

Ireland needs a  
Change of Heart

# Introduction to NAPS NCIS: Demographic and socioeconomic data standards

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# Background



- One of the NAPS targets relates to mortality from CVD
- Activities on the ground, especially by health promotion departments
- But – mortality as indicator crude and inadequate
- Some data re health behaviours from SLAN
- Dearth of data and challenging to measure morbidity

# NCIS



- National Cardiovascular Information Systems Steering Committee has been at work
- Design company about to report re hardware and software, at institutional and and national level

# Data Standards



- NCIS discussed data standards: variables, coding and definitions for each module, and compatibility in variables which overlap between modules
- Basis for EU CARDS Project - Cardiology Audit and Registration Data Standards - with European Society of Cardiology and Irish Cardiac Society during Ireland's EU Presidency

# CARDS



- Agreed data standards for acute coronary syndromes (heart attack)
  - percutaneous coronary interventions (angioplasty, stents)
  - electrophysiology - pacemakers, implantable defibrillators, ablation
- Irish Association of Cardiac Rehabilitation got agreement at European level on data standards for cardiac rehab.

# Gap in standards

- At European level, no agreement on data standards for demographic and socioeconomic data
- What is done as routine in one country would not be permitted in another e.g. ethnic group
- Recognised this as important gap in Irish context

# NAPS NCIS Working Group

- NAPS NCIS Working Group
- DoHC
  - National Anti-Poverty Strategy
  - Information Management Unit
  - CVD Strategy
- CSO
- Institute of Public Health
- ESRI

# Task

- To agree data standards for demographic and socioeconomic data.
- To pilot in modules of NCIS
- Could be used in other health information systems
- Acceptable from technical perspective
- Feasible in the context of the health services

# Methods and Principles

## Background paper

- Tables of relevant variables in health information systems: CSO, IMU DoHC, ESRI
- Important to have denominator and to be compatible with major ongoing national surveys of related factors
- Noted that coding could be hierarchical i.e. could be expanded in one setting e.g. rehab and collapsed (but compatible) in another

# Discussion Points

- Even demographic data can be complicated!
- Apparently 'simple' question can have complicated answer, as in paediatric data set: relatives living with the child?
- People with most complicated answers may be those most vulnerable

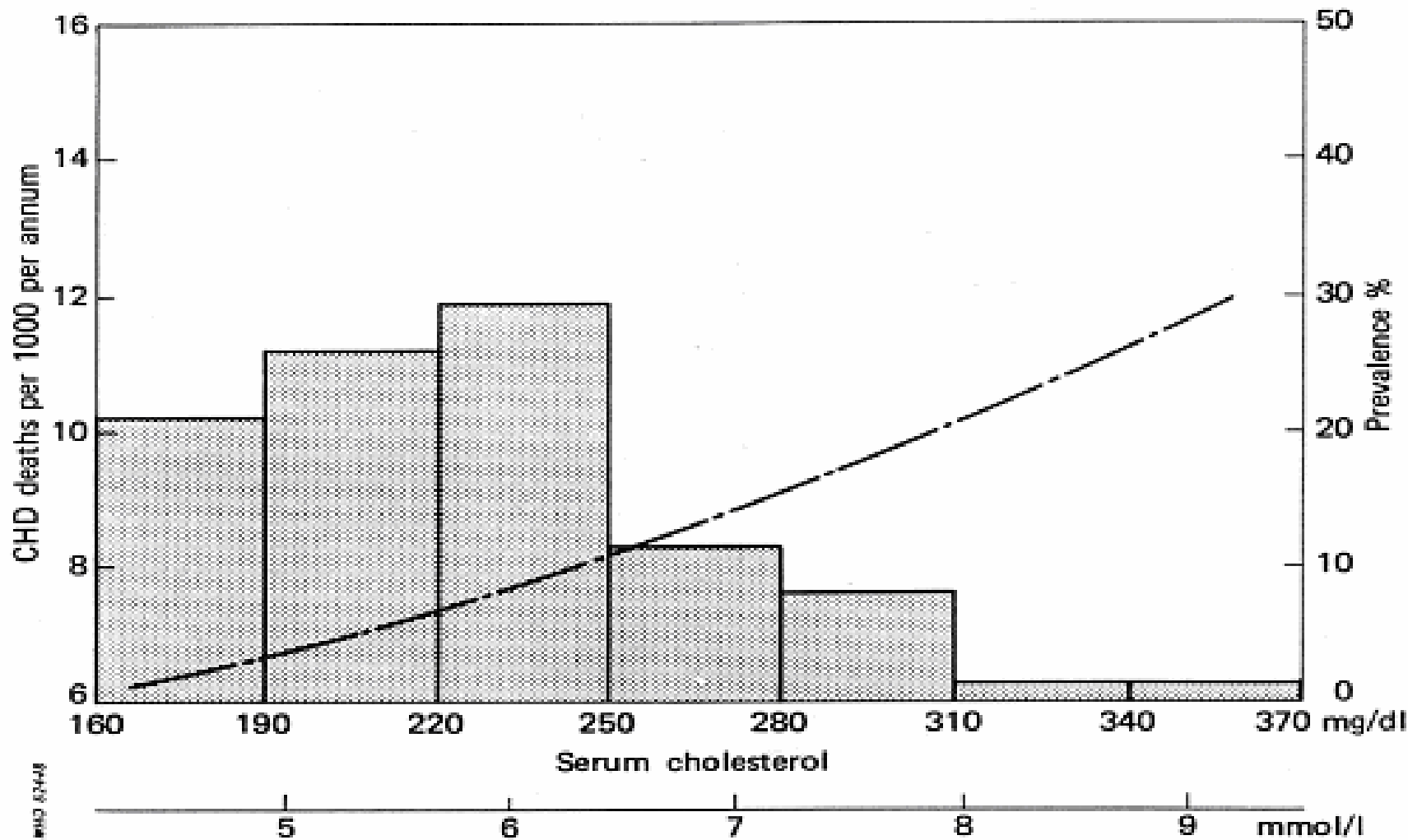
# Extent of detail to collect?

- If lump all unusual situations into 'other' then lose potential to break down into sub-groups
- If coding too detailed, more difficult to question the patient. Analysis may throw up too many categories and may lump all together into 'other' category!

# Discussion points

- Do we want to identify those at extra high risk and compare them with the remainder of the population, or with best group, i.e. in keeping with the NAPS target?
- Do we want to have measure of socioeconomic status across the spectrum?

# Relationship between serum cholesterol (histogram) and mortality from coronary heart disease (interrupted line) in men aged 55-64 years



WHO 82.448

# Occupation

- Most discussion centred on whether or not to include a variable derived from occupation
- All agreed important
- But, how to record without too many questions, so that data was accurate, valid, repeatable
- When analysed, want good distribution of the population into the sub-groups

# Deprivation Index?

- Propose to collect other indicators as well as occupation
- Some variables known to be good proxy for occupation-based classifications e.g. level of education completed
- If put a number of those together and construct an index, would that give information as good as that from occupation?

# Pragmatic or Evidence-based?

- Started from pragmatic perspective
- But recognise major unanswered questions
- Not acceptable to wait for answers to those
- Research in parallel to attempts to collect data

# Purpose of the Exercise

- Decisions re data standards – variables, coding, definitions - depend on why are we doing this?
- Answer: so that we can differentiate between those at different levels of health risk / outcomes, related to a person's 'place in society'

# Challenges



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- Many ....
- Differing views, so what is presented is the best we could agree. What is proposed has not solved all of the challenges
- This work is important.
- We thank you for your input

