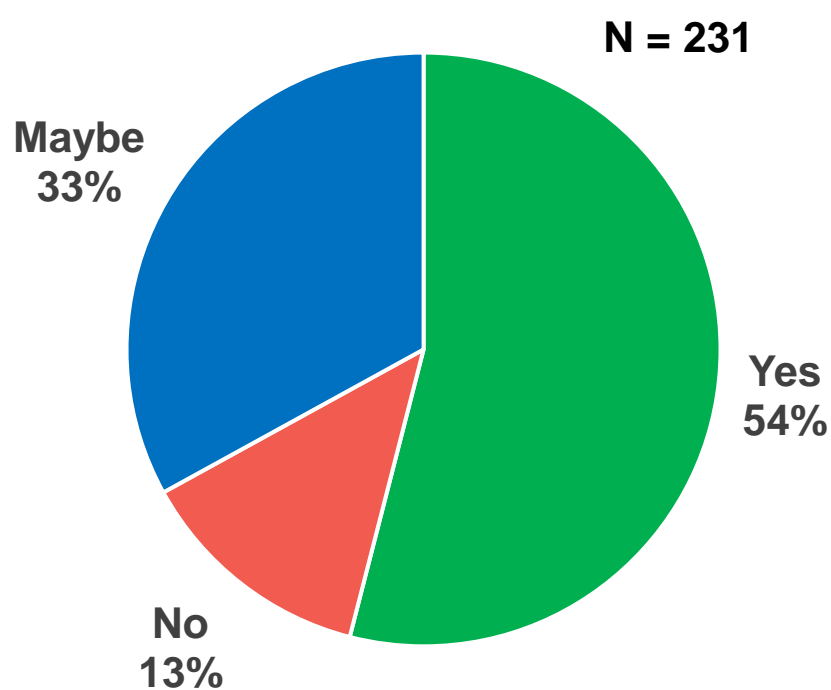


# Persons living with long-term ventilation & tracheostomy want to use a patient portal

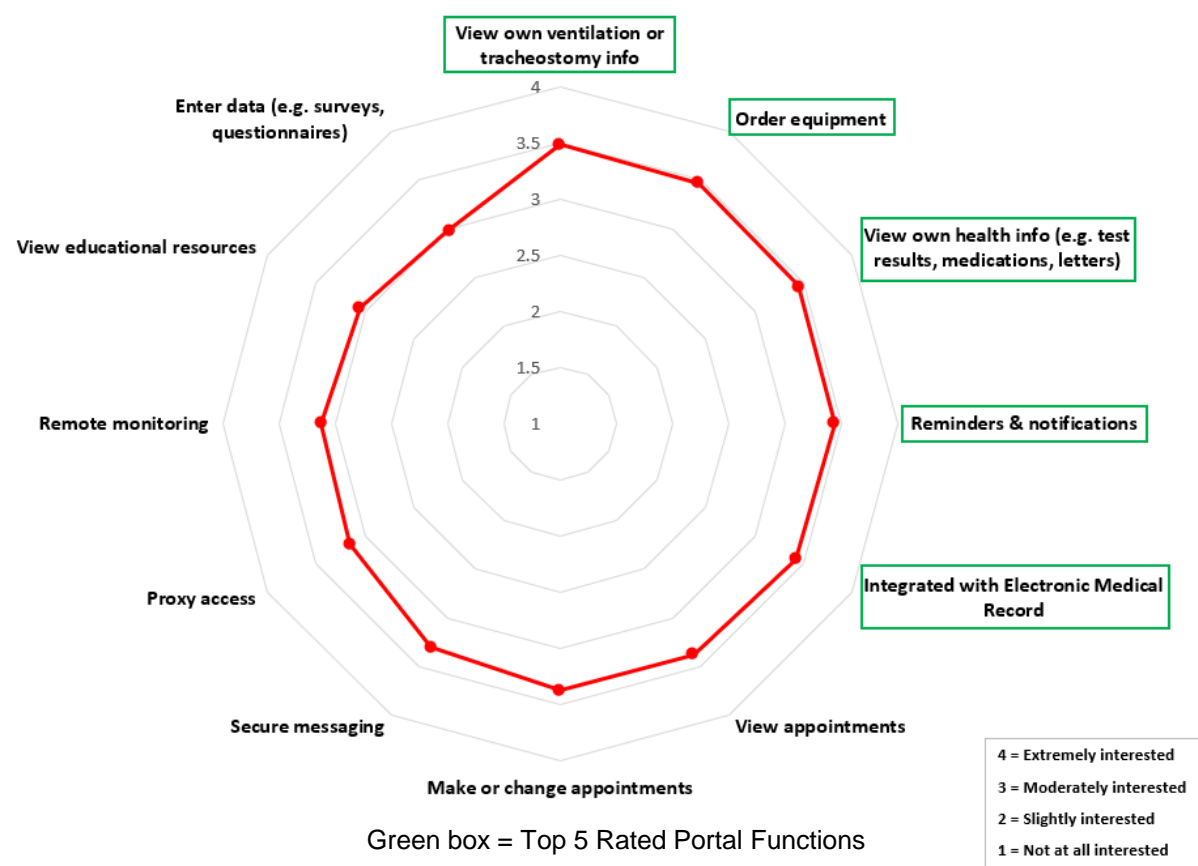
## User-centred design of a patient portal for persons living with home mechanical ventilation and long-term tracheostomy: A mixed methods study

**Background:** Patient portals are secure online platforms that offer patients access to their personal health information. While patient portals are being increasingly offered by health services, there is limited data on their use for persons living with home mechanical ventilation and/or long-term tracheostomy. This study aimed to explore the perspectives and attitudes of patients and their carers regarding the introduction of a patient portal.

**Survey question:**  
Are you interested in using a patient portal to manage your ventilation and/or tracheostomy care?



### Patient Portal Functions: Participant Average Ratings Of Interest



### Methods: Mixed Methods

- Online or postal survey, complemented by semi-structured interviews
- Data was collected from patients and carers of the specialist home mechanical ventilation & tracheostomy services of a tertiary hospital
- Informed consent was obtained and ethical approval received from the Austin Health Human Research Ethics Committee

### Quotes from study participants

Please do this soon, it is vital to improve outcomes for patients  
(Survey, Patient aged 41-60 years)

I live in the bush; sometimes it's hard to talk when you've got a BiPAP mask on. (With a patient portal) I'd feel more confident about my condition.  
(Interview, Patient aged 32)

**Conclusion:** The majority of people living with long-term ventilation and/or tracheostomy were interested in using a patient portal to navigate their health care. Some portal functions rated more highly than others. Key concerns were the inability to use a portal effectively, a perceived reduction in level of hospital services and security of personal data. To facilitate uptake and usage of a patient portal, reasons for hesitancy with using a patient portal also needs to be considered before and during implementation.