ICU TOUCH TO SPEAK

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

Jane Turnbull | 17 August 2019

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Executive summary

The literature on care of patients in intensive care units (ICUs) makes a strong case for better communication devices for patients unable to communicate through speech (e.g. if they are intubated or have tracheostomies). Many of the patients in an ICU at any one time meet this criterion. Patients whose limited range of fine motor skills prevent them gesturing or writing, are often worst affected, unable to communicate with medical staff and family. This report, 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, assesses the strategic case for a switch-operated, web-based device designed to help those patients communicate.

Such a device could fulfill the basic communication needs — functional, emotional and social — of a nonverbal patient. It could contain a broad range of content choices, to enable the patient to convey symptom-related messages, to participate actively in medical discussions, to converse with family about a range of issues and to share psycho-emotional experiences.

This report outlines the advantages of completing, testing and operationalizing the prototype device, which is being made available on GitHub. Compared to the alternatives currently available, this device would offer strategic advantages. When configured for use with either one or two switches operated with either hand or foot, it would be suitable for those with limited fine motor skills, and would allow the nonverbal patient to initiate communication, even when they have limited mobility. Furthermore, the device's interface can be adapted to a specific local context (which the generic apps currently available cannot be). Moreover, the device would be versatile enough to run in any common web-based browser.

The situation

THE PROBLEM

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

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 breaks 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). Almost all need to communicate with patients at some point.

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). 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.

Few such communication assistive devices 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 (shown in Figure 3), 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.

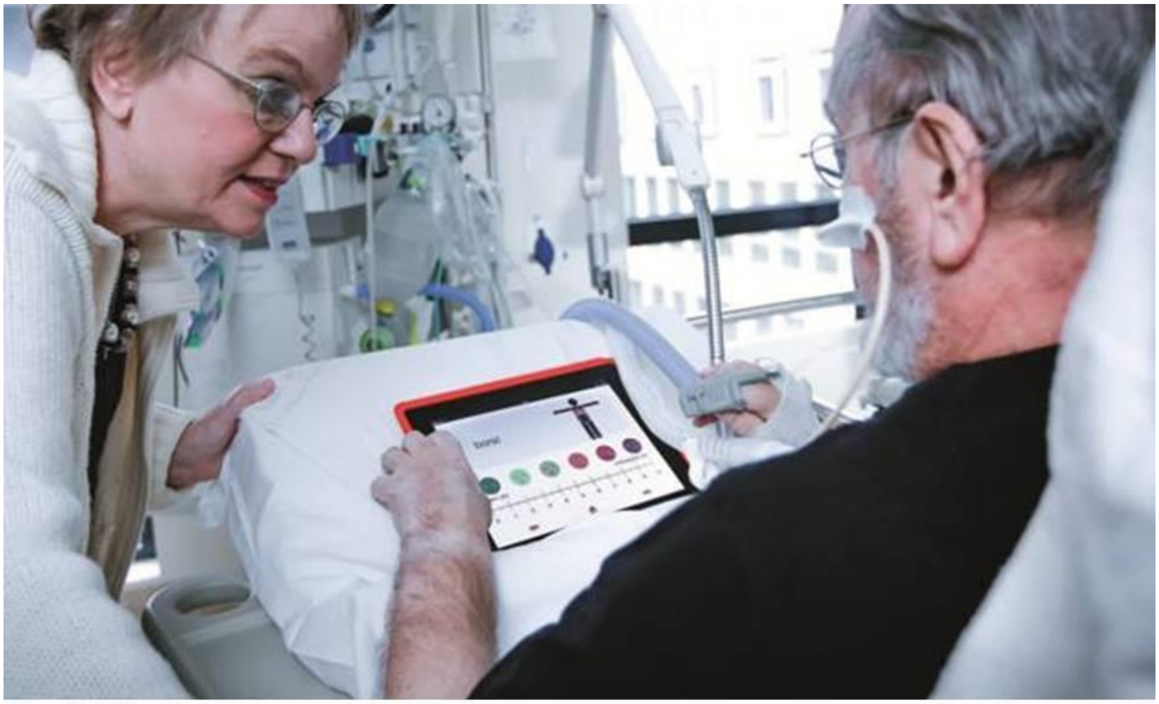
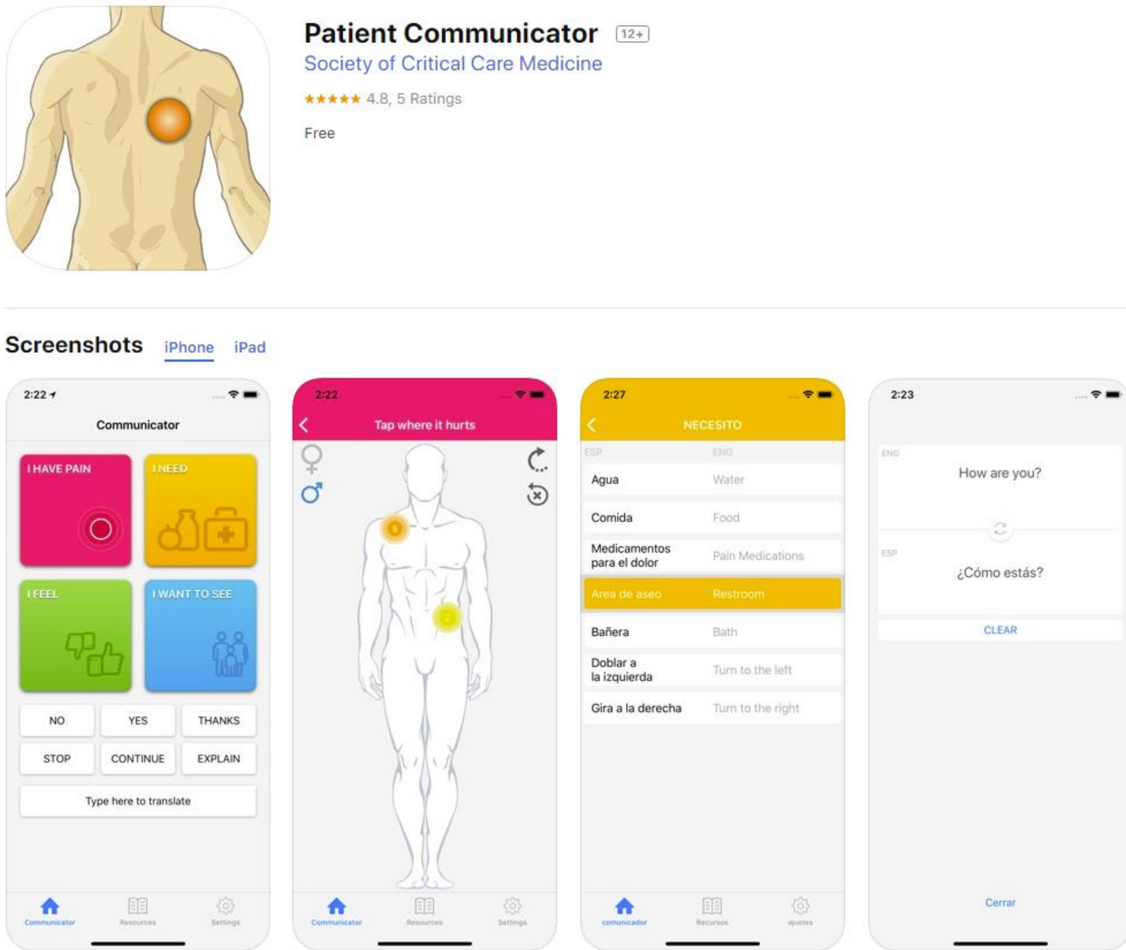


Figure 3: The VoICe app available in the European App Store

Source: https://www.efccna.org/news/300-special-communication-app-for-icu-patients

There are many apps available to assist nonverbal people or with speech impairment to communicate with medical staff, including Patient Communicator (shown in Figure 4), YoDoc and others on Pressman and Pietrzyk's list (n.d.). Few of these apps have been specifically developed for ICU patients however; instead they cover more general communication needs., the SmallTalk Intensive Care app shown in Figure 5, appears to be a clone of a series of general communication apps, adapted to the ICU but not specifically designed for that purpose.

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.



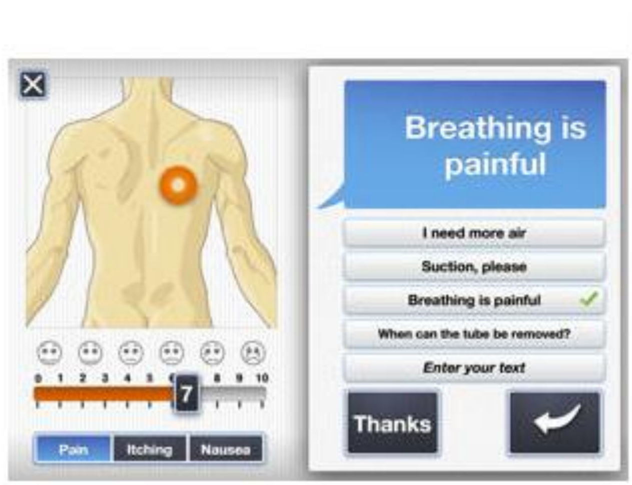


Figure 4: ICU Patient Communicator, available for iPads, released by The Society of Critical Care Medicine.

Source: https://apps.apple.com/us/app/patient-communicator/id732242570

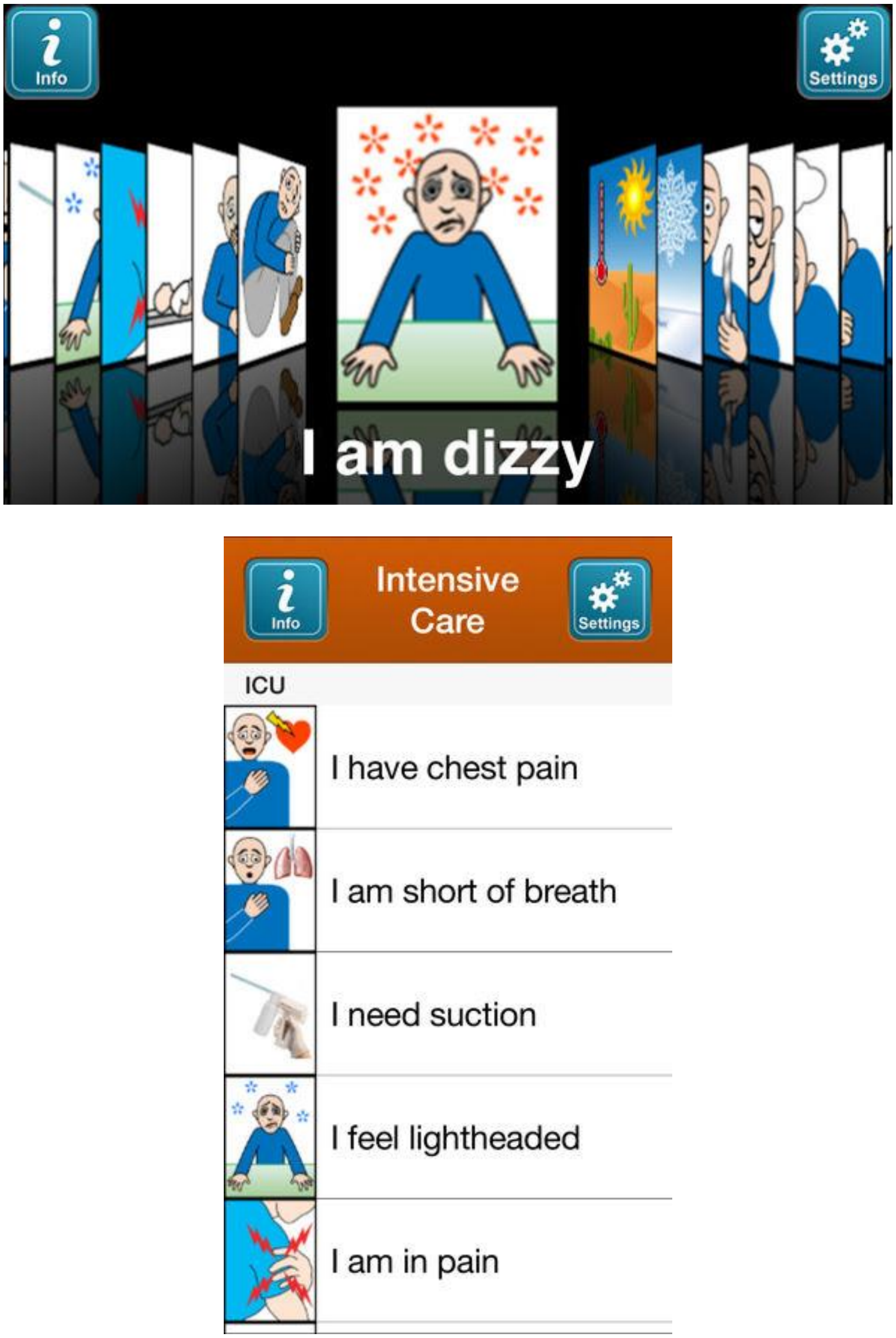


Figure 5: SmallTalk Intensive Care app, available for iPads from Lingraphica

Source: https://apps.apple.com/us/app/smalltalk-intensive-care/id403057381

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, joystick, tap strap, 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 6.

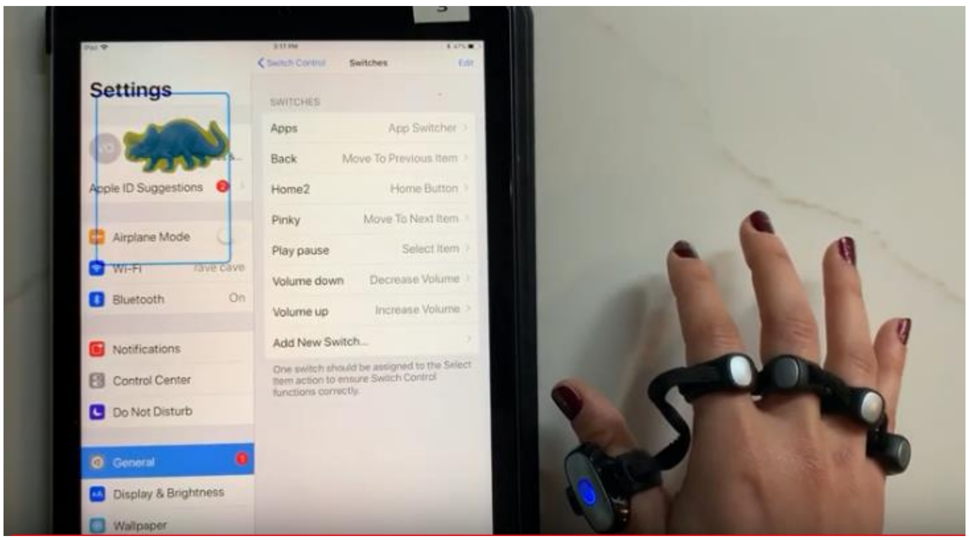


Figure 6: Using switch control to navigate an iPad with a tap strap

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, there is opportunity to develop a system suitable for use on any common browser. As the ICU-Talk research at the University of Dundee (discussed on page 5) demonstrated twenty years ago, this opportunity is not limited to an Apple system.

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 7 illustrates a commercially available product that combines an iPad with two button system.

Figure 7: Commercially available system linking an iPad with a dual button system

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

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 8. 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 8: 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[1] students at the University of Otago who were studying for a graduate diploma in Information and Communication Technology to develop this protype further. Dr Blyth's vision, combined with the technological opportunity described above, is the genesis for this strategic case and accompanying prototype developed by the SHIFT students, which is now being made available to the open source community for further development.

[1] See: https://signal.ac.nz/shift/ for an explanation of the SHIFT programme.

Opportunity, scope and objectives

OPPORTUNITY

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

Use of specialised ICU apps appears to be limited largely 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, possibly, to local culture as well. 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 is 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. The device should be adaptable to a range of physical limitations.

This technology also presents an opportunity for 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).

SCOPE AND OBJECTIVES

The scope of the project being assessed here is a switch-based computer system, encompassing hardware, software and human-computer interface, capable of running on any common browser and meeting the needs of a nonverbal ICU patient wanting to communicate with medical staff, carers and family. The scope of content provided for by the interface should be broad. It needs to range 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 (as highlighted by Leung et. al 2018).

The objectives that such a system should fulfill are these:

- it should meet the basic functional, emotional and social communication needs of a nonverbal ICU patient with limited fine motor skills;
- it should suit the physical setup of local ICUs (a New Zealand setup is portrayed in figures 9 and 10); and
- it should comply with local standards and guidelines for communication in an ICU and for web accessibility.

Appendix 1 sets out draft requirements for such a 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 9 and 10. The setup at Wellington Hospital ICU

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

Strategic assessment

STRATEGIC ALIGNMENT

In New Zealand, there is relatively little policy about the nature and standard of communication between ICU staff and patients. This section assesses the alignment of the proposed project with relevant ethical guidelines and standards.

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. These 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 three concepts (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 certain matters, many of which bear on the need for, and nature of, communication between intensivist and patient. The guidelines state that patients have the right to:

- 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 non-involvement 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, plus with the nursing standard cited above, support the need for devices that assist an ICU patient to communicate in a way that ensure their rights are protected. 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 device solutions already being used, which described on pages 4 to 8 above, a switch-operated, web-based communication device would offer the following strategic advantages:

1. Being switch-based, it would be 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 allow the nonverbal patient to initiate communication, even when they have very limited mobility.
3. It would be able to run in any common web-based browser.
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 list of such publications.

ANTICIPATED BENEFITS

The benefits anticipated from this project are:

1. 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 in the 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.

Moving forward: the need for investment

WHAT'S ALREADY BEEN DONE ON THIS PROJECT?

The team of University of Otago students who worked on this project in July-August 2019 developed a working prototype, comprising hardware, software and interface. The code, which is available on GitHub is self-contained in that, when completed, will include 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 bring it to the working prototype stage. The GitHub repository will include a user questionnaire for evaluating the interface 9which has already been tested).

WHAT NEEDS TO HAPPEN NEXT?

If the project is to succeed and the vision be 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. Further user testing to review, improve and expand the user interface, including testing in an ICU environment is then needed.

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.

ADDITIONAL FEATURES THAT COULD BE ADDED IN FUTURE

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 those patients that are disoriented or confused, inclusion of reminders about such matters as the patient's profile (name, age), their condition, the nature of incident that resulted in their admission, and regular 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 he/she wants;
6. inclusion of a glossary that allows patients to find information about their condition;
7. feedback to the user when a button is pressed, to help someone who is deaf use the device more effectively.

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 device

1. The system should run on all common browsers.
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 requiring 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 [New Zealand 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 for augmentative or alternative communication strategies.
17. The system must not interfere with the operation of other hospital equipment including electronics.

<u>Hardware</u>

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 have a secure mount that positions the screen near the patient, holds it firmly in place 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.