campaign resource (promotional material, leaflets, letters, etc);

- if Boards were to secure such information and target these individuals (e.g. ask them to attend a SLT assessment), it is unknown if current Speech and Language Therapy Departments would have the resource to accommodate such a potential surge in activity.

The above limitations mean that another approach may have to be considered, although again, who would undertake this and with what resource would need to be addressed. This would be for further consideration of Boards as to how best to take this forward in local areas.

Additionally, it should also be noted that although there is a difference in the predicted prevalence rate for AAC use and actual use, this will always differ for a number of reasons. For example, some individuals may not want AAC intervention and are content with how they currently communicate, others may purchase equipment themselves and have no problem in doing so and others may have a need for AAC equipment but may not be able to actually use it (e.g. physical capabilities do not allow this).

5. OBJECTIVE 2- REVIEW OF EXISTING DATA SOURCES & SYSTEMS CAPTURING AAC SERVICE USERS

5.1 Objective

Identify and review existing health, care and other data sources and systems which:
- record information about people already identified as AAC service users

5.2 Findings

Health Board Speech and Language Therapy

Anecdotal advice indicates almost all AAC service users will be seen by or have input from a Speech and Language Therapist and consequently will have been assessed and any communication equipment needs identified and provided by this service. Speech and Language Therapists providing healthcare are required by professional standards to always document when they come into contact with a patient, however, it varies greatly as to what they record and how they record it and this makes routine data collection and regular reporting very difficult. For some SLTs e.g. those working in learning disabilities, AAC is embedded within the core part of their job.

As detailed in the previous section, there may be other professionals (GPs, social workers, teachers, etc.) who record information about those who have an AAC need or use AAC but we don't always know if those identified are service users. This objective will concentrate on the data sources and systems used by SLTs to record information about AAC service users.

How SLTs Record Patient Information

SLTs may record information in a number of ways, including on paper, in local spreadsheets and databases or on electronic systems. What method(s) they use for recording varies greatly across the country and even within a Board area. For example, even within the same Board, community based SLTs may use a different system or method to those based in Acute Services, SLTs in different geographical areas within a Board may use different methods of recording or it may come

down to the multidisciplinary team the SLT is part of. The reasons for this will be explored in Objective 3 (e.g. variability of hardware infrastructure, Board eHealth resource to get staff onto systems, etc).

A number of SLTs currently record information on paper and local spreadsheets and databases, however, it is very difficult to collect and collate reliable, consistent national data in this way. Instead, national data should ideally be collected on electronic systems where data can be readily extracted and collated by Board eHealth departments and sent to ISD for national collection. Electronic systems are currently used to capture SLT information in some areas, with electronic recording slowly becoming more prevalent.

There are multiple systems used by SLTs throughout Scotland, including;

➢ Care Partner

➢ EMIS

➢ ePEX

➢ FACE

➢ MiDIS

➢ Morse

➢ PIMS

➢ RiO (unique to The State Hospital)

➢ Topaz

➢ TRAK

➢ Tynedale (Western Isles only)

Some of these systems may currently allow SLTs to identify patients as AAC users and record the details of these patients and their AAC equipment, however this varies greatly even when the same system is being used, as explained below.

Systems are procured on a Board by Board basis so even though a number of Boards may be using the same system, the modules, data fields and set up can vary drastically, with some possibly allowing the capture of AAC and others not. This can occur despite using the same system. For example, even though a number of Boards use TRAK, each Board will have procured it separately (and therefore use different versions) and have it configured in a different way for their needs and the resources they had available when procuring.

A single Board may also use multiple systems, for example one system for acute staff and another for community staff and these may vary greatly in terms of what AAC data they can capture.

Additionally, the same system within a Board may be set up in different ways depending on the team using it, for example, how they fit the system into their work flow may mean that only certain modules are set up and used. Again, this leads to great variation of AAC capture within Board areas.

All of the above may point to a one system solution for capturing AAC, where all SLTs (or even large clusters of SLTs) use the same system in the same way. However, this is unlikely to be the solution for a number of reasons. Firstly, it would be extremely difficult and unlikely that many or all Boards would work together to procure the same system and set it up in the same way as this collaborative way of working would be challenging. Secondly, Boards are tied into current system contracts of varying durations and lastly, a more straightforward (although still challenging) approach would be

for each Board to work with their own system supplier(s) to embed an AAC dataset onto current systems.

Information Recorded by SLTs on Electronic Systems

What information SLTs record varies greatly from Board to Board and as detailed above, even using the same system doesn't mean SLTs will record the same information. A limited number of SLTs have been consulted on during this scoping report and asked what AAC information is currently captured and where.

In most cases, AAC information is captured on paper notes or local spreadsheets with no or very limited AAC information recorded on electronic systems. If anything is recorded electronically then this is often in a haphazard way which is unlikely to be helpful. For example, in one area, a Z999 code (Aetiology AAC, ICD10 Description - Dependence on other enabling machines or devices) can be used to capture AAC but just at the referral stage, (a constraint of that local set-up). However, if a code of this kind was routinely used to identify patients assessed as needing AAC, this has the potential to facilitate extraction and analysis of other data recorded about those patients; for example, what equipment if any they are provided with.

EMIS Web is currently being rolled out to a number of community teams. As detailed previously, this system can allow for some recording on AAC and shows that there is potential in some Board areas to capture AAC data. However, as already mentioned, the set-up of the system can vary greatly between Boards and teams as they will all configure the system in their own way for their own working practices. This means that the local set up may or may not allow for the capture of AAC information.

It should be noted here that even if AAC information was to be captured by SLTs on electronic systems, this information would only be captured for the current caseload of SLTs and may not truly reflect all those who have accessed SLT services and are AAC (service) users. For example, a patient may have been discharged from AAC services as they are happy with the equipment they received and don't need further follow-up. How this cohort of patients would be captured may be difficult and how to do this would need further consideration, as their input may have been received prior to the publication of the AAC national core pathway.

SCTCI Database

In addition to Board area SLT services providing equipment and supporting patients with AAC needs, the Scottish Centre of Technology for the Communication Impaired (SCTCI) hosted by NHS Greater Glasgow and Clyde exists to provide a high quality tertiary level of AAC service to people referred to SCTCI from across Scotland. Two Health Board areas, NHS Fife and NHS Lothian, are content with their own local board based approach to meeting the needs of all AAC users within their local boundaries and they do not refer to SCTCI.

SCTCI staff work throughout Scotland with both children and adults who have significant limitations to their ability to communicate through speech. Their aim is to help improve an individual's communication opportunities through the use of AAC and provide a tertiary assessment (requested by other boards) on an outreach basis for people living in Scotland who may benefit from some form of AAC. Assessments are carried out on a joint basis, by an SCTCI Speech and Language Therapist and a Clinical Technologist working alongside local professionals.

The SCTCI uses a stand-alone database to capture patient demographics, diagnostic and referral information as well as AAC equipment and supplier details. As SCTCI only works with the most complex cases, this would cover only a small minority of people eligible for AAC under the legal duty.

A number of internal and external reports are currently produced out of this database and this could be a starting point for Boards to gain information on those who are AAC service users (information governance permitting). In 2018-19, there were 169 referrals to SCTCI.

Procurement Data

Procurement information may be another source of AAC information as SLTs tend to record this, especially for patients given hi-tech equipment. Health Board and / or Health & Social Care Partnership staff (with Education often being a partner in this) tend to record procurement data on local databases and often capture patient demographic, equipment, licence and maintenance information.

There are also a number of joint health & social care community equipment stores across Scotland, for example EquipU Community Equipment Service which is the biggest integrated service in Scotland covering 27% of the population. EquipU do not currently provide AAC equipment but this may be an option in the future (some scoping work already done by Education Partners and local NHS Services but on hold for national work). This system allows equipment to be ordered via an online, web-based ordering system and can be accessed anywhere by all services. The system allows for the management of data for all equipment provided and can show who ordered the equipment, from which team, who for, when, and whether the equipment was purchased new or recycled through the system. The system can also report on the types of needs being met, the care group, and the age profile of the person being provided with the equipment.

The SLWG on AAC procurement, with membership nominated by AAC Executive Leads, were convened to take forward work to better identify and understand expenditure on communication equipment, at board level building a picture across Scotland. The group have made recommendations for the consideration of AAC Executive Leads in May 2019 to make a local amendment to the NHS ordering system PECOS. The intention being this amendment will enable tracking of purchases from a list of complex devices. An extension to the life of this group to enable further consideration of purchasing activity of communication equipment out with the NHS is also proposed.

6. OBJECTIVE 3- ASSESS FEASIBILITY OF USING EXISTING DATA SOURCES & SYSTEMS FOR ROUTINE & REGULAR DATA REPORTING

6.1 Objective

Assess the feasibility of using these existing data sources and systems to generate routine and regular data reporting which could enable NHS Boards to monitor and report on their progress against the legal duty. For example:
- can they be accessed by SLTs or their administrative support?

6.2 Findings

What is Needed to Generate Routine and Regular Data?

National Dataset

The first step to collecting routine data that can be regularly used for reporting is agreeing a national minimum dataset – i.e. a specified set of data items which would be recorded consistently for each AAC service user, to facilitate Board-level analysis of service users which could also be aggregated for Scotland. Extensive work has been undertaken by the Assisted Communications Team with others on identifying the priority data items, and this is being progressed by the SLWG on Data and Evidence. A standardised national dataset should be produced by the Information Services Division of NHS National Services Scotland in consultation with key stakeholders. This dataset should be

made up of national codes and values and align with other national datasets so that there is no duplication of data capture and to allow for national comparison and linkage if required.

During this scoping exercise, a national dataset was discussed with a number of SLTs and managers and all thought that any dataset should be a minimum dataset that captures essential information only. As most SLT services don't capture any AAC information electronically currently, many felt that anything more than a small number of data items would be unrealistic as embedding this into any work flow would be a cultural shift and challenging enough. The reasons (who wants it and why) for an AAC dataset need to be carefully weighed against the work flow challenges it may create.

Electronic Capture of Dataset

The second step to routine data capture is embedding the dataset into the electronic systems used by SLTs. At this time, this is the major limiting factor to capturing AAC data.

Firstly, some SLTs do not currently enter data onto an electronic system. There are many reasons for this e.g. the electronic recording of data is not embedded into working practice, system changes are required to allow SLTs to record electronically (e.g. moving to a new system, waiting to be enrolled onto a system by Board eHealth) or a lack of infrastructure means that no electronic system exists for SLT use.

Secondly, any dataset produced and nationally agreed would need to be embedded onto the systems used by SLTs so that data could be routinely captured. This report has highlighted the numerous electronic systems used across and within Boards and how these systems are procured on a Board by Board basis. This means that each Board would need to approach their (often numerous) system suppliers to request that the dataset be embedded into their system(s). Making changes to any system may require financial resource and can often take some time.

Lastly, as many SLTs don't currently record information electronically, it would be a major cultural shift to embed this change into working practice and work flow and it may take time and resource for local departments to figure out, document and train staff on how they are to record data electronically.

Extracting Data from Electronic Systems

Even once a dataset is embedded into Board systems and the working practices of SLTs, extracting this data can also be a challenge. There are some systems currently used by the Boards where no or very little data can be extracted, this may be due to the system's capabilities or because Health Board eHealth departments do not have the initial resource (time and money) to develop data extraction. Extraction scripts have to be written and tested to extract and map data initially but once perfected, this process can become quite automated and non-labour intensive.

Sending Data to ISD for routine and regular data reporting

Any AAC data available within the Boards can be collated and used by them to assess and improve current AAC services, however, any national reporting is usually done via ISD.

Depending on the data being submitted to ISD, ISD would need to acquire the information governance permissions to receive such data and would need to build a data repository to hold the data. Both of which require resource.

The outputs from ISD would also need to be considered and may require resource, e.g. publication reports or feedback to Boards via dashboards.

Allied Health Professions Operational Measures (AHPOM) and Routine and Regular Data for AAC

The purpose of the AHP Operational Measures (AHPOM) project is to introduce a national minimum dataset which will provide administrative data regarding contact with AHP groups (including, for example, SLTs) at a patient level. This work has a long history and during its current iteration has experienced all of the issues outlined above. AHPOMs has certainly been a catalyst for change and continues to drive conversations concerning AHP data capture at both local and national levels, yet there is a wide readiness spectrum across the country with a variety of causes. No Board can provide the complete dataset and while some are more advanced, others are some time from submitting meaningful data. The AHPOM example shows that even facilitating the collection and extraction of the most basic AHP data at a local level has taken some time and is still far from completion.

While AHPOMs has been considered as a natural home for AAC data collection, when explored in more detail, there are a number of factors which suggest otherwise:

➢ There is a legislative duty to report on AAC metrics. There is no such requirement for the AHPOMs dataset.
➢ AAC data is a continuous clinical audit, AHPOMs is administrative patient level contact data and was not designed to be anything else.
➢ AHPOMs published a dataset in September 2017, AAC has yet to define one along with answering where, how, and who in terms of professionals and capture in clinical workflow.

There are a number of considerations in developing the AAC data metrics yet to be worked through. Any national data collection for SLTs regarding AAC is potentially several years away. It is acknowledged that the AHPOMs has the potential for expansion in future phases, however there are no plans at the moment to take this forward.

7.   OBJECTIVE 4- OPTIONS / RECOMMENDATIONS

7.1   Objective

Make recommendations on any changes to existing data sources or data systems, or any new data capture mechanisms, which would be needed to enable monitoring of progress against the legal duty.

7.2   Findings

Conclusion

To conclude, this scoping report has examined how data sources and systems may be used to assess Board progression towards meeting the AAC legal duty to provide or secure communication equipment and the support in using that equipment, to those who have lost their voice or have difficulty speaking.

The scoping work undertaken shows that fragmented information and data on AAC are currently captured in a number of formats in numerous data sources and systems. This makes current national data collection impossible and the following options and recommendations are given to begin the journey to national AAC collection subject to the barriers discussed above.

Options for Consideration

There are a number of short-term pragmatic options which could be explored by NHS Boards to improve the availability of data to track their progress against fulfilling the duty. It is acknowledged that the limitations of these options would include the issues discussed above: e.g. the variable use of electronic data systems and a reliance in some cases on manual record-keeping.

- Boards to confirm the diagnostic information that could be accessed and collated regarding those with conditions associated with AAC who are likely to benefit from AAC. This data could highlight clusters of people with those conditions for strategic consideration of how their AAC needs could be assessed.

- Identify any use of standardised codes within electronic data systems which could act as a means of identifying people who have lost their voice or have difficulty speaking, thereby enabling further analysis of their needs and services received e.g. READ codes in GP practices, ICD codes in acute or outpatient services.

- Capture manual information on a small number of data items on existing users, as a repeat and expanded snapshot of existing service users.

- Consider the feasibility of establishing, where appropriate, national or local registers for conditions that are likely to benefit from AAC, taking into account learning from existing or previous examples e.g. MND Scotland and Cerebral Palsy registers.

- Consider the role of SCTCI in delivering information to boards who refer patients and the potential for informing a Scotland wide picture on the AAC population who have the most complex of needs who cannot be served locally.

Recommendations

The following section shows some more substantive recommendations to Health Boards and AAC Executive Leads which would require significant time and resource, but could provide a comprehensive baseline of information about people who need and use communication equipment. The timescales involved in such work will be variable across Scotland and may come down to the level of prioritisation given to this work by each Board.

- Re-visit Recommendation 3 from a Right to Speak. "All AAC service providers should develop and implement a population based approach to the provision of support for people who require to use AAC equipment and services, ensuring that needs are recognised and responded to appropriately within the wider community".

- This will require the development of a systematic approach to identify people who could benefit from AAC and so e.g. promote AAC amongst people in targeted diagnostic groups (those with high potential to benefit from AAC), detailing the steps to be taken in their own local boards to deliver this.

- Commission ISD to do an immediate piece of work to establish a minimum dataset (a specified set of data items which would be recorded consistently for each AAC service user), so that what is to be captured is fully defined (taking into account details available from ongoing work), consulted upon and aligns with national codes and values of other datasets used by ISD throughout Scotland.

- Once a dataset is published, commission ISD to put in place the appropriate internal mechanisms to allow routine data flow to ISD for analysis and reporting, for example, information governance permissions, build a data repository to hold data (including system security), produce and agree reporting mechanisms (dashboards, publications, etc).

- People who need and use communication equipment continue to have their needs met by SLTs, therefore it is recommended that as a priority SLTs need the facilities to record consistent data including the minimum dataset. The following would need to be delivered by the Boards for them to report on the dataset;

- ➢ commission system suppliers to embed AAC dataset onto local systems used by SLTs

- ➢ give all SLTs access to an electronic system

- ➢ SLTs to adapt work practices so that AAC recording is undertaken on their electronic system

- ➢ ensure that data can be extracted from the system by local boards' information services, validated and sent to ISD.

  All of this would require major Board eHealth resource (infrastructure, procuring system changes and staff for extracting, mapping, validating and sending data) at a time when Health Board eHealth is extremely stretched. SLT resource would also be required in terms of training staff on using systems and embedding new work into their working practices.

- • Create a register of those with AAC needs so that over time, a full picture of AAC need could be developed. The feasibility of this would need further consideration and discussion with ISD.

8. APPENDIX A – READ CODES (THESAURUS OF CLINICAL TERMS) FOR AAC

communication aid		Filter	All	

Communication aid
Provision of communication aids
Uses voice output communication a

Code hierarchy Resources

▲ SNOMED CT/Read V2. Release v132	.1
▲ History / symptoms	1
▲ Social/personal history	13
▲ Communication skills	13o
▲ Communication support finding	13o8
Uses lipspeaker	13o80
Uses electronic note taker	13o81
Uses manual note taker	13o82
Uses speech to text reporter	13o83
Uses cued speech transliterator	13o84
Uses British sign language interpreter	13o85
Uses textphone	13o86
Uses alternative and augmentative communication	13o87
Uses Tadoma method for communication	13o88
Uses voice output communication aid	13o89
Uses communication device	13o8A
Uses symbols for communication	13o8B
Uses switches for communication	13o8C
Uses photographs for communication	13o8D
Uses low technology communication device	13o8E
Uses high technology communication device	13o8F

communication aid	Filter	All

Communication aid
Provision of communication aids
Uses voice output communication a

Code hierarchy	Resources	
Uses cued speech transliterator	13o84
Uses British sign language interpreter	13o85
Uses textphone	13o86
Uses alternative and augmentative communication	13o87
Uses Tadoma method for communication	13o88
Uses voice output communication aid	13o89
Uses communication device	13o8A
Uses symbols for communication	13o8B
Uses switches for communication	13o8C
Uses photographs for communication	13o8D
Uses low technology communication device	13o8E
Uses high technology communication device	13o8F
Uses apps on mobile device to support communication	13o8G
Uses voice amplifier to support communication	13o8H
Uses deafblind intervener	13o8J
Uses Personal Communication Passport	13o8K
Uses alternative communication skill	13o8L
Uses sign language	13o8M
Uses Deafblind Manual Alphabet	13o8N

ANNEX B

GLOSSARY OF TERMS AND ABBREVIATIONS

AAC   Augmentative and Alternative Communication
AHP   Allied Health Professionals
ISD   Information Services Division
NSS   National Services Scotland
READ Code   Read Codes are a coded thesaurus of clinical terms. They provide a standard vocabulary for clinicians to record patient findings and procedures, currently used in health and social care IT systems across primary and secondary care
SG   Scottish Government
SLT   Speech and Language Therapist
SLWG   Short Life Working Group