Rationale/Aims
Mobile electronic health journals (EHJ) which capture patient-reported 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) as 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 (FEV1), oximetry) and subjective measures (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 in clinical studies. This paper reports on the experience of a patient advocacy group over a 12-month observation period.

Results
27 people with self-reported PF participated in the initial survey. Baseline demographic data at baseline are summarised in Table 1. Twenty-four participants (100%) provided home spirometry data ≥ 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 ≥ once per day and 4 (17%) on ≥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. Fifteen participants (63%) 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. 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.

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

Discussion
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 health care apps (with associated sensor devices) is feasible for observational studies in PF.

Conclusions
Long-term use of the patientMpower application with integrated devices to record daily FVC, oxygen saturation, symptoms and other health outcomes 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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