Lessons learnt

Three key areas:

1. Power of interdisciplinary research
2. Understanding the clinical significance of research findings
3. Routinely collected data (RCD): Promises and limitations
Routinely collected data (RCD): promises and limitations
What is RCD?

- Data collected for purposes other than research or without specific apriori research questions developed before collection
Uses of RCD

- Disease surveillance
- Monitoring population health and health system performance
- Set up of disease registries e.g. National Hip Fracture registry
- Set up of clinical databases at national, regional or international level
- Identification of health problems
- Hypothesis generating
Benefits of RCD

- Population reach
- Longitudinal
- Cost effective
- Evaluation of outcomes of care where RCTs are unavailable
- Evaluation of impact of policies
Limitations of RCD

- Errors in coding (Measurement bias)
- Incomplete data
- Confounding
- Poor quality data
Garbage In, Garbage Out

YOUR ANALYSIS IS ONLY AS GOOD AS YOUR DATA

\[ f(\text{garbage}) = \text{garbage} \]
Examples of RCD in use

WHO National Tuberculosis Control Programmes:
Diagnoses
Treatment outcomes
Who is accessing treatment
Adverse outcomes
National and district drug forecast and procurement
1. Global burden of disease
2. Gross Domestic Product
3. Years lost to disability
East and Southern Africa (2017)

19.6m people living with HIV
6.8% adult HIV prevalence (ages 15-49)
800,000 new HIV infections
380,000 AIDS-related deaths
66% adults on antiretroviral treatment*
59% children on antiretroviral treatment*

*All adults/children living with HIV

Source: UNAIDS Data 2018
Data rich but information poor!!
Maximising the benefits of RCD

- What potentially useful databases are available?
- Which data items are available in the database?
- Are there alternative and/or innovative ways of using the database?
Publishing the data

- RECORD statement: REporting of studies Conducted using Observational Routinely collected Data
The RECORD statement – checklist of items, extended from the STROBE statement, that should be reported in observational studies using routinely collected health data.

<table>
<thead>
<tr>
<th>Item No.</th>
<th>STROBE items</th>
<th>Location in manuscript where items are reported</th>
<th>RECORD items</th>
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<tbody>
<tr>
<td><strong>Title and abstract</strong></td>
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<tr>
<td>1</td>
<td>(a) Indicate the study’s design with a commonly used term in the title or the abstract (b) Provide in the abstract an informative and balanced summary of what was done and what was found</td>
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**Introduction**

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<td>2</td>
<td>Explain the scientific background and rationale for the investigation being reported</td>
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**Objectives**

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<td>3</td>
<td>State specific objectives, including any prespecified hypotheses</td>
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**Methods**

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<td>4</td>
<td>Present key elements of study design early in the paper</td>
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<td>5</td>
<td>Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection</td>
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<td>6</td>
<td>(a) Cohort study - Give the eligibility criteria, and the</td>
<td></td>
<td>RECORD 6.1: The methods of study population selection (such as codes or</td>
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LET’S GET RECORDING!!