

Nuts & Bolts of Patient Registries

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CFRI established
2001



Independence from patient organisation
2005

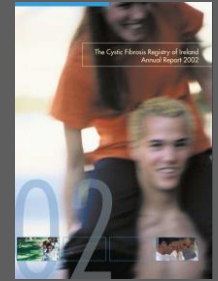
Attained >90% CF population coverage
2009



Encounter-based data capture begins
2015



2003
First Annual Data Report



2008
HRB-funded research project



2013
Lottery grant-funded registry software upgrade



2016
Patient Portal



Using patient data is vital to improve health and care for everyone

There is huge potential to make better use of information from people's patient records. Data is vital for your individual care, and to improve health, care and services across the NHS. The information can be used to help understand more about disease, develop new treatments, monitor safety, plan NHS services and evaluate policies.



Examples:

Individual care

- Making sure your whole care team, from GP to hospital to care home, has up-to-date information to help give the best and safest care
- Helping people to manage their condition, from psychosis to asthma, using smart phone apps

Understanding disease

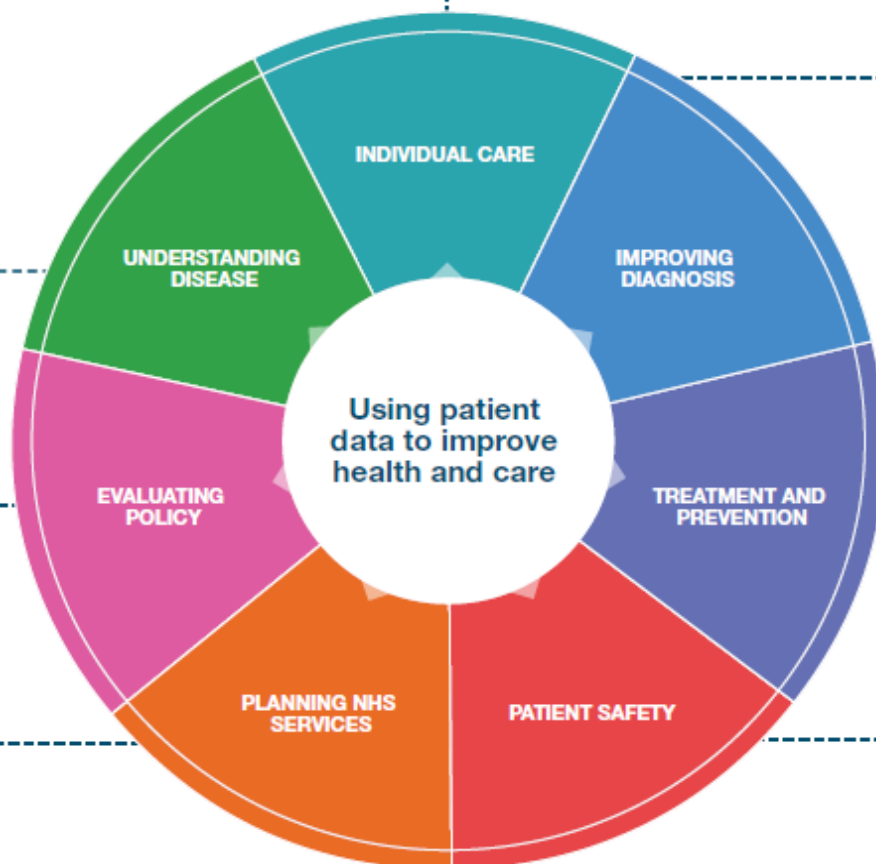
- Exploring why diabetes rates vary between ethnic groups
- Finding out about the biological changes involved in Parkinson's

Evaluating policy

- Comparing cancer survival rates between countries
- Showing the impact of a smoking ban on reducing premature births

Planning NHS services

- Finding out how many people have arthritis to inform planning
- Improving the delivery of kidney dialysis services



Diagnosis

- Demonstrating that bowel cancer screening is effective
- Finding new ways to identify early warning signs of dementia

Treatment and prevention

- Testing a treatment for lung disease in the real world
- Investigating the benefits of giving statins to men who haven't had a heart attack

Patient safety

- Monitoring the safety of whooping cough vaccination during pregnancy
- Checking the safety of hip replacements

Define your Dataset



- ▶ Minimal dataset
 - ▶ Identifies individual & allows follow-up
 - ▶ Describes condition & major co-morbidities
 - ▶ Describes health interventions
 - ▶ Describes processes of care
 - ▶ Captures prognostic information
 - ▶ Captures patient-reported outcomes of care
 - ▶ Enables risk-adjustment of health outcomes



Confine to routinely recorded, reproducible, objective data

Data Collection

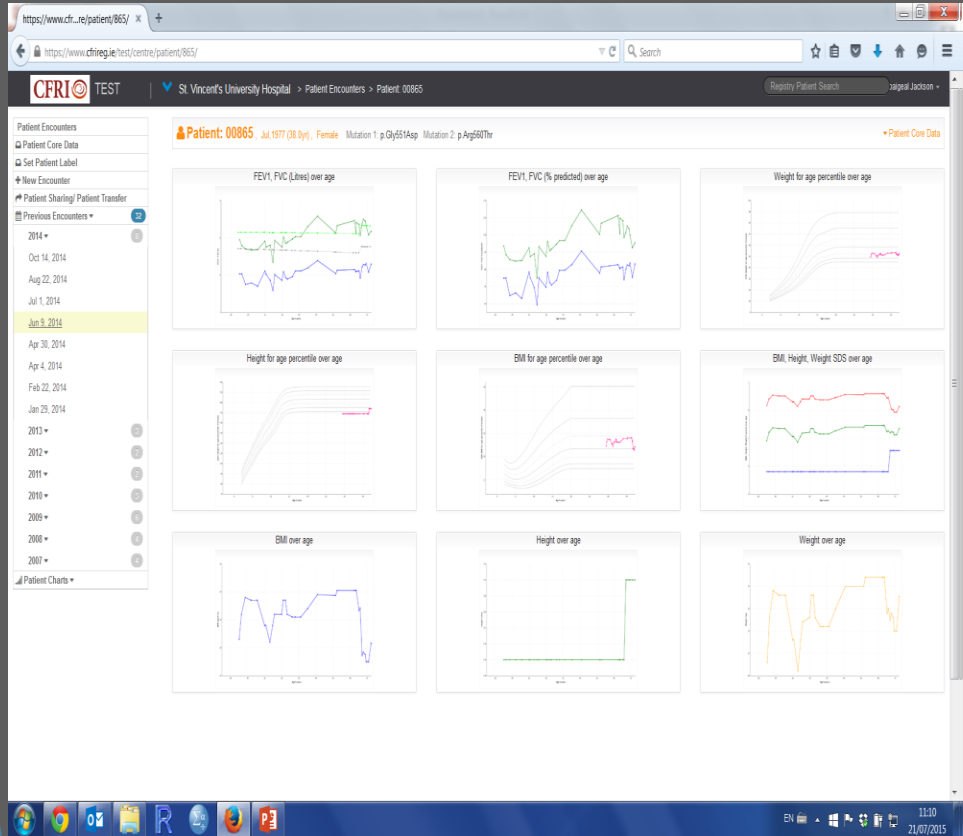


- ▶ Sustainable data collection
 - ▶ Identify data sources
 - ▶ Standardise measurement criteria/instrument
 - ▶ Population coverage
 - ▶ Define data capture time points
 - ▶ Avoid duplication
 - ▶ Who is best placed to collect data?
 - ▶ Data completeness



Systematically measure defined outcomes at predefined intervals

Registry Software



- ▶ Electronic, web-based software
 - ▶ Capacity to record longitudinal data
 - ▶ Annual summary vs encounter based
 - ▶ Reporting module
 - ▶ User friendly
 - ▶ Security
 - ▶ Data protection
 - ▶ Interoperability
 - ▶ Patient access



Select scalable software with integration capabilities