



# Sustainability of use of an electronic health journal (patientMpower) for pulmonary fibrosis in a US patient support group (PF Warriors) over 180 days.

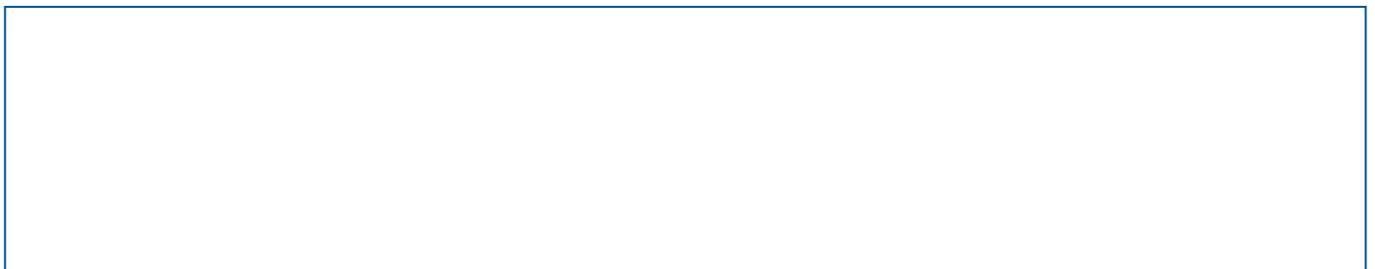
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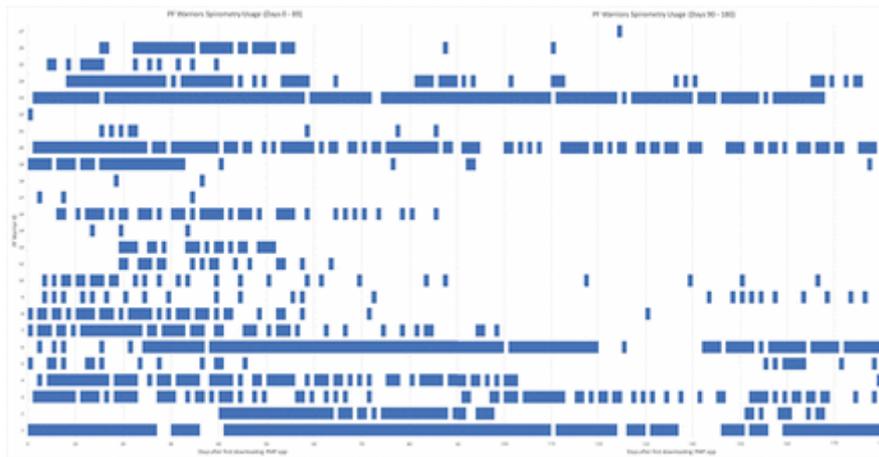
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## Abstract

The patientMpower platform (pMp) is an electronic health journal (EHJ) for pulmonary fibrosis (PF) to enable patients to record medication adherence, activity, forced vital capacity (FVC), dyspnoea & health outcomes. pMp was evaluated in an open-label, single-arm, prospective, observational survey (6 wks) of 27 patients enrolled through a support group (PF Warriors). Patients were asked to use pMp with daily seated home spirometry (Spirobank Smart) for  $\geq 6$  wks and then give feedback on acceptability. They could continue to use pMp after the survey. 27(100%) people [13 f/12 m; median 65Y; mean FVC 61% predicted] used pMp. Spirometry was recorded during the 6-wk survey by 23(85%). 18(67%) provided feedback questionnaires at  $\sim 6$ -wks (reported elsewhere). There was wide variation in duration & frequency of use of pMp + spirometry over 180d follow-up. 18 (78%) people recorded spirometry  $\geq$ once after  $\sim 6$ wks, 16 (69%)  $\geq$ once after 90d and 5 (22%) at 180d. 7 (30%) recorded spirometry regularly during 180d follow-up. Recruiting patient-volunteers to observational studies through support groups is feasible in PF. Using an EHJ + integrated home spirometry to record daily FVC and other data may be a useful approach to capture patient-reported long-term trends in health outcomes in patients with PF. Patients may continue to use an EHJ even if not in a formal trial or survey.





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## Footnotes

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