CYSTIC FIBROSIS REGISTRY OF IRELAND

2022 Data Highlights

CFRI particpants

1342 participants in CFRI in 2022

Registered, alive & not lost to follow-up.

+46 registry participants

824 adults

518 children <18

Male 57.3%

Female 42.7%

97.86% of individuals had data from a clinic visit recorded in 2022

Age distribution

15.1% of the CFRI population is over 40

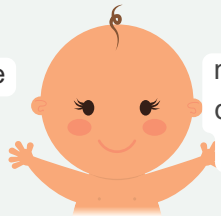
Median predicted age of survival*

45.7 2013-2017

50.8 2018-2022

*The median predicted survival age predicts how long we can expect half of people with CF born today to live

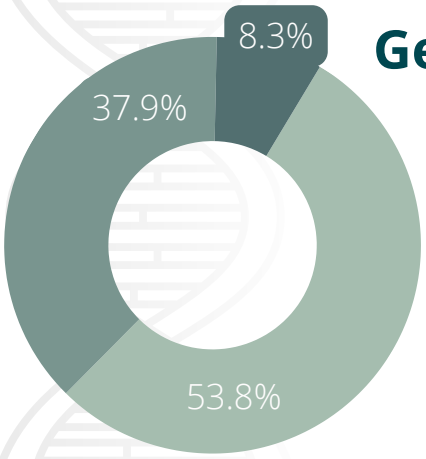
15 pregnancies were recorded in the CFRI



21 new-borns diagnosed with CF*

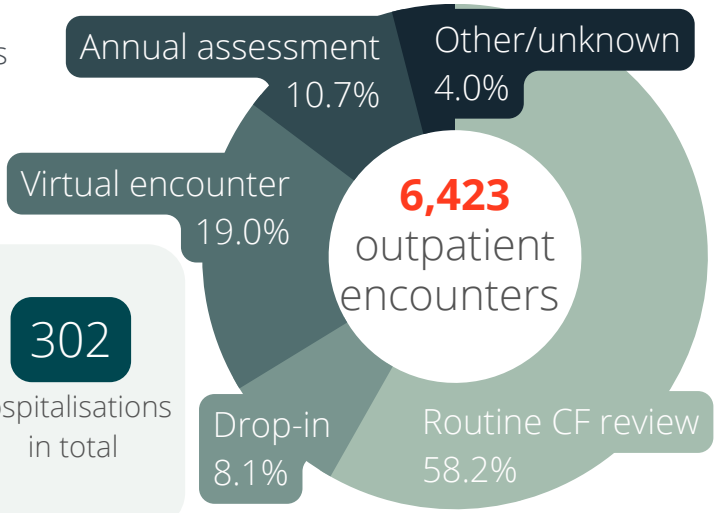
*Via the National Newborn Bloodspot Screening Programme

Genotype



- F508del/F508del
- Heterozygous F508del
- Not F508del

Outpatient visits

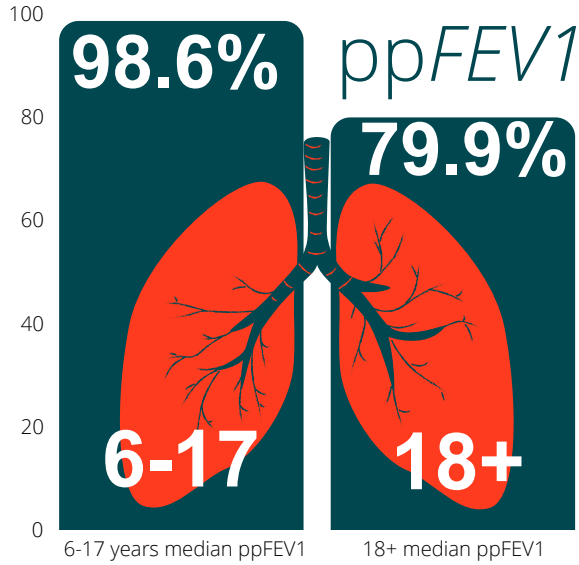


Hospitalisations

16% individuals required hospitalisation (n=217)

54% hospitalisations for a pulmonary exacerbation

302 hospitalisations in total



Microbiology

	<18	18+
Chronic *Pseudomonas aeruginosa*	1.2%	11.0%
Chronic *Staphylococcus aureus*	20.1%	8.8%

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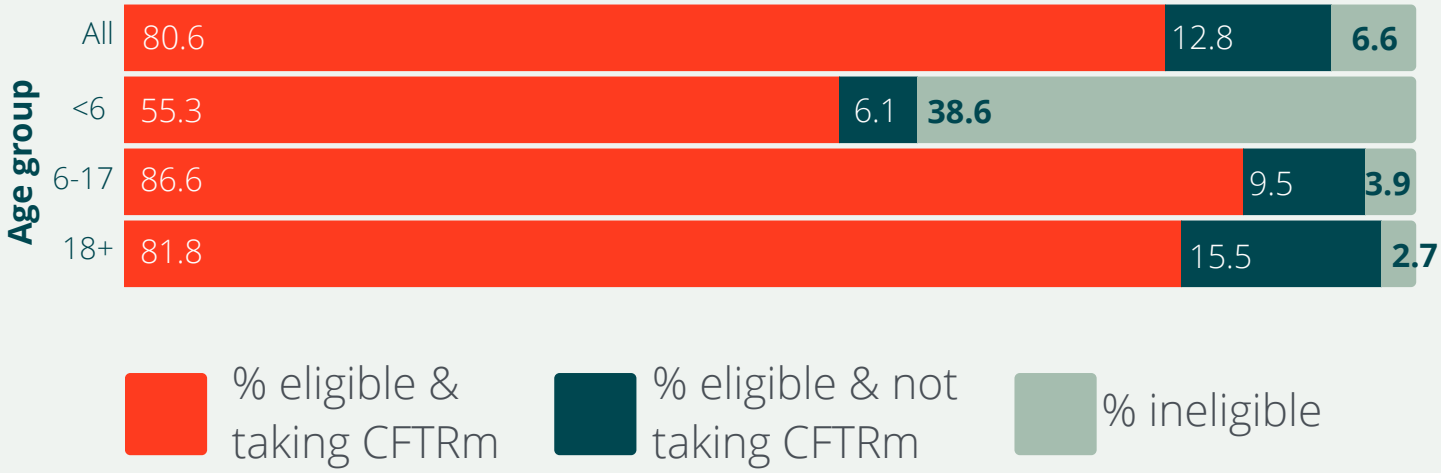
CFTR Modulator therapy*

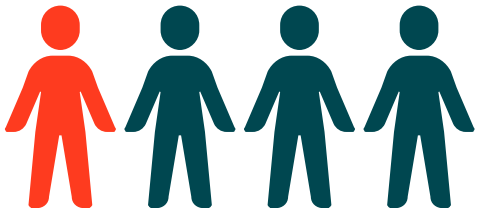
*shown as a % of **1327** individuals with data from a clinical visit in 2022



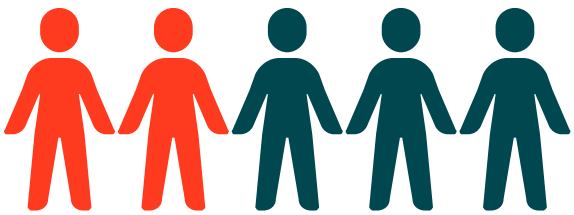
Modulator use for those eligible at last encounter 2022

N.B. Patients may be eligible for more than 1 CFTRm. Patients may have switched modulators over the course of the year. Totals may therefore exceed 100%.

Treatment burden



Over 1 in 4 (25.3%) adults reported to be using **3 types** of **inhaled therapies** vs only 1.4% of children



Nearly 2 in 5 adults (37.8%) are reported to be using **all of PERT, PPI and Macrolides** vs only 6.6% of children

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