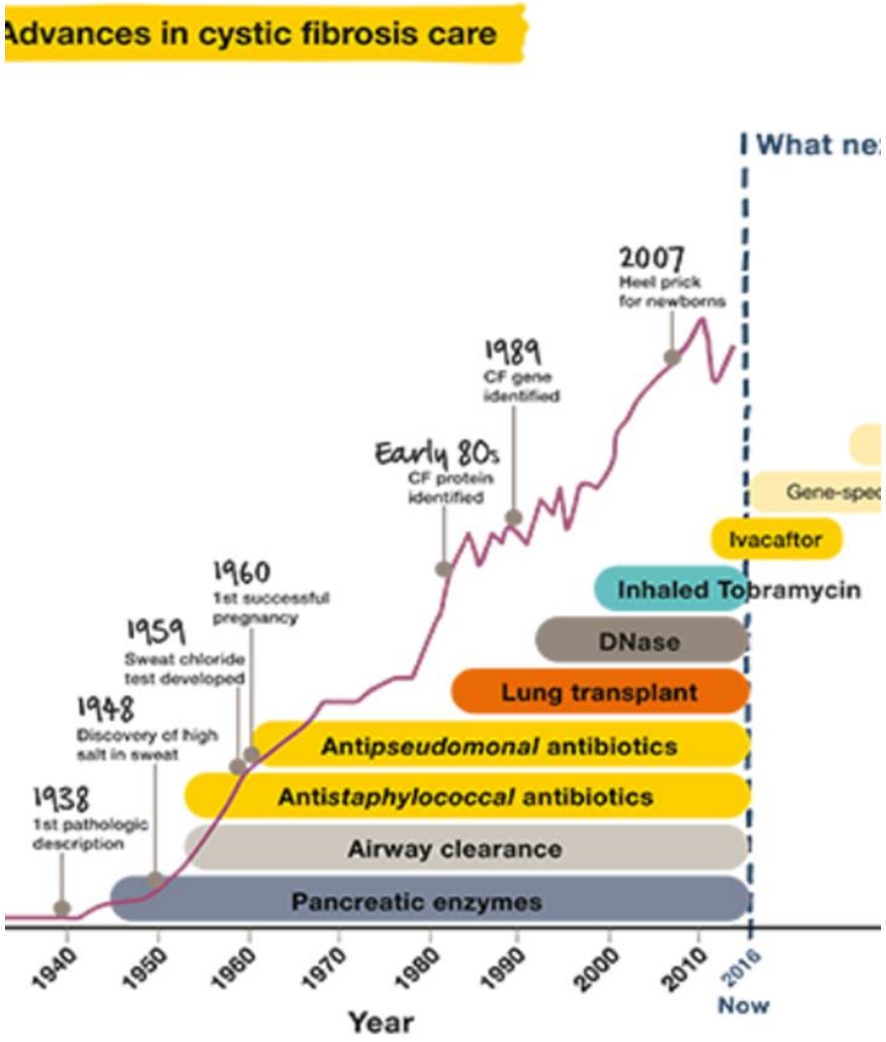
Adapting to Change – New Models of Care

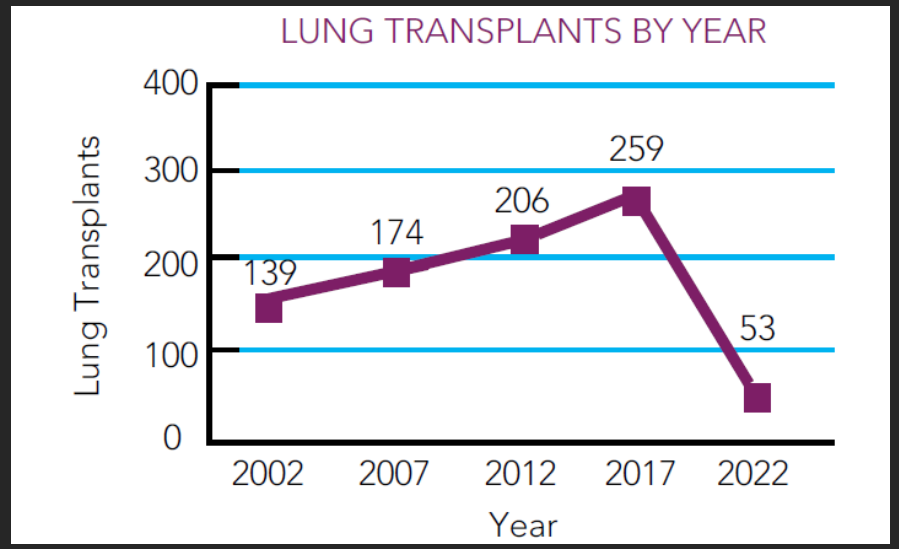
- Charlotte Dawson
- Lead CFCNS and CF Service Co-Lead
- Great Ormond Street Hospital
- London, UK

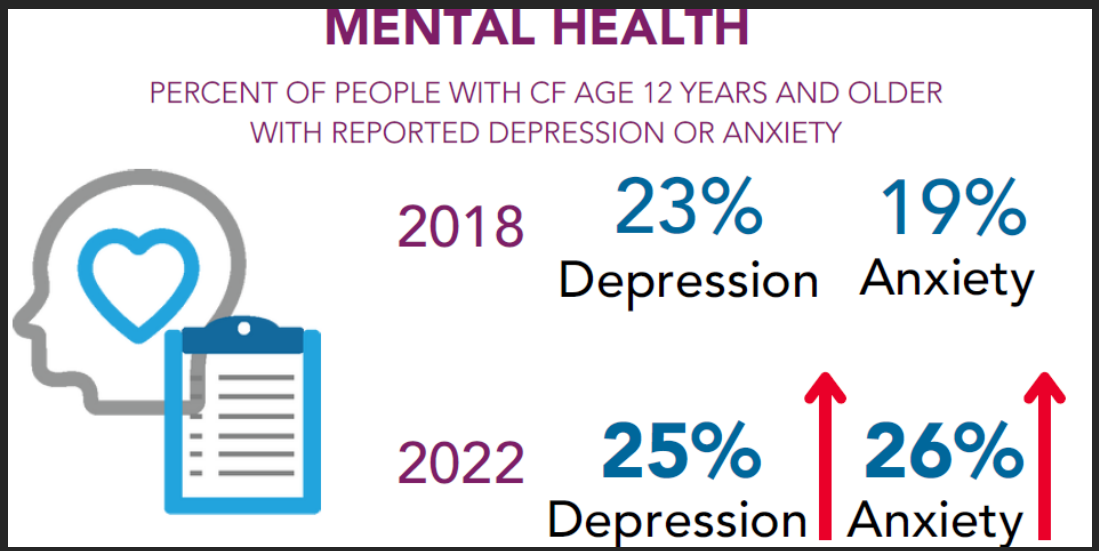
CF Today

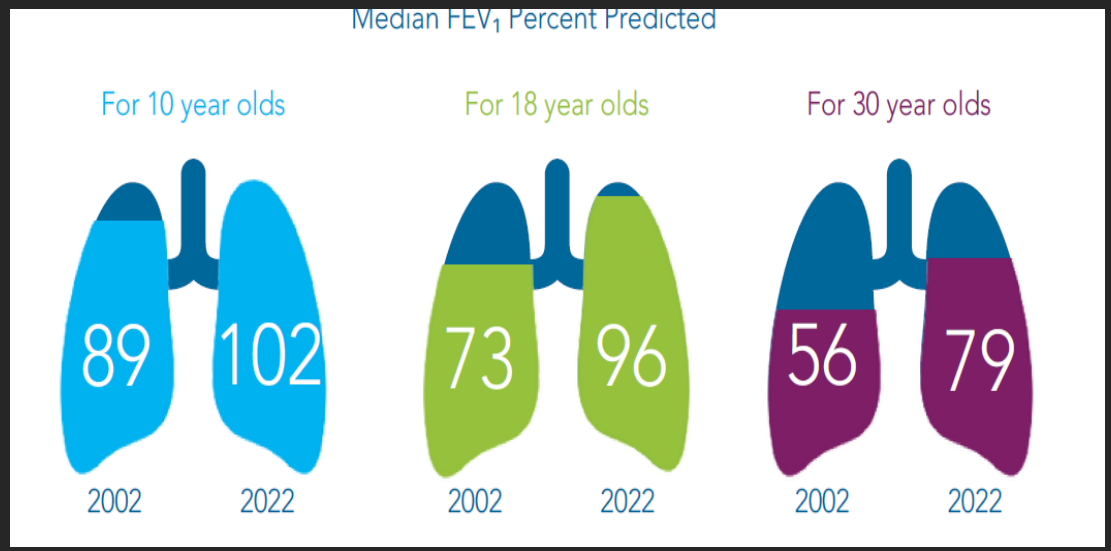
- Significant improvements in the health outcomes of PwCF over the last 6 decades.
- Improvements in health outcomes multifactorial
  - Formalised airway clearance
  - Effective P. Enzyme supplementation
  - Evolving pharmacological Interventions
  - Diagnosis – Diagnostic tools, CF Gene, NBS
  - CF Specialist Centre care by CF MDT
- This is all changing the landscape of our CF Population



Bacteria	2018 Percent With Infection	2022 Percent With Infection
Pseudomonas aeruginosa	44%	26%
Stenotrophomonas maltophilia	12%	5%
Methicilin-resistant Staphylococcus aureus	25%	16%
Achromobacter xylosoxidans	6%	2%
Burkholderia cepacia complex	3%	1%
Nontuberculous mycobacteria	14%	10%







UK CF Registry, 2022, CF Foundation, 2022)

Recent Influences that have/care driving change

- Segregation
- NBS – Earlier treatment initiation
- CFTRm
- Technology/Social Media
- COVID Pandemic

CF Population

CF no longer an exclusively paediatric condition

- Proportion of adults with CF exceeds that of children in developed countries

Disease severity in childhood is changing

- Babies born today predicted to live into their 5th decade
- Should translate into the adult population

Potential division in CF Population

- Determined by CFTRm eligibility and response.
- NBS identifying mutations of varying clinical significance (CFSPID)

Do the current services meet the demands of the changing population?

Traditional CF Care

Evidence supports CF Specialist centre care by specialist MDT +/- conjunction with network clinics

Abide by robust standards of care = Improved health outcomes for PWCF

MDT Skills to identify early subtle disease progression & initiate evidence-based protocols

Earlier Diagnosis/NBS & Ongoing monitoring

Opportunities to initiate early therapies, monitor for subtle changes & introduce interventions to delay damage

Development of CF Specialist Adult services & Transition

Improved survival – better suited to manage differing needs of an aging population

Throughout - Education and Psychosocial Support – to cope, understand and adapt

Diagnosis

Lifestyle limitations

Health decline – increased treatment burden

Transition

Independence/Relationships/Family

EOL

How do we provide this - Models of Management Vs Models of Care/Delivery

CF STORM

CF START

Saline US study

Local studies Exercise Vs Airway clearance

Elastase surveillance

Microbiome

Care

Specialist Centre care

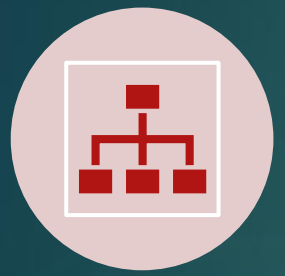
Network (Shared care)

Delivery

Virtual / Telehealth

Hospital at home/Outreach

Full Specialist Centre Care

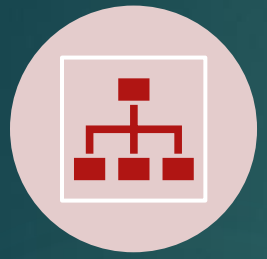


Geographically determined in Paeds and often the only option for adults

Gradual increase in PwCF having this model of care – NBS, Primary care time pressures, retirement/reduction in knowledge base, large research studies often centre based

Pros	Cons
• Equitable service for whole Pt cohort • Access to expert knowledge base of full CF MDT • Availability of advanced investigative technology – ILF, MBW, Nasal PD etc • Access to other specialities • Access to research studies	• Can be far to travel or limited travel options – cost and time implications • Less local support/knowledge for acute care needs • Less local resource knowledge or access • Heavy burden on CF MDT

Shared (Network) Care



Model is reliant on regular up-to-date communication between teams whilst utilising the expertise of the CF centre team.

Requires a clear delineation of roles and responsibilities and a robust mechanism for timely communication.

Pros	Cons
• Reduced travel and expense for pt and families • Geographically difficult/Remote areas covered • Share the workload between teams • Facilitation of specialist knowledge to local teams • Facilitation and access to local information and resources (Paeds and Adults) • Established in many paediatric centres	• Potential for poor communication and management errors • Pt need to attend more than 1 hospital with 2 different teams • Potential delay in up-to-date evidenced based care/new therapies locally = delay in patient initiation • Access to clinical records in both sites rare • New to many adult centres (UK) so programme of education and willingness required

The Future – Thoughts

If more sensitive specialised investigations and examinations are required to monitor the asymptomatic/healthier PwCF to identify early changes and initiate early treatments, is full centre care a better model for future care?

If PwCF are healthier and able to participate and meet their aspirations, should their care be geographically closer to where they live to reduce time away from school/work/relationships/social life?

Does shared care provide equity of care for all PwCF when the specialist centre have some PwCF as full care patients – do they have better or quicker access to new therapies?

Do we need to spend more time looking at how we deliver care?

Traditional Service Delivery

- Majority of CF service provision is hospital centric – Outpatients clinics, ambulatory care units and Inpatient wards.
- Outreach/Homecare – Not available in all services and usually just provided CF Nurses and Physiotherapists
- Investigative monitoring – Usually hospital based
- Standards of care direct CF Centre's to monitor PWCF as a minimum of 2-3mthly
- Healthier population = less lifestyle limitations & aging populations who want to achieve/maintain life goals

Now is the time to review how we manage and deliver care

Telehealth/Virtual Care

- COVID-19 Propelled healthcare services into adopting virtual models of care (Tele-health/telemedicine)
- Quick and easy access to financial support for IT equipment, web based virtual platforms and home monitoring devices
- Diverse and expanding pop -CF care may need to extend beyond hospital walls with telehealth and other platforms
- Novel technologies have potential to support self-monitoring.
- CF team need to remain central – evidence supports this
- Need to ensure there is equity of care for all – ? different models for different cohorts

Prickett et all, 2023

Telehealth and Remote Monitoring

- Prior to the pandemic - Tele-health and remote monitoring for CF services explored but not fully integrated into CF services in the UK. (> in adults)
- During the pandemic CF services had to adopt this new model quickly and with very little knowledge/guidance.
- Wealth of information post pandemic that needs to be reviewed to identify +ve and –ve impact but hard to disassociate from impacts of shielding.
- More studies required to determine if any negative impact on early detection of deterioration and mental health support

Telehealth and Remote Monitoring - ? For the Future

- Floodgates open
- Restrictions lifted/lifting – Some services reverting back to hospital centric models with some hybrid models adopted
  - No guidance or standards as yet
  - CF Services still have the resources & experience

- Does telehealth and remote monitoring have a place in the delivery of CF services?
  - Healthier population – demanding less intrusion
  - Burden to hospital centric care – time, financial and risk of infection
  - ?? Harder in paediatrics – 2nd hand reporting, recognition of subtle changes and less remote monitoring opportunities.

Patient Engagement – Education & Support - ? For the Future

- Web-based information, Social media and virtual contact form part of the current social world we now live in
- Younger generation access google, twitter, Facebook, Instagram etc to get their information and also interact with others.
- Healthcare services – not quick to keep up

- Do CF Services need to utilise these platforms to interact with their pt cohort?
- Are hospital web pages of information redundant?
- Will we lose the personal touch and opportunities to support PWCF?

Hospital at home/Outreach Care

- Home IV's are already well established for CF for certain pt cohorts – more in adults than paeds
- Outreach/Home visits already established in many centres – mainly Nursing and Physio
- Standards of care – PwCF should have access to outreach/home care.
- Opportunity to reduce the burden time and costs for PwCF attending hospital
- Mobile technology for monitoring

Hospital at home/Outreach Care

- Healthier/Asymptomatic cohort – initial focus post diagnosis is education, psychosocial support & nutritional monitoring
  - Do we need to review as often as current standards of care direct in a clinical setting?
  - Can education, support and nutritional monitoring be provided by a less hospital centric model?
  - If greater outreach/home care model developed – How can we ensure access to the whole MDT?
  - Is there the capacity to develop a toolkit/criteria to identify appropriate timepoints for hospital-based review, Outreach/home or a telemedicine review?

What is the Future CF Nurse?

Diagnosis – can this not be nurse led?

Paediatric current diagnostic pathway for the asymptomatic infant mainly nurse led – support & education

Adult – Diagnosis post fertility clinic – support & education

Maintenance – Nurse led review/monitoring at home

Robust management pathways

Support virtual MDT clinics

Interventions

Home IV's established, can MDT management or daily home review and primary care support be incorporated?

Evolution of the CF Nurse

- UK- Key role within for CF 1st documented in 1980 with numbers in 1988 of 14 – CFNA developed
- 1993 – qpprox 40 nurses
  - 75% provided inpt, O/P and community support
  - 39% performed Spirometry
  - Key function – provide direct care, educate other nurses, advocate for Pt and family
- 2023 – Scottish Nurse Group Audit – UK
  - Approx 40% prescribers
  - 40% manage AA and clinics
  - 30% Nurse led clinics
  - 54% manage/involved with CFD
  - Some lead services

CF Nursing Diversity

- Long history of adapting to change and incorporating into our role
  - Transition, Segregation, NBS, CFTRm, ETC
- Span the whole spectrum of CF care
  - Identified and categorised in the UK CFNA CF nursing competencies & CF Trust Guidelines
  - Ward based through to nurse consultants
- Highly skilled and knowledgeable nurses
- Forefront of the majority of CF care
- Case manage patient cohort

Is a new model of care one where there is a more nurse led CF service?

CF CNS Recognition

- Less than 10% paid an advanced nursing/management band
- Majority senior nursing band (approx. 60%) – equivalent to a ward sister
- Third CF Nurses equivalent to a senior staff nurse/junior sister
- Over 75% educated at Bsc level or more

- ANP – Majority Paid as nursing management
  - *Nurses who have undertaken a master's level in clinical practice. ANPs have authority in patient diagnosis and are trusted to independently assess, diagnose, manage and care for patients with complex clinical issues.*

Hold on one minute!

Continued to gain skills, academia and take on more responsible roles – prescribing, nurse led clinics etc with no recognition in pay grade or job title – proceed with caution

New models of care & delivery cannot disadvantage those who still require the traditional models to reap the benefits of this generation.

High-cost pharmacological interventions (i.e CFTRm) will mean cost savings will be sought – need to protect and justify roles and services without adding more responsibility for no more pay

Divided patient cohort – One size doesn't fit all

CFTRm eligible

Responders

Non resposnders/tolerators

CF SPID/CFRMS

New pathways in place

Evolving and may cross over

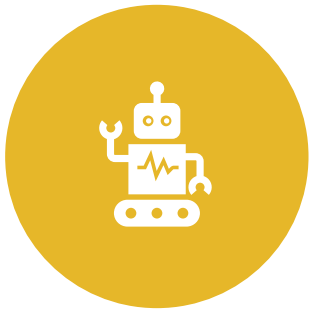
CFTRm non eligible

Symptomatic – sweat chloride, PS

Non symptomatic – Intermediate sweat chloride, PS

Future Directions

ADHERENCE – CHANGE THE NARRATIVE. COLLABORATION, NEGOTIATION, PT OWNERSHIP OF DATA AND ALLOWING TEAMS TO KNOW THIS, NOVEL DATA COLLECTION, REAL TIME DATA COLLECTION



TECHNOLOGY – ALREADY KNOW AND USING VIRTUAL PLATFORMS BUT USING SOCIAL MEDIA, WHATSAPP ETC MAY BE MORE ENGAGING, THE DREADED AI

PATHWAYS FOR DIFFERENT PT COHORTS – 10%, CFSPID +/- INT SWEAT, CFTRM ELIGIBLE

NOT JUST MODELS OF CARE – ALSO MANAGEMENT APPROACHES REQUIRED

NURSE LED SERVICES – DIAGNOSIS, MONITORING ETC

Summary

- Models of care
  - Shared and full centre care by CF MDT – Doubtful these will change as improvements in survival and quality of life can be attributed to this
  - Teams need to protect these models to ensure the advances are maintained but also for those not eligible for CFTRm.
- Delivery of care
  - Will need to adapt to our changing CF population's needs as they can achieve more in their day to day lives – Telehealth, virtual platforms, home monitoring, outreach/Homecare
  - Can more be led by CF Nurses – diagnosis, routine monitoring, initiation of management pathways – demand this is recognised!
- Models for CF Management
  - A whole other presentation not covered today but is very important

QUESTIONS? OR BETTER STILL - DISCUSSION

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