Provision of Communication Equipment and Support

Part 4 of the Health (Tobacco, Nicotine etc. and Care) (Scotland) Act 2016

Progress Report 2019

February 2020

Scottish Government
Riaghaltas na h-Alba
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MINISTERIAL FOREWORD

For people who have lost their voice, or have difficulty speaking, the ability to communicate is vital in helping them fulfil their potential, and to participate equally in our communities.

This is why the Scottish Government introduced a new law to ensure people get the communication equipment they need and the support to use it.

This report provides an update on the progress we have made.

I am encouraged by the range of activities that are underway. However, I know that there is more to do to ensure that those adults and children who need or could benefit from communication equipment are aware of the services available, and receive the support they need from staff, their communication partners and their families. We hope that the tools, training and guidance which have been developed will help those individuals to provide the necessary support.

Clare Haughey

Minister for Mental Health

CONTENTS PAGE

1. INTRODUCTION

1.1 THE LEGISLATIVE DUTY

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. Communication equipment, and support in using it, can make a real difference to people's lives and makes sure they have a voice to be heard.

This is why from 19 March 2018, NHS Boards in Scotland now have a legislative duty[1] to provide or secure communication equipment and the support in using that equipment, often referred to as Augmentative and Alternative Communication (AAC). This duty applies to children and adults, from all care groups who have lost their voice or have difficulty speaking. There is no comparable law anywhere else in the UK.

This commitment to people who need and use communication equipment and support builds on the earlier work the Scottish Government launched in **A Right to Speak[2]** in 2012 and **Now Hear Me[3]** (2015 NHS Education for Scotland), which set out a vision for Scotland where people who use AAC are fully included in our society.

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.

1.2 BACKGROUND TO THIS REPORT

Following commencement of the legislation, the former Minister for Mental Health, Maureen Watt MSP attended the National AAC Advisory Group (See **ANNEX A** for information on this group), to thank all members for their contributions, to hear the views of stakeholders, including contributions from a person who uses AAC and to collectively agree the priorities going forward.

As proposed by the then Minister for Mental Health, Maureen Watt MSP in 2018, this report sets out to capture the activities, actions and progress of the Scottish Government, health boards who hold the duty, and wider stakeholders in supporting the legislation. It includes input from National AAC Advisory Group members, who represent health boards, Integration Joint Boards, local government, professional organisations, people who use AAC, health professionals and third sector providers.

[1] Part 4 of the Health (Tobacco, Nicotine etc. and Care) (Scotland) Act 2016 - http://www.legislation.gov.uk/asp/2016/14/part/4/enacted
[2] A Right to Speak – Scottish Government Report - https://www2.gov.scot/resource/0039/00394629.pdf
[3] Now Hear Me Report - http://www.nowhearme.co.uk/wp-content/uploads/2015/07/Final-AAC-Report-24.06.15.pdf

Engagement with other Scottish Government policy teams with a relevant interest has also taken place and those activities are reflected within this report.

2. ACTIVITIES AND PROGRESS

2.1 ENGAGEMENT VISITS TO THE AAC SERVICE WITHIN HEALTH BOARDS

2.1.1 Background

An initial round of visits to Health Boards prior to commencement of legislation was undertaken by Scottish Government policy officials in winter/spring of 2016/17, with the aim of better understanding how local provision of communication equipment and support were being delivered. Those visits acknowledged variation in service models, and reflect the flexibility in historical service development, in response to local opportunities, pressures and priorities.

The visits revealed a network of dedicated practitioners across Scotland, who would be supported by AAC Executive Leads, nominated by boards in 2016, providing a clear point of contact within a board setting, and responsible for driving forward this work in collaboration with the Scottish Government, people who use AAC and their families, and other stakeholders including AAC service providers. AAC Executive Leads have and continue to raise the profile of AAC providing strategic leadership at senior team level for this programme of work, bringing an awareness of the needs of those without a voice to be heard.

A further round of visits and discussions with health boards took place between September 2018 and January 2019, with discussion structured around six questions. (See attached template at **ANNEX B**)

2.1.2 What Health Boards told us

There was limited evidence, at this early stage post commencement across the whole of Scotland, of impacts on service provision although there are some pockets where there has been clear change. Boards reported the legislation was making a difference in the following ways:

Impact

- One area mentioned they have been able to use the legislation to inform and improve services, through revision of internal processes resulting in quicker access, with all those identified as requiring AAC receiving it in a timely manner.

- Two boards commented *“it is too early to say as numbers relative to the general population are so small”* and *“too early to see any real time impact”*.

Financial Budgets

- Six boards highlighted the financial aspect of provision and is detailed below.

- As a consequence of the legislation five boards reported work has been undertaken to identify funding streams and improvements around the management of equipment.

- Legislation is reported to have had a positive impact on resources in two board areas, with quicker access and closer monitoring of expenditure.

- Six health boards have now allocated additional funding for the provision of communication equipment.

  "the legislation is definitely making a difference with secured funding, access is easier and quicker"

  "as part of our cost-pressures process this year and rather than dealing with demands on a case by case package of funding, we have allocated £220,000 into communication equipment and staffing as a response to the AAC implications. Currently this is not recurrent as we need to continue to map additional needs and continuing costs. Of this allocation, roughly £100,000 is for additional staffing to support users of the service'.

  "in light of the legislation, and recognition of demand the fund will be supplemented and kept under review with regard to equitable access. Demand has increased for funding since legislation commenced…."

Staff Resources

- Three boards highlighted amendments to staff resourcing.

- One area highlighted remaining concerns about the previously reduced staffing compliment of core teams. This was in contrast to another area reporting an infrastructure that included AAC Champions, robust supervision and good governance to support clinical decision making, all contributing to ways in which staff are supported.

- One further area advised, 'the workforce are committed to getting processes right, and staff are working to empower service users and their families and circles of support through the widely adopted use of universal support measures for communication'.

2.1.3 Contributions from health boards who hold the legislative duty

Scottish Government Assisted Communication policy officials invited contributions from health boards for inclusion within this progress report. Further detail is available at **ANNEX C.**

2.2 SUPPORT TOOLS

To support delivery of the legislative duty a suite of tools have been developed. AAC Executive Leads from the Health Boards strongly supported this work, nominating a range of participants to include AAC Specialists and expert practitioners to work alongside those from education, special interest groups and other perspectives having an interest in AAC.

2.2.1 Publication of Guidance

Guidance on the Provision of Communication Equipment and Support in using that equipment was published on 31 May 2018. This provides practical information on the use of communication equipment, the support needed to use this equipment, and a shared vision and principles. It is hoped the guidance will be helpful to people who currently, or in the future, may use communication equipment, their families, practitioners and partner agencies who are supporting them, as well as those responsible for delivering the legislation. Informal feedback from managers and practitioners indicates this guidance has been well received. An easy read version was published on 24 October 2018.

2.2.2 Publication of National AAC Core Pathway

The National Augmentative and Alternative Communication (AAC) Core Pathway has been developed in partnership with boards and was published on 31st August 2018. The pathway sets out what service users can expect from their AAC journey – incorporating information on assessment for, and provision of, communication equipment and support in using that equipment.

The launch of the tools was supported by NHS Inform and cascaded through wider networks to raise awareness. The tools have been well received by a broad range of stakeholders with positive feedback from people who use AAC, practitioners and their networks, and services.

> ***"****The AAC National Core Pathway has been an essential guide as part of an induction period for new staff and students. It outlines the key features which are important including: assessment, medium to long term loan of equipment and the importance of review and monitor for any AAC system.*
>
> *I have also used the Core Pathway in discussions with families and carers when introducing a new AAC system. It can provide reassurance that there is a standard framework……we are working within."* ***Deborah Jans, NHS Lothian, Keycomm Specialist AAC Service.***

2.3 AWARENESS RAISING

2.3.1 Examples of local activities

NHS Forth Valley conducted a survey of staff, to explore their awareness of the legislation within the Speech and Language Therapy (SLT) workforce. The results of that work were shared with the National AAC Advisory Group as an example of good practice. Forth Valley AHP Senior Managers have since built on this work in the following ways:

- Delivered refresher training and continue to plan for ongoing updates.
- Refreshing staff's awareness of the Forth Valley AAC Pathway.
- Encouraging greater use of and engagement at an earlier stage with the Forth Valley Team of AAC Champions, who are available to support and provide guidance to all SLT staff.
- Continuing to explore access to greater technical support including programming of devices.

NHS Lanarkshire working across Speech and Language Therapy and IT raised awareness of the one year anniversary of commencement through publicising this on PC desktop backgrounds on all NHS Lanarkshire devices, ensuring all board employees who accessed an NHS Lanarkshire computer received that message.

Some boards expressed a need to target awareness raising, in such a way as to effectively inform people who may want to access this provision. They advise this requires clear advice on what the local pathway is and information on who is most likely to benefit, to promote appropriate referrals and ensure effective signposting to advice.

These processes are in keeping with the approach set out in a Right to Speak[4] ensuring those who need communication equipment will be aware of their rights and appropriately signposted.

2.3.2 Examples of National Activities

NHS Inform has hosted a web page containing information on:

- Commencement of the legislation.
- The support tools and;
- Contact details for the policy team.

The page https://www.nhsinform.scot/campaigns/1st-anniversary-of-aac-legislation has been in place from the anniversary to November 2019.

[4] A Right to Speak Report - https://www2.gov.scot/resource/0039/00394629.pdf

NHS Education for Scotland who host the nowhearme website have supported awareness raising through messaging on the blog page of the site, signposting viewers to find out more on the NHS Inform web site and on the ScotGovHealth twitter page.

2.3.3 First anniversary of Commencement of the legislative duty

Scottish Government carried out the following to support activities leading up to and during this period.

- Attended the meeting of the AAC speech and language therapy (SLT) leads network in June of 2018 where members were asked to invite expressions of interest from people who use AAC to tell their story about what the legislation and the provision of communication equipment meant to them. The SLT leads representative from NHS Lothian helped collate the four stories that were submitted alongside a poem which was produced by a person who uses AAC and a collection of quotes from a number of AAC users. **Supporting documents refer**.

- Worked with Communication Healthier colleagues to provide a short video of quotes from patients as well as an AAC users story:
  Video of quotes:
  https://twitter.com/scotgovhealth/status/1107984714890133505
  AAC user's story:
  https://twitter.com/scotgovhealth/status/975753067156078593

- On 27 March 2019, the Minister for Mental Health, Clare Haughey MSP carried out an engagement visit to the NHS Fife AAC (FAACT) Service. This included an overview of the service, as well as a meeting with an AAC user to hear about the impact having a communication aid can have on their day to day life.
  https://twitter.com/haughey_clare/status/1110881015625584640

Keycomm (NHS Lothian) took part in activities to raise awareness of AAC and the legislative duty through an exhibition stall at the Annual AAC Study Day in March 2019.

Attendees were invited to contribute feedback on whether the legislation had made a difference, the main themes highlighted included:

- Areas developing local policies and pathways where previously these did not exist.
- Waiting times greatly reduced, easier to get permission to purchase equipment.
- There is easier access to funding.
- People are more aware but information needs to be shared more with people working with AAC users and their advocates.

> "*To those people who potentially need equipment this legislation will have hopefully been a positive difference to them".*

"Raising awareness of services required will make it better".

This work further builds on that of raising awareness of AAC as set out in a Right to Speak stating*:*

> *"Services should at all times be identifying need even if needs cannot be met within existing resources".*

2.3.4 Contributions to other Scottish Government Reports (Raising awareness of the legislative duty)

The contributions the Assisted Communication policy team made to other publications are included in the following:

- **Supporting disabled children, young people and their families' guidance** under the heading of Inclusive Communication. Details on the legislative duty, support tools of the definition of communication equipment and support guidance, the national AAC core pathway and information on what is AAC were included. The guidance was published on 24 April 2019. https://www.gov.scot/publications/supporting-disabled-children-young-people-and-their-families/pages/inclusive-communication/

- **Progressing the human rights of children in Scotland: 2018 report**
  A section on communication equipment and support, which details the legislative duty, guidance on the definition of communication equipment and support and the national AAC core pathway, were included in the report on progressing the human rights of children in Scotland, published on 20 December 2018. https://www.gov.scot/publications/progressing-human-rights-children-scotland-report-2015-2018/

- **Patients' Rights**
  The Person-Centred and Quality Team within the Healthcare Quality and Improvement Directorate carried out a review of the Charter of Patient Rights and Responsibilities for which the Assisted Communication team provided a contribution on the duty to provide or secure communication equipment and support, with reference to the easy read version of the Guidance on the Definition of communication equipment and support [which sits under the heading of communication support (page 12)]. The charter was published on 27 June 2019.
  https://www.gov.scot/publications/charter-patient-rights-responsibilities-2/.

2.4 DATA AND EVIDENCE: POPULATION ANALYSIS

2.4.1 Background

> *"Having an estimate of the numbers of individuals who may require a service not only assists in planning and commissioning of that service but also is important in order to identify unmet need and inequity of provision".*[5]

The overall purpose of improving the availability of data and evidence is to ensure that the AAC population (defined here as people who could benefit from AAC) have access to, and benefit from, the AAC provision to which they are entitled under the legal duty.

Building a Scotland-wide picture of information on the population has the potential to be used for the benefit of people who need AAC, and over time, to monitor progress against the duty. This may include the opportunity to:

- Improve identification of the AAC population to appropriate service providers, in order to ensure that they are offered the signposting, to services such as assessment, advice and any necessary interventions to which they are entitled under the legal duty.
- Support services to monitor their AAC provision.
- Enable analysis of the AAC service user demographics and underlying diagnoses, in order to identify potential unmet need and inequalities in access to services.
- Support capture and monitoring of AAC service user outcomes.

(Further explanation of the terms used in this report in relation to Data and Evidence is available at **ANNEX D**)

At present there is no reliable data available or consistent infrastructure in place to support gathering the numbers and characteristics of people who use AAC in Scotland, or advise reliably and consistently on the detail of costs associated with the purchase of the communication equipment or the personal outcomes achieved.

The Scottish Government, building on previous work from a Right to Speak, has undertaken extensive engagement pre and post commencement of the duty. This has included visits and discussions with Health Boards across Scotland and with providers of potential sources of relevant data and evidence, including other Scottish Government policy areas with a relevant interest. Examples are:

▪Strategic Planning (neurological conditions i.e. MND, Parkinson's; Stroke); Strategy and Delivery for Dementia; Pupil Census; Allied Health Professionals (AHP's); e-Health/Digital and; Workforce Planning.

▪Organisations including NHS National Services Scotland (NSS), SEEMiS and, health colleagues within the Welsh Government, NHS England and commissioned services in England.

[5] Creer, C., Enderby. P., Judge, S., John, A. (2016) *Prevalence of people who could benefit from augmentative and alternative communication (AAC) in the UK: determining the need.* International Journal of Language and Communication Disorders, Vol. 51, No. 6, pp. 639–653

(Refer to **ANNEX E** for further detail on policy engagement and activity).

2.4.2 AAC Prevalence and Unmet Need

The **Scottish Government health and social care analysts** have engaged in detailed work on prevalence since August 2018, undertaking analysis from existing available published research. This has included drawing on a broad range of information and advice from stakeholders, for example, Bobath Scotland, RCSLT, MND Scotland, Parkinson's UK, and crosscutting policy teams with an interest, in addition to information snapshots on AAC clients already known to services. Extrapolations from UK research[6]/[7] on the estimated prevalence of AAC need in the population highlights the disparity between the AAC population we are aware of, and the population not known to services but who may benefit from communication equipment and support. Research[8] estimates

"*… just over 0.5% of the UK population could benefit from some type of AAC" and "… approximately 0.05% of the UK population could benefit from powered communication aids".*

In Scotland, with a population of approximately 5.4 million[9], this would equate to around 27,000 benefiting from some type of AAC, with 2,700 benefiting from powered communication aids.

Research shows that over 97% of people who could benefit from AAC have one of the following nine medical conditions: dementia, Parkinson's disease, autism, learning disability, stroke, cerebral palsy, head injury, multiple sclerosis and motor neurone disease[7]. The proportion of people with these conditions who could benefit from AAC varies by condition. However, patients with these diagnoses are not necessarily 'flagged', recorded or recognised[10] as having a potential communication need which may require to be assessed, or as receiving AAC services. Therapists often prioritise recording the person's primary communication disorder rather than their underlying diagnosis.

Local professionals recognise that there is insufficient information available on the population of people who need and use communication equipment. Some have advised that the diagnostic profile of their AAC clients does not match the estimated AAC population profile, drawing on the research evidence cited above. This suggests that some population groups are not accessing services, or initiating requests for assistance or referrals, assessments or services.

Where people are not aware of their rights or that help may be available, they are unlikely to make that request of services.

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[6] 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)

[7] Creer, Enderby et al (2016) Prevalence of people who could benefit from augmentative and alternative communication (AAC) in the UK: determining the need

[8] https://communicationmatters.org.uk/wp-content/uploads/2019/01/2013_Shining_a_Light_on_AAC.pdf

[9] https://www.nrscotland.gov.uk/files//statistics/nrs-visual/mid-18-pop-est/mid-year-pop-est-18-info.pdf

[10] National AAC Core Pathway - https://www.gov.scot/publications/national-augmentative-alternative-communication-aac-core-pathway/

In 2017 and again in 2018, Scottish Government invited health boards who hold the duty to carry out a snapshot count to capture information on the numbers of people engaging with services. The one off snapshot approach was selected by the National AAC Advisory Group as their preferred means of information capture, given the existing system constraints.

In 2017, health boards reported 2,784 people who use AAC, of whom around 2,023 people were using high tech aids [not all areas reported the low tech users].
In 2018, a further snapshot was undertaken (including people who used high tech and low tech equipment). In response, reported numbers rose to 4,486.
There are no known reasons why there would be a sudden increase, but it is likely that this is a reflection of boards' increased efforts to identify those people who were previously, as well as currently, known to services and to include users of high tech, and/or low tech aids. However, the gap between estimated prevalence and snapshot survey data suggests some unmet need.

Activities to build on this work, using other means to capture progress from service delivery within health boards and information and statistic experts have been taken forward and further information is detailed below.

2.4.3 Data and Evidence Workshop for Health Boards in December 2018

In December 2018 Assisted Communication policy officials hosted a workshop for NHS Boards who hold the legislative duty. The workshop comprised of presentations from a Scottish Government eHealth national clinical lead and NSS staff implementing the rollout of the Allied Health Professions Operational Measures (AHPOMs), as well as working group discussions and the review of potential data items.

The purpose of the workshop was to identify practical, achievable steps which could be taken or recommended to identify the AAC population; propose a minimum dataset for people receiving AAC services; look at ways to improve data collection, recording and reporting and to achieve a broader understanding of information being a means to evidence the delivery of the duty.

There is now a level of understanding among local AAC Executive leads and some practitioners, that information is required by health boards to evidence that they are delivering the duty, in a way that is transparent and accountable in relation to that duty. Refer to **ANNEX F** for outcomes from the workshop.

Additional information providing context to data and evidence in relation to previous reports and recommendations is available at **ANNEX G** with information on other data challenges being available at **ANNEX H.**

2.4.4 Short Life Working Group (SLWG) on Data and Evidence

In response to stakeholders' ongoing requests for information such as waiting times, numbers of people assessed and provided with equipment, and timeliness of provision, the National AAC Advisory Group was invited to nominate representatives to a SLWG on Data and Evidence, with membership confirmed in the winter of 2018.

The aim of the group was to provide membership of the National AAC Advisory Group with advice on what information is feasible to capture and which will provide evidence of the extent to which the duty is being met.

The first meeting of the SLWG was held in January 2019, and followed on from the data and evidence workshop described above. Future meetings of this group were to be aligned to the availability of relevant commissioned reports, such as the NSS report, detailed below and the AHP National LifeCurve™ Survey – Analysis of Communication Support question described later on in this report. [See 2.4.6] Following advice from AAC Executive Leads and the learning from the workshop this has added to the growing understanding of the complexity of the systems and challenges in reporting on the population of AAC users, and further engagement with NSS is recommended.

In February 2019 Scottish Government met with the Associate Director at NSS, in the context of no further avenues being available to explore, health boards having no vehicle in place to statistically evidence the duty and following advice from AAC Executive Leads to secure a public health perspective, seeking their support to progress this work.

2.4.5 NHS National Services Scotland Report

'Scoping the Possible' Report by NHS National Services Scotland (NSS) (See Supporting documents)

Scottish Government commissioned NSS to undertake a scoping exercise to explore what, if any, potential there was for existing healthcare and other services data systems to:

- generate routine data to contribute to evidencing progress in fulfilling the legislative duty.
- use a public health approach to identify the total population who might benefit from AAC.

The exercise took place in May 2019 with findings detailed below:

Over-arching findings: 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. Thus evaluation of hard data is not currently possible, therefore this report seeks to capture progress across all work streams to date.

Key issues include:

- **AAC service provision or relevant underlying diagnostic data can be recorded in multiple data systems which do not link to each other**: e.g. 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, their possible AAC needs 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 Local Authorities (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) 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.

To continue to promote ongoing engagement, AAC Executive Leads were invited in July 2019 to provide an initial round of strategic level, qualitative feedback, highlighting areas from the scoping report that were important to them or their boards.

Feedback received is as follows:

- There is support for the general direction of travel to improve data and evidence and thereby bring a better understanding of this population. This needs to be underpinned by further work, provide clarification on the purpose of future data capture and how it would be used. Investing in data capture must demonstrate clear benefit and better outcomes for the people who need and use communication equipment. A more detailed explanation of how improved evidence could benefit the AAC population is at **ANNEX E.**

- A better understanding of where these recommendations sit in relation to other priorities at a time of significant resource constraint is also required. It may be helpful to have a clear articulation setting out why AAC Data and Evidence is a priority at this time. Again, refer to the explanation set out at **ANNEX E.**

- Some accepted the value of taking a public health approach to this work, while others highlighted concerns about the potential for impact on existing services from any increased demand. The majority of Boards have taken steps to highlight the duty and access to services.

- The need to protect the capacity of the workforce to see patients was highlighted with any new or different undertaking of local capture and analysis of information, requiring appropriate support.

- Boards requested further work with GPs' in relation to coding, recording, feasibility of processes, along with the need for advice and consultation with others who would be directly inputting to systems to achieve robust recording and reliable data. Scottish Government will be taking this forward as part of the future data and evidence work.

- Some boards specifically supported implementation of a minimum dataset: i.e. a specified set of data items which would be recorded consistently for each AAC service user. However, there was very limited feedback supporting the development of a national register which was one of the future options raised in the NSS report. There was limited and balanced feedback for and against further manual capture of information.

- Concern was expressed around information governance in respect of ensuring the identity of those most vulnerable, particularly from small populations. It should be noted that this data would only be used by health and care staff entitled to access it, in order to ensure that the AAC population are offered the signposting to services, assessment and intervention where appropriate.

- A few boards commented on the omission of qualitative data on user experience from the scoping report. This was out with the scope of the report and this will be taken forward by Scottish Government in the refreshed national work plan under communications and engagement. However, service user experience data can only be explored if mechanisms are in place where service users are identified and known to services. Therefore, a systems based solution may be a necessary pre-cursor to undertaking such work in a robust, reliable and credible way.

- The report findings were presented by NSS to the SLWG on data and evidence meeting on the 10 October 2019, with all members invited to submit their comments in advance of the meeting, enabling contributions from the full group.

- Members prioritised the options and recommendations from the NSS report, identifying three preferred aspirations, in chronological order being the establishment of the following:

    - National AAC minimum dataset – to underpin consistent recording of need.
    - Registers of specific diagnostic conditions associated with AAC – to ensure that each of the conditions most likely to cause an individual to have a communication need, have the scope to capture AAC needs within their infrastructure.
    - Specific Register for AAC - recording the needs of people from across all care groups regardless of age who need and use AAC.

The section '**Looking Forward' at para 3.3.2** sets out the plans to further progress work in this area.

2.4.6 Engagement on potential sources of data and evidence

Scottish Government
Education Analytical Services - Whilst there was useful information within the Pupil Census, which was able to identify the number of pupils (those with a record of need) who required a communication adaptation under the Additional Support for Learning Legislation, there was no information available which captured further detail on children and young people in education who need and use communication equipment.

Allied Health Professionals (AHP) policy leads within the Chief Nursing Officers Directorate (CNOD) advised on the potential relevance of the AHP Operational Measures Dataset, delivered by NHS National Services Scotland (NSS). The purpose of the AHP dataset is to collect a standard set of data items about AHP's and the clients they see.

Through the successful delivery of AHPOMs there will be data available that can:
- provide insight into the demand and volume of AHP contact with individuals;
- allow exploration of variations in service delivery and outcomes;
- highlight opportunities for service improvement.

Further information is available at https://www.isdscotland.org/Products-and-Services/Data-Definitions-and-References/Allied-Health-Professionals-National-Dataset/Operational-Measures.asp

The inclusion of AAC among these data items could improve the availability of data about people receiving AAC services from AHP's. However, NSS have confirmed this is out with the scope of the current rollout phase. It is intended that once the new Chief Health Professions Officer takes up post in CNOD in January 2020, work on the AHP Operational Measures dataset will be revisited as it is recognised there is currently variation in collection of the data by health boards.

In the meantime, AHP policy leads in CNOD have supported engagement with the AHP Directors national network, raising awareness of the duty on communication equipment and support and signposting towards workforce policy colleagues in relation to workforce planning advice.

National AHP LifeCurve™ Survey - Further discussions with AHP policy leads also highlighted and provided an opportunity for inclusion of a Communication Support Needs question (see below) within the work they were taking forward as part of the Active and Independent Living Program (AILP). AHP's undertook a National LifeCurve™ Survey (May 2017) which aimed to provide a unique understanding of where AHP's can concentrate efforts, strengthen existing and identify new partnerships, develop innovative interventions across the life-course to shift towards all levels of preventative and anticipatory care and contribute to addressing health inequalities. The survey took place in adult services, across all sectors and all AHP groups.

Communication Support Needs Question in the LifeCurve™ Survey:

> 'Do you have any communication support needs e.g. hearing or low vision aid, interpreter, large print, easy read, communication aid – Y/N/Not Applicable'

In January 2019, to progress analysis of people who responded 'yes' to the Communication Support Needs question within the LifeCurve™ Survey the Scottish Government appointed a PhD intern for 3 months from the Scottish Graduate School of Social Science. The results of this analysis have been captured within the Health and Social Care Social Research Report[1] published on 18 October.

The complete survey results (approximately 15,000) will be linked with other data to enable a comprehensive 'snapshot' of where people are on their own LifeCurve™ and when they are seen by an AHP, which will be used to inform, focus effort, and promote innovation and intervention in addressing health inequalities.

[1] Health and Social Care Social Research Report –
Full report
https://www.gov.scot/publications/scottish-allied-health-professions-lifecurvetm-survey-report-respondents-communication-support-needs/

Summary report
https://www.gov.scot/publications/scottish-allied-health-professions-lifecurvetm-survey-report-respondents-communication-support-needs-2/

Given the progress of Health and Social Care Integration and the changes this may bring, this needs to be a future consideration, with access to advice from COSLA and Social Work Scotland via the National AAC Advisory Group in the future capture of data.

Third sector organisations - such as Bobath Scotland, Parkinson's UK, MND Scotland and professional groups such as the Royal College of Speech and Language Therapists (RCSLT) have also shared information to help understand what systems were in place to capture information from within those organisations, and what is feasible to source from their data systems.
Valuable discussions and experience gained by the third sector in the development of their systems highlights some of the challenges involved, for example:

- the commissioning of a unique system;
- governance and ownership of information;
- can take years to develop;
- time required of practitioners;
- cost of software development;
- lack of interface with existing systems – which may then require information to be entered twice;
- availability of reporting, and variable uptake by practitioners.

The Scottish Government is grateful to those organisations for sharing their advice and expertise. However, the challenges they experienced highlight the complexity of information held and that the detail doesn't lend itself to evidencing progress in delivery of the legislative duty, as those systems were not specifically designed for that purpose.

2021 Census - Working with the Census 2021 team, Scottish Government policy officials and health and social care analytical colleagues raised awareness of the legislative duty and supporting tools available, to improve the knowledge and understanding of those who will have face to face engagement with people who use AAC and may require support to complete the Census.

This initial piece of work resulted in the development and submission of a proposal to the "question team" within Census 2021 for inclusion of a question on AAC, worded as:

'Full or partial loss of voice or difficulty of speaking' category, within the Long Term Conditions question.

Ongoing discussion has led to further work on supporting the model for online testing of the question and promoted this across AAC networks, to encourage sufficient response rates and meaningful comment to inform further refinement of the proposed question.

Whilst this question will not identify people who need or are using AAC, the benefits of inclusion of this question (subject to parliamentary due process) are that it will enable analysis of the population with loss of voice or difficulty speaking by other characteristics – for example, their demographic profile, living arrangements, employment status, self-reported health.

The Census 2021 team will update on progress and the outcome of the parliamentary process for Census in due course.

2.5 PROCUREMENT OF AAC EQUIPMENT

2.5.1 Background

The main focus of AAC procurement has been to develop and refine the means to evidence people are accessing services and where appropriate being provided with the necessary equipment.

In 2017 and 2018 information at a national level was provided from NSS in relation to suppliers and equipment purchase of communication equipment. Boards confirmed the exercise did not fully take account of all expenditure (both within the NHS, and that purchased via education or via Health and Social Care Partnership arrangements within community stores) on communication equipment. A further trawl by NSS pulled retrospective spend on equipment, and using that further detail and in dialogue with boards, highlighted the opportunity to consider the current processes with a view to options to refine to improve data quality.

AAC is procured through different agencies using different arrangements to provide communication equipment to people who need and use it, in both health, community and educational settings.

It is not currently possible to robustly and consistently identify and aggregate expenditure on the communication equipment being purchased and used to fulfil the legislative duty.

The existing arrangements for gathering information from boards, do not currently lend themselves to providing reports to support monitoring of expenditure, highlighting the potential impact of new products, emerging trends and the recycling of resources.

The exception to this would be where arrangements are in place within community, for example, most mainstream integrated community equipment services use custom designed IT systems which does provide this level of scrutiny, and management information which informs procurement, financial monitoring and analysis of trends and budget pressures. However, the procurement of most AAC equipment sits out-with these arrangements.

2.5.2 SLWG on AAC Procurement

A SLWG was established with representation to improve the consistency and transparency with which communication equipment is procured. Representation to the SLWG group is made up of specialist and generalist SLT practitioners, medical physics, an education senior manager, community equipment store leads, NHS national procurement advisors, with advice and support available to the group from the additional support needs network Association of Directors of Education in Scotland, the Technology & Information Transformation Lead from NSS, and policy officials.

The aspiration of the SLWG is to support boards to evidence in a consistent way the resource commitment to AAC equipment and to invite contributions from local authority and the third sector to build a more comprehensive picture of expenditure in this area.

This SLWG group carried out the following actions, updating the National AAC Advisory Group meeting on 17 June 2019:

- Identified the product suppliers for high tech AAC equipment.
- Confirmed a list of the “top ten” high cost AAC products as the basis for an AAC equipment catalogue, to be further developed by National Procurement in partnership with Boards and their practitioners, recognising this is not a fully comprehensive list.
- Confirmed the product codes for these products.
  - This will enable NSS to identify information in a retrospective search of items ordered, giving partial evidence that equipment purchase is taking place by NHS Boards. It is also recognised the list of products and codes is incomplete and therefore the search will only reflect health procurement of these items of equipment.
- Created a proposal for local amendment to NHS PECOS systems that will improve transparency in ordering equipment,
- Explored the complexity of financial coding options and their merits and limitations.

In addition other steps taken by the group:

- Engagement with Procurement Information Lead at NSS to provide ongoing advice and expertise.
- Set out to the National AAC Advisory Group that in future boards may wish to explore the full range of opportunities available from systems and technology across agencies that will provide evidence of the timely provision of equipment, tracking and recycling, in keeping with the duty.
- Secured senior IT advice to this group to consider a local policy development in relation to mobile devices (which includes devices for patient use) in the hope this may inform the national provision of these devices.
- Gained support from AAC Executive Leads to introduce an initial communication equipment catalogue to make the future order of communication equipment more transparent for all health boards.

Work progresses in partnership with National procurement to address the issue set out above and continues to be led by a refreshed membership of the AAC Procurement group to reflect the broader spectrum of local authority interests.

In preparation for the introduction of an initial communication equipment catalogue and a user defined field on PECOS, three health board areas have agreed to participate in a pilot, to be led by NHS Highland with NSS. This will test the impact of the proposed change and inform the next steps for the roll out along with advice and information to operational staff.

2.6 AAC LEARNING SUPPORT

2.6.1 Background - An Introduction to AAC Modules

This work builds on A Right to Speak, where NHS Education Scotland (NES) was identified as a key partner in facilitating the delivery of many of the recommendations; one of which was to help deliver an education, training and development programme.

As part of this commitment, in April 2019 the first in a series of online learning modules, 'An Introduction to AAC'[11] was made available on the new NHS Education for Scotland's (NES) learning and support resources platform, TURAS.

These Scottish Government funded modules, commissioned by NES and developed by CALL Scotland are designed for use by anyone (universal uptake), and are aimed at any broader health, social care and education staff who may come into contact with people and their communication partners, who need and use communication equipment. Members of the public can also access these modules at https://learn.nes.nhs.scot/

2.6.2 Short Life Working Group (SLWG) on AAC Learning

In terms of next steps, work is ongoing to make further modules commissioned by NES as part of a Right to Speak available in future on TURAS in a staged approach, which will include:

- **AAC in Education** from CALL Scotland, supporting learners with complex communication support needs in school;
- **AAC Assessment and interventions** from Manchester Metropolitan University and;
- **AAC Technology** from Dundee University.

All modules are aimed at services, teams or individuals to support development of current knowledge and best practice, underpinned by the self-assessment approach in Individual Profiling of AAC Knowledge and Skills (IPAACKS)[12] to ensure positive outcomes for people who use AAC.

[11] TURAS Learn- https://learn.nes.nhs.scot/

[12] IPAACKS - https://www.nes.scot.nhs.uk/media/2507407/nesd0214aacframework-re.pdf

A Short Life working group has been established to encourage the uptake of AAC learning and to raise awareness in particular, promoting and making use of the online learning resources hosted on TURAS to ensure availability of a consistent means of reporting, to inform a Scotland wide picture.

2.7 SECTION 10 GRANT FUNDING 2018/19

In April 2018, applications were invited to the Scottish Government Section 10 grant fund which demonstrated how organisations would contribute to delivering outcomes related to the implementation of the Communication Equipment and Support legislation and the wider work programme on Augmentative and Alternative Communication (AAC) and/or See Hear Strategy for people with sight loss, deafness and dual sensory loss, all of which the Assisted Communication team lead on.

Twenty three applications were received, resulting in 8 successful applications, evenly distributed across both policy areas, 4 of which were in relation to AAC totalling £57,643. (Further details and outcomes achieved are available at **ANNEX I**)

2.8 SECTION 10 GRANT FUNDING 2019/20

In March 2019, applications were again invited to the Scottish Government Section 10 grant fund which demonstrated and met the same criteria as set out in the 2018/19 application process.

Ten applications were received, with all applications being scored against an assessment criteria and resulted in eight successful applications, three of which were in relation to AAC, totalling £34,505. (Further details are available at **ANNEX J**)

3. LOOKING FORWARD

A review of the National AAC Work Plan was carried out in the summer of 2019, with feedback received from the National AAC Advisory Group members, informing the programme of work going forward into 2020. Further detail has been provided below with the work plan being included within the **supporting documents**.

3.1 Leadership and Governance

AAC Exec Leads are encouraged to engage with their boards Equality and Diversity leads to ensure the inclusion of AAC is specifically referenced within their local reports.

The National AAC Advisory Group membership will continue to provide advice and support in the delivery of the AAC national work plan.

3.2 Communications and Engagement

In co-production with local health boards and stakeholders, the development of a robust model for ongoing engagement with AAC service users is to be taken forward in preparation for meaningful capture of service user views.

The sharing of good practice and local awareness raising activities by health boards and other agencies to continue to be a regular agenda item for discussion at each National AAC Advisory Group meeting.

3.3 Operational Improvement

3.3.1 Local work plans

Local work plans to be in place in each health board, ensuring sustained and ongoing local improvements are included in the following:

▪provision of equipment and support; patient pathways and services and; AAC partnerships and local groups.

3.3.2 Short Life Working Groups (SLWG)

The SLWG's on AAC equipment procurement; data and evidence, learning and; assessment will continue their work whilst seeking advice and support from the National AAC Advisory Group.

3.3.3 Assessment

There is variation in practice across Scotland, with some areas building on expertise to develop frameworks that are evidence based and support assessment and decision making. A workshop to share examples of assessment, and evidence based work to date will be hosted early in 2020.

3.4 Policy and Guidance

3.4.1 Cross-cutting Policy Work

Policy officials to continue to provide information and advice for inclusion of AAC to support other Scottish Government policy areas.

3.4.2 AAC Logic Model

Work has now started on the development of a logic model, to underpin the refreshed high level AAC National Work plan. The logic model will be co-produced with our national advisory group members and stakeholders reflecting the broader and on-going program of work and priorities on AAC.

3.5 Workforce Development and Training

The Scottish Government will to continue to work with NHS Education for Scotland (NES), the SLWG on AAC Learning, Scottish Social Services Council (SSSC), Education Scotland and other partners to identify learning, innovation and good practice and promote and signpost relevant learning opportunities, ensuring widespread access to learning resources across Scotland.

3.6 Monitoring and Evaluation

The Scottish Government will continue to work with AAC Executive Leads, the SLWG on Data and Evidence and other partners to progress feasible means of capturing evidence on how the legislative duty is being met across Scotland – recognising the feedback from the NSS Scoping the Possible Report that references system change.

ANNEX A

NATIONAL AAC ADVISORY GROUP MEMBERSHIP

This programme of work is led by the Scottish Government, Assisted Communication Team and advice is sought through the National AAC Advisory Group. This group includes people who use communication equipment, AAC Executive Leads from each Health Board in Scotland, Education Scotland, the Additional Support for Learning Officers, Association of Directors of Education in Scotland, CALL Scotland, Social Work Scotland, the Royal College of Speech and Language Therapists, Communication Matters and third sector organisations.

In response to stakeholder's requests for additional representation from Education, the national advisory group membership was revisited and now includes new and sustained membership from Education Scotland and the Association of Directors of Education in Scotland.

Additional Service user representation to the group has been secured to support contribution and views from a user's perspective.

ANNEX B

TEMPLATE OF AAC SERVICE VISITS (SEPTEMBER 2018 to JANUARY 2019)

Purpose: As part of your ongoing involvement in the wider program of work on AAC, we will be keen to hear more from AAC Executive leads, your colleagues (who may be partners from other agencies in delivering this provision), managers and practitioners about the services delivering on the duty to provide communication equipment and support in using that equipment.

The focus of this second round of visits will be on the benefits to people who use communication equipment and support, examples of local progress and outcomes, any issues following on from commencement, innovation and opportunity, and immediate and longer term priorities. The intention is to structure our conversations around those areas.

Hopefully, there may be an opportunity to speak directly with or make contact with people who need and use communication equipment and support in using that equipment in your local area. As part of those visits, (or in advance of those meetings if more convenient) we would welcome your thoughts and views on:

Whether the legislation is making a difference and in what ways? – both benefits and challenges.
What are the priorities you would wish to see reflected in the refreshed AAC national work plan.
What activity is being undertaken locally in relation to e.g. audit, clinical governance, service user feedback, case studies, or other examples of implementing good practice that is of benefit to people who use AAC.
Any local progress in identifying unmet need and effective strategies to do so, (my thanks to those who have responded to the invite to join the short life working group on data and evidence).
Any additional areas for discussion you would wish to include at the visit.
What is your biggest challenge and how are you planning to address this?

ANNEX C

CONTRIBUTIONS FROM HEALTH BOARDS WHO HOLD THE LEGISLATIVE DUTY

The following are examples intended to reflect the views of boards across Scotland and describe the following:

- Recognition of the duty and actions in response.
- Items that highlight support.
- Concerns that respond to the key issues raised by stakeholders, namely finance, timeliness, equity and awareness.

NHS Ayrshire and Arran

"The AAC Executive Lead within Ayrshire and Arran has ensured the legislation awareness is targeted across NHS services, the three Health and Social Care Partnerships and Integration Joint Boards with a reach to our partners in education, social care and the independent sector. This builds on the success of the service established since 1996, to provide effective communication support to the residents of Ayrshire and Arran. Our focus now is establishing recurring funding to ensure a robust and modern equipment bank and to develop a governance framework to assure equity of equipment provision".

To underpin this work through sharing good practice, Ayrshire and Arran are working on the local development of an AAC scrutiny tool, to support AAC Assessment.

NHS Borders

"As part of our cost-pressures process this year, and rather than dealing with demands on a case by case package of funding we have allocated £220,000 into communication equipment and staffing as a response to the AAC implications. Currently this is not recurrent as we need to continue to map additional need and continuing costs. Of this allocation roughly £100k is for additional staffing to support user of the service."

NHS Dumfries and Galloway

- NHS Dumfries and Galloway welcomed the legislation, however the local context is there is a long history of supporting people who need and use communication equipment
- A local multi-agency AAC group was in place involving all key partners and this has continued
- A speech therapist working in Children's Services has been awarded an AHP career fellowship to explore the use of low tech AAC use in schools with a focus upon symbolic core vocabulary and aided language stimulation
- Processes for allocation of resources/funding of communication equipment have been reviewed, and as before, when there is an identified need equipment is provided and users supported in their use of that equipment".

NHS Fife
"This has been an exciting year for AAC across Scotland providing us lots of opportunities to continue to raise awareness of the impact of speech, language and communication needs as well as the need for AAC.

Fife AAC Team (est. 1987) continues to provide a one stop shop for AAC assessment, provision of equipment and support.

Over the past year there has been heightened awareness of AAC at both an individual and professional level which has led to a small but steady (2 to 3 year on year) increased number of referrals to the service. That is why sustained capacity building undertaken locally, has been so important to ensure support is available to those who need it.

To ensure consistency we have incorporated the National AAC core pathway into systems which support the need for capacity building in professionals working with clients in the initial stages before referral to the service".

NHS Forth Valley
"NHS Forth Valley conducted a survey of staff, to explore their awareness of the legislation within the Speech and Language Therapy Workforce. The results of that work were shared with the National AAC Advisory Group as an example of good practice. Forth Valley AHP Senior Managers have since built on this work in the following ways:

- delivered refresher training and continue to plan for ongoing updates
- refreshing staff's awareness of the FV AAC Pathway
- encouraging greater use of and engagement at an earlier stage with the FV Team of AAC Champions who are available to support and provide guidance to all SLT staff
- continuing to explore access to greater technical support including programming of devices"

NHS Greater Glasgow and Clyde (NHS GGC)
"The legislation has provided us with the impetus to address health inequalities experienced by people who are unable to speak. Communication is a human right and if a person requires support or equipment to speak in NHSGGC we will ensure this is received in a timely, person centred way" - Julie Murray - Chief Officer East Renfrewshire HSCP, NHSGGC AAC Executive Lead.

The work underway in NHSGGC is to review its provision of AAC equipment and support ensuring compliance with the legislation. This is overseen by an AAC Co-ordinating group established in April 2018, with membership from each HSCP, Acute and SCTCI. The remit is to:

- Oversee the implementation of the legislation locally and identify implications
- Refresh and develop the clinical pathways/practice guidance
- Look at issues of equity and funding
- Improve communication

- Improve access to equipment, including recycling
- Improve data collection and reporting

NHS Grampian
As a direct result of the legislation, NHS Grampian and the 3 Health and Social Care Partnerships within the Board have acknowledged the legal duty of the **Health (Tobacco, Nicotine etc. and Care) (Scotland) Act 2016 Part 4** and associated documents which came into effect from 19th March 2018.

All sectors across the Grampian health system now have clear arrangements in place to provide or secure communication equipment and support in using that equipment for anyone who has lost their voice or has difficulty speaking.

These arrangements ensure that individuals who require or use AAC are provided with the necessary and most appropriate equipment to meet their reasonable requirements and that support and assistance is provided to allow the individual to take advantage of the equipment and be able use it properly enabling them to meet their needs.

AAC is now included as an integral part of core service provision.

NHS Lanarkshire
One year on from the enactment of the legislation NHS Lanarkshire are proud to have achieved the following:
Convening a steering group to: promote awareness of Augmentative and Alternative Communication (AAC);
Revision of the existing AAC Pathway; devise and implement a training schedule, including coordinating peer support following training;
A dedicated speech and language therapy AAC Coordinator has been employed to coordinate the work from the steering group.
Over 35 pieces of highly specialist equipment funded for individuals since the legislation was enacted, with requests continuing to be fulfilled.

The AAC Pathway for Lanarkshire revisions are under consultation across a wide range of agencies and professions to ensure it is in line with the national core pathway and with our vision for Lanarkshire. It details the journey an individual will take from identifying their need for AAC to them being able to use their AAC system well and participate in society to the best of their ability. The pathway relaunch is planned for late 2019.

Looking to work that is beyond the legislation, NHS Lanarkshire is also proud to be the first board in Scotland to be involved with Communication Access UK (CAUK), a project that trains businesses and services to be accessible for people with communication difficulties. We have several mystery customers trained across Lanarkshire and have recently awarded the first service in Scotland, HOPE for Autism, the symbol for Communication Access as they have completed the staff training and signed an early adopter agreement.

Communication Access Symbol:

This project will continue to be rolled out across services in Lanarkshire over the coming years.

NHS Lothian

There has been no significant change in the numbers coming forward who require communication equipment and support in accessing services. It is noted individuals have more information on their rights and how to obtain communication equipment.

To further build the board's capacity, staff new to NHS Lothian have the opportunity to attend within their induction a session on using AAC with a wide variety of patients. Modular workshops have also been delivered to both health and education staff throughout the year including an Introduction to AAC and Using AAC within a school environment.

"Parents as Active Partners" Project started in 2018 to enhance support for parents and families of AAC users from an early stage. Working in partnership with the local authority's Head Teachers from Additional Support Needs (ASN) establishments, specialist AAC services have provided information to parents of children with complex needs through workshops such as Using AAC in the home, and an evening exhibition sponsored by City of Edinburgh Council Education Department. The "parents as active partners" workshops involved 25 families from across NHS Lothian. The exhibition of around 15 stands with services and third sector agencies, was attended by 50 people.

Additionally, work started in 2018 on a new CODES Framework (the previously developed effectiveness measuring tool) for use when working with Adults with Acquired Communication needs, is now being piloted for 6 months in 2019 as a further step in streamlining provision to people who need and use communication equipment. The Literacy and AAC Users Framework, being developed across NHS Lothian, was presented at the Communication Matters Best Practice Literacy Study Day in May 2019, with attendees from across Scotland.

NHS Lothian has further supported this national programme of work by contributing to multiple working groups throughout the year, including that to produce the national guidance.

NHS Orkney

"NHS Orkney is fully cognisant of the duty placed upon us by the Act. In support of this we have taken steps to publicise the intent and the relevant elements of the Act to our staff at all levels and in particular our SLT staff. There is a clear process of how to utilise the Act in support of our patients and importantly the process for escalation of concerns where services or equipment are not routinely available but required. Those patients who present with needs covered within the Act will receive appropriate assessments, treatments, equipment and support to meet their communications needs".

NHS Shetland
We welcome the legislation and recognise the duty on NHS Shetland to comply with the Act.

- Equipment will be funded where a need is defined in line with recommendations.
- Access to specialist advice as required is available from SCTCI (Scottish Centre of Technology for the Communication Impaired), although we have no formal contract in place, advice is available.

NHS Tayside
Existing arrangements for provision of equipment and the previous equipment bank were reviewed. This introduced sharing across all three (speech and language) services (children, adults and learning disability) in NHS Tayside and streamlined the available stock across the board area.

NHS Tayside has now allocated £50,000 on a recurring basis for the ongoing provision of Communication Equipment – the allocation is closely monitored on an ongoing basis, and will continue to be reviewed annually.

NHS Western Isles
NHS Western Isles advised a mixed impact, with some care groups (ASD and LD) considering minimal impact. However, for adult services a moderate positive impact is reported by practitioner, with better links forged with procurement and therefore necessary equipment, both hardware and software, can be acquired more promptly.

Practitioners and managers felt that staff are more confident about assessing a patient's AAC needs earlier in their journey so that they can be more fully prepared and familiar with the technology, as reflected in the patient story for Vital Voices (from January 2019) https://acipscotland.files.wordpress.com/2019/05/vital-voices-patient-stories.pdf.

NHS Western Isles also highlight:

1. Having the guidance and the support of the Assisted Communications team has encouraged us to 'keep on track' with implementing the Guidance and progressing our local plan.
2. Systems for the procurement of software have been revised with amendments to our local AAC pathway to include information about procurement. A review and improvement of the AAC loan documentation database has taken place.
3. Awareness raising related to AAC and the Guidance is a feature of all the regular communication training sessions delivered to Health, Care, and Education staff. An AAC awareness raising opportunity was part of our Speech and Language Therapy Open Day and a Local user of AAC, is raising awareness of the duty.

4. In progressing learning and development:
    - All Speech and Language Therapy, qualified and support staff, have now completed the IPAACKS self-assessment.
    - A member of the local Speech and Language Therapy team has been supported to complete the Talking Mats Trainer course and subsequently arranged training for Health, LA and third sector staff. This work is ongoing.
5. The team continue to engage with the national network of Speech and Language

NHS State Hospitals Board for Scotland (SHBS)
The SHBS are very aware of the duty and engaged in the program of work, but recognise the number of users is very small. Within the SHBS arrangements to highlight individual requirements, including communication needs are in place for all residents as part of the pre-admission. The AAC Pathway will be followed for all those who need and use communication equipment.

ANNEX D

TERMS AND DEFINITIONS (used in this report) ON AAC DATA AND EVIDENCE

"Accurate figures on the prevalence of need are required for service planning and commissioning. Determining the prevalence of need is also a prerequisite to identifying unmet need in comparison with use figures".[13]

What is the purpose of improving the availability of Data and Evidence about AAC?

The overall purpose of improving the availability of data and evidence is to ensure that the AAC population (defined here as people who could benefit from AAC) have access to, and benefit from, the AAC provision to which they are entitled under the legal duty.

Why is it necessary to take a population approach to AAC?

Taking a population or public health approach to AAC involves increasing our understanding, and addressing the needs, of the whole AAC population. Without such an approach, our understanding might only **include** people currently accessing AAC services, and could **exclude** people who need services but do not access them – possibly representing unmet need.

What is unmet need in the context of AAC?

Need can be defined as the capacity to benefit from services.
Unmet need can be defined as people who could benefit from services but do not or cannot access them. Applied to AAC, unmet need could arise because of:

- **Supply factors**: services are not identifying or reaching people who need AAC.
- **Demand factors**: people who need AAC are not aware that there are services that could help them; or are reluctant to seek or accept such services.

How could improving the availability of data and evidence benefit the AAC population?

Improving data and evidence has the potential to be used for the benefit of people who need AAC, and over time, to monitor progress against the legal duty.

Specific uses of improved data and evidence could include:

- Improving the identification of the AAC population to appropriate health and care service providers. This should ensure that those people are offered the signposting, assessment and any necessary interventions to which they are entitled under the legal duty.
- Supporting health and care services to monitor their AAC provision: for example, waiting times and quality of services.

[13] Creer, C., Enderby. P., Judge, S., John, A. (2016) *Prevalence of people who could benefit from augmentative and alternative communication (AAC) in the UK: determining the need.* International Journal of Language and Communication Disorders, Vol. 51, No. 6, pp. 639–653

- Analysing the characteristics of AAC service users in order to identify any unmet need and inequalities in access to services experienced by specific groups in the AAC population. For example:
    - Demographic analysis: such as by gender, age, geographical area (e.g. NHS Board, Health and Social Care Partnership), Scottish Index of Multiple Deprivation (SIMD).
    - Analysis of underlying diagnoses: to understand whether services are reaching people with the main conditions known to be associated with AAC need.
- Monitoring AAC service user outcomes, for example, functional status and quality of life.

ANNEX E

POPULATION ANALYSIS – FURTHER DETAIL ON POLICY ENGAGEMENT AND ACTIVITIES

Strategic Planning and Clinical Priorities – Neurological and Long Term Conditions

There has been ongoing engagement with the above team, where several organisations representing service users who have conditions that are prevalent amongst people who use AAC (such as MND, Stroke, and Cerebral Palsy). The publication of the National Neurological action plan recognises a similar picture of infrastructure constraints that cannot, within existing arrangements quickly, easily nor without adversely impacting on service delivery be addressed. It is not known if stakeholders support the pursuit of data at the expense of operational service delivery and this question needs to be raised.

Stroke

A proposal to explore the possibility of a stroke sprint audit was put forward by the Director of Services from Chest Heart Stroke Scotland at the AAC National Advisory Group meeting on the 13th June 2018. Discussion took place the following week (25th June) which clarified the necessary stages in progressing this as being:

- key stakeholders being involved from a stroke perspective
- AAC Exec Lead(s) being best placed to support this work
- seeking support from said Exec Lead
- inclusion of some historical learning that could inform the approach taken in this new proposal for a stroke sprint audit.

Following this a discussion took place with the AAC Executive Lead in NHS Lanarkshire on the 29th June, with the advice being:

- to formulate the necessary questions
- to describe the associated challenges and potential outcomes, engaging with the national clinical nurse lead for stroke to scope out operational detail
- to set out the desired outcomes, and;
- the consideration of what further steps may be in relation to unexpected outcomes.

The AAC Exec Lead, having considered the information, could then consider taking forward the questions with the chair of the national stroke audit group to explore feasibility, amendment and possible outcomes.

Engagement with the clinical nurse lead for stroke to determine the operational feasibility of carrying out such an exercise, and to understand the strategic priority revealed this approach was not currently feasible. The following challenges would require to be addressed:

- to become a priority for the national stroke audit group
- consistent recording of information

- identification of the data items to be captured and;
- an agreed, recognisable location within the patient record for the recording of any recognition of AAC or communication need, assessment or intervention with that individual
- training and advice to the workforce in the necessary recording actions
- training and advice to the stroke audit nurses, or others identified to carry out any future audit.

Priorities within the stroke audit have historically been targeted at acute care, however there is to be a future focus on provision within the community.

Further work is required both to consider the feasibility of the proposal and to set out the detail of the broad range of preparatory work that would be required to underpin any audit plans.

Strategy and Delivery for Dementia
Engagement with dementia policy colleagues resulted in an invitation to attend the National Dementia Strategy Group, seeking the advice and expertise of that group to advise on ways to support this program of work.

Further discussions have taken place with the adults with incapacity policy leads and National AHP Lead for Dementia to raise awareness of the legislative duty.

Education Analysis - Pupil Census
Meeting with the pupil census team enabled better understanding of the drivers for their capture of information, clarifying:

- local authorities participating in the pupil census were reporting on information they were already gathering, consequently there was no additional impact
- the legislative framework for the local authority to report that information was in place (as evidence of meeting their duty within the Education (Scotland) Act 2016[14]
- there is no additional requirement to report on AAC equipment, which would require significant additional work at an operational level to carry out and create an additional pressure to local authorities
- amendment to systems used to capture information would require to be identified and supported (i.e. SEEMIS –see below for further information)

Links to SEEMiS
SEEMiS Group is an Education Management Information System (MIS) provider. As the standard MIS within Scottish Education, all local student data is processed and managed by SEEMiS software offering interfaces with external agencies such as ScotXed.

[14] Education Scotland Act 2016- http://www.legislation.gov.uk/asp/2016/8/introduction/enacted

SEEMiS is owned and operated by the 32 Local Authorities who are their membership. Engagement with their business analysts clarified the type of data being sought by Scottish Government was within the ScotXed census area (the pupil census). Further guidance and information on what is collected is available from the ScotXed website.

However, SEEMiS captures an enormous amount of data related to students, varying by local authority and is dependent on what areas of the application available from SEEMiS they use.

Once a functionality is developed, it is for LAs to choose and to what extent it is used. However, all LAs without exception maintain student basic records and all census information within the application.

In response to the specific request from Scottish Government, the limitations identified from SEEMiS recording of school age children with communication needs was that it does not capture those who use equipment specifically. Therefore such a request would be a new requirement to capture additional information and on specific equipment.

Requests from out with their Local Authority membership, if approved, are prioritised by the Governance groups within the SEEMiS work programme alongside the other work commitments and completed as charged pieces of work. Submissions should be supported by robust detailed evidence and if available, short tests of change that provide baseline proof.

E-Health/Digital
Advice from the policy team has signposted the team towards advice from Primary Care; Professional advisors and the National Lead for TrakCare. This engagement is ongoing.

NHS National Services Scotland (NSS)
Broad engagement has taken place with NSS in the development of the work on data and evidence, from early discussions on the development of new community based solutions; the role ISD have within NSS; the governance arrangements to protect confidentiality; the consultation on the development of the AHP Operational measures; advice and guidance on data and support to commission a “Scoping the Possible” report.

Health colleagues within the Welsh Government
Welsh Government and NHS Wales operational services colleagues have advised on their countrywide single model approach that includes environmental control provision, sharing learning from establishing a new service from scratch.

Commissioned services in England
Engagement resulted in a better understanding of the system differences. In England a set of key performance indicators are in place as part of contractual arrangements within the commissioning of the specialist AAC hub services.

The hub and spoke model is replicated across regional areas in England with a range of independent and NHS providers delivering this service to a set of agreed access criteria. A supporting infrastructure is a necessary requirement to enable monthly reporting to the commissioner, providing components of a national overview.

Reflections of both the Welsh and English areas highlight the differences in service models, both geographically, contractually and in the range of services provided.

Census 2021:
The Census team have developed a proposal for the online version of the questions, to include additional guidance within the question using the functionality of a digital platform. The additional guidance will be in the form of pop-up screens with a list of most commonly known and/or prevalent health conditions within each category. This is to aid respondents in choosing the most relevant response option to describe their long-term health condition(s). For example, if a respondent was not sure if they should select 'learning disability' to describe their health condition, they would click on additional guidance with a list commonly known conditions under this category, which will help them to decide whether to select that response option or not.

The lists are not exhaustive as these should be kept at a manageable length taking into account that people will be filling in the whole questionnaire, so that it does not significantly impact of the time spent scrolling through a large list of conditions.

The Census team have continued to work with policy officials to ensure the largest possible participation of people within the census.

The category for 'Full or partial loss of voice' is slightly different from other categories in that it includes a list of equipment used to aid speaking (as opposed to conditions only).

ANNEX F

DATA AND EVIDENCE WORKSHOP FOR HEALTH BOARDS IN DECEMBER 2018 – KEY OUTCOMES

OUTCOMES FROM THE WORKSHOP

- recognition of primary care as the only location with the potential to identify the whole population of people who need and use AAC, recognising Read Codes[15] are available but these are not routinely coded or recorded.
- the aspiration for clinicians is to have a system where data can be entered once but can be shared across other systems.
- a plea from clinicians and managers for a clear narrative on why collecting the right data is important, an understanding of the contribution clinicians can make to robust data, and clarity on the benefits they can expect from data outputs for their clients and service provision.
- recognition that AAC developments are not within the existing eHealth programme and there is no capacity within these arrangements to include this in national data capture at present.
- further work was needed to develop the information shared across practitioners and managers as the basis for a minimum dataset. The dataset is a specified set of data items which would be recorded consistently for each AAC service user".

[15] Read Codes - https://www.scimp.scot.nhs.uk/better-information/clinical-coding/scimp-guide-to-read-codes

ANNEX G

REFERENCE TO PREVIOUS REPORTS AND RECOMMENDATIONS ON DATA AND EVIDENCE

The reports mentioned highlighted the need for improvements in the data available on the AAC population in order to best meet their needs and assess the extent to which this was being done.

Publication	Key Points
A Right to Speak: Supporting Individuals who use Alternative and Augmentative Communication (Scottish Government, 2012)	Included the following recommendations: The use of standardised data collection within routine practice as well as the regular use of goal setting and outcome measures will support gathering further information on the effectiveness of AAC and AAC interventions. National statistics to be gathered by relevant agencies to support future gathering of cost effectiveness data.
Data collection systems used in Scotland of relevance to AAC service delivery (commissioned by NHS Education Scotland, 2013) (informed 'Now Hear Me' report below) The report drew on an online survey for NHS speech and language therapists, local authority education and social work staff and third sector organisations involved with people with communication support needs who potentially may use AAC.	Found that: Although some useful information is collected, it is ad hoc, not easily aggregated and frequently incomplete. The majority of respondents from all sectors were unable to easily identify the numbers & nature of service users currently accessing high-tech electronic equipment for spoken communication. The findings of this study reinforced the need for improved data collection systems to enable services to evidence and improve quality, efficiency and effectiveness. One stakeholder suggested that adding one extra field to an existing caseload management database was a minimal change which could provide useful additional information where an electronic system was already in place. "*A system that allowed collection of comparable data within and across board areas would be fantastic*" (quoting a Speech and Language Therapist).
Now Hear Me: Report on the implementation of the recommendations of A Right to Speak to support Alternative and Augmentative Communication (AAC) in Scotland. (NHS Education Scotland, 2015)	The report noted that a datasets research project had been completed, with two reports concluded, and that work towards nationally agreed datasets for AAC across all sectors in Scotland was under way. There was no evidence that work initiated in A Right to Speak and reported in NowHearMe, was progressed further to the report in published in June 2015. Work recommenced early in 2017, with direct engagement from the Scottish Government, Assisted Communication policy team with a report author. An early draft of a dataset for the consideration of wider networks, was developed in discussion with the author of the SLT survey, and taken forward in parallel with a proposal paper to the National AAC Advisory Group. A presentation to the e-health national clinical leads group in May 2017, alerted them to the legislation, impending new duty and to the data gaps.

Despite the recommendations in these reports and engagement efforts across all sectors and agencies, there is still no readily available information on the numbers and characteristics of people who use AAC in Scotland.

ANNEX H

OTHER DATA AND EVIDENCE CHALLENGES

These include the following:

- **NHS Information Systems:** We are aware that even among NHS service providers, data about AAC service users and services is recorded in different electronic data systems which do not link to each other, which are not accessible to all professionals involved in a person's care and which vary across NHS Boards. There have been examples in the past where some practitioners have been entering information on two separate systems e.g. Disease register related system and a patient management system. There is also continuing use of paper records to record some relevant data. The consistency and quality of data recorded is variable.
- **Developing a minimum dataset**: Data items had previously been circulated to the National AAC Advisory Group and the Speech and Language therapy managers' network to gain their feedback on a minimum dataset for AAC clients. Feedback was helpful, however it is clear that there are still a number of challenges in improving the data available on the AAC population.
- **NHS community health services IT system**: a "Once for Scotland" approach for the community and replacement for MiDiS is not currently being taken forward.
- **Service Providers**: AAC clients could be known to one or more of a range of different health, care, education and other services and independent agencies and practitioners with the risk of clients being recorded by multiple services on fragmented data and duplicated recording.
- **Professional groups:** AAC assessment and service provision could be undertaken by one or more professional groups across these different services: e.g. Allied Health Professionals (AHP's) such as speech and language therapists; special education teachers and support from a range of social care workers. Within the NHS, there is no nationally agreed approach beyond the AHPOMs (refer to paragraph 2.4.3) currently in a phased roll out, to the collection of AHP data or detailed information on where and how AHP services are delivered across all health and social care sectors.
- **Stakeholder groups:** Stakeholder groups continue to seek transparency on how the duty will be evidenced, monitored and evaluated. Meanwhile services and staff would want any information to be drawn from existing data systems and do not want to record the same information more than once. They are concerned that labour intensive data collection could adversely impact on operational service delivery. This is particularly challenging in an environment where staff may need to undertake manual counting of paper records.
- **Focus on Outcome based Care:** Clinicians are mindful of the shift towards outcomes based approaches, how in future this will be recorded, and the need to take a forward looking approach to build in such capacity now, in anticipation of future reporting requirements. However, to support access to all who may benefit, outcomes for those individuals can only be measured when all are identified and known to services.

ANNEX I

SECTION 10 GRANT FUNDING 2018/19

AUGMENTATIVE AND ALTERNATIVE COMMUNICATION (AAC) SECTION 10 GRANT FUNDING 18-19		
Organisation	**To do what?**	**Outcomes achieved**
MND Scotland	Providing the operating costs of the delivery of the Scottish Communication Aid Loan Service which aims to provide loans to those who are, or are becoming, communication impaired, while statutory services seek funding for equipment to meet that person's needs.	During 2018/19 23 pieces of AAC equipment have been loaned to 17 people with motor neurone disease. The equipment loaned included ▪ laptops, ipads, speech recognition software, and peripherals (i.e. head mouse). The clients were based throughout Scotland, and a breakdown of the location by health board is as follows; Ayrshire & Arran; Dumfries and Galloway; Greater Glasgow & Clyde; Grampian; Highland; Lothian and; Tayside The average response time to complete provision was 3.8 working days (excl. weekends) from receipt of notification. The fastest response was same day, and the slowest was 10 days.
Chest Heart and Stroke Scotland (CHSS)	The development of a free, publically available tablet/smartphone app that aids conversation for people with aphasia.	The 'Talk with me' app for people with aphasia has been developed and sits on apple and android platforms. Download the Talk with me app free from Google Play or the App Store. Activities to raise awareness included marketing material, social media posts, demonstrations of the app to user groups, and promotion through health care professional networks. Posters and promotional material was also available in all CHSS shops and services. Evaluation has been built into the app, therefore work to establish how the app is being used will be carried out on an ongoing basis by CHSS.

Bobath Scotland	The establishment and testing of a model for a regular peer led social and learning group for people with cerebral palsy who use AAC	Bobath Scotland has designed, delivered and reviewed a pilot project for adults with Cerebral Palsy who use AAC. There were 24 attendances over 6 group sessions which covered the following topics: 1. Introduction session 2. Using AAC to use voice activated devices to make everyday life easier 3. AAC Troubleshooting session 4. Preparing presentations with a superhero theme! 5. Joining the children's AAC holiday club for a joint session and delivering superhero presentations 6. Storytelling training Up until now, no other similar group existed. The grant funding has enabled group members to develop their skills such as speaking at a group, using voice controlled technology to carry out tasks (e.g. playing music or turning lights on). Being able to complete these everyday tasks can have a huge impact on confidence, independence and quality of life. Feedback has included: 'It was the only opportunity I had to meet other AAC users in a group setting. I enjoyed having a chance to get some support with my talker which was really good because I don't have anyone in the community that does this'. 'I hope that the group continues. I hope to get tips on my talker that I can use outside and be able to reach out to more people.' 'One parent said 'from the feedback that I have had I think that it is giving her confidence in using her device. She doesn't usually want to get involved too much as she can't communicate as well as some others can and the advice and suggestions on how we can develop her social communication skills have been extremely helpful and beneficial to her.' The project has helped meet the aims by ensuring that people with CP who use AAC devices have started to improve their wellbeing, communication skills and social connections.
CALL Scotland	To update and replace a number of communication aids and eyegaze	Providing communication equipment and support to people with communication support needs and their carers/families.

	systems and expand the stock of iPads, together with the necessary software, apps, cases, mounting systems and other accessories in the CALL Scotland National Assistive and Communication Technology Equipment Bank.	Providing free access to professionals in order to carry out valid and independent assessment and trial according to the AAC national core pathway and best practice. The AAC equipment purchased comprises: 1 x GridPad 12 high tech communication aid with eye-gaze camera and accessories 4 x Windows Surface tablet-based communication aids with eye-gaze camera and accessories 3 x iPad Mini with cases and accessories for use as high tech AAC device 6 x iPad 9.7" with cases and accessories for use as high tech AAC device 4 x iPad Pro 12.9" with cases and accessories for use as high tech AAC device AAC software and apps Wheelchair and desk mounts Simple tech single and multiple message AAC devices High tech AAC access devices such as switches, trackballs, head operated mouse Low tech communication books

ANNEX J

SECTION 10 GRANT FUNDING 2019/20

AUGMENTATIVE AND ALTERNATIVE COMMUNICATION (AAC) SECTION 10 GRANT FUNDING 2019-2020	
Organisation	**To do what?**
MND Scotland	Delivery of the Communication aid loan bank service
Bobath Scotland	The funding will be used for an AAC Programme that will; Support for adults with CP to address specific issues around their current AAC usage. Work with children and adults who are currently not engaged with community services to re-engage with community support around AAC. Support opportunities for user-led social groups. Consult with people using AAC and their families/carers to respond to current issues through focus groups and interviews to understand the challenges they face**.**
CALL Scotland	**An Implementation Tool for building AAC capacity and competencies in the classroom.** Staff time to research, write and develop the Framework. **AAC Implementation Resource Kit** Staff time to: develop and create the resources; purchase resources; engage with pilot schools and gather evaluation feedback; write and produce instructional booklets, guides, course materials. Cost of printing and preparing resources for the kit. Costs for purchase of AAC devices for the Kit. **Delivery of Professional Learning** Staff time to research and deliver Professional Learning. Travel and accommodation costs.

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