Routinely collected data – a strategic resource for research and policy
Louisa Jorm 22 June 2016

Data live utilitarian lives. From the moment they are conceived, as measurements of some thing or system or person, they are conscripted to the cause of being useful. They are fed into algorithms, clustered and merged, mapped and reduced. They are graphed and charted, plotted and visualized... Always, though, the measure of the life of data is in its utility. Data that are collected but not used are condemned to a quiet life in a database.

Summary

- Value of routinely collected data
- Routinely collected data in health
  - sources
  - benefits and limitations
- Examples of use
  - acute myocardial infarction
  - serious road transport injury
- Priorities and opportunities

Big value in big data

“... making data more widely available in shareable formats... has the potential to unlock large amounts of economic value, by improving the efficiency and effectiveness of existing processes; making possible new products, services, and markets; and creating value for individual consumers and citizens”

Big value in big data

... we estimate the aggregate direct and indirect value of government data in Australia at up to AUD 25 billion per annum... assuming a doubling of accessibility and use, we estimate the return on Australia’s investment in government and research data at around AUD 34 billion per annum
Australian policy climate supports data use

Sources of routinely collected data in health

- By-product of operating health services
  - Hospital inpatient stays, MBS and PBS claims, private health insurance claims
- Meeting regulatory requirements
  - Births, deaths, health practitioner registration
- Monitoring health
  - Cancer notifications, communicable disease notifications, perinatal data
- Produced through operations of “non-health” sectors
  - Child development, education, housing, environment

Benefits of routinely collected data

- Population reach
  - Can be used to study rare outcomes and population subgroups
- Longitudinal (when linked)
  - Supports studies across the lifespan, enables long-term follow-up
- Avoids nonresponse and bias
  - Surveys are increasingly non-viable
- Cost-effective
  - Studies over many decades can be undertaken time- and cost-efficiently
- "Real world"
  - Often the only way to evaluate outcomes of services or interventions where there is no evidence from randomised trials

Limitations of routinely collected data

- Event-based
  - Difficult to define denominators or appropriate comparison groups
- Data quality
  - Relies on correct information being present and entered correctly
  - "Rare" values in large datasets may be more likely to represent keystroke or coding errors than valid entries
- Limited data items
  - Often limited information on confounders and risk factors e.g. smoking, BMI
- Lack of metadata
  - Detailed metadata and other documentation may not be readily or publicly available.

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- Routinely collected data in health
  - Examples of use
    - Disparities in acute myocardial infarction
    - Disparities in serious road transport injury
- Priorities and opportunities

Indigenous Health Outcomes Patient Evaluation (IHOPE)

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IHOPE
Aboriginal health gap

- Life expectancy 11.5 years less for males and 9.7 years less for females
- Estimated that 59% of total burden of disease for Aboriginal Australians could be avoided if they have the same rate of disease burden as the general population (Vos et al, data for 2003)

Aims of IHOPE

Where are the gaps?

In health outcomes
In treatment and access
What is the contribution of:
- Area, SES, Remoteness?
- Hospitals, Health system?

Research focus

- Acute myocardial infarction
- Road traffic injuries
- Unintentional injuries in children
- Cataract procedures
- Otitis media procedures in children
- Potentially preventable hospitalisations
- Breast-conserving surgery
- …

Multilevel modelling

- Models data that are clustered
  - e.g. live in same neighbourhood, go to the same hospital
  - more similar than those in other areas or hospitals because of shared exposure (often unmeasured)
  - can impact on standard errors and parameter estimates if not taken into account
- Particular issue for Aboriginal health research
  - geographic distribution of Aboriginal people in NSW
  - ~40% of Aboriginal people live in major cities compared with ~70% of non-Aboriginal people
Characteristics of people admitted to hospital with AMI

<table>
<thead>
<tr>
<th></th>
<th>Aboriginal</th>
<th>Non-Aboriginal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average age</td>
<td>54 yo</td>
<td>66 yo</td>
</tr>
<tr>
<td>Current smokers</td>
<td>51%</td>
<td>27%</td>
</tr>
<tr>
<td>Private health insurance</td>
<td>16%</td>
<td>45%</td>
</tr>
<tr>
<td>Live in most disadvantaged areas</td>
<td>48%</td>
<td>26%</td>
</tr>
<tr>
<td>First admitted to:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- major city hospital</td>
<td>33%</td>
<td>67%</td>
</tr>
<tr>
<td>- hospital with specialist cardiac facilities</td>
<td>27%</td>
<td>44%</td>
</tr>
</tbody>
</table>

Findings: AMI incidence rates

- The age-standardised incidence of AMI in NSW was:
  - 464 per 100,000 for Aboriginal people
  - 234 per 100,000 for non-Aboriginal people
- An Aboriginal person had 2.1 (2.0-2.2) times the risk of an AMI as a non-Aboriginal person of the same age, sex and year of event, from the same area of residence.

Findings: AMI incidence rates

- The disparity is greatest in younger age groups and for females.

Where are the higher rates for Aboriginal people?

Rates of AMI for Aboriginal people vary by Statistical Local Area, with higher rates generally in regional and rural areas.

Where is the higher disparity for Aboriginal people?

Almost all areas in NSW have a higher incidence of AMI for Aboriginal people compared with non-Aboriginal people.

“High incidence, high disparity” areas
AMI: disparity in revascularisation rates

An Aboriginal person in NSW has a 37% lower hazard of revascularisation within 30 days of AMI than a non-Aboriginal person of the same age, sex, year of admission and AMI type.

Variation between hospitals?

Revascularisation: “unpacking” the gap

Once we compare within hospitals, the disparity reduces - an Aboriginal person has a 18% lower hazard of revascularisation than a non-Aboriginal person of the same age, sex, year of admission, AMI type, admitted to the same hospital.

Comorbidity burden on admission

Aboriginal people have higher rates of these conditions recorded in hospital data than non-Aboriginal people.

Once we adjust for comorbidities the gap is further reduced.
Revascularisation: “unpacking” the gap

<table>
<thead>
<tr>
<th>Age, sex, year, MI type</th>
<th>Hazard ratio (CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>+ Hospital of admission (random effect)</td>
<td>0.63 (0.57, 0.70)</td>
</tr>
<tr>
<td>+ Selected comorbidities</td>
<td>0.82 (0.74, 0.91)</td>
</tr>
<tr>
<td>+ Substance use (incl. smoking, alcohol, drugs)</td>
<td>0.90 (0.81, 1.00)</td>
</tr>
<tr>
<td>+ Private health insurance</td>
<td>0.92 (0.83, 1.02)</td>
</tr>
<tr>
<td>+ Substance use (incl. smoking, alcohol, drugs)</td>
<td>0.96 (0.87, 1.07)</td>
</tr>
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</table>

After adjusting for substance use and private health insurance, there is no longer a significant difference

AMI: Summary

- Aboriginal people on average 4 years younger at first AMI
- Greater disparity in young and women
- Related to hospital of admission and higher rate of comorbidities such as diabetes and renal failure
- Aboriginal people admitted with AMI less likely to get revascularisation
- No difference in 30-day mortality after AMI
- Aboriginal people more likely to die within 1 year

Is there a disparity in injury rates?

<table>
<thead>
<tr>
<th>Injury Type</th>
<th>Aboriginal Rate Higher</th>
<th>Non-Aboriginal Rate Higher</th>
</tr>
</thead>
<tbody>
<tr>
<td>All road transport injuries</td>
<td>1.18 (1.09-1.28)</td>
<td>1.08 (0.99-1.17)</td>
</tr>
<tr>
<td>Small vehicle</td>
<td>1.14 (1.09-1.20)</td>
<td>1.01 (0.94-1.09)</td>
</tr>
<tr>
<td>Pedestrian</td>
<td>1.76 (1.55-1.99)</td>
<td>1.46 (1.39-1.53)</td>
</tr>
<tr>
<td>Bicycle</td>
<td>1.25 (1.19-1.31)</td>
<td>1.18 (1.08-1.28)</td>
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<tr>
<td>Motorcycle</td>
<td>0.89 (0.83-0.97)</td>
<td>0.69 (0.59-0.80)</td>
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Disparities by area

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Bicycle injury rate ratio

- Coffs Harbour (Pt A)
- Kempsey
- Griffith
Conclusions

- Whole-of-population linked routinely collected data and multilevel modelling methods have unique power to explore health disparities
  - “unpack” contributions of personal, geographic, and service factors
  - Identify targets for intervention
- It is essential that geography is taken into account in studies of health disparities
  - especially where there are significant urban-rural differences in the distribution of disadvantaged populations and health services
- The simplest of data linkages hugely increases the value of routinely collected data

Summary - Serious road traffic injuries

Aboriginal people have higher risk of small vehicle injuries in NSW on average, but due to area of residence within areas, there is no difference in risk.

Overall risk for all is highest in regional areas, and safety campaigns and urban interventions are needed to address this.

Where are the gaps?

Within areas, Aboriginal people have higher risk of bicycle and pedestrian injuries.

Targeted interventions needed in high risk areas.

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  - disparities in serious road transport injury
- Priorities and opportunities

Priorities and opportunities

- Address current data limitations
- Link across sectors
- Address barriers to data access and use
  - especially state-national divides
- Involve consumers and patients
- Pre-empt workforce needs

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Limitations of routinely collected data

- FIX: Create a population “spine” (e.g., using Medicare data)
- FIX: Use the data
  - Feedback to data providers
  - Optimize use of technology
- FIX: More interaction between “IT people” and data users
  - Optimize use of technology
- FIX: “Surface” existing metadata
  - Optimize use of technology

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(Click showing unpublished data)
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Medicine is an information profession and the underlying basis of investigation must increasingly include data science.

Harlan Krumholz, 2016