



5 – 8 JUNE 2024  
GLASGOW, UNITED KINGDOM

# 47th EUROPEAN CYSTIC FIBROSIS CONFERENCE



THE KEY ROLE OF THE CYSTIC FIBROSIS  
CLINICAL NURSE SPECIALIST - 30 YEARS  
ON

Presented by Lesley Blaikie



**CFNA**

Cystic Fibrosis  
Nursing Association

## Conflict of interest(s):

We have no declarations to declare



## Context

- ❖ To explore how the role of the CF nurse has changed since 1991 (last in-depth survey of role of CF nurse)
- ❖ **Dyer J. Cystic fibrosis nurse specialist: a key role. J R Soc Med. 1997;90 Suppl 31(Suppl 31):21-5. doi: 10.1177/014107689709031S05. PMID: 9204007; PMCID: PMC1296094**
- ❖ As a small group met to response to the paper
- ❖ Abstract in ECFS 2024
- ❖ Next write a clinical paper

Scotland 92% response rate  
11.18 minutes average  
time to complete

QR code shared – CFNA  
meeting Birmingham 2023 –  
captured further 59  
responses

Total 80  
Highlights of data shared today

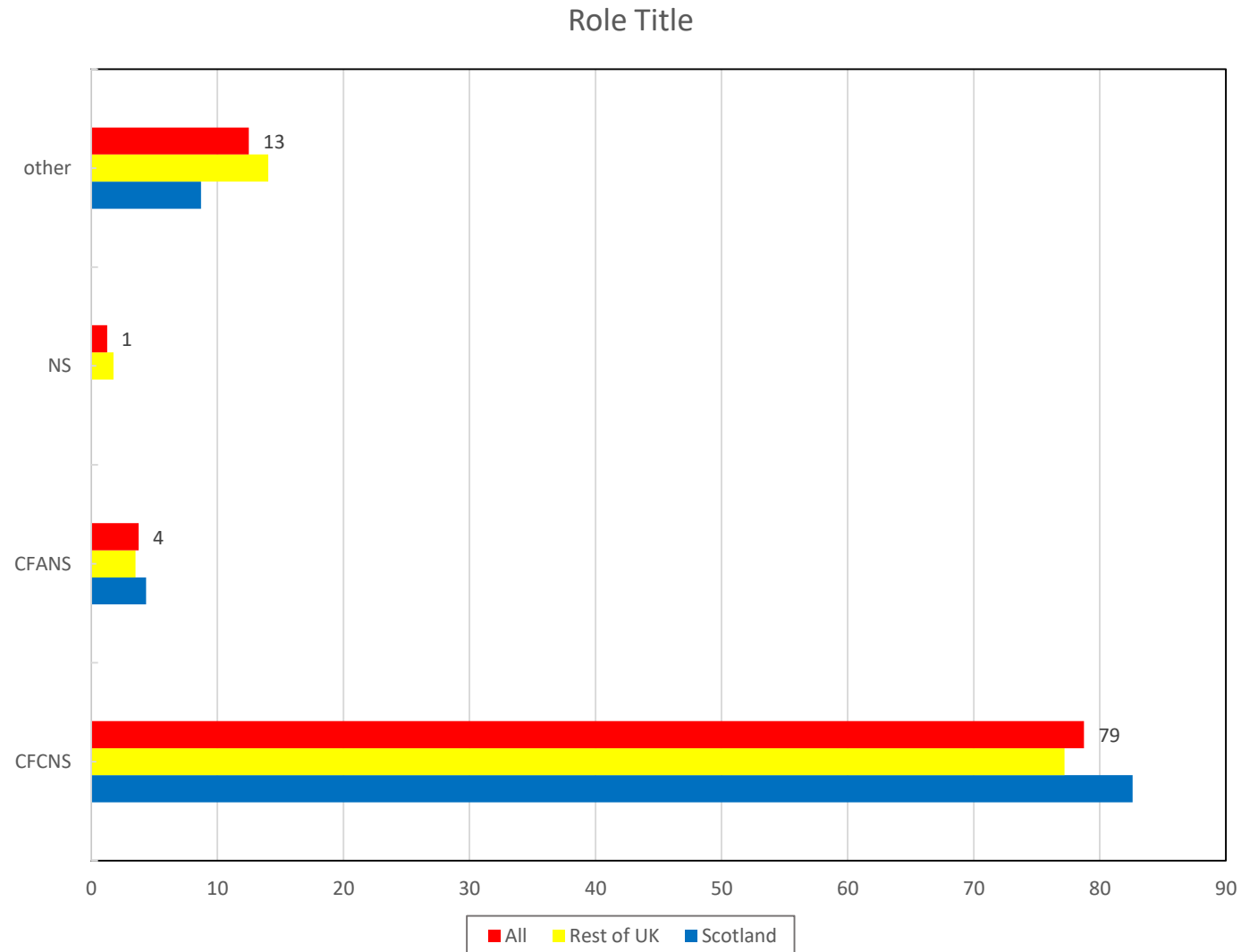


Microsoft Forms

[This Photo](#) by Unknown author is licensed under [CC BY-SA-NC](#).

# All in a title

- CYSTIC FIBROSIS CLINICAL NURSE SPECIALIST MOST COMMON TITLE (79%)
- New roles – healthcare support workers
- Nurse consultant
- Lead paediatric respiratory clinical nurse specialist

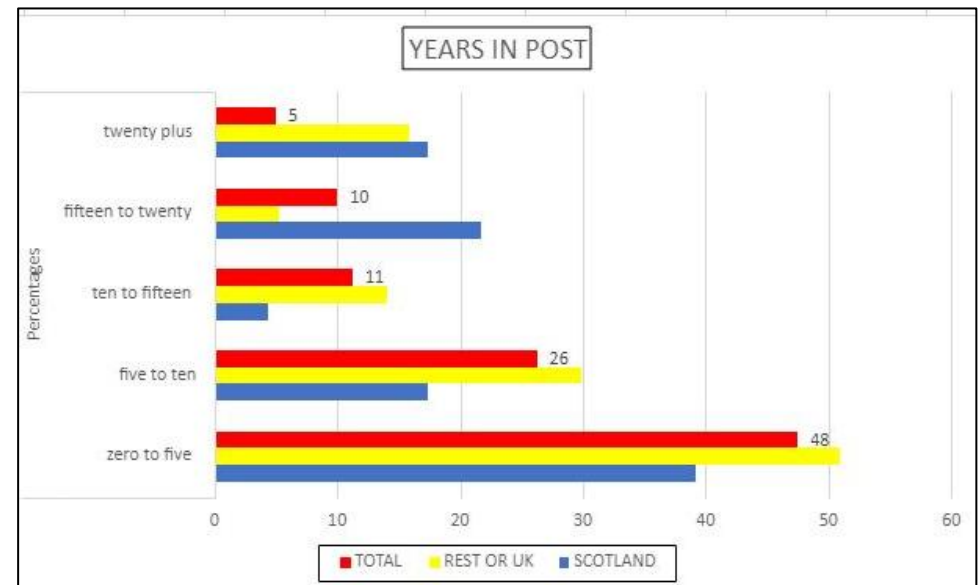


# Years worked in CF

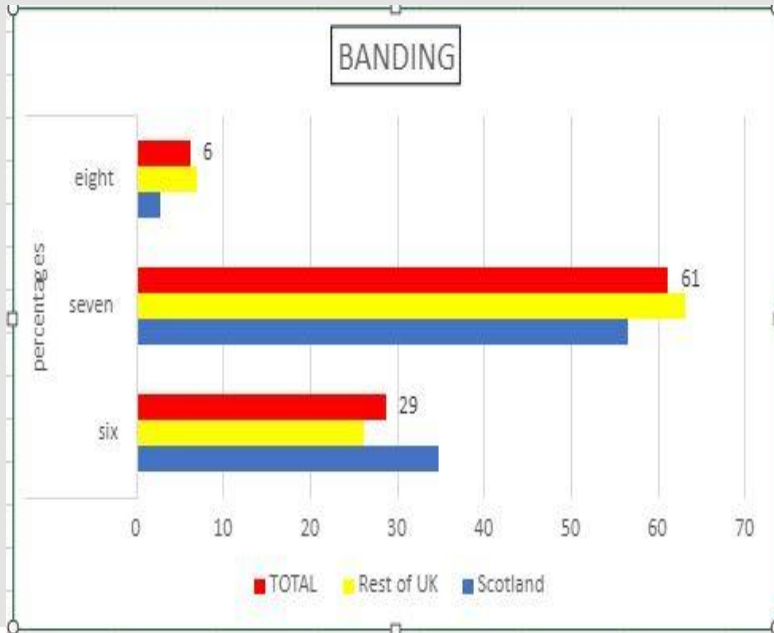
48% OF THE NURSES HAVE WORKED 0-5 YEARS (TOTAL)

SCOTLAND 38% HAVE WORKED IN CF MORE THAN 15 YEARS

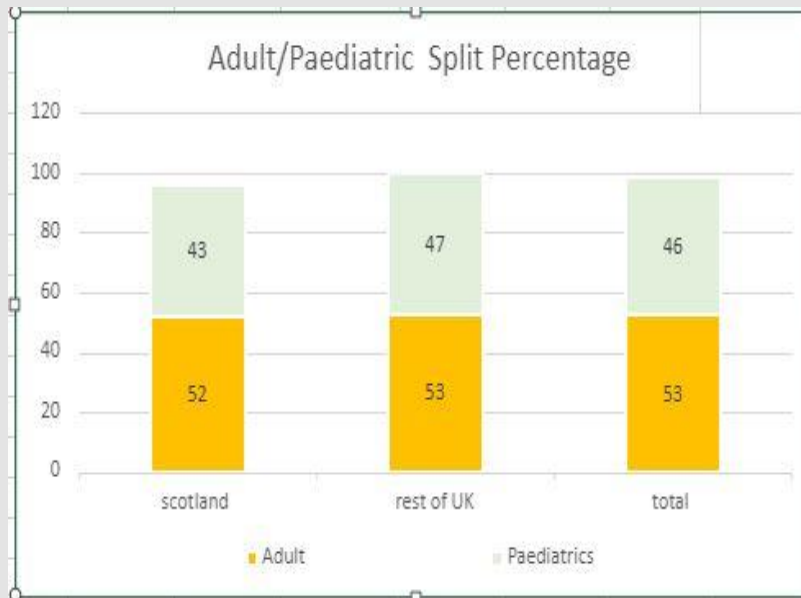
## SCOTLAND DATA



# Banding



# PAEDS/ADULT

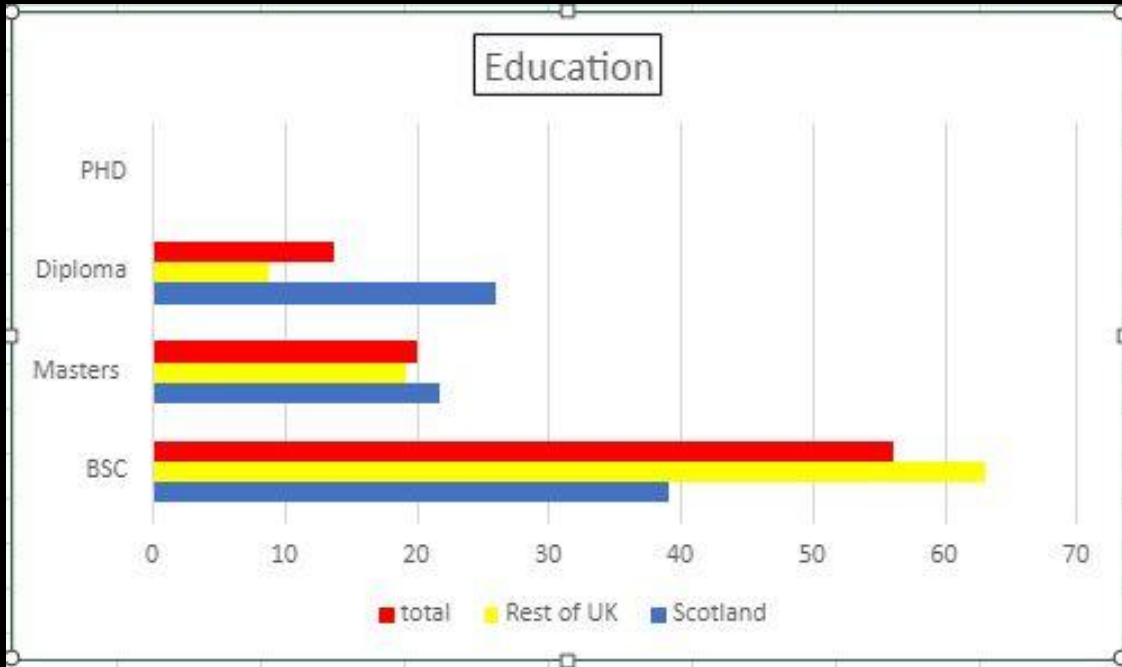


# Hours of working

**60% full time 40% part time**  
**Both paed and adults**

**Wearing a uniform**  
**>70% wear a uniform**

BANDING , DEPARTMENTS , HOURS OF WORKING,  
Uniforms



EDUCATION

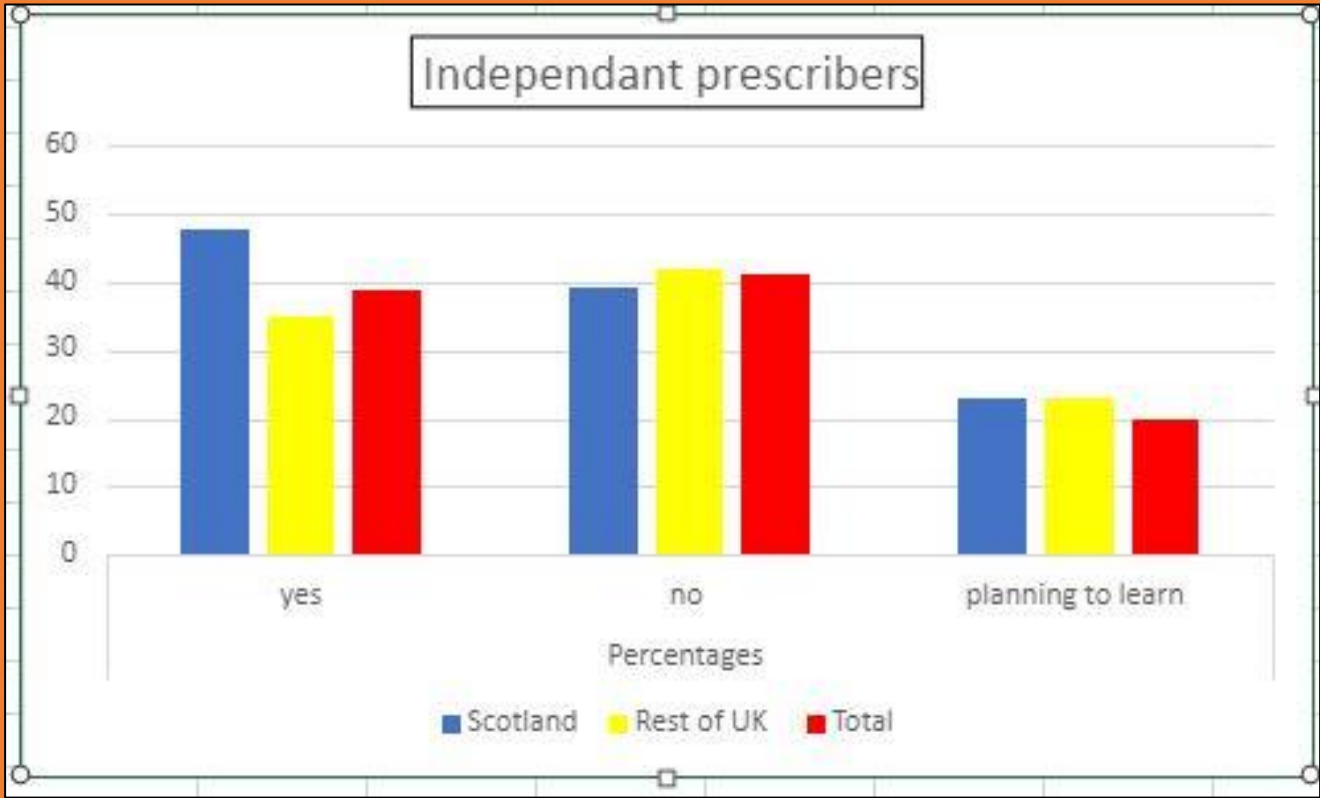


---

## INDEPENDENT prescribers

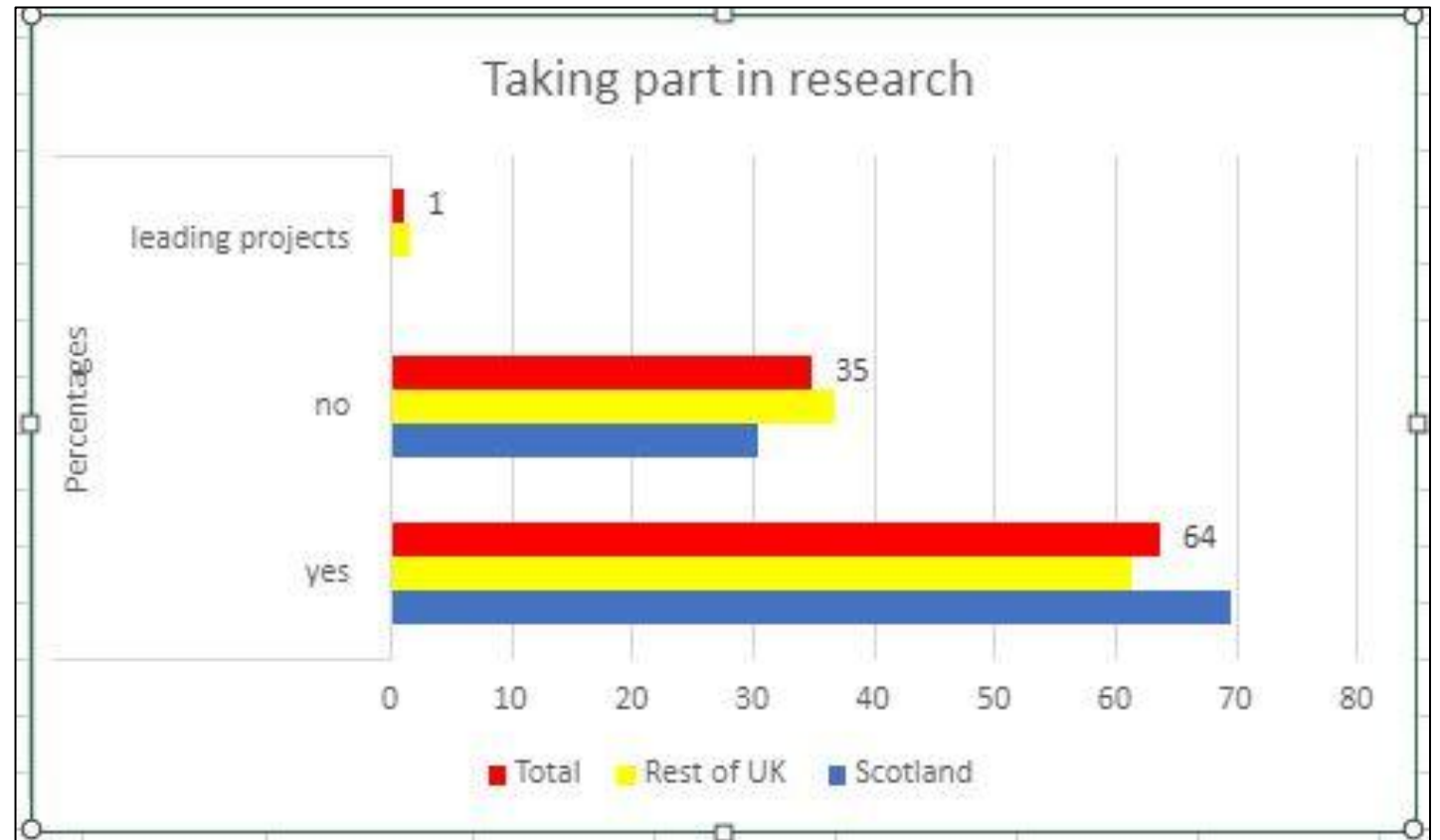
Scotland 48% yes / 39% no

Rest of UK 35% YES 23%  
planning to learn

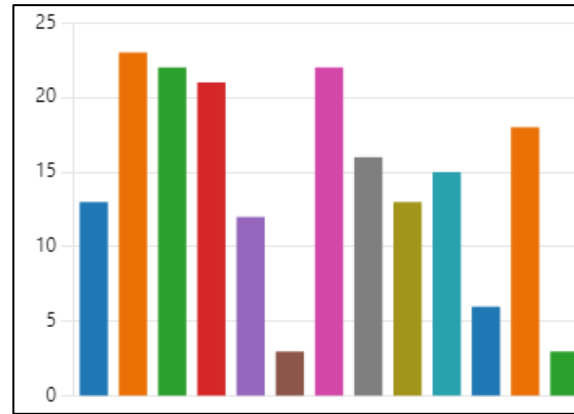


64 % said yes to taking part in research

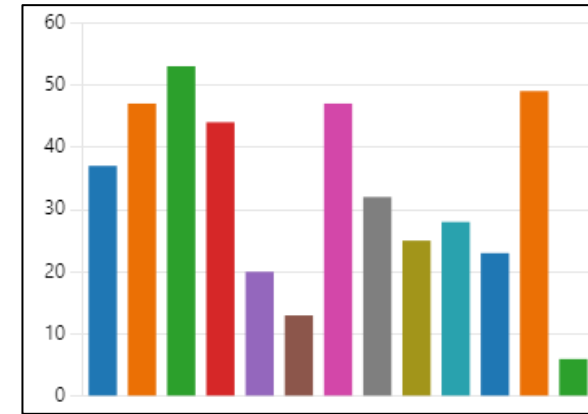
Nurse lead research projects



- Diagnosis
- Home visits
- Teaching - training :- medical an...
- Home IVs
- Modulator Prescriptions
- Inserting lines - mid lines /picc li...
- Maintenance of TIVAD devices
- End of life care
- Educational establishment
- Nurse led clinics
- Managing other team members
- managing clinics/annual reviews
- Other



SCOTLAND



REST OF UK

Other included QI work, Audit , Transition, Co ordinating links with other specialities, obstetric clinic, writing protocols/policies

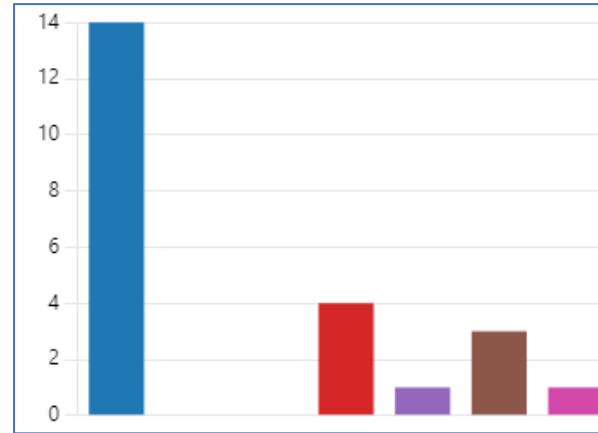
## OUR ROLE

Thinking of your role are you involved in any of the following ?

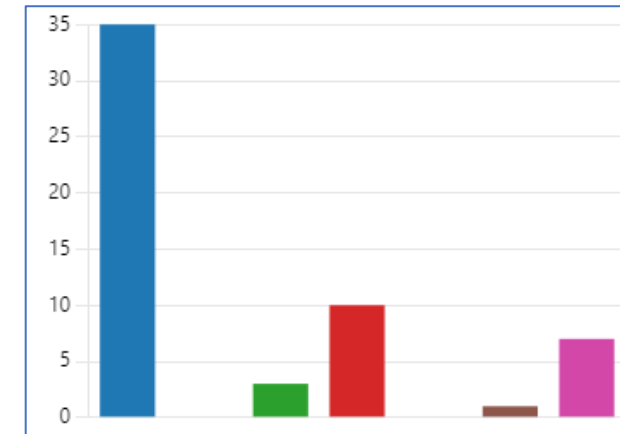
## Who coordinated the clinic

- CF Nurse(S)
- Physiotherapist
- Doctors
- Secretaries – red
- Healthcare support worker purple
- Data manager
- Other

## Scotland



## Rest of UK



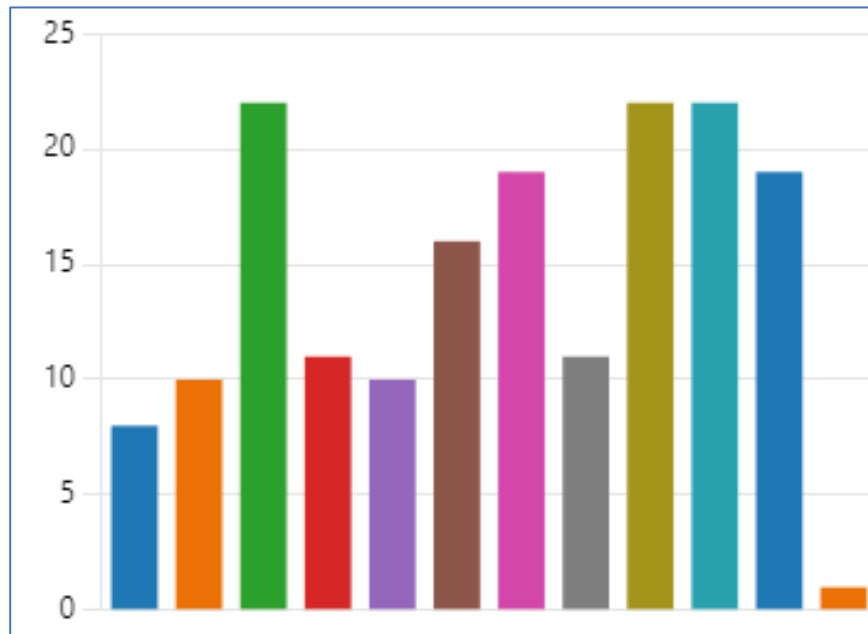
Other – included network manager , mutiple people , nurse and physio, admin team, MDT approach

WHO COORDINATES CLINICS/ANNUAL  
REVIEWS/OTHER REVIEWS-61% SAID THE CF NURSE

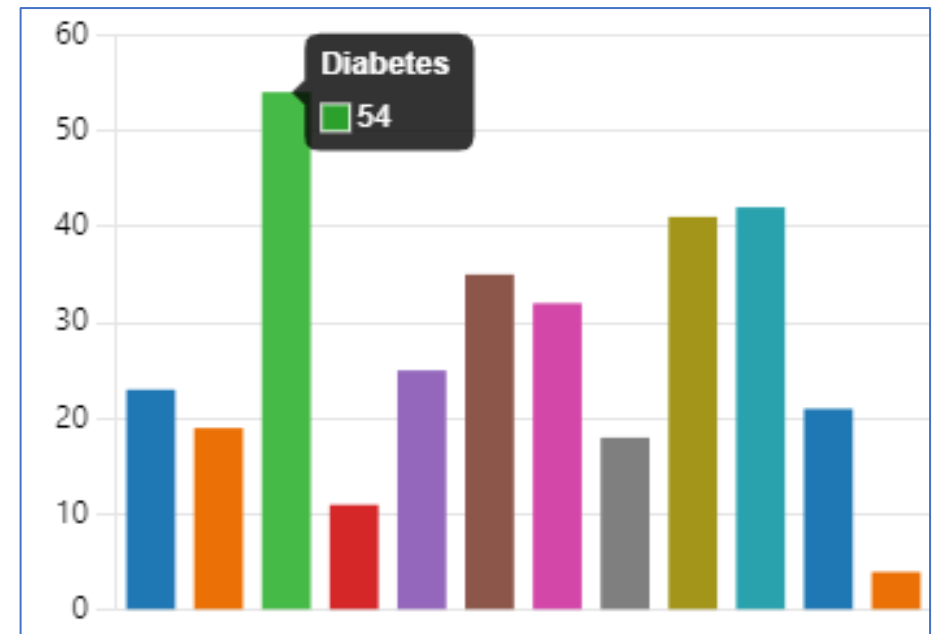
Thinking of all the specialties you are directly involved with - this is not exhaustive

- Fertility
- Obstetrics
- diabetes
- renal
- transplant
- liver
- gastro
- hospice/palliative care
- infection control
- pharmacy
- primary care teams
- Other

### SCOTLAND



### REST OF UK



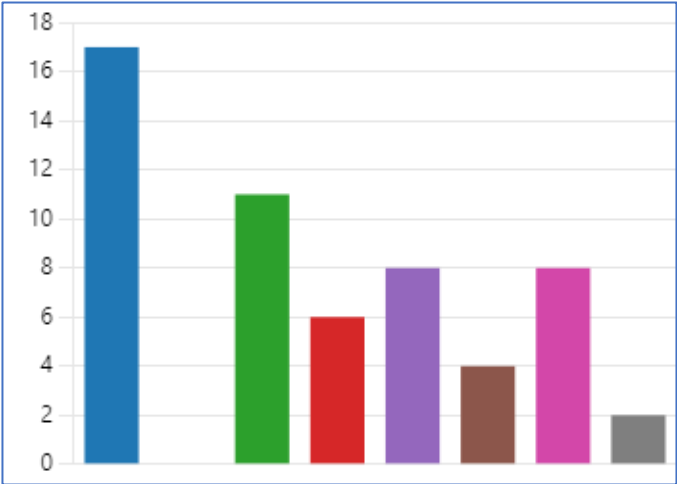
most common diabetes , infection control and pharmacy

# Impact of Modulators

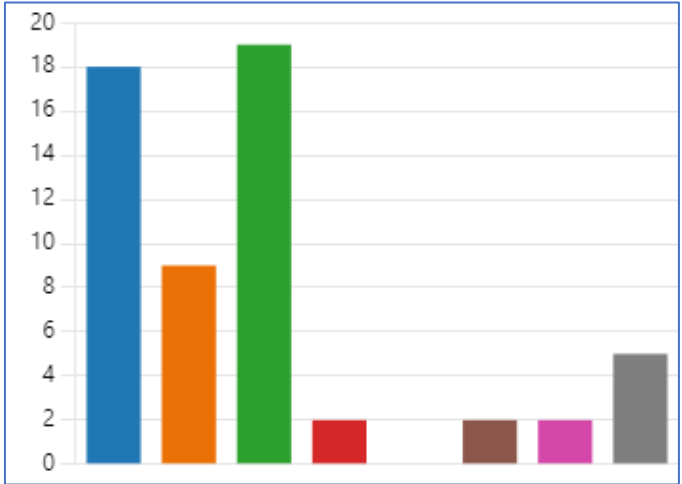
Has the CFTR modulator therapy impacted on your MDT CF clinics

- Hybrid virtual clinics
- No change
- Less frequent reviews
- Quicker clinic visits
- Not all MDT members attending...
- more ad hoc patient reviews
- More home visits
- Other

## SCOTLAND



## REST OF UK



Other included -more intense reviews needing pharmacy input, liaising with different specialities now caring for CF patient, Combination of changes

LTV Asthma PCD Team lead Oximetry/ tosca Oxygen  
 cf bronchiectasis Cf nurses respiratory and respiratory  
 Bronchiectasis and PCD  
 asthma  
 community nurse bronchiectasis cf team lead CF Service  
 cf admin CF diabetes PCD nurses team CF nursing  
 Inpatient diabetes team Cf diabetes  
 patients with Bronchiectasis

bronchiectasis adult non Asthma & other respiratory  
 clinic - TIVAD team lead bronchiectasis  
 policy and procedures clinical shift complex cf<sup>x1</sup>  
 shift per fortnight CF patients cf bronchiectasis Asthma infection patients  
 complex respiratory central lines TIVAD maintenance  
 respiratory service

other responsibilities

- The role of the CF nurse is still pivotal in the journey for CF patients and families and should not be lost as services react to the effect of highly effective modulator.

Huge amount of psychosocial support with families/children

*Emerging hypertension, high cholesterol and cardiology reviews from a lifetime of high fat/high calories diets.*

*We work acutely and in the community - wrap around care/services for our paediatric patients to avoid duplicating care.*

*I love my role! And the changing face of CF has not made my job any less demanding or intense.*

*The role of the CF nurse is evolving. Patients are well overall and parents are less anxious. My role is harder than it used to be, CF seems like an afterthought to families and in respiratory medicine..... it's great to be in this position, but everything feels like a fight. A struggle to get families to priorities coming to clinic and their CF routines and a bit of a battle to get managers to see the importance of a full MDT.*

*Education and educating wards is a growing need and we need to be part in ongoing training in a trust because ward staff are becoming deskilled due to reduced admissions.*



# Next steps – conclusions

- This is the largest group of CFNS in UK analysed.
- Significant differences in banding and skill mix are evident; many are educated to Masters level and working towards greater autonomy and responsibility, One Nurse Consultant role was identified.
- Pressure within healthcare teams risks eroding the role of the CFNS, with other responsibilities spreading to their role responsibilities.
- In 1997 nurses felt unsupported by peers, today the CFCNS support each other.
- Careful succession planning of the role of CFCNS posts is essential.



[This Photo](#) by Unknown author is licensed under [CC BY-SA](#).

---

Thanks from all of us to you



- Lesley Blaikie
- Elaine Jackson
- Vicki Carlisle
- Genna Wood
- Jane Davis

