# A7038/P1067 - Real-world usage of a mobile electronic health journal (patientMpower) for pulmonary fibrosis in a US patient support group (PF Warriors) over 12 months.

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# **RATIONALE/AIMS**

Mobile electronic health journals (EHJ) which capture patient-reported health outcomes in real time have potential to be a powerful tool for longitudinal studies of disease progression in chronic respiratory conditions. The patientMpower platform (pMp) is an EHJ developed for patients with chronic respiratory conditions which enables them to regularly record medication adherence, activity, objective [e.g. forced vital capacity (FVC), forced expiratory volume in 1 second (FEV<sub>1</sub>), oximetry] and subjective measurements (e.g. dyspnea) and other health outcomes (e.g. quality of life).

We have evaluated pMp in patients with pulmonary fibrosis (PF) in user experience surveys with patient advocacy groups and in clinical studies. This paper reports on the experience of a patient advocacy group over a 12-month observation period.

# METHODS

pMp was evaluated in an open-label, single-arm, prospective, observational survey (6 weeks) of participants with PF enrolled through invitation by the PF Warriors support group. (Previously reported: Am J Respir Crit Care Med 2018; 197: A4932.) After the initial 6-week observation period, participants were free to use pMp with home spirometry (MIR Spirobank Smart; www.spirometry.com) as often as they wished. There were no prompts to record spirometry. This report describes the participants' use of pMp in a real-world setting over 12 months of observation.

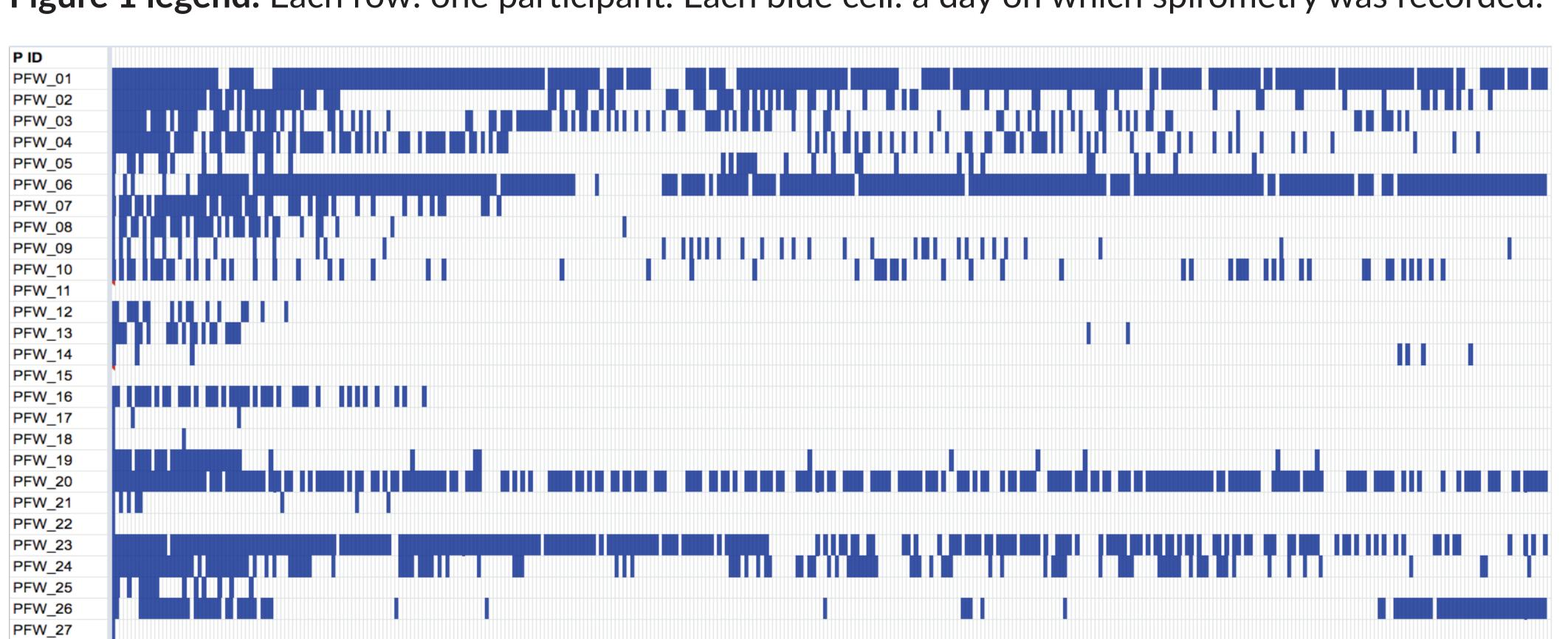


Figure 1 legend: Each row: one participant. Each blue cell: a day on which spirometry was recorded.

## RESULTS

27 people with self-reported PF participated in the initial survey. (Baseline demographic data at baseline are summarised in Table 1.) 24 participants (100%) provided home spirometry data  $\geq$  once. There was wide variation in duration and frequency of recording of home spirometry on pMp over 365 days (see Figure 1).

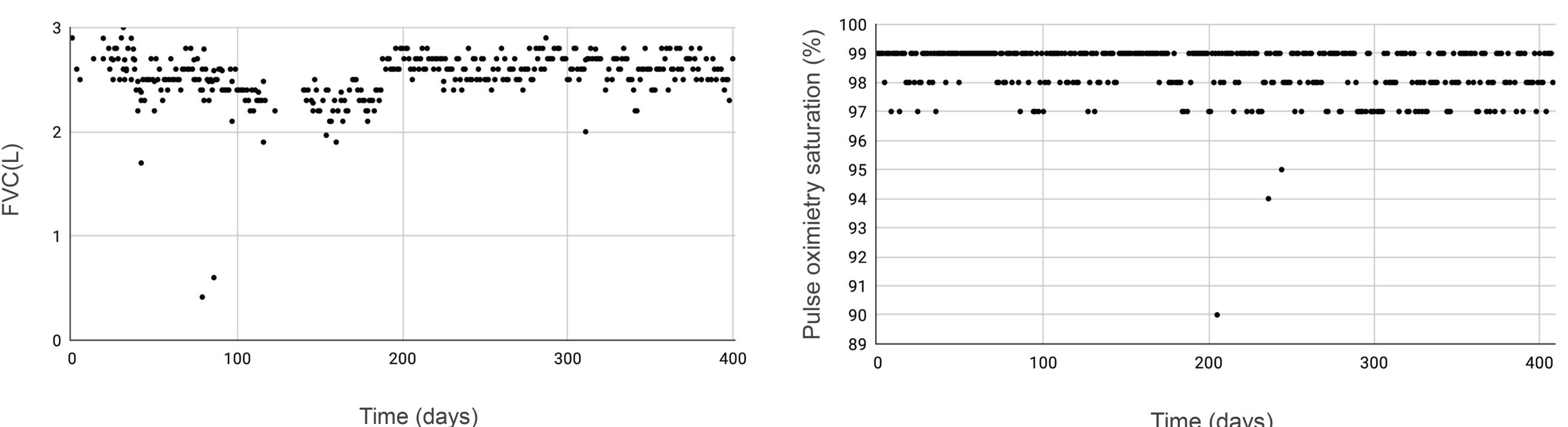
Eight participants (33%) recorded home spirometry on ≥25% of days and 4 (17%) on  $\geq$ 50% of days over a 365-day period. (Six participants recorder spirometry after day 360; see Table 2.)

Fifteen participants (63%) provided dyspnea data [modified] Medical Research Council (mMRC) score]. Most (13/15) reported some degree of dyspnea (mMRC score >0) at baseline. Twenty participants (83%) provided pulse oximetry data (via a Bluetooth-connected Nonin 3230 pulse oximeter; www.nonin.com). The frequencies of reporting dyspnea and pulse oximetry are summarised in Table 3.

Figure 2 shows an example of multiple data recorded by a single participant over ~400 days. This participant's FVC was 65% predicted and they reported nintedanib 150 mg twice daily at baseline. They reported breathlessness (mMRC score 1 or 2), regular use of oxygen (flow-rate 3 or 4 L/min) and described their overall quality of life as "good" throughout the observation period.

There were no reports of exacerbation of PF or death in this survey.

FVC vs. time







## Table1: Baseline demographic data

Total participants (n, %)		27 (100%)
Gender (n, %)	male female not stated	12 (44%) 13 (48%) 2 (7%)
Age (years: mean, range)		62 (31-79)
FVC1 (L: mean, range)		2.28 (0.6-4.72)
FVC1 (% predicted: mean, range)		62% (36-108)
On antifibrotic therapy <sup>1</sup> (n, %)	yes no not stated	23 (85%) 0 (0%) 4 (15%)

Home spirometry data. Ethnicity: white 24. other 1. not stated 2. <sup>1</sup>As reported by study participants.

#### Table 2: Number of participants recording home spirometry ≥once versus duration of observation

<b>Observation duration (d)</b>	Participants (n, %)	
≥ 42	18 (75%)	
≥ 90	15 (63%)	
≥ 180	14 (58%)	
≥ 360	6 (25%)	

#### Table 3: Frequency of reporting dyspnea, pulse oximetry

	Participants (n, %)	Reports (average number per participant; range)	Duration of follow-up (days; range)	Number with ≥ 1 report after day 180
Dyspnea	15 (63%)	28 (1-363)	0-401	6 (25%)
Pulse oximetry	20 (83%)	73 (1-406)	1-409	10 (42%)

## Figure 2 Legend: All participant-recorded values of FVC and pulse oximetry are displayed with no exclusion of outliers.

## Pulse oximetry saturation vs. time



# CONCLUSIONS

Recruiting participants for observational studies via patient support groups is achievable and some participants demonstrate a very high level of engagement.

Electronic informed consent and remote installation of healthcare apps (with associated sensor devices) is feasible for observational studies in PF.

Long-term use of the patientMpower application with integrated devices to record daily FVC, oxygen saturation, symptoms and other health outcomes data is acceptable and feasible for PF patients. These patients appear willing to record home spirometry regularly without prompting which suggests they are interested in monitoring their lung function at home.

Some patients are willing to continue to record home spirometry and other outcomes on a long-term basis even if not involved in a formal trial or survey. It is anticipated that use of prompts would result in more sustained and frequent collection of data.

Collaboration with patient advocacy groups in the design and implementation of studies is important in delivering relevant outcomes data.

Our observations suggest that the patientMpower mobile device-based application linked to appropriate sensor devices can reliably capture multiple long-term patient-reported objective and subjective outcomes within a single platform for real-world studies in pulmonary fibrosis.

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