

GUIDELINE TITLE: Remote Monitoring / Hybrid Cystic Fibrosis Clinic using Attend Anywhere	Document No: Version No:
Document Type: Clinical Guideline	
Owner: Grainne Bauer Title: Chief Director of Nursing	Policy Author: Geraldine Connell Title: Clinical Nurse Specialist CF
Date of Approval: September 2026	Review Date: September 2029

1.0 GUIDELINE STATEMENT

- Ensure comprehensive and structured guidance in the management of children and young people with Cystic Fibrosis (CF) using remote consultations.
- This guideline underpins the **National Clinical Programme for Cystic Fibrosis (NCPCF 2019)** and the already established **Model of Care for CF in Ireland (2019)**.
- Promotes HSE Telehealth Roadmap vision and ambitions of Sláintecare by increasing adoption of telehealth platforms (**HSE 2023**).
- Compliant with HSE approved remote telehealth guidelines and GDPR privacy requirements.

2.0 PURPOSE

- To provide a structured approach for the multidisciplinary team in managing, assessing and monitoring children greater than 2 years of age diagnosed with CF using remote-hybrid model.
- Remote clinics will be integrated with existing CF OPD appointments.
- Remote clinics will use HSE approved platform Attend Anywhere along with MPower home monitoring equipment (if possible).

3.0 SCOPE

This guideline applies to:

- CYP with Cystic Fibrosis who attend CF Centre @CHI.
- Clinicians, Clinical Nurses Specialist, HSCPS's, Clerical staff within the CF Department.

4.0 DEFINITIONS / ABBREVIATIONS:

CF: Cystic Fibrosis

MDT: Multidisciplinary Team

CFTR: Cystic Fibrosis Transmembrane Conductance Regulator

NCPCF: National Clinical Programme for Cystic Fibrosis

HRCT: High Resolution CT

IPC: Infection Prevention Control

KPI: Key Performance Indicators

5.0 ROLES and RESPONSIBILITIES

It is the responsibility of:

- **All staff** involved in the care of CYP within the CF service.
- **Heads of Department** to ensure staff in the area are aware of, have read and understand, and attend any required training, in relation to this guideline.
- **Guideline Owner** to ensure the guideline is communicated and disseminated to appropriate staff.

6.0 OBJECTIVES

- CYP with (CF) have equal access to high quality care from a Multidisciplinary Team (MDT) of specialists ensuring comprehensive and evidenced based practice.
- MDT Care will be accessed remotely in line with International Guidelines (**ECFS 2018**).
- Virtual clinics should not replace all face-to-face clinics (**JofCF 2024**) but would instead compliment meeting with CF Team (**NCPCF 2019**).

7.0 EXPECTED OUTCOMES

- Children will have improved outcomes due to flexibility of clinics – hybrid clinics – easier attendance ensuring the holistic needs of the child and family will be met.
- Reduced travel time and are cost effective for families (**JofCF 2024**).

- Use of home monitoring – spirometry, weight, oxygen saturation using HSE approved equipment e.g. M-Power
- Promotes patient satisfaction by decreasing disruption to home life
- Reduced risk of cross-infection (**JofCF 2024**)

8.0 GUIDELINE STEPS

8.1 Inclusion criteria

- Greater than 2 years of age.
- Patient choice.
- On CFTR Modulators > 1 year.
- Access to smartphone, tablet or computer with camera/internet.
- Stable CF/Consultant decision.
- Routine clinic appointment.

8.2 EXCLUSION CRITERIA

- Less than 2years.
- Not on CFTR modulators.
- First year of CFTR Modulator therapy.
- Patient choice.
- Consultant decision/unstable CF.
- Not used for an Annual Assessment appointment.
- No access to smartphone, tablet or computer with camera/internet.

8.3 Virtual Clinic Considerations:

- Appointments are scheduled by the Department Secretary, with the Attend Anywhere link sent, along with instructions on how to use, to the parent/guardian.
- Remote Clinics will include full MDT input using the existing CF Routine clinic sheet/EVOLVE as a template.

- Remote Monitoring will adhere to guidance in Appendix 17.1 in conducting effective video consultations.
- Home spirometry, weight and oxygen monitoring are sent prior to appointment, to the CF Department, using the platform M-Power via e-mail.
- Relevant laboratory results (sputum cultures, blood analysis etc.) will be available in advance where possible.
- MDT members document their input on the clinic sheet/EVOLVE (Appendix 17.2)
- 30 minute timeslot allocated to each patient.
- Summary of visit sent to local GP following the consultation (Appendix 17.2)
- Prescriptions sent electronically via Healthmail and PCRS HUB as requested.
- Follow up appointment made – in-person or remotely.
- Follow up tests are booked e.g. Imaging, OGTT if they are required.
- If clinical concerns arise during consultation, an in-person appointment will be arranged.
- Initiation of new therapies should be monitored directly at clinic (**JofCF 2024**).

8.4 CONTINGENCY PLANNING

- In the incidence that the video consultation drops, the consult will revert to phone call.
- Support of ICT required in order to maintain service.

9.0 COMMUNICATION AND TRAINING:

- **Communication:** This guideline will be posted on Q-Pulse.
- **Training:** will be provided ensuring that staff are trained in the principles of remote monitoring (JofCF 2024).

10.0 COMPLIANCE MONITORING

- This guideline will be updated within a 3 year period or sooner if there is evidence to change practice
- Annual audit of Virtual Clinics – patient satisfaction questionnaires and patient attendance

- Develop KPI's in relation to remote-hybrid clinic's as envisioned by HSE Telehealth Roadmap 2023.

11.0 APPROVAL

Proposed: Geraldine Connell Clinical Nurse Specialist Cystic Fibrosis	February 2026
Concurred: CHI Nurse Practice Committee	February 2026
Approved: CHI Nursing Documentation Approval Committee	March 2026

12.0 VERSION CONTROL HISTORY:

Date: dd/mm/yyyy	Revision Number	Summary of changes/ Reason for change	Section ref:	Author:
January 2026	New			As above

13.0 REFERENCES:

- ECFS 2018. Castellani, C., Duff, A.J., Bell, S.C., Heijerman, H.G., Munck, A., Ratjen, F., Sermet-Gaudelus, I., Southern, K.W., Barben, J., Flume, P.A. and Hodková, P., 2018. ECFS best practice guidelines: the 2018 revision. Journal of cystic fibrosis, 17(2), pp.153-178.
- HSE 2023 :HSE Telehealth Roadmap 2024 – 2027. Building Blocks for the Embedding and Expansion of Telehealth.
[https://assets.hse.ie/media/documents/HSE Telehealth Roadmap full report.pdf](https://assets.hse.ie/media/documents/HSE_Telehealth_Roadmap_full_report.pdf)
- <https://healthservice.hse.ie/staff/procedures-guidelines/digital-health/attend-anywhere/>

- National Clinical Programme for Cystic Fibrosis (NCPCF 2019)
<https://www.hse.ie/eng/about/who/cspd/ncps/cystic-fibrosis/resources/ncpcf-model-of-care-final-september-2019.pdf>
- Southern, K.W., Addy, C., Bell, S.C., Bevan, A., Borawska, U., Brown, C., Burgel, P.R., Button, B., Castellani, C., Chansard, A. and Chilvers, M.A., 2024. Standards for the care of people with cystic fibrosis; establishing and maintaining health. *Journal of Cystic Fibrosis*, 23(1), pp.12-28. Jan 2024

14.0 APPENDICES:

Appendix I: Guideline Development Group/Key Stakeholders

Appendix II: Reference as above –JofCF 2024

Appendix I: Guideline Development Group/Stakeholders

Development Group/ Key Stakeholders

1. Ms. Geraldine Connell, Respiratory CF Clinical Nurse Specialist
2. Dr Lucy Perem, Respiratory Consultant
3. CHI Nurse Practice Committee

Appendix II: JofCF 2024

Environment (for the CF team and the person with CF) • Reduce background noise • Reduce disturbances/interruptions • Ensure comfortable positioning • Ensure privacy – from public and from family/pets if needed • Opportunity to assess home environment – consider safeguarding issues • Dress appropriately and avoid distractions in the background
Technical issues • Ensure effective audio-visual hardware • Appropriate internet connection with suitable speed • Clarify with the person with CF if the sound and visuals functional/acceptable • Have a backup communication option planned in case connection fails • If issues arise ensure troubleshooting carried out before terminating consultation
Communication • Consider whether consultations conducted 1:1 or with person with CF and several CF members – adjust communication style accordingly if group consultation • Consider consent issues if the person with CF is paediatric or vulnerable • Utilise different skill set to face to face assessment which may require upskilling of CF • Effective history taking critical • Reduced reliance on clinical signs • Alter body language assessment to account for limited perspective • Adapt questions as needed considering environment of the person with CF • Consider if others may be present/listening out of sight • Consider comfort of the person with CF in using this format • Maintain eye contact and visual cues – as even more important when only face/upper torso is visible • If looking away from the camera at another screen or paper results, explain what you are doing (and that you are still listening)
Effective use and integration of home monitoring • If remote monitoring in use ensure this is considered as part of consultation • If additional monitoring needed after consultation, ensure results are obtained and a clear plan of action agreed with the person with CF before consultation ended
Outcomes • Clarify wishes of the person with CF regarding future virtual consultations • Ensure outcome clear to the person with CF and the CF team • Consider whether next review is face to face vs virtual

14.1 CYSTIC FIBROSIS (CF) CLINICAL ASSESSMENT

Height _____ cms Weight _____ Kgs BMI _____ SaO2 _____ % FEV1 _____ %p

Centile _____ Centile _____ Z Score _____

1. **Cough:** ☐ Daily ☐ Morning only ☐ Throat clearing ☐ With Physio ☐ With RTIs

2. Does the patient have **wheezing/difficulty breathing** ☐ Often ☐ Sometimes ☐ Never

Comments on cough and respiratory symptoms:

3. Oral Antibiotics since last clinic: Number of courses

≠ 1. Antibiotic name: Duration: Sympts resolved ☐ Yes ☐ No

≠ 2. Antibiotic name: Duration: Sympts resolved ☐ Yes ☐ No

≠ 3. Antibiotic name: Duration: Sympts resolved ☐ Yes ☐ No

≠ 4. Antibiotic name: Duration: Sympts resolved ☐ Yes ☐ No

Comments.....

4. Admissions: Admission 1 ☐ Respiratory Infection ☐ Other..... Duration (Days):.....

Admission 2 ☐ Respiratory Infection ☐ Other..... Duration (Days):.....

Comments (Include IVs/Home IVs

.....

.....

5. Drop ins: Month: ☐ Respiratory Infection ☐ Other.....

Month: ☐ Respiratory Infection ☐ Other.....

Comments.....

6. Did the patient have Gastro Oesophageal Reflux (GOR) symptoms since last OPD ☐ Yes ☐ No

☐ Vomiting: times per day..... ☐ Wet Burps/Swallows/Heartburn..... ☐ Vomit with coughing

7. Did the patient have constipation/DIOS symptoms since last OPD ☐ Yes ☐ No

8. ☐ Crampy abdominal pain ☐ Need for laxatives ☐ Decreased stool frequency. Average number of stools per day since last OPD..... Consistency.....Other GI symptoms.....

.....

9. Headache ☐ Yes ☐ No 10. Snoring ☐ Yes ☐ No 11. Nasal Congestion ☐ Yes ☐ No 12. Facial pain ☐ Yes

☐ No 13. Last BAL/Bronchoscopy.....14. Last HRCT..... 15. Last OGTT..... 16. Last Dexa.....

17. Medications

A..... B..... C.....
D.....E.....F.....
G..... H..... I.....
J..... K..... L.....

18. Examination: General ☐ N ☐ Abn Chest ☐ N ☐ Abn Nose ☐ N ☐ Abn
Abdomen ☐ N ☐ Abn Crackles ☐ Yes ☐ No Coryzal Symptoms ☐ Yes ☐ No
Coughing on the day ☐ Yes ☐ No Current Respiratory Infection ☐ Yes ☐ No

Relevant findings:.....
.....
.....

Abnormal Lab results In last year ☐ *S.aureus* ☐ *S. pneumoniae* ☐ *M.catarrhalis* ☐
H.influenza ☐ *S.maltophillicia* ☐ *Candida* ☐ *Aspergillus* ☐ *P.aeruginosa* ☐ *Other*

Comments

Last Sputum culture.....

19. Impression.....
.....

20. Treatment changes:.....
.....

☐ Prescription for medications and antibiotic backup

☐ Vaccinations discussed

Signature:

NMBI PIN/IMC:

Date :

Created by: Geraldine Connell, Clinical Nurse Specialist, CF services CHI, Issue Date: October 2026, Review Date: 2029, Owner: Grainne Bauer, Chief Director of nursing, CHI, Approver: Caitriona Dennehy, NPDC on behalf of NDAC