**Introduction**

- The Cystic Fibrosis Reproductive & Sexual Health Collaborative (CFReSHC) is a patient-driven, national online collaborative committed to improving sexual and reproductive health (SRH) of women with CF.
- After addressing priority areas for CF SRH research in Tier I PCORI funding, we sought to solidify the structure of CFReSHC in alignment with its mission.

**Objective**

To evaluate the engagement influence and process in building a sustainable CF SRH research partnership between women with CF, researchers, and advocates.

**Methods**

- **Governance Board (GB)**
  - Group Norms Subcommittee (n=3)
  - Communication Subcommittee (n=2)
  - 4 patient partners
  - 3 clinician researchers
  - 1 nurse

- **CF Patient Task Force (PTF)**
  - (n=66)
  - Monthly online World Café sessions + private and public social media groups + monthly newsletter

- **Research Advisory Panel (RAP)**
  - (n=8)
  - Monthly conference calls based on PTF sessions + email interactions + shared electronic documents

**Meeting topics:** Pregnancy and parenthood, female hormones and CF, body image, and urinary incontinence

**Deliverables:** 3 grant applications, 2 letters of intent, and a national online patient mini-conference around SRH in CF

**Results**

<table>
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<th>Table 1: Evaluation of engagement process</th>
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<td><strong>Process</strong></td>
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**Modifications made:**

1. CFReSHC instituted mechanisms for providing feedback and procedures for discussing research
2. GB communication was transitioned to a cloud-based platform and efforts outlined to improve PTF and RAP communication

**Conclusions**

- This project demonstrates virtual engagement for building a sustainable national patient-provider-researcher partnership.
- CFReSHC has continued to advance inquiries into female SRH in line with relevant patient-centered outcomes in the provision of comprehensive CF care.

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