

Implementation of an e-health self-management tool for Idiopathic Pulmonary Fibrosis: a pilot study

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Rationale and aim

Idiopathic Pulmonary Fibrosis is a progressive deadly disease in mostly an elderly population. E-health tools could improve understanding of disease, promote patient participation in care, and capture longitudinal data for clinical and research purposes. This can lead to better and personalised care.

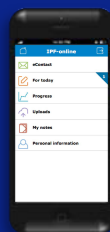
We evaluated the feasibility of a web-based patient self-management tool called IPF-online and assessed patient satisfaction with the tool.

Methods

We first questioned patients, at the yearly IPF meeting in our centre, if they were interested in having an e-tool.

IPF online (www.ipfonline.nl) provides:

- A secured personal platform with information about IPF, available on smartphone and computer
- Personal information about lung function test results, symptom scores, quality of life questionnaires and an e-consult option



Data ownership

- Patients remain owner of their data
- Digital informed consent for specified clinical or research use can be given

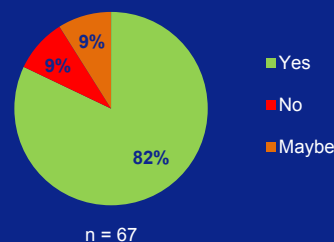
Patients were asked to complete health status questionnaires and report symptoms and medication at baseline and at 14 days. Afterwards we asked patients to fill in an evaluation form. The tool remained at their disposal if they wished to continue. Ethical Committee approval was granted.



Results

Patients interested in the tool

I would like to see and keep up with my own data online ...



Patients participation

- Eighteen patients were asked to participate
- 17 filled in the tool at baseline, 15 at 14 days
- Twelve spontaneously continued use after the pilot

Use of IPF online

Information platform

Used	205 times
Requested info found	79%

E-consult

Used	34 times
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Preference on presentation of data

Data presented as	Patients (n=17)
Table	56%
Graphic	6%
Both	18%
No preference	12%
Unknown	6%

Patients experience and satisfaction

IPF online	Patients (n=17)
Easy to use	82%
Useful	88%
Would recommend it to others	88%
Wished to continue	94%

Patients suggestions

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Quotes

"Clear questions and useful interaction with health carers"

"I like having my own follow-up data"

"Useful, because I won't receive all kind of separate forms"

"I am immediately updated"

Conclusion

- IPF online is a feasible web-based patient self-management tool with high user satisfaction
- IPF online could facilitate a more active role of patients in care and research

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