

The strategic case for a switch-operated, web-based communication device for nonverbal patients in an Intensive Care Unit

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Cover image source: Intensive Care app

Executive summary

This report outlines the case for investing in better communication devices for nonverbal patients in an Intensive Care Unit (ICU), such as those with tracheostomies. It presents the 'strategic case' for a switch-operated, web-based communication device to assist these patients to communicate with ICU staff and with their family. Compared to the alternatives currently available, a switch-based computer system, encompassing hardware, software and human-computer interface, would offer the following strategic advantages.

- It is suitable for those with limited fine motor skills and could be configured for use
 with either one or two switches, with these switches able to be operated with either
 hand or foot.
- It would be able to run in any common web-based browser.
- It would allow the nonverbal patient to initiate communication, even when they have limited mobility.
- It would have an interface that could be adapted to a specific local context (rather than being a generic app).

The scope of content (that can be) provided for the interface of this system is broad, extending far beyond task-focused subject matter. It ranges from conveying symptom-related messages, to active participation in medical discussions, to conversing with family about a range of complex multi-disciplinary issues, to sharing psycho-emotional experiences.

This report is written for those in open source community of developers and for researchers or researcher funders who might be looking for a project to undertake or fund. It outlines the advantages of further developing the working prototype being made available on GitHub, to complete, test and operationalise a communication device that:

- meets the basic communication needs (functional, emotional and social) of a nonverbal ICU patient with limited fine motor skills;
- suits the physical situation found in Australasian ICUs; and
- and can be configured to suit local situations elsewhere.

The situation

THE PROBLEM

In recent decades, demand for intensive care has steadily escalated, and the ratio of intensive care unit (ICU) to hospital beds is increasing everywhere and ICUs hold a key position in all hospitals (Vincent *et al.* 2010, Topçu *et al.* 2017). Worldwide, millions of people are admitted to an ICU unit each year. In Australia the figure exceeds 150,00 and in New Zealand it exceeds 23,000 (Martin et. al 2010). (These numbers are a decade old, and likely to be an underestimate.)

One of the most difficult things for an ICU patient to cope with is their inability to communicate (Russell, 1999). Almost half of ICU patients require mechanical ventilation to assist with breathing (Carruthers *et al.* 2017). During this time, they are unable to communicate using speech because they are intubated, either through a plastic tube inserted in their throat via their mouth (as shown in Figure 1) or via a tube in their neck (the latter is referred to as a tracheostomy) (MacAulay et. al 2002). Other ICU patients who may also have difficulty communicating through speech include those with strokes.



Figure 1: An intubated patient

Source: https://www.youtube.com/watch?v=PXebHXbeonE

With the trend towards light sedation or daily interruptions in sedation, mechanically ventilated ICU patients are likely to have significant periods of time when they are awake, alert, attempting to communicate but unable to speak (Leung *et al.* 2018). Many patients

attempt to mouth words, but if they are intubated orally, ICU staff and family usually find it difficult comprehending what they are trying to communicate. Moreover, using an augmentative or alternative method of communication can be very difficult for an ICU patient. Movement of their hands and arms is restricted by the drips and monitors usually attached; furthermore, they are often too weak to write or gesture clearly (MacAulay 2002). Although nurses who work in ICU are often highly skilled at anticipating the communication needs of their patients, they find these attempts at communication time consuming and difficult (Ashworth 1984. MacAulay, 2002).

ICU patients who are left temporarily voiceless often suffer psychological distress, frustration and even panic. Patients reported feeling powerless, and incomplete, like an integral part of their body was cut off (Tembo *et al.* 2015). Emotional distress experienced in ICU often contributes to a patient's post-traumatic stress disorder during recovery and the psychological effects can be long-lasting (Russell 1999, Carruthers 2017).

SOLUTIONS THAT ARE BEING USED AT PRESENT

ICUs are staffed by large and varied teams including specialised doctors and nurses, as well as pharmacists, dieticians, physiotherapists, occupational and speech therapists, orthotists, radiographers and social workers (College of Intensive Care Medicine of Australia and New Zealand, no date).



Figure 2: Example of cue card used for communicating with non-verbal people

Source: www.speakingofspeech.com

Often communication events between patients and the staff in ICUs consist of more than one method e.g., gesture, mouthing words, head nods, and writing (ten Hoorn *et al.* 2016). Much of the communication between nonverbal ICU patients and the medical staff appears to be largely one-way however and initiated by the staff.

In New Zealand, the most common means of communicating with nonverbal hospital patients utilises laminated cue cards, or boards, with either the alphabet or symbols of common phrases, such as the one shown in Figure 2. These boards can be cumbersome and time-consuming to use, leading to frustration on the part of the patient. Moreover, the topics of communication are restricted to those on the card.

Augmentative and alternative communication (AAC) strategies using personal devices such as cell phones, MP₃ Players, iPads and personal computer tablets have been available for twenty years or more (e.g. Flores *et al.* 2012). Few such approaches have been adopted widely in the critical care setting, however (Mobasheri *et al.* 2016). In an American study, Happ *et al.* (2011) reported that although despite the availability of communication assistive devices, nurses hardly ever used them; the researchers attributed this to a lack of staff education about effective communication strategies. Communication competencies and use of assistive communication tools are yet to be incorporated into the standard of care in ICUs (Happ 2016; Phil Blyth, Otago Medical School, Dunedin, *pers. comm.*, July 2019).

There has been relatively little research aimed at refining and applying computer-based communication tools for non-verbal ICU patients (Happ 2016). A seminal study, a university/ hospital collaboration undertaken in Dundee in the early 2000s, developed a system that used a large touchscreen before the advent of tablets), and either mouse emulation or a single switch. This device is no longer available although the ideas it generated have been included in current augmentative and alternative communications used in the United Kingdom (Professor Annalu Waller, University of Dundee, *pers. comm*. August 2019).

Another university hospital research project at Radboud University Medical Centre in The Netherlands produced an app, voICe, reported to be used in 100 hospitals in The Netherlands and Belgium (Anon n.d. a). The voICe app is unavailable in New Zealand, however. YouTube videos refer to other apps for iPad developed in Mumbai (Anon 2016) and Singapore hospitals (Anon 2012), which appear to be used only in those countries.

While there are dozens of apps available to assist people with speech impairment, or those who are nonverbal, to communicate with medical staff, including Patient Communicator and YoDoc for example — see Pressman and Pietrzyk's list (n.d.) — few of these apps have been specifically developed for ICU patients and therefore cover more general communication needs. One example, the Intensive Care app, appears to be a clone of a series of general communication apps, adapted to the ICU but not specifically designed for that purpose.

In 2016, ten Hoorn *et al.* reviewed methods used to communicate with conscious and mechanically ventilated critically ill patients, including nine studies of electronic ACC devices. All had common topics about basic communication needs in the ICU on the main screens (e.g. emergency, pain and emotions). A small number used voice output communication aids; some handheld devices allowed patients to touch a word-picture icon on a keypad to produce a prerecorded voice message.

The review by ten Hoorn (et al. 2016) identified two other means of communicating with conscious mechanically ventilated, critically ill patients. One involved types of specialized talking tracheostomy tubes which allowed most patients audible voicing but required more studies to facilitate safe and effective use. The other method, an electrolarynx (a battery powered handheld device which is pressed onto the skin of the neck to help the user create speech), improved communication for tracheostomy patients. This would not suit every nonverbal patient however, only those able to hold the device to their neck.

Impetus for the project

Technological opportunity provides one impetus for this project. Apple's incorporation of accessibility features, including switches, into the iOS operating system created an opportunity to adapt an iPad for use by nonverbal ICU patients, to allow them to initiate and sustain conversation, as well as to respond to medical staff's queries. Apple's Switch Control assistive technology lets someone use built-in features — switches or a joystick, or other adaptive devices — to control what's on the screen, so they can interact fully with their iPad (or iPhone or Mac) without touching it as demonstrated in Figure 3.

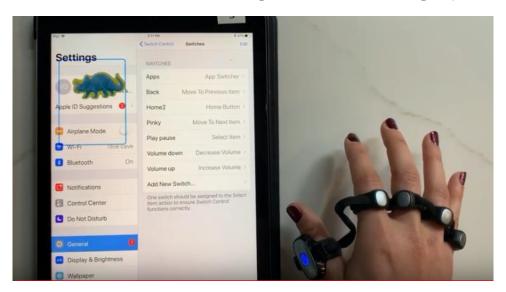


Figure 3: Using switch control to navigate an iPad with a tap strap

Source: https://www.youtube.com/watch?v=ftIzRYoVRKY

Of 38 postoperative patients with head and neck cancer, studied by Brunner *et al.* (2018), 25 (66%) were able to use a customized iPad to communicate. Of these 25 patients, 15 (60%) were satisfied or somewhat satisfied with it and 84% found the customized iPad to be very or somewhat helpful for communication after surgery.

While the iOS platform lends itself particularly well to a web-based interface because its built-in accessibility features allow the use of Bluetooth button presses to be utilised, there is opportunity to develop a system suitable for use on any common browser. As the ICU-Talk research at the University of Dundee demonstrated twenty years ago, this opportunity is not limited to an Apple system.

One option for these patients to communicate is by pressing buttons. An interface capable of translating button presses to phrases has the capability of relieving much frustration for both the patient and the medical team. Figure 4 illustrates a commercially available product that combines an iPad with two button system.



Figure 4: Commercially available system linking an iPad with a dual button system

Source: https://store.rjcooper.com/collections/access/products/tablet-dual-button-box

This technology presents an opportunity not just to patients but also to hospital management. Leveraging of communication technology could "extend scarce critical care expertise to underserved settings and improve care uniformity throughout the 24-hour cycle" (Vincent *et al.* 2010).

The second impetus leading to this project is the vision of Dr Phil Blyth at the Otago Medical School, University of Otago. A severe trauma incident suffered by Dr Blyth's parents left both in intensive case with limited mobility, unable to communicate for several weeks. Wishing to help but not finding any suitable devices in New Zealand, Dr Blyth developed a system that consisted of an Arduino-based device utilising Bluetooth and physical buttons, connected to an iPad using the Switch Control function of the iOS platform. This device is shown in Figure 5. The two button pads can be operated by pressing them with either a foot or hand, making the iPad capable of translating button presses into simple words/phrases.



Figure 5: Dr Phil Blyth's prototype

Source: author's photograph

After his parents recovered, Dr Blyth stopped working on the project until mid-2019, when he asked a group of SHIFT students at the University of Otago — students studying for a graduate diploma in Information and Communication Technology — to develop this protype further. Dr Blyth's vision, combined with the technological opportunity, is the genesis for this strategic case and its accompanying prototype, developed by the SHIFT students, which is now being made available to the open source community for further development.

The opportunity

OPPORTUNITY

A combination of communication methods is needed to meet the needs of mechanically ventilated, critically ill patients in ICUs (ten Hoorn, 2016). These communication methods — augmentative and assistive strategies, and devices and human-computer interfaces—need to be tailored to both the needs of nonverbal patients in an ICU and to the complexities of the acute care environment (Rodriquez *et al.* 2012).

Use of specialized ICU apps appears to be limited to the countries in which they were developed, suggesting that while the technology of the physical devices may be universal, apps need to be tailored to local situations, language and, probably, to local culture. The way that communication with nonverbal patients in New Zealand ICUs remains dependent on gestures and communication boards, supports this deduction.

As part of providing a suite of suitable communication methods for ICU patients, there remains an opportunity to develop a touch-sensitive device that enables patients with limited movement / fine motor skills to use either one or two switches (e.g. on a hand or foot) to communicate: switch-based hardware, linked to browser on a tablet or iPad, with an interface designed to suit both the specific situation in an ICU and the local context. The device should be designed to be adaptable to a range of physical limitations.

SCOPE AND OBJECTIVES

The scope of this project is the development of a switch-based computer system, encompassing hardware, software and human-computer interface capable of running on any browser and meeting the needs of a patient wanting to communicate with medical staff, carers and family.

The scope of content provided for by the interface is broad. It ranges from conveying symptom-related messages, to active participation in medical discussions, to conversing with family about a range of complex multi-disciplinary issues, to sharing psychoemotional experiences (as highlighted by Leung et. al 2018).

The system should fulfill these objectives:

- it should meet the basic communication needs, functional, emotional and social, of a nonverbal ICU patient with limited fine motor skills;
- it should suit the physical set up of New Zealand ICUs (portrayed in figures 6 and 7); and
- it should suit the New Zealand culture.

Appendix 1 sets out draft requirements that the system should. A working prototype, the code for which is available on GitHub at https://github.com/touch-to-speech/ICU Touch to Speak, also forms part of these requirements.





Figures 6 and 7. The setup at Wellington Hospital ICU

Source: https://www.stuff.co.nz/national/health/95743151/major-expansion-plans-for-wellington-hospital-icuwill-add-six-beds. Rachel Thomas, Stuff, 2017.

Strategic assessment

STRATEGIC ALIGNMENT

This section assesses the alignment of the proposed project with relevant strategy and policy, relating to the clinical care model used in New Zealand ICUs.

The New Zealand standards for critical care nursing practice (Critical Care Nurses Section of the New Zealand Nurses Organisation 2014) require critical care nurses to promote open honest communication and information sharing with the patient and their family/whanau, as appropriate.

The College of Intensive Care Medicine of Australia and New Zealand's 2013 guidelines for the ethical practice of intensive care medicine recognise the overall welfare of the patient as the principal goal of Intensive Care management. The guidelines require that the relationship between the intensivist (the specialist doctor(s) who look after patients in an ICU) and the patient must have regard to the following concept (amongst others), which reflect on the need for effective communication between patient and intensivist:

- patient autonomy, meaning the patients have the right to decide their own treatment, with intensivists respecting the principles of truthful disclosure and informed consent;
- the principle of beneficence, or the obligation to do good;
- the principle of non-maleficence, or the duty to do no harm.

Under the guidelines, patients (themselves or through their legally recognised representatives) have the right to these matters relating to the standard of communication that patients could expect when in an ICU:

- Expect that the services provided are of optimal quality and that they will receive the most appropriate care available.
- Be treated with care, consideration and dignity including the respect for personal, religious, cultural and social beliefs.
- When realistically possible, know the identity and professional status of all attending medical and other staff.
- When realistically possible, be informed, with a clear, concise and understandable explanation of the proposed care and procedures, including the relevant alternatives and known side effects and risks, unless precluded by an emergency.
- Give verbal or written consent for a procedure, after explanation and before treatment, unless precluded by an emergency.
- Know what services are available in the hospital.
- Receive a second opinion when requested, without prejudice to any aspect of future treatment.

- Be provided with appropriate information and give appropriate consent for involvement in teaching or research activities, and to understand that noninvolvement will not prejudice treatment.
- Refuse treatment without the requirement to justify that decision, and to be informed of the consequences of such refusal.
- Expect that all aspects of care will remain confidential, including personal privacy relating to conversations and physical examinations

These ethical guidelines, along with the nursing standard cited above, all support the need for devices that assist a patient to communicate while staying in an ICU. A switch-operated, web-based communication device would align with these strategic intentions, and help intensivists comply with the goal and ethical principles in the Australasian College of Intensive Care Medicine guidelines for intensive care medicine.

STRATEGIC ADVANTAGES

Compared to the communication strategies and devices solutions already being used, which described on pages 4 to 6 above, A switch-operated, web-based communication device would offer the following strategic advantages:

- 1. As a switch-based system it is suitable for those with very limited fine motor skills. Ideally, it could be configured for use with either one or two switches, and these switches would be designed for use with either hand or foot.
- 2. It would be able to run in any common web-based browser, whether android or iOS.
- 3. It would allow the nonverbal patient to initiate communication, even when they have very limited mobility.
- 4. It would have an interface that could be adapted to a specific local context (rather than being a generic app).

WHO WANTS IT?

The nursing and critical care journals, in the academic literature, have for a decade or more highlighted the need for effective communication devices and strategies for carers and patients in ICUs, particularly those who are intubated but alert and wanting to communicate. The bibliography included with this document contains a long list of such publications.

ANTICIPATED BENEFITS

The benefits anticipated from this project are:

- A reduction in the trauma suffered by those ICU patients unable to communicate verbally, along with a reduction in these patients' post-traumatic stress disorder during recovery and associated psychological after-effects.
- 2. Facilitation of a level and style of communication between nonverbal ICU patients and intensivists and nurses that would comply with Australasian guidelines for the ethical practice of intensive care medicine and the New Zealand standards for critical care nursing practice.
- 3. Easier, less time-consuming and stressful communication for nurses and a concomitant increase in job satisfaction.
- 4. Better allocation of the scarce resource of staff time in an ICU.

The need for investment

WHAT'S ALREADY BEEN DONE ON THIS PROJECT?

The team of SHIFT students who worked on this project in July-August 2019 developed a working prototype, comprising hardware, software and interface. The code that is available on GitHub is self-contained in that it includes setup instructions (all setup is done within the website) plus styling of the interface (done with CSS grid).

The team did some initial user testing of the interface, to develop to the working prototype stage. The GitHub repository includes a user questionnaire for evaluating the interface.

WHAT NEEDS TO HAPPEN NOW

If the project is to succeed and the vision realised, then the next step is for someone to build physical switch-based hardware and use the code on GitHub to recreate the working prototype. The next step should then be further user testing to review, improve and expand the user interface, including testing in an ICU environment.

To guide further development of the device, Appendix 1 contains a suggested list of requirements that the final product should meet. This list has largely been constructed from the literature in the bibliography and needs to be validated by testing with ICU patients and staff

Moving forward

WHAT REMAINS TO BE DONE?

Future iterations of the system could include:

- 1. integration with other third-party apps, to allow users to gain control over things such as entertainment;
- 2. for patients that are disoriented or confused, inclusion of reminders about such matters as the patient's profile (name, age), hospital they are in, their condition, the nature of incident that resulted in their admission, and visitors;
- 3. inclusion of a feature reminding the patient about what the nurse told him/her that day;
- 4. addition of a mechanism to store a patient's most frequently used phrases (customisable to the patient);
- 5. inclusion of features that allow family to leave a message on the device and to record a video that is then available for the patient to watch wherever they want;
- 6. inclusion of a glossary feature that allows patients to find information about their condition.

THOSE TO WHOM MIGHT THIS INVESTMENT BE ATTRACTIVE

Investing time or other resources into this project could be of interest to:

- developers interested in working on an open source with public good
- a PhD student
- university researchers
- a philanthropic organisation looking for a public interest project to fund.

CONCLUSION

There is clearly a need in Australasia, if not more widely, for better devices to assist those nonverbal ICU patients with limited fine motor skills to communicate with ICU staff and with their family. This is a communication problem that would benefit from a technological solution. This strategic case, combined with specification of requirements — the combination of the working prototype and the list in Appendix 1 — provides a basis for someone to develop the next, improved version of a solution to this communication.

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Appendix: Requirements for the proposed system

- 1. The system should run on the common browsers used on iOS and android.
- 2. The system should be relatively quick to set up for a patient.
- 3. Once set up, patients and nurses should be able to use the system intuitively.
- 4. The system should be easy and fast to learn.
- 5. The system should allow a patient to initiate conversation.
- 6. Once set up, it should be capable of storing settings input settings between sessions and should be able to be reset easily when the device is allocated to another patient.
- 7. It should be relatively fast to use with (as a suggestion, the user should require no more than five actions to communicate a specific pain, feeling or need).
- 8. The interface should offer a range of clinical and social/emotional content relevant to patients, along with the ability to customise the content.
- 9. The software should comply with NZ Government standards for web accessibility.
- 10. Both voice output and text generation should be offered.
- 11. It should be capable of voice banking when patients pre-record messages.
- 12. The system should be modular and extendable to fit future user groups.
- 13. The system should be relatively inexpensive.
- 14. The system should be reliable.
- 15. The system should be easy to maintain and update.
- 16. The system should be able to be adapted to a user's needs, providing ensuring ease of access for all individuals who require this augmentative or alternative communication.
- 17. The system must not interfere with the operation of other hospital equipment including electronics.

Hardware

- 18. The hardware incorporating the screen should be lightweight and easily moved.
- 19. The hardware should also be able to be activated with little physical effort.
- 20. The hardware should respond to limited mobility capability.
- 21. The hardware should be able to be held firmly held in place. The screen should have a secure mount that positions it near to the patient, and ensures it is not accidentally dropped or stolen.
- 22. The hardware should be easy to clean, waterproof, durable and capable of withstanding the rigorous cleaning regime in an ICU.