

# Journey To Establish The DFdiscover Platform At The University of Manitoba



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Andrew Morican

#DFUG2018



# Disclosure

- I have no financial relationship with industry
- I have no other conflicts

# Sadeesh

- Full time Thoracic Surgeon
- Experience with iDataFax as investigator -
  - VISION, POISE-3, MANAGE
  - established these studies at U of M
- spent many years at McMaster University

# Andrew

- Computer guy
- Violinist
- Freelance programmer

# Not experts...

- no significant experience with databases
- NO experience with creating studies
- Just starting with DFdiscover

# Why are we here then?

- Jim Choi said we should come
- Eric said we should give a talk
  - A unique experience in establishing the platform
  - A business model adapted to local realities
  - Perhaps a unique use of the platform

# A word on clinical databases

- Increasing use of clinical databases in clinical practice
  - Local - National- International
- Real time analysis of clinical outcomes
- Benchmarking

- Wanted to take part in the Canadian Association of Thoracic Surgeons Quality Improvement Program



L'ASSOCIATION CANADIENNE DE CHIRURGIE THORACIQUE  
CANADIAN ASSOCIATION OF THORACIC SURGEONS

- To develop a real time reporting of clinical outcomes to guide quality assurance in our department

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# The CATS database...

- Program sitting on a local server in the hospital and collecting local data via an electronic interface. ●
- Sends data to central repository
- Central repository has remote access to the software on local server for updating program, supports etc.

# Followed the usual steps...

- Asked the hospital IT department to help
- TWO years later.... a quote for \$100,000

# Hospital IT systems...

- Hospital IT administrators reluctant to allow ANY access to local server remotely
- Delay, delay....restructure...new “policies”
- Repeated at most institutions in Canada

Did the only rational thing...

Give up!

# moved on to my own project...

## Risk prediction model for thoracic surgery

- Widely applicable
- Representative

# The ThORaciC surgery Health Outcomes Study TORCH

- Prospective cohort study to derive a risk model for adverse outcomes after thoracic surgery
- Need a large and representative population

- 10,000 patients
- global population
- 1000 surgeons-“centers” -
  - **no money** for research
  - **no time** for entering data
  - **no patience** for bureaucracy

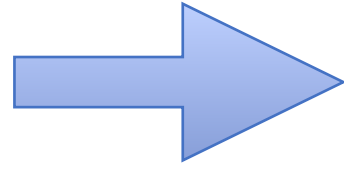
most surgery is NOT done in  
academic centres



# Guiding principles...

- Move as much of the cost of participating centrally
- Full flexibility of data entry to adapt to local clinical environment - i.e. minimal disruption of clinical activity
- **Avoid having to deal with the hospital IT administration**

# iDataFax

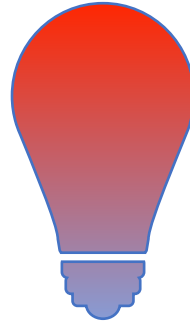


# DF Discover

- Multiple data input methods
  - paper
  - EDC
- Ability to store supporting documents including images, videos
- Limitless number of centres
- Ability to “nest in” subsidies without changes to the main study
- No need for IT support / obstruction for the centres

# But...

- DFDiscover ..... NOT cheap!
- Persuade the University to support the platform
  - No granting agency will support this type of investment
- University of Manitoba
  - Not a very large institution
  - Lacking critical mass of researchers to justify a large investment



- Can use this platform for non-research uses?
- A quality improvement database is really an ongoing cohort study....

# Business model...

## Maximise Stakeholders

- University departments
- Clinical departments
- Government
- researchers
- clinicians

## Multiple uses for platform

- For clinical research
- For quality assurance and audit

## All contribute

# Current status

- Licence fee for initial year - Centre for Health Innovation
- IT support costs - Me
- A portal for data entry to the national thoracic surgery database
- Have number of studies/clinical databases to go on line over the next year

# Limitations so far in DFDiscover

- Visit maps have start and end
- An API or tool for multiple custom report
- Character recognition – text recognition beyond numbers
- Interface to EPR systems

# Take home message

- Task not technology
- Main limitations are human not technical constraints
- The technical solution has to be flexible - people are NOT flexible
- To engage active clinicians in research, we have to overcome real world problems
- **Research and clinical practice are not distinct activities**



# Thank You

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