

## **Project Title**

Help Me Speak Programme

## **Project Lead and Members**

Project lead: Tan Xuet Ying

Project members: Zenne T'ng, Lee Jia Wen

## **Organisation(s) Involved**

Tan Tock Seng Hospital

## **Project Period**

Start date: January 2017

Completed date: Ongoing

## **Aims**

Patients with ALS have limited communication abilities due to muscle weakness with poor support. There is poor awareness of technology out there for alternative and augmentative communication (AAC) means. Even if patients are aware, eye gaze devices are too expensive and inaccessible to these patients. Traditionally, these patients had to purchase devices on their own from overseas to try out; however its benefits or feasibility is also not well studied for patients to invest a hefty sum for it. There were also no locally available vendors.

Therapists or professionals who are keen to explore the devices for their patients have difficulty getting trial devices and have limited skills in assessing patient's ability to determine success rate prior to advising for purchase.

There were a few cases that triggered the discussion to mitigate the gaps in services – one patient passed on prior to getting any form of communication devices to communicate his last wishes, one patient bought the device but had difficulty troubleshooting issues and healthcare professionals who visited were unaware on how to use it to communicate with the patient. The team collectively decided that it was time to improve the service standard.

The plan to overcome the issue was to get adequate access to the devices, provide adequate training and allow patients adequate trials prior to purchase of devices.

## **Background**

See attachment

## **Methods**

See attachment

## **Results**

See attachment

## **Lessons Learnt**

- 1) Expansion of services – to include a variety of devices as well under the loan programme to cater to a larger population
- 2) Expansion of target group
  - a. as the devices were part of donated fund from hospital's charity funding, devices can only be loaned to patients under our catchment areas
  - b. to consider establishing a nationwide initiative after initial phase to include other charity bodies/funds so that patients from other institutions can also benefit
- 3) Tracking of devices are done manually
  - c. to consider app-based stock checking/tracking of devices (currently in trial now)

## **Conclusion**

See attachment

## **Project Category**

Care Redesign

**Keywords**

Tan Tock Seng Hospital, Care Redesign, Speech Therapy, Patient-Centred Care, Patient Reported Outcome Measures, Home Ventilation and Respiratory Support Service, Amyotrophic Lateral Sclerosis, Alternative and Augmentative Communication, Therapy Outcome Measure

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# Enabling the Community by Improving ALS Patient's Communication through Care Redesign and a Loan System

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## Background

Eye-gaze communication devices are expensive and inaccessible to many patients who require it for communication especially those with Amyotrophic Lateral Sclerosis (ALS). Patients with ALS gradually become bed-bound, or on tracheostomy tube and/or ventilator support with high dependency on carers. Yet, these patients have limited communication abilities with poor support that further lead to social disconnection and reduce their quality of life. The benefits or feasibility of these high technology devices has not been well studied for patients to invest a hefty sum to use them. There is also poor awareness of technology out there for alternative and augmentative communication (AAC) that are capable to assist the patients in their communication.

Setting up a loan programme for helping these patients access to these devices aims to increase awareness, knowledge and skills in using the devices in the community and determine if these devices bring about value to these patients. Hence, a loan programme for eye-gaze devices for communication was set up to promote and increase the accessibility of these devices to impact and boost the patient's activity, participation and well-being. The study aim to bring this effective care to the community to further boost the overall quality of life of patients in the community.

## Methodology

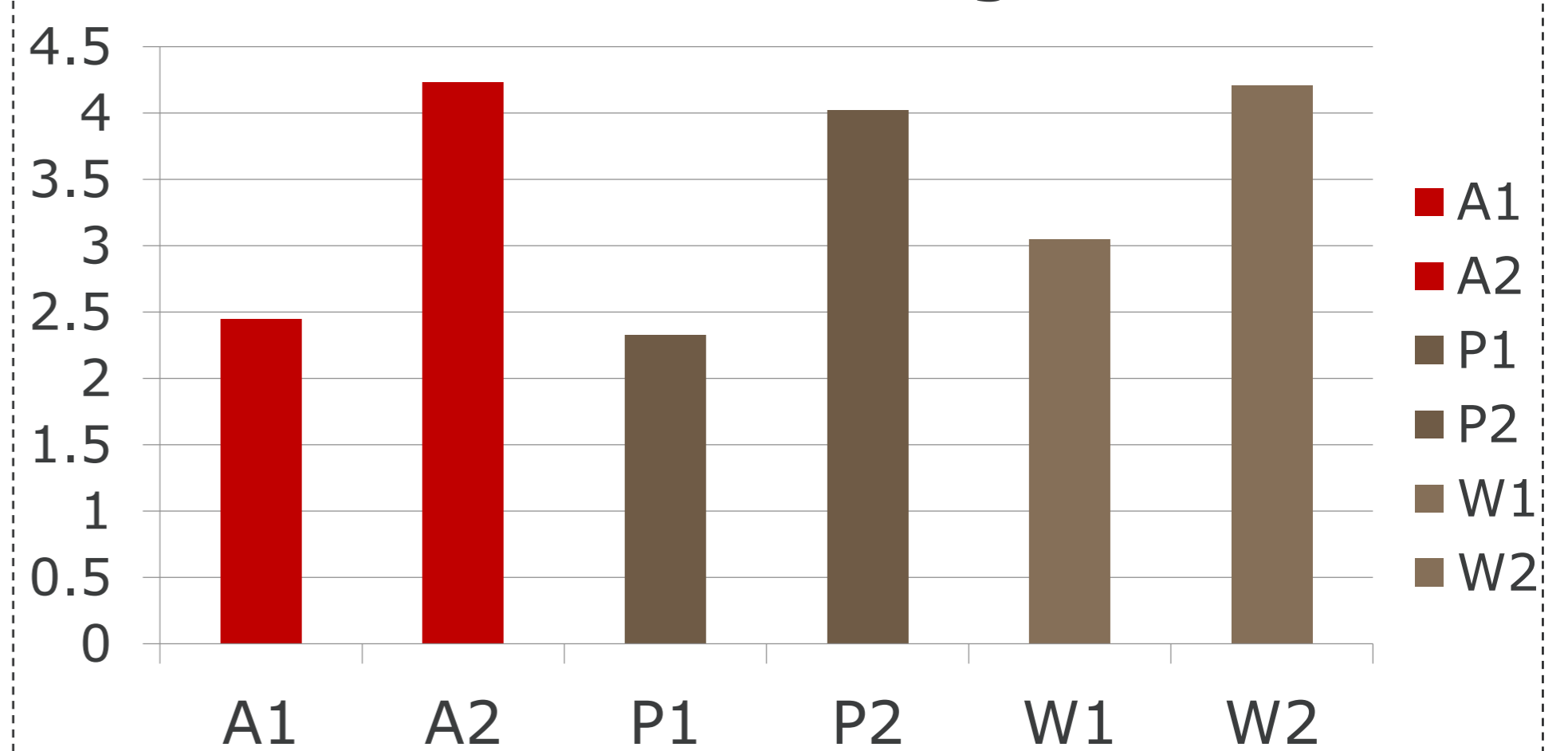
A total of 21 patients with ALS were recruited to participate in the study. Patients that have moderate to severe difficulties in speech/voice production, or on tracheostomy tube, or minimal limb movement and control for writing/typing are included in the study. Patients also need to be able to read and spell in alphabets, have fairly intact eye movements/control, able to sustain attention for more than 15 minutes and with capability of following at least 1 step command consistently. A 5-point scale based on WHO ICF model – Therapy Outcome Measure (TOM), adapted for AAC services (Murphy, Boa, & Enderby, 2015) was used. For this study, only activity, participation and well-being scale will be recorded for easy access. Measures were taken prior to introduction of the eye gaze devices and post-trial or loan of the devices.

## Result

Comparing the value of pre-activity (A1), pre-participation (P1) and pre-well being (W1) scoring with post-activity (A2), post-participation(P2) and post-well being (W2) respectively there is significant improvement of p-value of all < 0.05 significant value. There is significant improvement in patient's ability to communicate with others with 86% of patients having an increase in their activity scores by at least 1 point. 90% of the patients improved, with at least 1 participation score point increase, in their ability in autonomy and control over life and at times fulfilling their social/family role. Lastly, 76% of the patients, improve with at least 1 score point in well-being score, show reduction in frustration in communication.

	A1	A2	P1	P2	W1	W2
Mean	2.45	4.23	2.33	4.02	3.05	4.21
SD	1.25	0.52	1.13	0.68	1.09	0.25
P-Value	9.57 x 10 <sup>-6</sup>		2.93 x 10 <sup>-7</sup>		2.51 x 10 <sup>-5</sup>	
Improvement %	85.7		90.5		76.2	

### Mean Scoring



## Discussion

With the exposure of the eye-gaze communication devices to patients with ALS increase the overall quality of life and independency in the community. In conclusion, this loan system allow the changes in the care model by shifting the care from outpatient setting to the community setting. It has increased the accessibility and affordability of patients to these expensive high technology devices and set the new benchmark of AAC care in Singapore. This new service delivery model increased awareness and receptivity towards this alternative form of communication, increased patient's quality of life during the shortened lifespan and provided hope for a more enabling life despite their physical limitations.