

Inspiration

How to create your own register...

Gustaf Edgren, PhD

Example – transfusion register

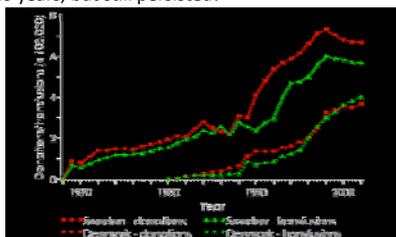
From the Swedish Medical Journal, February 1969

Computerized blood bank registration

- Began in Sweden in the mid 1960's
- Data on all blood donors, donations and transfusions were recorded using punch cards and (very) primitive computers
- The purpose was very explicit (in order of importance):
 1. Create infrastructure for research
 2. Simplify clinical work
 3. Save money

Computerized blood bank registration

- The Swedish blood bank registers has been running continuously since 1966
- According to the creator, they had little use for it during the first 20 years, but still persisted!



What we did?

- Responding to an NIH RFP, we set out to analyze the transmissibility of cancer through blood transfusion
- This is a rare exposure and a rare outcome, so we needed a lot of data
- All available computerized transfusion registers were combined in one database

Success factors?

- Naturally, the studies I've talked (way too much about) all depended on availability of very special data
- The key success factor is therefore very simple:

SOMEONE ELSE WAS CLEVER...

Sweden is a nation of hamsters...



SINGAPORE SHOULD BE TOO!

Singapore should be too!

- You have a reasonably small, well described population
- There is considerable genetic and environmental variation
- There is a very well developed infrastructure for health care and for subject registration
- It is possible to track individuals over time
- Some (?) outcome registers already exist!

So you want to start collecting data?

- As clinician-researchers with epidemiologic training, you are in an excellent position to begin prospective registration
- As noted, Singapore has good prerequisites for this which makes it unique in Southeast Asia!

Why collect?

- Research utility
 - Fundament for current and future studies
 - Source of pilot and preliminary data
 - Source of research ideas
- Clinical utility
 - Benchmarking: "What gets measured gets managed!"
 - Keeping track of patients and patient treatment

Is there anything you can base your data collection on?

Should I work alone?

Should I go for completeness?

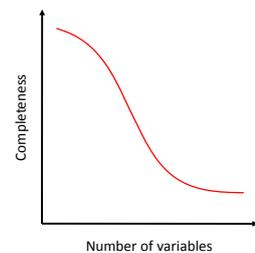
Know what you collect
(and what you don't)

What should I record?

What variables should I include?

So what should I record?

- The cautious solution may seem to be: "Record everything!"
- Its not!
- The information gathering needs to be optimized!
- Get what you need – No more, no less!



How should I record data?

Electronic vs. papers?
Online vs. periodic?
User-entered?

Think first – collect later

Think first – collect later

GOOD LUCK!