

# Nuts & Bolts of Patient Registries

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# Topics to be covered

- ▶ Introduction to CFRI
- ▶ A broad view of registries and vision for the future
- ▶ Funding of registries
- ▶ Governance
- ▶ Connecting data in registries



CFRI established  
2001



Independent  
organisation with a  
constitution  
2005



Service Level  
Agreement  
with HSE  
2011

Change  
governance to  
CLG  
2018



Setup  
funding  
CFAI &  
Dept of  
Health



Annual Grant  
DoH - HSE



2008  
HRB-funded  
research  
project allowed  
addition of  
internal  
personnel



Contract  
funding



# Registries - A Broad View - Present

- ▶ 2017 - 120 National Health & Social Care Data Collections - HIQA
  - ▶ Less than 20 are disease registries
- ▶ MRCG/HSE - 2012 Patient Registry Survey - 47 identified
  - ▶ 69% less than 3 staff members
  - ▶ Often dependent on a single visionary / mentor
  - ▶ Majority operating on limited funding
- ▶ Without the proper resources it is an uphill battle



**THREAT!**  
**UNDER-RESOURCED**

# Registries - Future

- ▶ 2017 120 National Health & Social Care Data Collections - HIQA
  - ▶ Less than 20 are disease registries
- ▶ MRCG/HSE - 2012 Patient Registry Survey - 47 identified
  - ▶ 69% less than 3 staff members
  - ▶ Majority operating on limited funding
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## Vision

- ▶ An Independent Federation of Registries
- ▶ A trusted third party - filling gaps in health intelligence
- ▶ Appropriately funded
- ▶ Sharing common resources



# Registry Funding

- ▶ Know and understand your timelines
- ▶ Budget and resource accordingly - CapEx & OpEx
  - ▶ Planning - Design phase
  - ▶ Implementation - Deployment phase
  - ▶ Operation phase
  - ▶ Future growth phase
- ▶ Build Strategic Alliances



Don't underestimate it will take longer or cost more or both!

# Registry Governance

- ▶ Know your stakeholders
- ▶ Involve stakeholders from the beginning
- ▶ Retain independence - TRUSTED THIRD PARTY
- ▶ Establish correct legal structure
  - ▶ Governing board
  - ▶ Advisory committees
- ▶ Skilled management / operations team / research team



Spend time on M&A/Constitution - get your structure right

# Connecting Data



- ▶ Domestic
  - ▶ Registries are too paper dependent
  - ▶ Silos of unconnected data that could feed registries
  - ▶ Centre to national
  - ▶ Patient connectivity
- ▶ International
  - ▶ Be part of an international community
  - ▶ Retain ownership
  - ▶ Common standards and definitions



Huge power of connected data - comparators have to be right