Supporting Coproduction of Healthcare Services in Cystic Fibrosis:
A Formative Evaluation of a Same-Page Care Dashboard

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Background
Healthcare coproduction engages patients and healthcare professionals (HCP) to design and execute services, yet little is known about tools that facilitate coproduction. Patients, families, and HCPs co-designed a shared dashboard to:
- Summarize overall health and healthcare history, and
- Test new and more profound communication between patients and HCPs.

The dashboard:
- Received patient-reported outcome (PRO) data
- Graphed PRO & Cystic Fibrosis (CF) Foundation Patient Registry data
- Migrated PRO data to the Registry on a nightly basis

Project objective: To understand uptake, experiences, and perceived benefits and limitations of the dashboard among the CF community.

Methods
Co-design team: 7 adults with CF, 4 parents of children with CF, 7 physicians, 5 nurses, 3 researchers, and 1 registry coordinator

Implementation: 8 CF care programs (4 adult, 4 pediatric), 21 multi-disciplinary HCPs, and 131 patients

Data and analyses: Descriptive statistics and thematic analyses
- Surveys
- 82 patients
- 21 HCPs
- Semi-structured interviews
- 13 patients
- 8 multi-disciplinary care teams
- Passively-collected usage data

Demographics: Patients enrolled were similar to the larger population seen at each CF care program.
- Age: 26 years
- Gender: 55% female
- Genetic characteristics: 52% F508del-CFTR x 2
- Marital status: 34% married or living together
- Education: 27% college graduate

Dashboard Screenshots

Uptake & Experience
CF care programs (n=8):
- All CF Foundation accredited
- 7 academic medical centers, 1 private practice
- 2-4 HCPs per program evaluated the dashboard

Patients (n=82):
- 66% used dashboard during a visit
- 59% used dashboard outside of a visit

HCPs (n=21):
- 76% used dashboard for visit planning
- 48% used dashboard during routine CF clinic visits
- 24% used dashboard during clinic encounter to assess exacerbations, severe GI issues, or other complications

“"It has changed the character of the interactions without it taking more time. From my perspective, it’s efficient, because we’re focused. We’re focused on what they’re concerned about, and then we can focus on what we’re concerned about. That hasn’t taken us more time.” - HCP

Perceived Benefits & Limitations

Impact of Dashboard on Communication between Patients & HCPs

Noteworthy: Patients and families viewed the dashboard more favorably than HCPs.

Four Primary Themes Identified
- Expanded registry access allows users to learn more deeply
- Participation in visit planning matters
- Coproduction is made possible by inviting new ways to partner
- Embedding data streams within existing IT tools is critical

We have demonstrated the feasibility of a co-production dashboard to capture, display, and exchange PRO and clinical registry data.

Conclusions
While patients and families found the dashboard useful, the lack of integration with the electronic medical record (EMR) was a salient barrier reported by HCPs.

Future iterations should provide patients access to their data, be simple to use, and integrate with IT systems in use by HCPs and patients.

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