Simplifying the treatment burden in Cystic Fibrosis

Voted the number 1 research priority in CF

Which Treatment?
64% of pwCF feel some work better than others

Top 5
- Physio
- Hypertonic
- Exercise
- DNase
- Creon™

70% of pwCF miss some out when busy/tired

Top 5
- Nebulisers
- Physio
- DNase
- Exercise
- Vitamins

Specific Treatment plans
81% feel it helps them, but...
58% feel it does NOT take personal situation into account

Around symptoms not life
Difficult to fit work in
Not listened to
Personal situation not discussed
“just another patient”

Medication Admin
78% have difficulties getting their medication

Not available/out of stock
Time consuming
Communication issues
Errors
Repeat prescriptions

Stopping Treatments
78% of health care professionals would support a ‘stopping’ trial

Top 5 Most Important & Most Burdensome Treatments

People with CF & family

- Pancreatic enzymes
- Airway clearance
- Ivacaftor/Orkambi™
- Exercise & physical activity
- Long-term neb antibiotics

Health care professionals

- Pancreatic enzymes
- Airway clearance
- Ivacaftor/Orkambi™
- Long-term neb antibiotics
- Exercise & physical activity

- Airway clearance
- Long-term neb antibiotics
- Intravenous antibiotics
- Insulin
- Long term oral antibiotics

This information came from surveying 941 members of the global CF community. Thanks to all. This work is funded by Cystic Fibrosis Trust and the University of Nottingham. Follow @questionCF to get involved.