

A4932/P143 - User Experience of patientMpower Electronic Health Journal for Pulmonary Fibrosis in Volunteers Recruited Via the PF Warriors Support Group

Authors: C. Edwards¹, B. Vick², E. Costello¹.

¹patientMpower Ltd., The Digital Depot, Thomas St., Dublin D08 TCV4, Ireland, ²PF Warriors, 3325 Landershire Lane, Plano, Tx 75023, US.

RATIONALE

Idiopathic pulmonary fibrosis (IPF) is associated with progressive dyspnea, worsening of pulmonary function [reflected as decline of forced vital capacity (FVC)] and serious limitation of physical activities with major impact on quality of life.

The patientMpower platform (pMp) is an electronic health journal developed for PF patients. It enables them to record medication adherence, activity, objective (e.g. FVC) and subjective (e.g. dyspnea) measurements & health outcomes. pMp is downloaded as an app to the patient's mobile phone/device and connected wirelessly to a spirometer to allow longitudinal collection of patient-measured FVC.

The objective of this study was to assess the users' opinions on the utility and acceptability of pMp (with home spirometry).

METHODS

Prospective, open-label, single-arm, observational survey (42 days).

Entry criteria:

Diagnosis of PF, owns a smartphone/tablet, e-mail address, internet access, written informed consent. No changes to usual healthcare.

Recruitment & onboarding:

Study concept & description communicated to PF Warrior Support Group via social media (including video broadcast). Interested participants gave e-consent. All were supplied with a spirometer (Spirobank Smart; Medical International Research, Italy; www.spirometry.com). Instructions on installation of pMp and Bluetooth pairing with spirometer were emailed (YouTube clips) to participants who independently installed pMp.

Measurements:

FVC (seated; 1/day), dyspnea [modified Medical Research Council (mMRC) score], medication adherence, impact of pulmonary fibrosis on life [13-question Patient Reported Outcome Measure (PROM); 1/week]. Participant's opinions assessed by 17-point questionnaire at the end of the observation. Participants were asked to use pMp daily for ≥42 days.

Disposition of subjects:

Fifty subjects expressed initial interest and 40 gave e-consent. Twenty-four (24; 100%) downloaded pMp and used it ≥once with 23 (96%) recording home spirometry ≥once. 18 (75%) provided a response on utility and acceptability, 22 (92%) recorded PROM and 14 (58%) recorded dyspnea ≥once.

RESULTS

Baseline demographics:

Total subjects (n, %)	27 (100%)
Ethnicity (n, %)	white: 24 (89%) other: 1 (4%) not stated: 2 (7%)
Gender (n, %)	male: 12 (44%) female: 13 (48%) not stated: 2 (7%)
Age (years, mean, range)	62 (range 31-79)
FVC1 (L; mean, range)	2.28 L (range 0.6-4.72) Predicted FVC2 (%; mean, range) 62% (range 36-108)
Time from diagnosis (years, mean, range)	3.2 (range 0.4 to 3.3)
Diagnosis confirmed by clinical expert1 (n, %)	yes: 25 (93%) no: 0 (0%) not stated: 2 (7%)
On antifibrotic therapy (n, %)	yes: 23(85%) no: 0 (0%) not stated: 4 (15%)

1Mean of first seven days patient-reported FVC in 23 subjects. 2Calculated from FVC data in 21 subjects.



Usage metrics:

pMp used for median 24 days (range 1-42). FVC was recorded on median 26 days (range 1-34). PROM was recorded on median of 4 occasions (range 2-6). Some level of dyspnea (i.e. mMRC score ≥1) reported by 12/14 subjects.

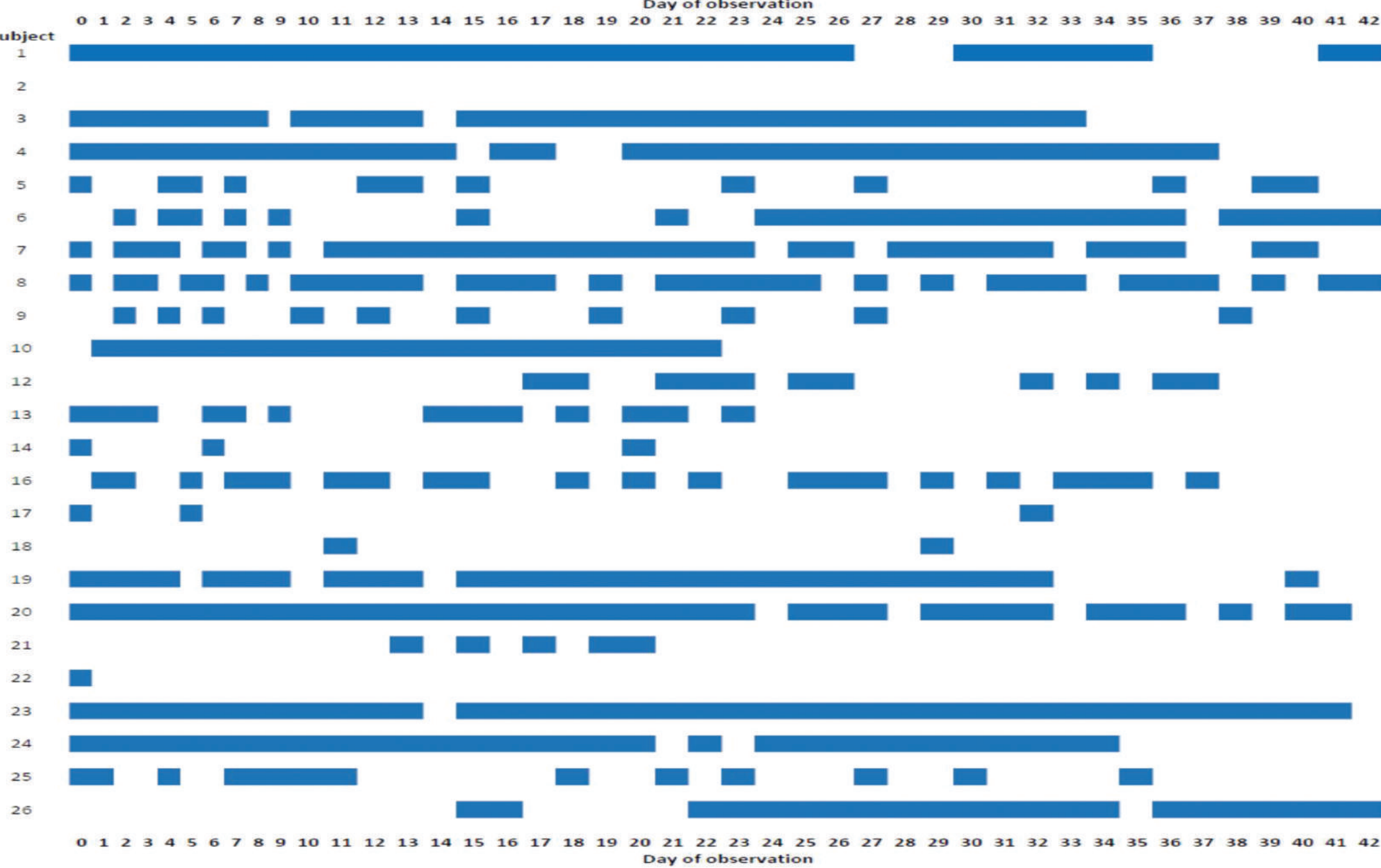
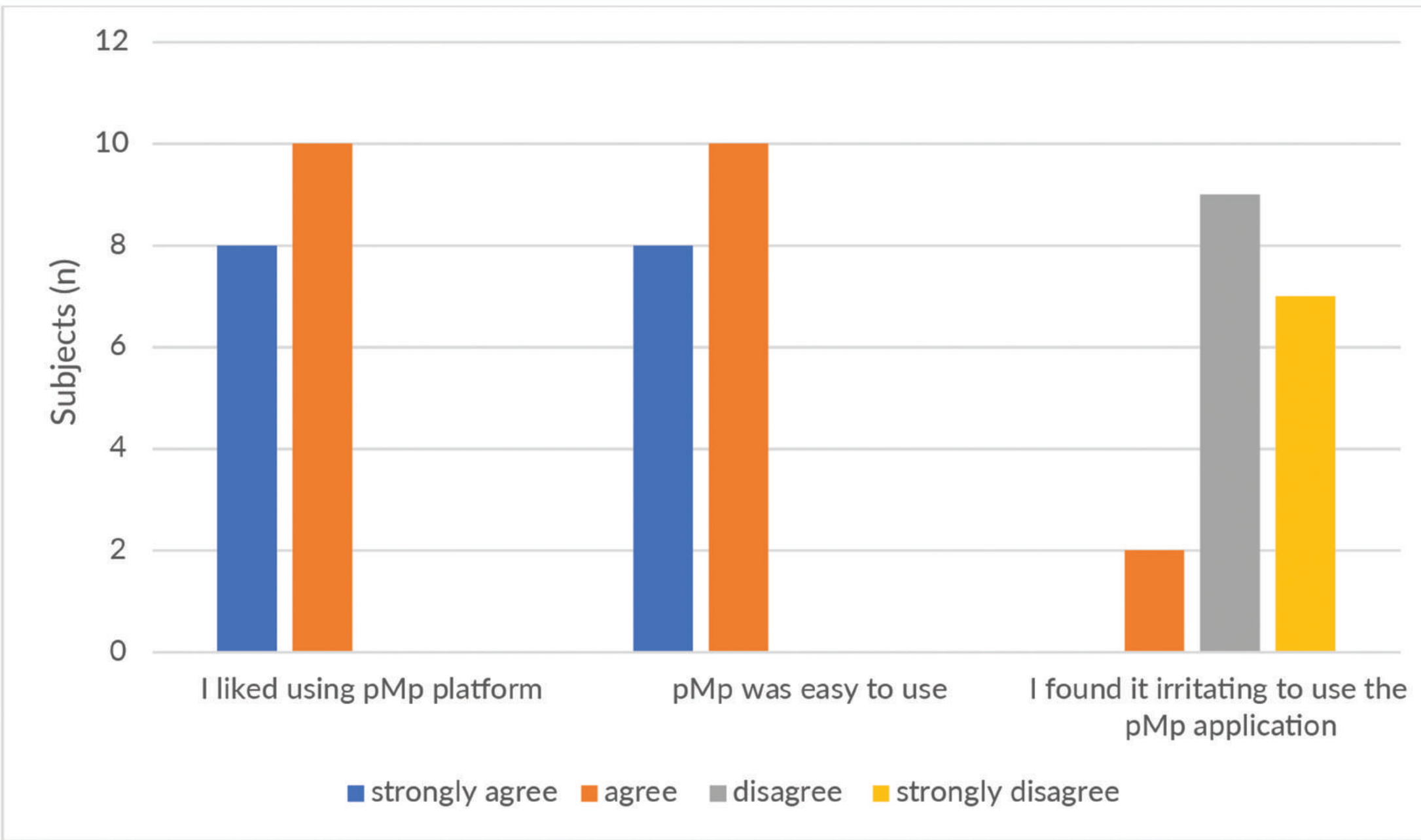
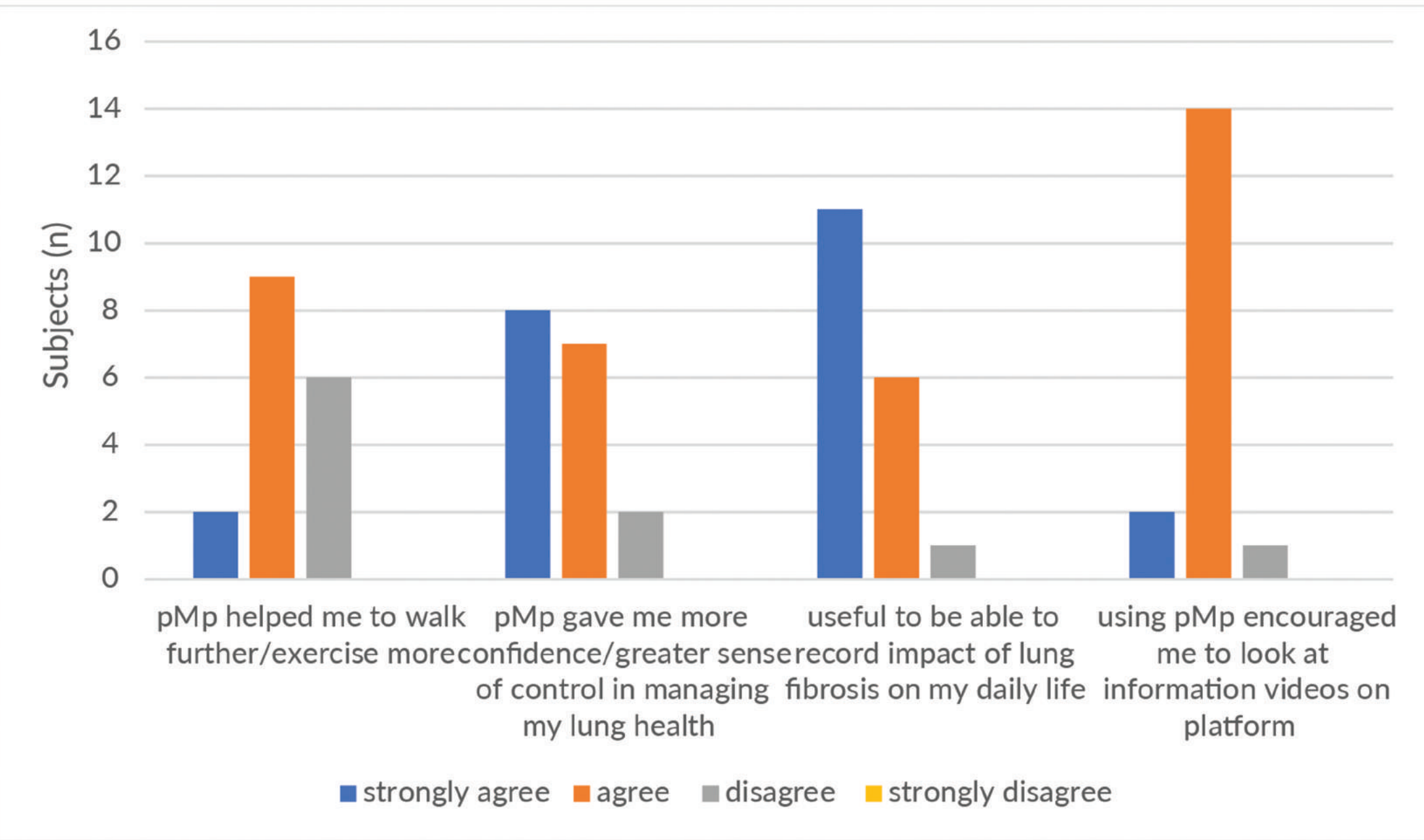
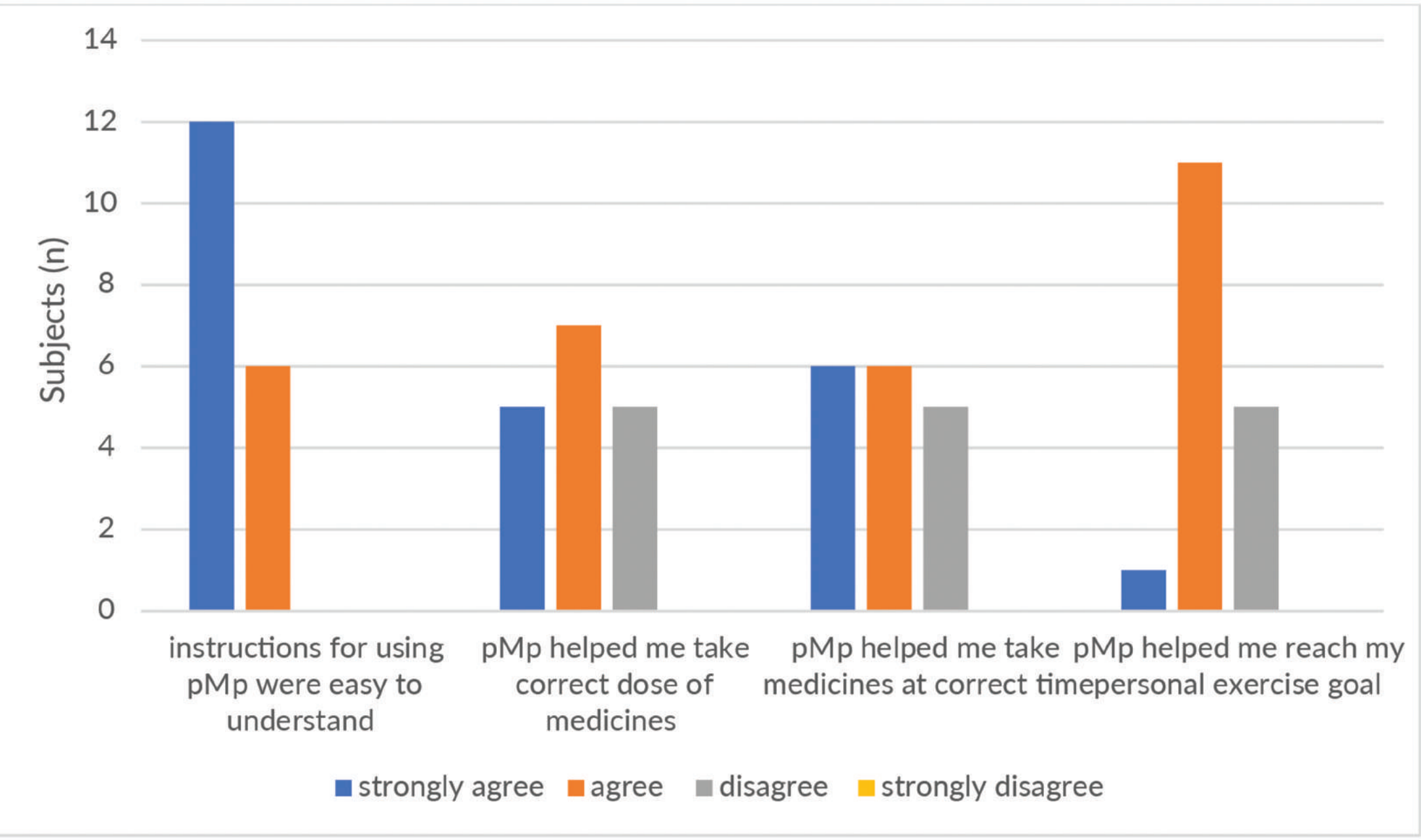
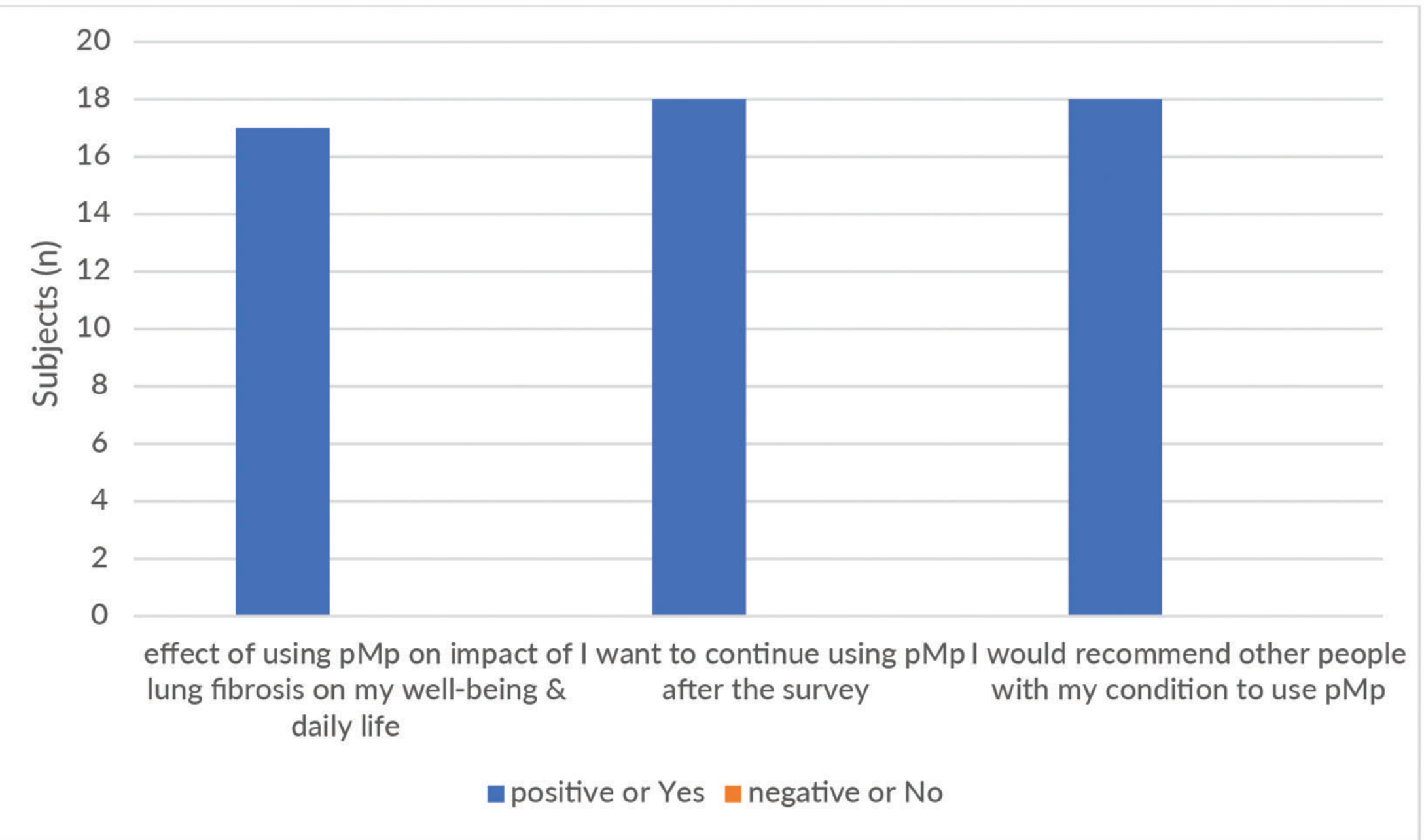
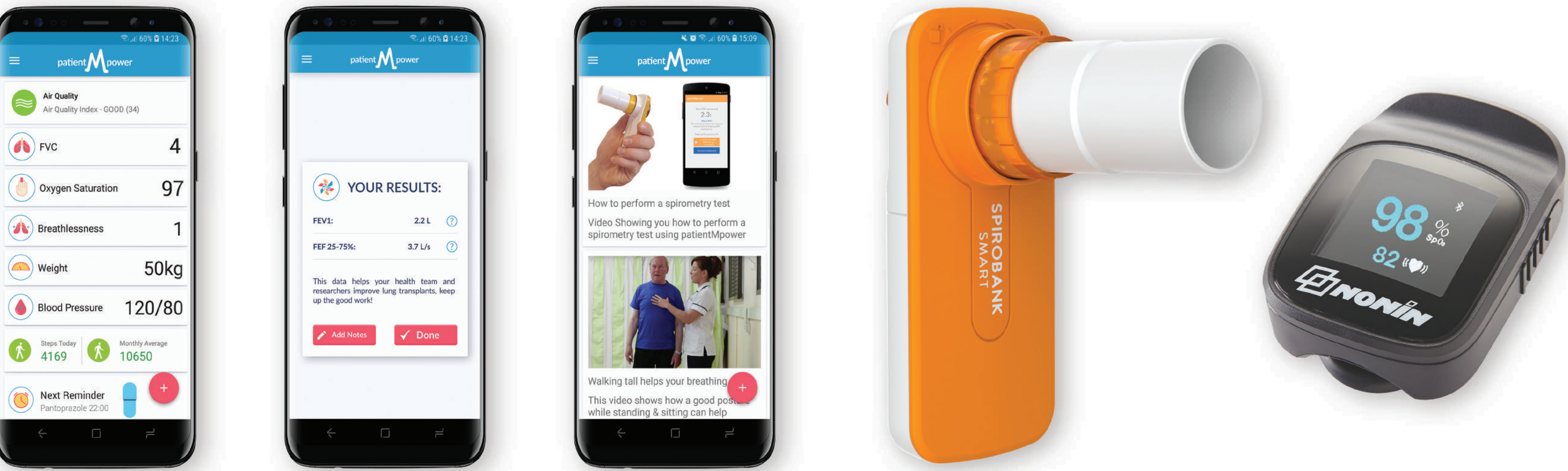


Figure 1: Time pattern of spirometry recording per subject. (Each cell represents a day on which spirometry is recorded).

18 subjects (75%) provided feedback at median 77 days (range 48-96). Respondents' feedback was positive. All found the platform easy to use, liked it, wished to continue using it after the study and would recommend it to other people with PF.



patientMpower Pulmonary Fibrosis Care Kit



CONCLUSIONS

People with PF are willing and able to use an electronic health record to record spirometry, symptoms and outcomes in a real-world setting. Consideration should be given to additional prompts to improve the frequency of recording of certain outcomes (e.g. dyspnea).

Recording regular home spirometry and health outcomes was feasible and acceptable to this group of volunteers recruited through their patient support group via an e-consent process.

Implementation of studies using the patientMpower platform and associated sensors (e.g. spirometers) can be managed remotely and may be helpful for some patients with respiratory conditions. This approach may be useful to recruit subjects remotely to clinical studies and can capture data on long-term trends in patient-reported FVC and other outcomes in patients comfortable with technology.

The results suggest that the patientMpower platform is feasible and acceptable to patients with PF as an electronic health journal to record home spirometry and other relevant outcomes over a period of ≥six weeks in a real-world setting.

We would like to thank all of the PF Warriors who took part in this study.

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