



**St Oswald's
Hospice**

Finding Lost Voices:

Enhancing Communication with Children and
Young Adults within a hospice/short break setting

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BACKGROUND

Communication difficulties affect a substantial number of adults and children in the UK, with up to 14 million people expected to experience them at some point, and over 10% of children facing long-term communication needs (Communication Access UK, 2024).

Augmentative and Alternative Communication (AAC) is a term used to describe the range of communication tools required to communicate with people with communication difficulties. Examples include Makaton; Intensive Interaction; Eye gazer; Picture Exchange Communication System (PECS®); and there are many others.

Children's and Young Adult's Hospices

Children's and Young Adult's (CYA) hospices and similar short break settings catering to those with life-limiting or shortening conditions are relatively new. Helen House in Oxford was the first CYA hospice in the UK to open its doors in 1982. St. Oswald's' CYA unit in Gosforth opened more recently in 2003, providing short break services for 64 children and young adults.

Ninety-four percent (94%) of the children arriving at St Oswald's Hospice for short breaks present with communication challenges, with most attending the Hospice unable to communicate verbally. Therefore, those working with CYA also need to be skilled at alternative forms of communication.

Advances in medicine and surgery have extended the lives of CYA with life-limiting or shortening conditions. The Make Every Child Count study (Fraser et al, 2020) indicates a significant increase in these cases in England, from 32,975 in 2001/02 to 86,625 in 2017/18, projected to reach 96,280¹ by 2030. This growth, attributed to better data recording and improved care, underscores the influence of medical advancements – and highlights the increased need for services like those provided by St Oswald's Hospice.

Guidelines and Governance

While hospices and short break services typically operate independently, they have been under the scrutiny of the Care Quality Commission (CQC) since 2009, ensuring adherence to specific care standards. This includes the requirement for availability of registered nurses on a shift (CQC, 2020) The CQC base their staffing standards on the RCN Workforce Standards (RCN, 2021)

¹ Confidence of 95%

Registered nurses are governed by the Nursing and Midwifery Council (NMC) Code of Professional Conduct. Organisations like "Together for Short Lives" focus on improving care quality and promoting research, fostering governance, collaboration, and research across organisations.

The Nursing and Midwifery Council (NMC), Future nurse: Standards of proficiency for registered nurses (NMC, 2018) state that:

“Where people have special communication needs or a disability, it is essential that reasonable adjustments are made in order to communicate, provide and share information in a manner that promotes optimum understanding and engagement and facilitates equal access to high quality care” (Annex A, p27)

However, despite efforts to standardise care, individualised models sometimes lead to isolated units. Nevertheless, the CQC encourages benchmarking to mitigate practice variations, promoting a more connected approach.

The CQC Key Lines of Enquiry identify specialised communication techniques that are an essential requirement for those working in this field [Box 1 below]. It is of note that, although the collective term for the specialised collective communication term is ‘Augmentative and Alternative Communication’, neither the CQC nor NMC use this term within their guidelines.

Box 1: CQC Criteria for effective communication (Care Quality Commission Sector-specific guidance: Hospices for children and young people, 2020)

- Ensure that staff take the time to interact with the children/young adults in a respectful considerate way (Caring 1.2).
- Staff to highlight where people’s choices and needs are not being met, this is to be identified and used to inform how services are improved and developed (Responsive 1.2)
- Service is to be accessible and coordinated to take into account those with protected characteristics under the equality Act (Responsive 2.1).
- The service is to be delivered and coordinated in an accessible and responsive manner to people with complex needs (Responsive 2.2)
- Technology and equipment are to be used to enhance the delivery of effective care and treatment and to support people’s independence (Effective 1.3)

Need for this research

Reflecting on the past twenty years, CYA hospices have faced increasing challenges due to the rising complexity of conditions, leading to higher demand and waiting lists. This necessitates tailored care and upskilling of healthcare professionals, including nurses and allied health professionals, in communication techniques like AAC.

At St Oswald's Hospice, achieving AAC objectives has proven challenging due to staff's varied experiences throughout their careers. While there are conscious efforts to maintain clinical expertise, specific AAC skills are not, always, grasped consistently across the care team as a whole.

The career routes of healthcare professionals at St. Oswald's Hospice vary depending on their role and background:

- **Registered Nurses (Paediatric, Adult, and Learning Disability):** Typically undergo three years of nurse education, then work on a general ward before specialising. Those working with children may transition directly from a general paediatric ward to the hospice unit.
- **Allied Health Professionals (AHPs):** Have diverse backgrounds, including healthcare and special education. Many have experience with AAC techniques.
- **Paediatric Nurses:** Often have experience with children with complex needs but may lack exposure to AAC unless they've worked in a specialist learning environment.
- **Registered Learning Disability Nurses:** Arrive from education or hospital settings, usually with some experience in AAC.
- **Care Support Workers:** Come from various care and education settings, leading to varied skills and exposure to AAC.

The emphasis for practitioners at St. Oswald's Hospice has been on developing clinical skills, competencies, and staying updated on technical clinical care and treatments. Traditionally, the focus has been on ensuring practitioners are safe and competent. However, children and young adults are now increasingly empowered through schooling to learn new methods of communication using AAC techniques, which are continuously evolving and improving.

Considering the rapid changes to the CYA patient care needs over the last twenty years, it is an ideal time to evaluate the use of AAC techniques at St Oswald's Hospice's Children's and Young Adult's service. Before commencing the research, and to broaden understanding of the issues related to AAC, a comprehensive literature review was undertaken.

The literature review also helped to inform the appropriate research methodology for the investigation.

LITERATURE REVIEW

A literature review was conducted to explore the most recent research findings related to AAC and to guide the methodological approach for this study. The literature review began with a systematic process of defining the question that would guide the review

The “PICO framework” was used to inform the review – PICO is a mnemonic used in evidence-based practice (and specifically evidence-based medicine) to frame and answer a clinical or health care related question. It is also used to develop literature search strategies, for instance in systematic reviews

The PICO acronym has come to stand for:

- P** Patient, problem or population
- I** Intervention
- C** Comparison, control or comparator
- O** Outcome(s) (e.g. pain, fatigue, nausea, infections, death)

This structure was used to ensure suitable key words were identified and applied, as shown below, therefore ensuring as full a range of literature was included in the review (Gerrish and Lacey 2015).

PICO Structure for a systematic Literature Search

PICO	KEY WORDS
Population Children with communication deficits	Children Young People Paediatric Communication deficits, problems Non-verbal
Intervention Communication techniques	Makaton PECS® Eye Gazer Voice Output Communication Aids (VOCA)
Comparator	None
Outcome	Augmentative Alternative Communication Use Skills Views, Feeling, Experience

The literature review question was then defined as:

How is Augmentative and Alternative Communication used with children with communication disabilities within a paediatric setting in a hospice or short stay setting?

The Cumulative Index to Nursing and Allied Literature (CINAHL) database was used to search for published literature related to the above question. The specific search terms can be found in Appendix 1 and 2.

There were some challenges in locating articles. Initial searches used 'Advanced Communication' as a search term, but this term did not appear to be used routinely by authors. Consequently, search terms were broadened to capture as many terms for AAC as possible. It was not until the search began that the collective term AAC was uncovered. [NB: AAC being the collective /umbrella term used to define the specialised techniques such as Makaton, Hand over hand, PECS® and Eyegazers.]

This new insight led to an alteration in the questions posed to participants in the interview schedule: **'Have you heard of the term AAC?'**

Having used AAC as a search term, a further 68 papers were identified. This led to seven articles being considered contemporary and of suitable research quality to be included in the review. The seven articles deemed appropriate for inclusion in the review are included as a summary which can be found in Appendix 3.

Each article was examined for research quality using the Critical Appraisal Skills Programme Search tool (CASP on-line) - each paper was then ranked in order, according to their CASP assessment (Appendix 4). All articles that were deemed to have worth and connections were used in this review.

None of the located articles related directly to the same clinical environment as St Oswald's Hospice; however, there were similarities and therefore they were reviewed for any transferable data.

- Gumm et al., (2017); Sharkey et al., (2014); Hemsley et al, (2001) - focus on communicating with children with communication difficulties.
- Bailey et al, (2014); Balandin et al, (2007); Finke et al, (2008) - focus on adults with learning disabilities and communication difficulties.
- Vinales, (2013) - focuses on Makaton and training for student nurses.

Themes reported within the articles were compared and contrasted between papers, and a hierarchy of common themes identified as shown in BOX 2 below:

BOX 2: Key themes identified

Nurses'/Workers' Perspectives	Impact upon the patient considered
Communication not prioritised <ul style="list-style-type: none"> • Lack of training • Lack of knowledge • Culture change • Not prioritising communication in their role • Reliance on family members • Ward staff find communicating with children challenging 	Communication disadvantages <ul style="list-style-type: none"> • Mental health issues • Frustrated • Family communication • A preference was noted for staff to use lower tech devices • Poor inpatient service for children with disabilities • Issues with pain management
Awareness of their own inadequacies <ul style="list-style-type: none"> • Avoidance of the patient • Fear 	Absence of direct communication <ul style="list-style-type: none"> • Discuss with parent not the child • Families knowing they are the best person
Time <ul style="list-style-type: none"> • Professionals not making the time to communicate. 	Time <ul style="list-style-type: none"> • Affected their treatment • Prolonged hospital stay
Culture <ul style="list-style-type: none"> • Changing practice • Job descriptions • Collaborations increased information 	Culture <ul style="list-style-type: none"> • Poor information sharing • Voicelessness • Growing populations
Facilitators <ul style="list-style-type: none"> • Good relationships with the families/family-centred care • Quiet environment • AAC Resources available • Other professionals with the skillset 	Barriers <ul style="list-style-type: none"> • Communication with the family not the patient • Sometimes not using their AAC but an easier alternate method • Time
Training <ul style="list-style-type: none"> • Repetition helps • Communication is not prioritised • Use of communication aids • The quality of training is important • Post training give the practitioner confidence to ask • Governance 	Training <ul style="list-style-type: none"> • Lack of training • Nurses not understanding their cues • Nurses confusing intellectual disability with communication disability

The themes arising from the review are addressed in further detail below:

Culture

The need for cultural change was identified within the papers reviewed. Finke et al (2008) discusses embedding the use of Makaton in nurse education so as to encourage nurses to be more engaged in the practice of AAC throughout their whole career. This is echoed by Gumm et al (2017) with a commitment to universal cultural change in how nurses and medical staff communicate with disabled children, including mandatory training to instil the importance of communication and associated techniques into practice.

Within paediatric nursing, a culture of family-centred nursing is central to care provision. However, this approach may hinder the disabled child as they can be overlooked when communication is directed mainly to the family and not to the child themselves (Sharkey et al, (2014). Hemsley et al., 2001 found that while a sound caring culture in community nursing was embedded in practice, there was recognition that further adaptations to communication were required due to the growing population of patients with communication disabilities.

Gumm et al (2017) recognised that shortfalls in communication meant that nurses were not always meeting all their patients' needs. The overall culture of the workplace was viewed as having a significant impact on communication according to Gumm et al (2017). Investment in culture change was made as it was seen as imperative to improvement in communications and sustaining the changes.

Communication not prioritised

All studies identified a common theme throughout that communication was not prioritised as a necessary skill. Gumm et al (2017) noted that it had previously been identified that communication with children with a disability on the hospital ward was not effective. This lack of effective communication between staff and children, was also highlighted as being the key issue in delivery of sub-optimal care. To address this issue a change in culture was facilitated so the care team better understood the importance of communication for the disabled child and the impact upon their care. Hemsley et al (2001) and Bailey et al, (2014) established that the experience of the disabled child /adult in hospital was poor and that, to improve this experience, better communication by ward staff was needed. Similarly, Gumm et al (2017) and Hemsley et al (2001) both noted that nurses often lack the skills needed for AAC use thus reducing the opportunity to provide effective communication with patients.

By not prioritising the use of AAC, this reduced the quality care for clients according to Balandin et al (2007) and Finke et al (2008). In a study focused on student nurse training in communication techniques, Vinales

(2013) reported that exposing student nurses to AAC helped the students to be more confident in its use and encouraged a positive culture with practising nurses as they observed the student nurses utilising their AAC skills.

The patient with a communication difficulty was considerably disadvantaged compared to other patients, in respect of communication with healthcare staff. According to Sharkey et al, (2014) communication with disabled children was avoided, with staff choosing to communicate with other staff or parents ahead of communicating with the child. Patients found this frustrating (Hemsley, et al., 2001) and this had the potential to increase issues in relation to pain management (Bailey et al, 2014), leading to fear, frustration, panic, and loss of control (Balandin et al, 2007 and Finke et al, 2008).

Professional awareness in respect of communication

Gumm et al (2017) found that ward staff found communicating with disabled children was challenging

Sharkey et al, (2014) also reported professional doubt and inadequacy by healthcare staff who felt they lacked knowledge and skills to support their clients. These professionals clearly expressed awareness of poor communication behaviours and personal frustration as they failed to meet the children's communication needs. In addition, nurses acknowledged that specialist members of staff, such as Learning Disability nurses or play therapists, or parents were often better placed to communicate with a disabled child than themselves.

In a study within adult care, Finke et al (2008), noted that although nurses had received training with regard to disabilities none received training with regard to communication strategies with patients with communication disabilities. Such a lack of training in this area left many nurses frustrated due to unsuccessful attempts in practice to communicate with patients with communication disabilities and no access to AAC.

Bailey et al, (2014) also found nurses had a lack of confidence in communicating with people with an intellectual disability and reported that intellectual disabilities and palliative care disciplines largely work independently of each other. Greater collaborative working practices between such disciplines could support and counteract the challenges experienced by each party for the benefit of the patients.

Impact on the patient

Ineffective communication with patients with communication disabilities affects the individuals in many ways.

Balandin et al, (2007), described how some patients were aware that some staff actively avoided them, talked over them or they were not listened to which impacted upon their mental health, making them feel undervalued. Nurses' inability to understand them led to emotional responses such as feeling frustrated, angry, distressed, depressed, sad, lonely, unsafe, and guilty. Patients said too that their language ability suffered, that they became apathetic and would not take their AAC tools/equipment into hospital for fear that they would not be used, be lost or broken.

Bailey et al (2014), concurs that there are challenges in communicating with patients with an intellectual disability, resulting in issues with pain and symptom management, presenting direct impact to their care.

Balandin et al, (2007) highlights that some nurses presume that a lack of ability to communicate also means a lack of intellectual ability, this is also an indicator of inadequate nursing assessment. The consequence of such an assumption is that the nurse may feel the patient cannot understand what they need to know, therefore they do not explain it to them. This is of particular concern when the patient has a prolonged hospital stay and are unable to communicate their medical needs that can impact upon their progress.

Facilitators to improve the use of AAC

Family-centred care was seen as a useful model in enabling communication; extracting direct information from parents/carers about the patient helped in knowing the patient and their cues (Sharkey et al, 2014). The environment was also seen as key in facilitating effective communication, particularly recognising that using a quiet setting without distractions was beneficial to communications (Hemsley et al 2001).

Bailey et al (2014) notes that in a community-based team, the support of the learning disability nurses sharing their experience and skills with the palliative nurse team was found to be invaluable.

Gumm et al (2017) addressed the problem of lack of interaction with children with communication disabilities by devising an implementation program for culture change. With the deliberate emphasis on highlighting change as a positive force for the team of medics and nurses. Training sessions were developed, the learning objectives were:

- To understand the impact of communication behaviours on disabled children
- To be motivated by change
- To feel capable of change,
- To make a commitment to change and
- To feel supported by the organisation in changing behaviour.

The change programme training resulted in acknowledgement of an overall learning deficit regarding communication with children with disabilities. The practitioners then felt an increased sense of confidence to ask, explore and learn more collectively as they appreciated that the issues were not due to their own inadequacy but a universal problem.

Barriers to Communication

Multiple barriers to communication can be identified within all the studies. Sharkey et al (2014) notes that time is a key determinant of effective communication. Not having the time to have quality conversations with relatives, limits how the patient might be understood.

Time was also identified as something needed to help build up trust with the patient, therefore in lacking time there was limited opportunity for trust building between staff and patient (Bailey et al,2014).

Some nurses will even avoid patients with communication deficits altogether to the detriment of their patients' needs, (Balandin et al, 2007). Finke et al (2008) noted that where a nurse presumes a patient cannot communicate and has lack of understanding, they were likely to communicate with family members rather than the patient to establish the patients' needs. Avoiding patients and not meeting their individual needs are all contrary to the Nurse Professional Code (Nursing, Midwifery Council, 2018)

According to Bailey et al (2014) and Finke et al (2008) a lack of training and resources in AAC was blamed for limited use of AAC in practice. Similarly, Balandin et al (2007) acknowledged that simply not having the skills needed for AAC is a major barrier to its use with patients. Some practitioners felt fear due to their own lack of knowledge, education and experience, when caring for a patient with a communication or learning disability. These practitioners reported that families were hesitant to engage with the team who were not skilled or experienced in caring for people with disabilities. (Bailey, 2014)

Prioritisation of clinical needs over communications was recognised in the children's hospital setting where staff often focused on the acute care needs of the child rather than getting to know the child. Although the parents were identified as the interpreters in these circumstances (Sharkey et al, 2014) this lack of direct communication between nurse and patient may limit the nurse-patient relationship and requires parental presence for communications to take place.

SUMMARY

Carer to patient communication shortfalls, where children or adults have a communication disability, have been echoed across all articles.

When examining communication with a child or adult with a communication deficit, findings indicate that there are well-identified impactful communication problems in care settings. Reasons too, as to why communication issues are occurring within this care setting have been uncovered.

From the patients' perspective, being unable to communicate in the care setting leaves them considerably disadvantaged compared to patients without communication deficits.

The absence of good communication can have direct implications for their health and their hospital experience; affecting their mental health, physical health which can prolong their hospital stay significantly.

The patient with a communication disability become perplexed and apathetic to their sense of voicelessness and can then disengage altogether.

From the perspective of the carer's whether that be nurse, AHP or medical staff it is recognised communicating using AAC techniques is not a skill that they possess. Though overall it is a skill they wish to possess but restrictions apply in having the appropriate resources, time to learn and then the time to use the skill in practice.

This lack of skill in communication can create feelings of self-doubt and reduced confidence around the patient. In feeling awkward and uncertain the practitioner may not engage with the patient as much as they would if the patient did not have a communication disability. Therefore, if the practitioner does not engage and interact, they do not learn and pick up skills and patient cues as they go.

Positively, all nursing, AHP and medical staff recognised that current practices need to improve. They are aware of their own inadequacies.

Poor communication practice can be attributed to a lack of training, time constraints and the practitioner's lack of use of appropriate AAC resources. However, the overarching enlightenment to improving communication practices appears to be attributed to be the set culture within the workplace; that communication is simply not prioritised in care settings.

The following solutions were identified:

Pre-empting communication issues, early within universities, by educating student nurses in Makaton as an AAC measure. This can prevent

disengagement later and will promote AAC use as standard throughout their career.

Working collaboratively with multi –agency education, care providers and family too. Sharing skills and knowledge of the individual patient; knowing your patient holistically; their behaviour, education, emotional and physical needs and knowing what skills the practitioner requires to interact with the patient on their level.

Within care settings an overall care culture and governance of the importance of AAC should be defined; recognising that care staff require support from their managers to fulfil this essential skill. There needs to be a culture within the work place to support the use of AAC, and provide time for people to learn and practice.

FINDING LOST VOICES

The research project examined the nurses and /or allied health professionals' journey and experiences of AAC – both good and not so good – within a hospice setting and examined by comparison other hospices in England to see how they have progressed with their AAC skills. The strategic aim of the project was to utilise the research as a change agent.

By spotlighting AAC in current practice and examining the associated attitudes of the care team, the purpose was to improve culture and develop skills within the team. In addition, the goal was to engage, understand and interpret the needs of the children and young adults, meaning we will have more opportunities to understand our patients and deliver the appropriate care to our children and young adults.

Study Aim

The aim of the project was to:

- Locally – investigate and establish an inclusive environment for communication between nurses/ allied health professionals and children and young adults within a short break setting.
- Nationally – establish, via an electronic survey, the AAC practice and attitudes across similar services in the country.

Study Objectives

- To understand what helps and hinders acquisition and utilisation of AAC skills.
- To understand the level of AAC skills development required and, nationally, to better understand how other similar services are approaching this area of practice.
- To determine what existing AAC skills and resources are in use.

Ethics

Before commencing the study, ethical approval was sought from Northumbria University's Ethics Committee.

The study was approved in September 2022 [number 53062].

Methodology and Methods

This research used a mixed methods approach and was conducted in two phases.

a) Phase 1 - Survey

A survey distributed to 24 hospice/short break settings across the UK who provide services for CYA with life limiting and shortening conditions.

The electronic survey was formatted using Microsoft Forms (see survey questions in Appendix 7) and was sent to the service leads of CYA units within hospice/short break settings for completion. Email invitations were sent to service leads. The survey took 10-15 minutes to complete and was emailed back to the Principal Investigator. Returning the survey implied consent to participate.

b) Phase 2 – Qualitative interviews

A review of the literature indicated that there was limited research on the use of AAC within the hospice and day care setting. Therefore, a qualitative methodological approach was felt an appropriate way to explore the experiences of communicating with children who were non-verbal.

One to One interviews were conducted with nurses and AHPs who worked on the CYA unit at St. Oswald's Hospice (the staff roles of those Interviewed can be seen in Appendix 6). All staff (54) were invited to take part via email. Interviews were conducted by a member of the Children and Young People's teaching team at Northumbria University. The interviewer was unknown to staff so they could feel comfortable sharing their views. Staff agreeing to an interview were given allocated time within their working day. A topic guide was used within the interviews to shape the conversation between researcher and participant. (See attached topic guide in Appendix 8).

Before interview, each participant was given a study information sheet and a consent form. Confidentiality and anonymity were assured at all stages of the research process.

Analysis

a) Phase 1

The data from the survey was analysed to provide descriptive statistics and ordinal data, and additional comments from participants were thematically analysed and reported.

b) Phase 2

Interviews were digitally recorded and transcribed verbatim. Burnard's (1991) analysis framework was used to thematically analyse the transcripts. The research team shared transcripts and then met to compare analysis processes and findings (peer coding), this added dependability and credibility to the findings.

Research Governance

All electronic information was treated in accordance with General Data Protection Regulation, plus St Oswald's Hospice and Northumbria University's policies. No personal data were collected during the survey and data collected during the focus groups were pseudonymised.

The electronic survey was distributed to other hospices offering services to children and young adults. During analysis and reporting, the names of organisations were not included.

The data collected in the interviews were analysed by the research team and all data anonymised so that no personal identifiable data will be reported. The research team ensured no one was identifiable by virtue of place of work or profession thus preserving anonymity when reporting comments. The participant information sheet and consent form assured participants that anonymisation and pseudonymisation of the data collected via survey and interviews occurred.

All data were stored securely in electronic format and password protected on a secure site at St Oswald's Hospice. Any transfer of data between St Oswald's Hospice and Northumbria University research team members was undertaken using the safe transferring site (<https://wettransfer.com/>). All files saved electronically were password protected.

Individual interviews took place face to face or via MS Teams and were recorded for transcription purposes. A back up recording device was also be used in case of device failure. These recordings were shared with a validated transcriber.

Research Quality / Trustworthiness

The quality of the research was attended to at all stages of the research process. The principles of trustworthiness and the steps taken to ensure rigor are shown in Box 3 below.

BOX 3: Principles of Trustworthiness (Lincoln and Guba 1985)

Trustworthiness Criteria	Actions Taken
<p><u>Credibility</u></p> <p>Fit between the participants' views and that of the researchers.</p>	<p>The research team peer coded all transcripts to ensure all agreed with the emerging themes.</p>
<p><u>Transferability</u></p> <p>Adequacy of the description to judge similarity to other situations so that findings might be transferred.</p>	<p>A clear audit trail of research actions described within this report.</p> <p>Systematic literature review prior to commencing the research.</p>
<p><u>Dependability</u></p> <p>Transparency of the findings</p>	<p>Clear audit trail of actions and researcher decisions.</p>
<p><u>Confirmability</u></p> <p>Data and findings interpretations are clearly linked.</p>	<p>The researcher presented early emerging themes to staff at St Oswald's Hospice. Staff were given a chance to share thoughts and comment on findings (Member Checking).</p> <p>Participants' words are used within the report to highlight the content of themes.</p>

FINDINGS

Analysis of the data from this study uncovered an over-arching theme of **lost voices**, with three further sub-themes identified:

1. **Multiple and Different**
2. **Knowing the Child**
3. **Our Culture**

In the following sections, the key theme and sub-themes will be explored to provide a better understanding of the complexities underlying the care team's communications with non-verbal CYA in the hospice setting. Insights gained from this analysis will provide guidance for future developments to improve this area of practice.

[All staff interviewed are referred to as 'carers' in the sections below to ensure anonymisation.]

Lost Voices – Key Theme

Examination of the views of the care team enabled an exploration of their individual practice reflections, and it was evident that the children and young adults' (CYA) 'voices' were not always heard. For non-verbal CYA their 'voice' was not the spoken word but instead they relied on different ways of communicating their needs and wants to others using AAC methods. Data analysis revealed a range of factors that might help or hinder non-verbal children and young adults as they attempt to be heard and indeed understood by the care team within the hospice/short-break service.

Within the carers' interviews, it is clear they could each recall a time when they felt the CYA's voice had not been heard or where they had been misunderstood. One of the interviewees recalled a time when a little girl asked for something, and nobody knew what she was asking for.

"One of the young girls was rubbing her arm. The nurses were saying is she itchy? I said, "no, she's actually signing for biscuit". "The girl went, "aw". She was so relieved. And so the nurses were going to put some cream on, ask for the doctors to come and asking did she have a rash?" **Carer 4**

The 'biscuit story' had already generated much conversation and concern at the time of the incident because there was recognition of miscommunication and the possibility that if someone had not understood her, then the little girl would not have received what she wanted. This incident was the inspiration for this study and such examples of miscommunication also resonated through other carers' experiences.

"I can't remember what sign they did but I thought it meant toilet and I took them for the toilet and it didn't mean toilet. I took them to

get changed. It didn't mean that at all. It meant something else" [He wanted his iPad]. **Carer 2**

The implications of not understanding the CYA in practice potentially leads to wasted time, delays in meeting needs and requests and to potential frustration and disappointment for the CYA. In the previous scenario, the child wanted his iPad and ended up being taken to the toilet through a misunderstanding – through not being heard. Many carers believed that, generally, staff do communicate well with CYA but also thought that when there were more challenging communication issues, they need extra help from those more expert in AAC use.

"I think we are great at communicating generally everyday – chatting to non-verbal children who are not cognitively aware. However, children who are cognitively aware and who can't verbalise what they want - we are not so good at communicating to them - we struggle with them and those are the days when you want the support in." **Carer 9**

Other staff also described how they looked for clues in the child's behaviour and responses to help understand the CYA's 'voice' without calling for expert support. In these situations, there appears to be an element of guesswork and trial-and-error to discover what is needed.

"You try repositioning; venting their gastrostomy, and cuddles, just try cuddles, because why won't they like cuddles? But, then some really don't and it's just like get off! It makes them worse. So, you know very quickly. Yeah, and then sometimes it boils down to, what we got left to try." **Carer 5**

There are risks when taking the trial-and-error approach. For example, see below.

"...it takes time, and the child could become frustrated. This can lead to associated behaviours that could then escalate from this. In addition, their need may not be met, and their experience will be unsatisfactory." **Carer 12**

Ultimately, the trial-and-error approach could result in apathy from the child who might then not even attempt to use their voice in future situations. As the next examples below demonstrate:

"A young man who came in, and I feel like we often let him down because nobody knew how to use his VOCA properly.... It frustrated him, you could see that it frustrated him." **Carer 8**

"At first, he called answer yes or no. He answered yes by lifting his leg and no by arching his back. So we all knew that, but that's not good enough when he could have done a full sentence on his VOCA for what he wanted, because then you were trying to guess." **Carer 8**

In interviews, it was clear that the team were aware of the considerable impact on the child if their voice is not heard, and this can lead to frustration.

"I'm not going to do it! I witnessed a child shutting down as no one was making the effort". **Carer 6**

The potential to misunderstand the CYA's needs in relation to pain, hunger, thirst and other activities is apparent from these carers' recollections. Such problems may also have an impact on the accuracy of nursing assessments and evaluations. Despite these challenges, carers that were interviewed showed empathy and understanding in their responses as they tried to do their best for the CYA. They acknowledged they can get it wrong sometimes and that this can affect the CYA.

"It must be frightening to be suddenly approached if you can't hear."
Carer 1

"How do we know what they want? It can lead to confusion, frustration or misdiagnosis too." **Carer 4**

"There are assumptions made of what the CYA want when they are non-verbal." **Carer 5**

Not all voices are unheard. Carers were able to present several examples of when the team connected successfully using their knowledge of the child and by using AAC.

"One of the young lads loves motor-bike racing and that's only recently been added to his eye gaze, whereas before that people were, he's 18/19 years now, putting Bob the Builder on for him and he doesn't wanna watch Bob the Builder. So, as soon as he gets the opportunity, he will say, I wanna watch motor- bike racing!!" **Carer 10**

"You can tell when you get to know them [the young adults], like how they react as to whether they're comfortable or whether they're in distress, because a lot can't show their feelings. When you get to know them, you know everything about their character. For example, I was working with a little boy who was non-verbal, and I instantly knew he wasn't himself. I could just tell how he was responding to my voice."
Carer 1

A further important example of effective communication was shared within one interview,

"There was a young lady communicated by her VOCA and she disclosed some sexual abuse that she's gone through to me via the VOCA." **Carer 10**

This situation shows the importance of carers being competent and confident to use AAC skills in practice so that the voice of the CYA is not lost.

In another example, carers found approaches that worked for an individual child but did not realise that they were carrying out a recognised communication technique. For example, below, copying/mimicking is a known form of AAC called Intensive Interaction but the carer did not appreciate that is what they were doing.

"We get a kind of relationship with him if we copy his actions as well..."
Carer 3

The data supporting the theme of lost voices has shown that although sometimes the CYA voice is lost there are also many examples of carers trying to overcome the communication difficulties so that the CYA's voice is heard by them.

Multiple and Different – Sub-Theme 1

The 'Multiple and Different' sub-theme reflects the many variations in the carers' pathways as they arrive to work and engage with the CYA. There are additional themes underpinning this sub-theme: 'Multiple and Different Backgrounds', 'Levels of Confidence', 'Training and Approaches'.

In the introductory sections of this report the increasingly unique and complex needs of current CYA service users were acknowledged alongside the rapidly changing equipment, technologies and techniques. Such variation and complexities amongst the CYA who needed to be heard, was generally well recognised on the unit but analysis also showed that carers themselves came from multiple and different backgrounds, training and experiences (work experiences are shown in Appendix 5), all of which could influence how well the CYA voices were heard on the unit.

Carers reported that some of the team members came to work at the hospice after working in the NHS. Transitioning from the NHS to working in the hospice appears to be a huge leap for some staff, particularly if the staff have worked in the NHS for most of their career.

a) Backgrounds

There appeared to be a relationship between previous experiences, level of confidence and the use of AAC in practice.

"... willingness to and confidence to just have a go. You know, I don't always sign correctly, but I suppose perhaps ... I have the knowledge that says that it's important that I'm signing so it doesn't matter really what I'm signing. As long as I'm making the effort to sign and to interact". **Carer 12**

Nurses/carers who had started working at the hospice having previously worked in a hospital and caring for children with complex needs but not necessarily with communication issues, reported feeling anxious at the hospice.

"I remember meeting new staff, new nurses especially who came from hospitals, and they'd say, 'I'm absolutely terrified, I don't even know how to speak to these children'." **Carer 2**

"Several years in care setting before coming to St Oswald's - yet intimidated and scared initially!" **Carer 2**

While some carers reported previous AAC experience, other carers reported having had no previous experience or formal communication training.

"Actually, when I asked about training, it was kind of a, 'you don't need to worry about that' when I first started, obviously I was coming in completely new. So I don't know whether it just wasn't a priority?" **Carer 10**

Some participants said they had gained confidence in talking to children with disabilities via their own life experiences, such as communicating with a disabled child known to them outside of the care setting. For others, they described how they slowly gained confidence through time on the unit.

"...you pick up so much from the team and I do you think your confidence develops as you go." **Carer 10**

"Gaining the confidence to chat without retort as when communicating it may seem unnatural when the person you are talking to, does not respond." **Carer 12**

Some participants described how they once had AAC skills gained in previous settings but were not enabled to use them at the hospice. This had led to them losing the skills they once had (an issue which is re-visited in the theme of Our Culture).

"I was proficient at Makaton but not now. So I learnt quite a bit of Makaton because we were more or less using it quite regularly, but since I came here, I must admit I've forgot a lot of it. Because I'm not using it." **Carer 2**

b) Training

All twelve interviewees said they wanted more training in AAC techniques. There was agreement that in order for AAC to be effective, training needed to be more of a priority, and some felt that greater investment in high quality training was needed.

"Lack of investment in training for AAC, does this show lack of priority?" **Carer 6**

"Lack of investment in quality training." **Carer 7**

In addition, to general comments about training opportunities and training, the carers felt that training alone was not the solution and that AAC needed to be used on a regular basis.

"But it's doing it all, you got to keep it going. Or you forget." **Carer 6**

"It's just things that I don't do repeatedly, so I forget how to do it."

Carer 7

"I think by the way of eye gaze, or computer-based technology that's something that we don't have a huge number of children and young people using. So we don't have the opportunity to practice using that very, very often." **Carer 12**

Although some AAC training had been undertaken by staff, it was noted that these skills were not always practised once the training session was over.

"Attended a Makaton course here but didn't use it after..." **Carer 5**

In addition, several issues were highlighted as a consequence of carers' limited AAC training, carers:

- Avoids using equipment.
- Equipment not used as team don't know how to use them.
- Team do not have technical ability.
- Confusion to terms – Pic exchange vs now and then books.
- Unable to use all communication resources / eye gazer.

Many of the care team wanted to improve their communication practices and expressed ideas on how to do so. Some are self-motivated to learn, as shown below.

"I've been looking for training myself." **Carer 1**

"I'm eager to learn more." **Carer 6**

"A continual AAC learning cycle is required." **Carer 12**

Improvements to AAC training were, by those interviewed, as they had concerns that it was difficult to learn aspects of AAC using existing methods of teaching. They offered solutions to ensure staff engagement, which included:

"Make it fun and non-threatening to learn." **Carer 3**

"Not learning signs from paper." **Carer 2**

"Could receive info from [the CYAs] home and school." **Carer 5**

There were also examples of carers showing real consideration about communication and thought about AAC in practice. The analogy of treating AAC like a foreign language surfaced several times.

"Let's see AAC as a foreign language – you have to practice and it's ok to make mistakes." **Carer 6**

"When abroad I attempt to speak their language, it's respectful."
Carer 10

However, some felt that current skills were at an acceptable level, believing that they did indeed connect effectively with children and young adults.

"Do the best we can- you know what you know." **Carer 1**

"I think there are subtle things we would use every day with our children." **Carer 9**

"You don't know me. And I need to get to know you. Once you've got that, I think when you start getting to know anyone, it's a bit like, oh I don't know... I don't know, then you're fine." **Carer 7**

The above quote might be challenged. It does seem to reflect the notion of needing to get to know the CYA and once a relationship is established that understanding the child will naturally follow. However, this strategy may not always optimise communications in the way that learning to use the CYA's chosen AAC methods could. In addition, competence in AAC use may help to diminish the anticipatory anxiety around communicating with these CYA.

c) Approaches

There was a heavy reliance amongst some carers on verbal communications (with other staff) or direct requests for expert AAC users to help them care for non-verbal CYAs. It appeared that written care documentation was not the first-place carers went to when needing information to assist in communicating with non-verbal CYA. Carers explained there was a tendency to value verbal discussion or direct help when faced with a non-verbal CYA with whom they were unfamiliar.

"Verbal over written used more." **Carer 9**

"Obviously we have the notes and care plans and things will be updated in there ..." **Carer 9**

"But obviously in time you may miss something, and someone will say oh no she doesn't do that anymore." **Carer 8**

They sometimes found it challenging to locate the right information in a timely way and some information was not always shared in a consistent way.

"...finding the information can be difficult." **Carer 1**

"Notes not fully informative." **Carer 3**

"Information needed isn't always available – reliance on team members to document." **Carer 1**

It was also noted that some carers were naturally more extrovert than others in how they interacted with CYAs. One interviewee remarked on how these differences affected communication styles,

"Staff have different skills. Some may shy away from reading expressively." **Carer 7**

"And people are shy of using it (Makaton). I'm shy of it? And a lot of what I learnt when I was on that team [not at the hospice], I forgot a lot of it because we're not using it all the time." **Carer 2**

Whilst others consistently used AAC in their practice and did not appear to feel such shyness about displaying their skills. One carer commented on witnessing such confidence,

*“Admiration... for a practitioner who signs all the time as she speaks to the CYA.” **Carer 7***

The practitioner described in this quote was someone who was a competent AAC user and such consistency of use of signing while speaking perhaps comes from continual practice leading to confidence. The care team also rejoiced in current practice changes that promoted the use of AAC in practice.

*“New behavioural plans help in communicating and knowing the child.” **Carer 10***

*“Visual prompts help use of AAC.” **Carer 4***

*“Routines help – sometimes we don’t know where we are heading.” **Carer 9***

Knowing the Child - Sub-theme 2

The ‘Knowing the Child’ sub-theme focuses on staffs’ previous knowledge of the child or young adult and the formation of a relationship with that individual. This was viewed as important by the interviewees, and it was often identified as fundamental in any communication they were able to have with that CYA. A further theme of time was also identified within this sub-theme as being an important factor in knowing the child and is also reported here.

Knowing the child was viewed by staff as central to their work with the CYA and was also considered by some as not something that could be acquired through education.

*“It’s all down to getting to know the child. I don’t think it’s something you could just teach.” **Carer 7***

Several staff talk about how they ‘Become tuned in to the CYA’ as they get to know them and can better predict what is needed.

*“After time - know them and their ways.” **Carer 8***

Running alongside the need to know the CYA was the need to know their own communication equipment. Within the interviews there were examples from carers where they could not communicate as effectively as they would have wished to with the CYAs because they did not know them or the individual equipment, they used e.g. PECS®, eye gazer, VOCAs.

*“We often have to ask each other, how actually do we use this, how do we attach it to a chair and you know, just like things that you just don’t realise until in that situation...” **Carer 1***

In instances where they did not know the child or their way of communicating, problems arose,

"He repeated, repeated, repeated but we said sorry we don't know what you mean. It wasn't until his mother come in and we asked her what he meant. It was Mickey Mouse." **Carer 6**

"...and there is one little girl, she's very clever and she gets quite upset. Because she wants something. And you know we can't, some of us obviously don't know what, what she needs." **Carer 7**

Where staff did not know the child or had not cared for them previously, they reported first seeking help from other staff that did know the child or who were proficient in that child's AAC method. The clear preference by staff to rely on the knowledge and expertise of other staff members rather than referring to existing individual patient assessment documentation, DisDat tool (Regnard et al, 2003; Regnard et al 2007) and bespoke communication plans was evident in the data. While some staff may not have been fully aware of the communication plans for each CYP, or where to locate this information, others may have viewed such documentation as not the most effective, reliable or easily accessible resources to use when trying to connect with the child or young adult in a real-time situation.

"I'm not sure what it is under [which section in the record]. I'm not sure, actually." **Carer 1**

"Communication assessment is not in-depth enough and is found in different places. It's not always filled in." **Carer 2**

"I'm looking after you and I'm perfectly happy to look after you. But if somebody can help me to help you then it's a no brainer for me, 'can you just come with me and just help me'." **Carer 7**

Communication is a two-way process. However, for some CYP who are unable to communicate back to staff, staff cannot know how they feel about the communication process. Interviewees had to draw on what they know about the child to aim to get the communication right. Observing the child and young adult, looking for their non-verbal, and verbal signs that the CYP may possibly be able to share with them.

"Knowing what is right, what is the alternative?" **Carer 2**

"Our CYA can be talked to without any notion of what is being said and maybe no interest in what is being said- but what is the alternative? Silence?" **Carer 12**

Time

There were many references to time within the participant interviews. Time was viewed as a resource for carers to get to know the CYP over time.

"Not always overnight wins." **Carer 7**

"Coming to know the CYA ways through cues." **Carer 1**

"Time is a resource – coming to know their cues in time." **Carer 1**

"In time, gain confidence to know CYA ways." **Carer 10**

It was noted that carers frequently explained the need to take time building up a knowledge of the CYA to help with understanding their individual behaviours, cues and signs. The infrequency of the CYA's residence in the unit (often only 2-4 nights once a month), 12-hour shifts and staff rota patterns meant that there were limited opportunities for carers to look after the same CYAs, thus threatening their ability to build up their knowledge and get to know the children well. Carers commented on these issues and the impact on how often they would see the children:

"Consistency - care staff see some CYA more than others, particularly when working 12-hour shifts." **Carer 5**

"It can be a matter of chance which children you care for and when – not having to care for some children from one year to the next." **Carer 5**

In situations where a longer stay in the unit was planned, the carers were able to familiarise themselves more readily with both the young adult and their specific equipment and this was viewed positively by the carers.

"We had a young adult stay- long stay. Core staff were allocated who became accustomed to her and her equipment." **Carer 8**

Carers also remarked on how over the last ten years the unit has become much busier, with increased demands on their time due to the complexity of the CYAs' needs and the clinical and supportive care interventions required. When the unit was busy, carers felt the pressures on their time and commented on how this affected their interactions.

"Sometimes in a rush and AAC techniques are not considered." **Carer 8**

"...it was easier to get to know the child when there were less demands." **Carer 5**

"CYA have more complex health needs - increased therapies." **Carer 10**

Our Culture - Sub-theme 3

The final sub-theme identified was 'Our Culture' and this incorporated the further themes of 'Leadership', 'Differing Perspectives' and 'Emotional Barriers'. The data within this theme provided insight into the unique stage on which interactions between all parties took place.

a) Leadership

The Leadership Team were seen, by those interviewed, as having an important role in determining unit priorities for care provision, staff training and organising day to day practice and, as such, being influential in the culture of the unit and the way that AAC was valued and used in the service.

"It comes from above – policy, procedure, expectation – not just training." **Carer 8**

At the time of the study, the Leadership Team had established a range of strategies and resources at unit individual patient level, to support carer /patient communications. These strategies were often referenced by staff in their interviews (a long-standing inter-professional communication group, individualised care plans, individualised communication plans, primary workers, multi-professional carers, experts in AAC, mentorship, role-modelling and training opportunities). Despite this wide range of strategies and resources, some staff perceived that there remained room for improvement in AAC use in the unit and that further balancing was needed between the clinical and social needs in care.

*“AAC - not driven, there is a clinical focus.” **Carer 10***

*“AAC - not pushed as day-by-day work....” **Carer 6***

Alongside these perspectives, there were comments that there needed to be more clarity from the communication group (a multi-professional group established over twelve years ago) about their aims and scope. Similarly, others felt that this group’s work was impeded by not being part of the management structure, thus limiting its reach and impact.

*“Communication team were self- directed but not part of management – therefore not respected or listened to...” **Carer 2***

*“Who is in charge.... what are their aims?” **Carer 7***

b) Differing Perspectives

The levels of confidence and competence in AAC use varied across the care team as did previous experience and training in these methods. Those carers with expertise in AAC and who consistently used these methods with all non-verbal CYAs, described a number of factors that may influence successful communication including environment, competing priorities and culture. These carers highlighted the impact of the environment when communicating with CYAs and were perplexed at others who seemed less aware of this issue, as shown below.

*“It’s a busy social hub – with multiple conversations going on. I’m concerned that CYA are not being heard visibly or audibly when noise is heightened or staff embroiled in their own story.” **Carer 8***

Similarly, they felt that the complex clinical needs of the CYA were always at the forefront of the carers’ attention and that using AAC to support more effective communications was not given as high a priority as other care needs. The tensions between these aspects of a CYA care were noted and for some, proficient in AAC use, it appeared that the clinical needs would often over-ride communication needs.

"There is a clinical versus social culture – communication is not driven." **Carer 6**

"AAC is not seen as important." **Carer 4**

For those carers championing the use of AAC in the unit, it was disappointing for them to find that others appeared not to view it in the same way.

"So it gets a bit disheartening then too. You know, when you want to do sessions [about AAC] and you're doing all this and people don't see it is important. You know that feedback from the team sometimes." **Carer 4**

These perspectives from the expert AAC users are helpful in better understanding their beliefs and to appreciate their conclusions that the current position of AAC use in the unit may be linked to levels of staff awareness, willingness to engage with AAC and an emphasis on clinical rather than social needs. The expert AAC users' perspective did, however, differ from the perspectives of the less experienced or skilled carers. In their accounts, emotions connected with AAC use emerged as being a substantial barrier to its use in practice.

c) Emotional Barriers

The interviews with carers who were less experienced or skilled in AAC carers and who did not use it in practice provide insight to a much more hidden problem that affected AAC use in the unit. The issues that were uncovered demonstrated that even where carers had previous experience and skills in AAC they did not always continue to use it at the hospice, with some becoming de-skilled. Embarrassment and anxieties about how others might perceive them were reported as the main reasons carers with some AAC skills were not regularly using these skills in their interactions with CYA. Lack of consistent use of AAC in the unit by other team members impacted on carers' feelings and behaviours and even de-skilled some carers,

"...embarrassed using my skills, like I was showing off." **Carer 4**

*"Lots of AAC experience pre-St. Oswald's – uses less frequently now...
...and I think because it's probably inconsistent here."* **Carer 6**

"... like I say, this is what we do every day, but I don't say this here.

Then look at me, to be honest, not signing, you know..." **Carer 4**

"I was proficient at Makaton but not now..." **Carer 6**

"...so I learnt quite a bit of Makaton because we were more or less using it quite regularly, but since I came here, I must admit I've forgot a lot of it. Because I'm not using it." **Carer 6**

Similarly, such feelings of fear, anxiety and embarrassment were also expressed by the carers with more limited AAC skills and experience.

“Fear of getting it wrong.” Carer1

“I have anxiety about using AAC.” Carer 4

“Embarrassed and worried that I could get it wrong.” Carer 2

The physical environment also appeared to affect carers, suggesting that they felt somewhat exposed when using AAC in practice. It seemed that the environment may not lend itself well to promoting a culture of trust and learning when it comes to using AAC in practice.

“It’s a fishbowl like workplace...” Carer 8

The less experienced or skilled carers reported using the AAC experts to help them in their communications with the CYA in their care. Reflecting on the way they dealt with their own limitations in AAC skills, some carers recognised they have become reliant on support from the experts in AAC, commenting on their own “dependence on experts” and acknowledging “reliance on the experts is not good enough”. **Carer 9**

The influence of therapists on the care team seems quite considerable, with many carers commenting on how they valued, admired and used the knowledge and skills of the therapists to support them with the CYA’s care.

“Observing them [therapists] and learning from them.” Carer 5

Similarly, newer members of staff spoke of watching therapists and the rest of the care team to learn in practice. While this initially looked like role-modelling, closer examination revealed that unlike the usual definition of a role model as someone to ‘look up to and imitate’ these carers were mainly observing and consulting with these AAC experts but with no reports of attempting to imitate their skills.

“Dependence on therapists – seek her out”. Carer 7

“Dependency on this role.” Carer 5

“Leans heavily on her role for support.” Carer 10

These carers’ comments show their acknowledgement of this situation as they reflected and then characterised the relationship as one of reliance and dependency.

Limitations

Unfortunately, due to lack of responses to the survey, this study was only able to provide very limited evidence about how other short break and hospice services communicate with non-verbal CYA. It is envisaged that the team will re-circulate the survey to the CYA short break/hospice service providers with the aim of obtaining further data to understand their AAC practices.

CONCLUSION

The main aims of this study were achieved: firstly, to understand how carers acquire and utilise AAC skills with non-verbal CYA and secondly, to identify future training needs. Although the additional ambition to better understand AAC practices nationally proved challenging due to a poor response to the study's survey. (Further re-circulation of the survey will need to take place later this year.)

This study has examined the skills and experiences of CYAs' carers from the unit, in relation to AAC, through in-depth interviews. A mismatch of languages between academics and carers was found at the study's outset and it quickly became apparent that the terminology used in the communication literature differed to that of the carers of non-verbal CYA. This issue was demonstrated clearly when none of the carers interviewed for the study had heard of the term AAC despite some being expert users of AAC and all of them working with CYA using these communication methods. Before this study was undertaken, carers within the unit generally referred to AAC approaches as 'advanced' communication methods.

Lost voice

Carers used a range of different ways to help them hear the voices of the non-verbal CYA including using other carers' AAC expertise, or their perceived extra knowledge of the CYA, to interpret the CYA voice for them. Other strategies employed included some guesswork or trial-and-error alongside close observation for behavioural clues or responses special to that CYA.

When the CYA could not be understood by carers there was potential for this resulting in; frustration, time wastage, unmet needs, shutting down or escalation of challenging behaviours. Despite carers trying their best to overcome the communication challenges there remained occasions where misunderstandings and miscommunications occurred and the CYA voice was lost.

Multiple and different – background levels of confidence approaches

It was evident that the care team was composed of many different health care professionals and together this mix of skills and knowledge was usually viewed as a real strength in the unit. However, the multiple and different theme identified that such various professional backgrounds, career pathways and approaches alongside the range of unique behaviours, communication needs and AAC equipment of the non-verbal CYA had the potential to create an environment in which communications were not always optimised.

Carers had different levels of competence and confidence in the use of AAC methods. Some, feeling anxious or even terrified in communication situations or when first introduced to the unit and the CYA. There appeared to be a relationship between previous experience, level of confidence and AAC use in practice. Carers with backgrounds in NHS settings arriving at the hospice with less experience and skills in communicating with non-verbal CYA than those coming from education or social settings.

Carers appeared to gain confidence over time by learning from other carers and becoming more familiar with the CYA.

There was an apparent lack of training in AAC skills and an acknowledgement that practising the skills was also needed. Carers used different approaches to meet the CYA needs e.g.

"I spent a lot of time working with her to gain her trust to kind of show that we are gonna listen to her" **Carer 4**

"children who are cognitively aware who can't verbalise what they want - we are not so good at communicating to them" **Carer 9**

Without a universal approach, there is potential and a danger that the CYA's voice could be lost. The multiple and different backgrounds and approaches hindering AAC use in practice.

Though there is also a need to understand and learn from each other's' perspectives to embrace and fully benefit from the multiple and different carers and their tailored skills and abilities; respecting and utilising their expertise in learning and developing others.

Knowing the child, time

Getting to know the child was deemed central to successfully communicating with non-verbal CYA. Factors that helped this process were having the time to get to know the child, receiving information from parents, practitioners who are skilled in AAC, information from school, documentation, increased use of AAC resources in practice. Factors hindering the 'getting to know the child' process included: documentation; lack of AAC skills; a clinical culture overriding social aspects of care, lack of skill in using AAC; lack of confidence; exposing open environment; time shift patterns; dependency upon AAC experts; noisy atmosphere/busy environment; and depending on others' opinions rather than accessing notes.

It may be helpful in future to consider better ways to support carers to get to know the children e.g. ensuring the information about children's communication needs and wishes are always updated, easy to access, presentation of the information is useful for practitioners and captures the unique ways of the child.

Our culture, leadership, differing perspectives, emotional barriers

AAC use within the unit was found to be influenced by the existing culture. Varying different perspectives emerged in the findings that appeared to be dependent on the level of skills and knowledge in AAC with non-skilled AAC users reporting, *“we struggle with them (CYA with communication deficits) and those are the days when you want the AAC experts in”* **Carer 9**

This was helpful in understanding that there is a need to upskill all carers, that there are times when the expertise and support is not available. Several emotional barriers existed that hampered use of skills by less expert AAC users such as feeling exposed and less confident to use AAC in practice. These staff described managing this type of situation by circumventing the problem of being faced by a child who they had not had time to get to know (building up knowledge of their individual cues, behaviours and reactions), they did this by seeking help from staff familiar with the child or by asking for AAC experts to interpret for them.

Even when staff had some AAC skills their feelings of embarrassment, anxiety or lack of confidence prevented them from putting this knowledge and skills into practice and for some this meant they had become de-skilled. The culture on the unit appears to have grown out of these fears and anxieties related to AAC use and may have deterred others from practising AAC.

In summary, this study has highlighted a multitude of complex factors impacting successful AAC use with non-verbal CYA in the unit. Further skills training may be beneficial to carers but this needs to be reviewed and different approaches used to help carers develop their skills and encourage them to continue practising their skills. Merely providing skills training without addressing the issue of unit culture and overcoming the emotional barriers that deter people from practising AAC or their dependency on AAC experts will not necessarily improve practice.

These issues were previously unrecognised and the uncovering of these previously hidden factors impacting on AAC use will now enable the team to tailor comprehensive solutions that take account of the real issues impeding their practice rather than just addressing the skills gaps.

The better you understand the problem the better you can create the solutions.

RECOMMENDATIONS

These recommendations and associated actions are available in more detail in Appendix 9:

- Defining a culture – communicating messages of new governance and expectation
- Communicating to the team the findings of the project and the responsibility to change
- Issuing team with Platform of roles
- Increased collaboration with schools/ education
- Increase internal training
- Creating a strong clear identity for the unit and what the future goals are.
- Communicating this to the team via posters, team meetings
- Altering job specifications – establishing clear identity of roles
- Issuing AAC competencies from induction to self-assessment to training portal
- Communicating the plan to families
- Measuring performance, after six monthly initially
- Devising bespoke communication care plan
- Producing unit song with key Makaton daily signs
- Complete/ reissue Phase 1 survey to hospices
- External training
- Increase Investment in appropriate AAC resources

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APPENDIX 1 – Search Terms Used (Original Set)

Main in search line	AND	Research paper	Author(s)	Appropriate to analyse further
Advanced communication	Paediatric nurse 1 found	Medical futility in children's nursing – making end of life decisions	Irene Obrien et al , British Journal of Nursing, 2010, Vol 19, No.6	No correlation to topic
Makaton	Paediatric nurse 3 found	1.Traillblazers who are breaking down barriers	Dental Nursing 11,2018 Vol 14	No – Dental nursing
		2.Evaluation of Makaton in practice by Children's nursing students	Jude Vinals, Nursing Children and Young people. 4,2013; 25(3)	Yes- Program within university to introduce Makaton and other forms of AAC within their 2 nd year of learning Student nurse evaluations are included in the work Not used in final draft – no investigation into views and opinions of nurses and patients
		3. Learning to communicate with children with disabilities	Sellars G, Paediatric Nursing, Nov 2006; 18(9)	Yes – describes a positive observed student nurse experience between special ed teacher and child with communication difficulties.
Children with Communication deficit	Nursing 1 found	Perspectives worth learning. Reading and writing at camp		Not appropriate. Educational
Communication	Complex health needs 50 found	Nursing the patient with severe communication impairment.	Hemsley, et al 2001	Patient and nurse perspectives - Yes
		Communicating with nurses: The experiences of 10 adults with cerebral palsy and complex communication needs.	Balandin, et al, 2007	Yes – relevant to explore further. Though adults it is interesting to explore as they do not have intellectual disability and can be the voice of those unable to communicate how they receive care

Communication disabilities	Communication skills 30 found	Improving Communication between staff and disabled children in hospital wards : testing the feasibility of a training intervention developed through intervention mapping -	Gumm et al , May 2017	Yes – Directed Implementation research. Themes gathered – proactive response to previous research
Intellectual disability	Palliative care 224 found	Surveying community nursing support for persons with an intellectual disability and palliative care needs.	Bailey, et al 2014	Surveying nurses opinions and challenges in communication

Initially the term 'AAC' was not used in the search as it was unclear if the term was widely used; it was also felt that use of the collective term might skew the results. However, having included the term, further literature became available (see appendix 2)

APPENDIX 2 – Search Terms Used (Including Term ‘AAC’)

(From 2000 – present)

Main search line	AND	Research paper	Author	Appropriate To analyse further
AAC	Children's hospice 0 found	/	/	/
AAC	Paediatric nurse and Hospice care 0 found	/	/	/
AAC	Disabled children 68 found	A Systematic review of Augmentative and Alternative Communication Interventions for children aged from 0 to 6 years.	Leonet, et al	Yes, though only in terms of highlighting as rewarding to the CYA with comm disabilities. Not appropriate at this time focus on introducing AAC to children
		Communication skills among children with SMA type 1: a parent survey		No – on further reading population scope to narrow
	Complex needs 3 found	A systematic review of the effectiveness of nurse communication with patients with complex needs with a focus on the use of augmentative and alternative communication-	Finke et al, 2008	Yes Qualitative piece on the perspective of both patients and nurses

Following a review of abstracts, unsuitable papers were excluded.

More detailed reading of the remaining led to identification of the most appropriate papers to answer the project questions. These are shown below in Appendix 3.

APPENDIX 3 – Literature Selection

Study	Ethics	n	Participant pop. ⁿ	Design	Summarised Results	Themes
<p>1. Improving Communication between staff and disabled children in hospital wards: testing the feasibility of a training intervention developed through intervention mapping – Gumm et al, May 2017</p> <p>Follow on from qualitative research above.</p>	Royal Devon & Exeter NHS Foundation Trust R&D office	80	Medical staff, nursing, allied health professionals housekeeping staff	Qualitative feedback	<p>In response to previous research, an implementation program was devised. Culture change and awareness of the existing problem was seen as a priority to change. Four times training sessions were devised. the learning objectives were:</p> <ul style="list-style-type: none"> • To understand the impact of communication behaviours on disabled children • To be motivated by change • To feel capable of change • To make a commitment to change • To feel supported by the organisation in changing behaviour 	<p>Post training</p> <p>Considering your patient as an individual</p> <p>Training meant they felt confidence to just ask</p> <p>They would take more time to think</p> <p>They would use more techniques to communicate</p>
<p>2. Communicating with disabled children when inpatients: Barriers and facilitators identified by parents and professionals in a qualitative study. (Sharkey et al, 2014)</p>	Approval via South West REC	25 15	<p>staff working on a paediatric ward</p> <p>Parents of children with a disability were consulted</p>	Exploratory qualitative Data was collected via interviews and focus groups.	<p>It was recognised that the views of the children would have strengthened the project due to the though due to subject matter it must be recognised that refined communication with the children is impossible to achieve.</p> <p>The Framework approach was used to analyse the data collected to filter themes and sub themes.</p> <p>Results –</p> <p><u>Barriers</u> -</p> <p>Time</p> <p>Professionals not prioritising communication in their roles</p> <p>Poor information sharing between parents & professionals</p> <p><u>Facilitators</u></p>	<p>Time</p> <p>Professionals not prioritising communication in their roles</p> <p>Poor information sharing between parents & professionals</p> <p>Use of communication aids</p> <p>Nurse aware of the importance of comm. with disabled children</p>

					<p>Professionals building rapport with a child</p> <p>Good relationships between professionals and parents</p> <p>Professionals having a family centred approach</p> <p>Use of communication aids</p> <p><u>Conclusion</u></p> <p>Communication with disabled children on ward was perceived to be less than optimal. Parents are instrumental in the communication between child and professionals. Although aware of the importance of comm with disabled children.</p>	
<p>3. Nursing the patient with severe communication impairment.</p> <p>Hemsley, Sigafos et al 2001</p>	<p>Unable to source this information</p>	20	Nurses	<p>Qualitative Interviews</p> <p>Experience and training with patients with severe communication</p> <p>Impairment - half have received training on communication with those who have severe comm impairment but none had received specific training or learnt strategies with speech pathologist</p> <p>Hospital policies – half responded that there were no policies and half responded that they were not aware of any.</p> <p>Communication experiences – half rated their experiences as both positive and negative whereas half rated their experiences as positive.</p> <p>Cited lack of AAC strategies or lack of resources or aids</p> <p>Patient frustration</p> <p>Too weak to use AAC like write</p> <p>Communication successes = more than half – successful use of signing or gesture, alphabet board</p> <p>Factors which helped - = quiet environment, availability of AAC, patient health and attitude</p>	<p>Even experienced nurses have difficulty with AAC</p> <p>Patient frustration</p> <p>Limited understanding and availability to AAC</p> <p>Training and support</p> <p>Inhibited recovery</p> <p>Willingness to learn</p>	

					<p>Ideas to improve – yes/no system, repeating back, adding animation</p> <p>General difficulties- lack of knowledge of alternate communication methods</p> <p>Time factor – takes long time to explain a system</p> <p>Agreed that communication impairment affected pt recovery</p>	
<p>4. Surveying community nursing support for persons with an intellectual disability and palliative care needs. (Bailey,2014)</p>	<p>University Research Ethic Committee</p>	<p>94</p>	<p>Public health nurses, hospice at home nurses and palliative care nurses</p>	<p>Qualitative Exploratory descriptive survey.</p>	<p><u>Aim</u> – examine the provision for community support for persons with an intellectual disability requiring palliative /EOLC</p> <p>Study recognised changing demographic trends-people with learning disabilities now living in the community and living longer. Increase of patients requiring end of life care. Representing 1.2% of the nurse in community workload currently.</p> <p><u>Issues identified</u> –</p> <p>Challenges in communicating with patients with an intellectual disability. Issues with pain and symptom management, Time needed to gain patient trust. Collaborative approach required. They felt they had lacked knowledge and skills to support this group. They received support, guidance from their LD nurse counterparts – good resource</p> <p><u>Conclusion</u> – Collaborative approach required Suggests for palliative care services to link with Intellectual disability services. Increased learning and development of communication methods and interpreting the patients' needs Families know their person best and should be acknowledged as valuable and integral to care planning care</p>	<p>Time</p> <p>Collaboration – sharing skills</p> <p>Working with families</p> <p>Increased learning</p>

<p>5 Communic-ating with nurses: The experiences of 10 adults with cerebral palsy and complex communication needs.</p> <p>Balandin, Hemsley et al, 2006</p>	<p>University of Sydney human research Ethics Committ ee</p>	<p>10</p>	<p>Adults with Cerebral palsy who used AAC aids to communi cate. They had been inpatients one to four times in 2 years</p>	<p>Quantit-ative and Qualitative semi-structured interviews</p>	<p>The interviewer gathered perspectives on the following topics:</p> <p><u>Ratings of comm in hospital</u>: 1 rated as successful as his mother acted as interpreter for him; 7 both positive and negative; 2 mainly negative experiences</p> <p><u>Communication barriers during hospitalisation</u>: 1. Not having a way to communicate; 2. not having the opportunity; 3. Nurse not understanding the communication attempts; 4. Nurses not responding to comm attempts</p> <p><u>Difficulties accessing the call system</u> – only 2 they were always able to contact a nurse, 4 reported being able to reach call aid sometimes not always, 4 reported they were never able to use the call aid because of their own limitations.</p> <p><u>Consequences of the barriers</u></p> <p>General perceptions of treatment as a result of communication barriers- all felt that some nurses treat them differently from how they treated others- patronising or assuming intellectual disability./ some nurses ignored, avoided eye contact or walked away during an interaction</p> <p>Length of stay and recovery: 2 felt their stay was prolonged and inhibited their progress; 4 felt the comm difficulties increased as their stay increased</p> <p><u>Strategies for improving communication experiences in hospital?</u></p> <p>6 – nurses should know how to use alphabet board and about AAC</p> <p>5 – not assume that they have intellectual disability</p>	<p>Avoidance of communication</p> <p>Limited understanding of AAC</p> <p>Nurse avoidance altogether</p> <p>Nurses appeared to have a lack of interest in the as individuals</p> <p>Some nurses do try to learn and assist them with their AAC boards</p> <p>Training need</p> <p>Reliance on care giver to communicate for them</p> <p>Resources not always available</p> <p>Health care inhibited</p>
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<p>6. A systematic review of the effectiveness of nurse communication with patients with complex needs with a focus on the use of augmentative and alternative communication Finke , 2008</p>	<p>no</p>	<p>12</p>	<p>Inclusion criteria – published between 1990 - 2007, primary research methodology, importance, barriers and recommendations made</p>	<p>This was a systematic review of research of the time. 14 articles examined (though 6 date back to 1991 – 1999)</p>	<p>Focused on perspectives of nurses, patients Works analysed were Qualitative interviews Patients reported:</p> <ul style="list-style-type: none"> • When unable to communicate their care was not satisfactory • A preference was noticed for low tech devices • Feeling frustrated , fear , panic and loss of control, • Voicelessness affected their treatment <p>Nurses reported:</p> <ul style="list-style-type: none"> • Relied on carers family members to be the patients voice • Effective use of AAC will mitigate the detrimental effects of their voicelessness • Received training re disabilities but not about communication • Limited opportunities to learn- time, increased patient frustrations, lack of AAC resources 	<p>Quality of care is maximised when communication is prioritised Frustrated patients Nurses should no more AAC Reliance on care workers to communicate for the patient Humorous and patient nurses made the whole experience better Training in AAC Time to talk Understanding that comm is fundamental to recovery Huge onus on the nurse to improve her communication skills</p>
<p>7. Evaluation of Makaton in practice by Children's nursing Students Jude Vinales Senior Lecturer, Gibraltar Health Authority. 2013</p>	<p>Peer review</p>	<p>33</p>	<p>2nd year children's nursing students</p>	<p>Qualitative Student evaluations</p>	<p>Students received 2 hour teaching on Makaton. Followed by an evaluation of the teaching of the effectiveness, as a prep for their placements in a special needs school and for communication in nursing practice when they return from the placement. Results 89%- Makaton session should be offered in their 1st year 15 % said Makaton wouldn't be useful to them as they didn't work upon a LD placement in their first year 88% said they should have more exposure to Makaton users to retain the skills</p>	<p>Repetition of learning Learning skills sooner Makaton is a transferable skill The learning program may have impact on nurses when they see students engaging in the process There is an expectation that with increased use of AAC tools that a person can respond, important messages back and forth.</p>

APPENDIX 4 – Research Review (as defined with CASP Tool)

Study	Focused Question	Right papers	Important papers inc.	Did author do enough ?	Com-bined results	How precise are results?	Can results be applied to local pop.?"?	Import-ant outcome consid-ered	Benefits worth the harms/ costs
1	✓	✓	✓	✓	✓	✓	✓	✓	✓
2	✓	✓	✓	✓	na	✓	✓	✓	✓
3	✓	✓	✓	✓	na	✓	✓	✓	✓
4	✓	✓	✓	✓	na	✓	✓	✓	✓
5	✓	✓	✓	✓	na	✓	✓	✓	✓
6	✓	✓	✓	✓	✓	✓	✓	✓	✓
7	✓	✓	✓	✓	na	✓	✓	✓	✓

VALIDITY - ARE THE RESULTS OF THE REVIEW VALID?

1. Did the review address a clearly focused question
2. Did the authors look for the right type of papers?
3. Do you think all the important relevant studies were included?
4. Did the authors do enough to assess quality of the studies?
5. If the results of the studies were combined, was it reasonable to do so
6. What are the overall results of the review?
7. How precise are the results?
8. Can the results be applied to the local population?
9. Were all important outcomes considered?
10. Are the benefits worth the harms and costs?

APPENDIX 5 – Work Experiences of Staff Interviewed

Started working in care about 15 years ago. That first care job was working in the Centre for people with dementia.

Mainly working with kids from seven to 17 and there was sometimes where occasionally we work with people with disabilities and things. From there I worked in a residential home in for people with learning difficulties and mental health

I worked in a Bank, had my Children, and became a Teaching assistant. Then have worked as care support for 13 years at St Oswald's.

Before care, I worked in an office. Then looked after children with mild, moderate, behaviour problems for 6 years then came to St Oswald's, where I have worked these past 10 years

I was a swimming teacher where I met people from a local special education school, I then worked there as teaching assistant there. I then came here where I have worked for around 12 years now

Paediatric nurse; BMT – 4 years, Oncology, Career break had my children, Nurse bank, Special education School then 4 years at St. Oswald's

Since 16 years has worked in special ed- Gaining degree education studies for special inclusive needs. Worked in class- focus education then moved to St Oswald's where I have worked these last four years.

Physio - special school residential – 7 years working with children with Complex needs and I've worked here for five years.

Supporting people with LD in their own home, Nursery Nurse, Children's ward in hospital and then here -now 19 years

School nurse in Special educational needs schools for a few years then I have worked here for nearly 20 now.

I have had multiple nursing jobs within paediatric settings for 12 years, I have worked here for 2 years

Worked as a nurse on paediatric wards and units for 30 years before coming to St Oswald's over one year ago

APPENDIX 6 – Roles of the Staff Interviewed

The Interviewees – the final sample of interviewees consisted of:

- 1 x Activity Coordinator
- 1 x Physiotherapist
- 4 x Care Support Workers
- 2 x Nursing Associates
- 4 x Registered sick children nurses

Their years of experience ranged from 2 to 20 within a short break setting.

It is an important factor of this study that the team is made up of multi experienced therapists and caregivers coming from Health and Education settings.

This results in a mixture of disciplines with varying priorities, skills and outlooks. Their opinions can vary as to what service we are delivering to the CYA.

APPENDIX 7 - Survey to Hospices

- Do you use the collective term A.A.C? if not what term do you use?
- Do your care staff actively engage in A.A.C techniques?
- Do you have set A.A.C competencies?
- What other resources do you have to support staff?
- Do you intentionally recruit people with A.A.C skills?
- Is A.A.C documented as a preferred skill within a job description?

APPENDIX 8 – Topic guide for staff Interviews

Interview questions for St Oswald’s Nurses, care support workers and allied health professionals:

1. Can you tell me about your background and experience prior to working at St. Oswald’s?
2. How long have you worked at St Oswald’s for?
3. A. Can you reflect on how you felt, earlier in your career, when you communicated with children/young adults (CYA) with communication difficulties?

or, alternatively, if the interviewee is still relatively new to the role

Can you tell me how you feel when communicating with someone with communication difficulties?

- B. If you had any concerns in your ability, did you share this?
- C. Were you offered advice and support in how to communicate with CYA with communication difficulties?
4. Can you recall and describe a time when you communicated well with a child or young adult who had communication difficulties?
5. Can you identify and describe a time when you found it challenging to communicate to a child or young adult who had communication difficulties?
6. What do you understand about Augmentative and Alternative Communication?

(If the interviewee is unsure what this means the interviewer will explain that it is a collective term for specific communication tools such as Makaton, intensive interaction, hand over hand technique, etc which has been referred to as Advanced communication locally)

7. A. Do you use AAC skills routinely with the Children/Young Adults?
B. If yes; what skills do you use? what are you less skilled at using?
C. If no; what stops you using these skills?

8.
 - A. Have you received any training in A.A.C at St Oswald's?
 - B. Have you received any training in A.A.C elsewhere?
 - C. Would you benefit from extra training in A.A.C?
 - D. Are there any specific areas you would prefer training on and why

9. Has there ever been a time you have been unable to practice AAC through either:
 - A. Lack of resources; for example, broken or limited equipment?
 - B. Attitude of surrounding staff?
 - C. Time?
 - D. Lack of knowledge/ experience/ confidence?

10.
 - A. Does the CYA's Communication assessment guide help you to use the appropriate A.A.C tools for the CYA?
 - B. Do you refer to the Communication assessment when caring for a CYA?

11. Do you think that the Child/young adult benefit from you being upskilled in A.A.C?

APPENDIX 9 – Recommendations & Action Plan

Specific	Measured	Achievable / Relevant	Timed
Defining a culture – communicating messages of new governance and expectation	<ul style="list-style-type: none"> • Devising Robust policy • And standard operations procedures • Meet with Quality Lead 	Connected to quality team ; access and meetings	September. 2024
Communicating to the team the findings of the project and our responsibility to change	<ul style="list-style-type: none"> • Study days • email 	Study days to share	May 2024
Issuing team with Platform of roles	<ul style="list-style-type: none"> • Devising bespoke team of specialists including ; • Learning disability nurse, specialised activity coordinators, Physiotherapists, Occupational therapists and Speech and language therapists 	To issue on study clarity of roles	May 2024
Increase internal training	<ul style="list-style-type: none"> • Share findings with learning and development department 	Funding Search for relevant trainers	May 2025
Increased collaboration with education	<ul style="list-style-type: none"> • Increased connection with schools • Retrieving AAC plans and objectives for the individual CYA 	New therapy role	August/Sept 2024
Creating a strong clear Identity for the unit and what our future goals are-communicating this to the team via Posters, Team meetings	<ul style="list-style-type: none"> • Leadership meeting • Discuss re goals • Devise a new Mission statement • Share in Nov study days 	Study days to share	November 2024
Altering job specifications – establishing clear identity of roles	<ul style="list-style-type: none"> • Email HR • Discuss with Quality Lead 	HR meeting	November 2024
Issuing AAC competencies from Induction to Self-assessment to Blue stream portal	<ul style="list-style-type: none"> • Work on new set competencies • In levels – bronze, silver , gold • Liaise with Learning and development 	Access to Bluestream Portal required	November 2024

Communicating the plan to families and delivering. Measuring performance six monthly initially	<ul style="list-style-type: none"> • Sharing project with families via Newsletter. • Pledging our aim 	Next issue - Mid summer	May 2024
Devising Bespoke communication care plan	<ul style="list-style-type: none"> • Currently preparing new documentation 	Use skills of Therapist	May 2024
Producing unit song with key Makaton daily signs	<ul style="list-style-type: none"> • Created by DN, LA and music therapist 	To repeat in May study days	May 2024
Complete Phase 1	<ul style="list-style-type: none"> • Share project with similar services – benchmark results. 	Share study results and re send survey	September 2024
External training	<ul style="list-style-type: none"> • Share project results 	Liaise with hospice research team and learning and development team	Ongoing
Increase investment in appropriate AAC resources	<ul style="list-style-type: none"> • New sensory room plans to include AAC devices • Wish list of usable, not individualised, AAC devices 	liaise with external and internal experts in AAC	Ongoing