

# Cystic Fibrosis Trust

'Challenging the norm'  
A sustainable registry

## Executive summary

Through the use of Net Solving's market leading (Case Capture™) software, the Cystic Fibrosis Trust have been able to create a scalable, versatile and revenue generating registry that is respected worldwide.

This registry provides a comprehensive view and deep analysis into the progression of Cystic Fibrosis over time. With 100% participation from all specialist centres and clinics in the UK and a 99% consent rate from patients, this valuable data puts the Cystic Fibrosis Trust at the forefront of influencing policy and academia on the disease. Furthermore, the registry data is of such quality that randomised registry based clinical trials and pharmacovigilance studies can be run on it.

## About the client

The Cystic Fibrosis Trust is the only UK-wide charity dedicated to fighting for a life unlimited by cystic fibrosis (CF) for everyone affected by the condition. Since it started in 1964 they have dedicated themselves to promoting excellence in research and clinical care, as well as providing practical support and advice to people with CF and their families. Their mission is to create a world where being born with CF no longer means a life-long struggle, when everyone living with the condition will be able to look forward to a long, healthy life.

## The challenges

The CF Registry began its life at the University of Dundee in 1996 as a small and research study.

The CF Registry had a reputation for excellence for many years, but they had ambitious plans for developing it to meet the evolving needs of people with cystic fibrosis - including creating bespoke study modules running seamlessly alongside the core system - They needed new state of the art technology to get them there.

## The results

The CF Registry, powered by Net Solving's (Case Capture™) software has created the following core capabilities:

- ▶ Collect all relevant information pertaining to CF patients, accurately, and with the appropriate validations.
- ▶ Log every time there is an annual review.
- ▶ Log every 'encounter' (visit to a hospital which is not an annual review).

Further capabilities

### COMMISSIONING

The system produces a banding report that enables commissioners of CF care to make payments to care centres that reflect the complexity of their patients' needs

### REGISTRY BASED CLINICAL TRIALS

An expansion of the existing registry was made to capture further information for clinical trials. The Cystic Fibrosis Trust have been able to run a Paediatric study looking at antibiotic prescribing utilising this data.

## The business case

The CF Registry is a high priority strategic program of work for them. The power of the registry often underpins applications for findings and steers their strategic direction as a charity:

The key factors in the procurement process were:

- ▶ Simple and intuitive system that needed minimal training
- ▶ Capability to run randomised registry based clinical trials.
- ▶ Scalability to allow many studies to be conducted on it
- ▶ High data quality and validations
- ▶ Smooth and comprehensive data migration process

*"We had a lot of fundamental questions about cystic fibrosis that were going unanswered because it costs too much to run a traditional clinical study. Whereas a registry based clinical trial costs about a 10th as much as a normal study and is far quicker"*

The Cystic Fibrosis Trust kicked off a procurement process and Net Solving were asked to join that process. They were known to the Trust through their notable work on the:

- ▶ SSNAP (Sentinel Stroke National Audit) - the single point for stroke data in the UK
- ▶ NELA (National Emergency Laparotomy Audit)

Net Solving came out on top of the procurement process due to the following factors:

- ▶ Extensive experience with registries
- ▶ Value for money
- ▶ Consultative approach
- ▶ Flexibility and scalability of system

### FLEXIBILITY

*"One of the key critical success factors in the tender process was to choose a company that would engage us as a charity and the cause that we are seeking to address. Net Solving have gone above and beyond to achieve this, even when we as a customer have been a little bit demanding"*

### INCREASED ACCURACY

*"We have much more sophisticated validation rules and consistency checks on the data"*

### SIMPLE AND USER FRIENDLY SYSTEM

*"Many fields showed an improvement in data completion in the new platform"*

### SCALABILITY

*"We needed something where technically we could be running 10, 12, 20 studies at any one time and net solving worked with us to make that possible"*

\* interview conducted with Rebecca Cosgriff of Cystic Fibrosis Trust.

If you would like to find out more about how we can help you, please get in touch...

Net Solving Limited  
Financial House  
14 Barclay Road  
East Croydon  
CR0 1JN

☎ 020 3883 8310  
✉ [info@netsolving.com](mailto:info@netsolving.com)  
🌐 [www.netsolving.com](http://www.netsolving.com)