Hospital activity and patient outcomes – some lessons from record linkage

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Nuffield College, March 7 2012
The records – brief statistical summaries of records of hospital admissions [Hospital Episode Statistics] and of deaths [ONS death registrations]

In standard systems – the HES record is made for each admission, and successive records for the same person are not routinely brought together; and the HES records not routinely linked to the person’s death record

Matching - the process of comparing ‘personal identifiers’ on records to decide whether or not the records belong to the same person

Linkage - the process of physically bringing together records that belong to the same person, so that they can be held together and analysed as ‘the person’
Datasets

• Oxford record linkage study – all hospitalisations, all deaths, some birth certificates: 1963-2010 (population 2.5 m – Oxfordshire, Buckinghamshire, Berkshire, Northamptonshire)

• English national linkage of all hospitalisations (HES), all deaths: 1998-2010, and we also have unlinked (and un-linkable) English hospital data from 1968

Examples:

• Trends in hospitalisation; geographical variation...the contribution of record linkage is to count each person once, and once only

• Outcomes following care, eg death rates, re-admission rates, complication rates, and inter-relationships between diseases over time...record linkage to ask ‘what happened next’ questions

• Volume of hospital care used by individuals...the contribution of record linkage is to identify, and sum, successive episodes to give a cumulative measure of care per person
Hospital admission rates for cataract surgery in the Oxford record linkage study (ORLS) area: rates per 100,000 population, 1963–2003.
Time trends: macular degeneration: treatment by injection of anti-vascular endothelial growth factor. For each patient, several injections per year are recommended (at a cost of $1950 per vial)

Hospital admission rates for intravitreal injection (operation code C79.4)

Keenan, Goldacre et al, Br J Ophth 2011
Intra-vitreal injection rate per 100,000 population (age-standardised) in each local authority area:

Range from 0.9 (95% CI 0.2-2.2) to 42.2 (39-45)

Estimated cost to the NHS if/when generally used, at the rate of the ‘high adopters’: £500 million per annum

[Example of cost pressure on the NHS from innovation]
Trend study: Research question - Was the introduction of measles vaccine and/or MMR vaccine associated with an increase in Crohn’s disease in the immunised cohorts?

Answer: no.

Person-based admission rates for Crohn’s disease, counting first admissions, for people aged less than 20 years of age, and 20 years and greater (age-standardised within age groups).
The data by age and period reorganised into birth cohorts:

Relative risk of (hospitalised) Crohn’s disease in cohorts born after, compared with cohorts born before, the introduction of measles vaccine: 0.93 (95 C.I. 0.6 to 1.3)$^1$

Relative risk of (hospitalised) Crohn’s disease in cohorts born after, compared with cohorts born before, the introduction of MMR: 0.95 (95% C.I. 0.84 to 1.08)$^2$

$^1$ Journal of Epidemiology and Community Health 2003; 57: 883-887

$^2$ BMJ 2005; 330: 1120-1
MMR The facts

MMR news

11-Dec-03: Study confirms measles vaccine in this country played no part in causing Crohn's Disease


A new study has confirmed that the introduction of measles vaccine in this country played no part in causing Crohn's Disease and Ulcerative colitis. The theory that measles vaccine was linked to bowel disease and then autism depended on a belief that measles virus damaged the bowel. This study adds to the available evidence that says that this is not the case.


To view entire paper:

http://jech.bmjournals.com/cgi/content/... (Long link)
Mumps cases that were serious enough to result in hospitalisation… epidemics pre-1988, fall to about zero by 1990, back up to epidemic levels in 2004/5
Trend study: Are serious road traffic injury rates in England really falling? Rates per year from Police Statistics – the official record

[PSA target to reduce KSI by 40% from 1996-2010]

[Definition of ‘seriously injured’ includes all injuries that resulted in hospitalisation]
Trend study: Are serious road traffic injuries in England really falling? Rates per year from Police Statistics and Hospital Admission Statistics

(Gill M, Goldacre MJ, Yeates DGR. British Medical Journal 2006, 333:73-75)

The DfT argued (among other things) that there must have been an increase in ‘multiple admissions per person injured’. Not so, as shown by linkage. The police statistics under-estimate the scale of injuries; and the scale of under-estimation has widened over time.

[n.b. the forthcoming creation of Public Health England in the civil service]
Geographical variation
Diabetes mellitus: average annual admission rates per 100,000 population (age-standardised, and person-based)

<table>
<thead>
<tr>
<th>English local authority areas</th>
<th>Rate</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chiltern</td>
<td>29</td>
<td>(24-34)</td>
</tr>
<tr>
<td>York</td>
<td>47</td>
<td>(43-52)</td>
</tr>
<tr>
<td>Manchester</td>
<td>221</td>
<td>(214-228)</td>
</tr>
<tr>
<td>Nottingham</td>
<td>255</td>
<td>(247-264)</td>
</tr>
</tbody>
</table>

Reasons for variation: variation in incidence/prevalence; clinical thresholds for referral/admission; etc

Consequences of variation: costs; clinical quality; etc
General medical specialties: local authorities’ IMD scores plotted against their person-based age-standardised admission rates
Surgical specialties: local authorities’ IMD scores plotted against their person-based age-standardised admission rates

General surgery all admissions: average IMD score plotted against the FCE-based rate for each Local Authority, both sexes

\[ y = 0.0047x - 0.4971 \]

\[ R^2 = 0.1748 \]
The prevalence of multiple sclerosis increases with increasing distance from the equator in both hemispheres. Geographical distribution of admission rates of MS in England (linked to provide rates based on people):
Relative risk for multiple sclerosis admission by region, deprivation quintile of the local authority areas within each region, and LA place of birth quintile; and relative risk for each factor after adjusting for the other two

<table>
<thead>
<tr>
<th>Regions (9)</th>
<th>Unadjusted RR</th>
<th>Adjusted RR</th>
<th>Lower 95% CI*</th>
<th>Upper 95% CI*</th>
</tr>
</thead>
<tbody>
<tr>
<td>North of England</td>
<td>1.23</td>
<td>1.19</td>
<td>1.11</td>
<td>1.28</td>
</tr>
<tr>
<td>London and South East</td>
<td>1.00</td>
<td>1.00</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Index of Multiple Deprivation quintiles</th>
<th></th>
<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td>least deprived</td>
<td>1.01</td>
<td>1.08</td>
<td>1.01</td>
<td>1.16</td>
</tr>
<tr>
<td>most deprived</td>
<td>1.00</td>
<td>1.00</td>
<td></td>
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</table>

<table>
<thead>
<tr>
<th>Percentage born outside UK quintiles</th>
<th></th>
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</thead>
<tbody>
<tr>
<td>lowest % born out of the UK</td>
<td>1.24</td>
<td>1.12</td>
<td>1.04</td>
<td>1.20</td>
</tr>
<tr>
<td>highest % born out of the UK</td>
<td>1.00</td>
<td>1.00</td>
<td></td>
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</tr>
</tbody>
</table>

*CIs for the adjusted relative risk (RR)

(Ramagopalan et al, JNNP 2011, 82:682-687)
Outcome studies
Explaining the downward trend in population-based mortality rates for myocardial infarction: a decline in incidence or a decline in case-fatality?

Acute myocardial infarction: trends in sudden AMI death per 100,000 population, 1999-2007 [Kate Smolina et al BMJ 2012]
Explaining the downward trend in population-based mortality rates for myocardial infarction: a decline in incidence or a decline in case-fatality?

Acute myocardial infarction: trends in case-fatality rates in patients admitted to hospital with AMI, 1999-2007 [Kate Smolina et al]
Fewer smokers and better care mean...

HEART ATTACK DEATHS HAVE HALVED IN 8 YEARS

DEATHS from heart attacks have halved in less than a decade, a study has found.

Experts say the dramatic decline has been fuelled by fewer people smoking and better treatment in NHS hospitals. Improvements to diet and diabetes - both key risk factors. The conclusions come from a study by Oxford University academics, which found the death rate from heart attacks between 2002 and 2010 fell by 50 per cent in men and 53 per cent in women.

Researchers were attempting to discover whether the drop was driven by prevention through

Turn to Page 2
Salute to the NHS

AMID all the pessimism over the NHS comes a truly remarkable achievement. Thanks to better treatment, and effective messages about healthier lifestyles, deaths from heart attacks have halved in eight years. The Mail salutes the professionals on this giant step towards conquering Britain’s biggest killer.
Trend in standardised 365 day all cause mortality ratio for all people discharged from hospital with principal diagnosis of bipolar disorder or schizophrenia.*

(* Shows that SMRs for people with schizophrenia or bipolar disorder are actually increasing)

Hoang U, Stewart R, Goldacre M. BMJ 2011;343:bmj.d5422
All cause mortality rate within 365 days after discharge per 1000 people discharged with principal diagnosis of schizophrenia by age.

Hoang U, Stewart R, Goldacre M.. BMJ 2011;343:bmj.d5422
Survival curves for patients with inflammatory bowel disease, over three years after hospital admission (BMJ 2007, 335, 1033-7)

[shows worse survival for people admitted but not operated on than for people admitted for elective operation]

[raises question of whether the surgical threshold is too high]

Fig 2 | Relative survival during three years after elective colectomy, emergency colectomy, and no colectomy in England
Outcome Study: international comparison. Case-fatality rates within 30 days of elective operation for aortic abdominal aneurysm

- England, national data linkage: 6.8%
- World literature - 66 studies

[Filipovic et al, J Epidem Community Health 2007, 61, 226-231]
Case fatality rates after elective surgery for abdominal aortic aneurism, comparing English national rates (x) with those from elsewhere.

[shows that post-operative mortality in England is higher than that in most published studies]
‘Disease association’ studies
Does head injury predispose to multiple sclerosis? No¹

Is infectious mononucleosis a risk factor for multiple sclerosis? Yes²

¹ Journal of Neurology, Neurosurgery & Psychiatry 2006, 77, 351-353
² J Epidemiol & Community Health 2004, 58, 1032-1035
Does cholecystectomy predispose to colon cancer?  No¹

Does hip arthroplasty increase the risk of cancer?  No¹

¹ Epidemiology and Infection 2009, 137, 672-680
² Br J Cancer 2005, 92, 1307-1309
³ Br J Cancer 2005, 92, 1298-1301
Disease Association “safety” Studies from ORLS

Does abortion predispose to breast cancer? No\(^1\)

Does vasectomy predispose to prostate or testicular cancer? No\(^2\)

Does vasectomy predispose to coronary heart disease or stroke? No\(^2\)

Does vasectomy predispose to immune-mediated diseases? No\(^3\)

\(^1\) JECH 2001, 55, 336-337
\(^2\) Fertility & Sterility 2005, 84, 1438-1443
\(^3\) Human Reproduction 2007, 1273-1278

Some practical points about record linkage as a method:
• Completely non-intrusive [should be an Ethics Committee’s delight!]
• No burden on subjects
• Retrospective cohort using data that are already collected – results available quickly, with long follow up
Disease association study (example): Controversy about whether interruption of pregnancy – especially through abortion - increases the risk of breast cancer

• Most studies have been interview-based case-control studies

• Reporting bias?

• Are women with breast cancer more likely than controls to tell the interviewer if they have had an abortion?

• Reporting bias is impossible in studies based on the linkage of prospectively-recorded, independently-compiled records
Breast cancer and abortion: collaborative reanalysis of data from published studies*, showing relative risk (RR) of breast cancer in women who have undergone abortion compared with others

Induced abortion recorded prior to, and independently of, breast cancer.
Record-linkage and cohort studies: RR = 0.93 (0.89 to 0.97)¹

Self-reported induced abortion, reported after diagnosis of breast cancer
Interview-based case-control studies: RR = 1.11 (1.06 to 1.16)²

Equivalent RR’s for spontaneous abortion:
¹RR = 0.98 (0.92 to 1.04)  ²RR = 0.98 (0.94 to 1.02)

*Collaborative group on hormonal factors and breast cancer, Lancet 2004; 363: 1007-16
First three years of Urabe MMR vaccine: was it causing aseptic meningitis?

**Answer:** Yes*.

**Method:** Oxford record linkage of hospital records of aseptic meningitis to immunisation records.

**Policy implication:** One of several strands of evidence which led DH to change type of MMR vaccine in the national programme (from Urabe to Jeryl Lynn).

* Lancet 1993, 341, 979-982

[This study would be much harder to do now than it was then…data protection/privacy etc]
ORLS and All-England studies: Rate ratios (and 95% CIs) for pneumococcal disease\(^1\) in people with chronic diseases

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<thead>
<tr>
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<tbody>
<tr>
<td>Asthma</td>
<td>2.8 (2.6-3.0)</td>
<td>2.8 (2.6-3.0)</td>
<td>2.7 (2.67-2.74)</td>
</tr>
<tr>
<td>COPD</td>
<td>3.1 (2.9-3.4)</td>
<td>4.1 (3.9-4.3)</td>
<td>4.2 (tiny)</td>
</tr>
<tr>
<td>Diabetes</td>
<td>1.8 (1.6-2.0)</td>
<td>2.0 (1.7-2.3)</td>
<td>1.9 (tiny)</td>
</tr>
<tr>
<td>Rheumatoid arthritis</td>
<td>2.3 (2.0-2.6)</td>
<td>2.4 (2.2-2.6)</td>
<td>2.5 (tiny)</td>
</tr>
</tbody>
</table>

\(^1\) for which there is now a vaccine

*
Risk of venous thromboembolism in people with psoriasis, systematic lupus erythematosus (SLE), polyarteritis nodosa, compared with control population and expressed as rate ratios

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<thead>
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</thead>
<tbody>
<tr>
<td>Psoriasis</td>
<td>1.6 (1.3-1.9)</td>
<td>1.7 (1.2-2.2)</td>
<td>1.7 (1.6-1.8)</td>
</tr>
<tr>
<td>SLE</td>
<td>3.6 (2.4-5.3)</td>
<td>4.6 (3.2-6.4)</td>
<td>3.7 (3.4-4.0)</td>
</tr>
<tr>
<td>Polyarteritis</td>
<td>2.9 (1.7-4.6)</td>
<td>4.4 (0.9-12.8)</td>
<td>3.5 (2.8-4.4)</td>
</tr>
</tbody>
</table>
Risk of breast cancer in women following discharge from hospital with benign breast disease, by years from BBD discharge

<table>
<thead>
<tr>
<th>Years after BBD</th>
<th>ORLS, Rate ratio</th>
<th>England Rate ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-4 y</td>
<td>2.4 (2.0-2.8)</td>
<td>2.3 (2.1-2.5)</td>
</tr>
<tr>
<td>5-9 y</td>
<td>2.0 (1.7-2.4)</td>
<td>2.0 (1.6-2.4)</td>
</tr>
<tr>
<td>10-19 y</td>
<td>1.8 (1.6-2.0)</td>
<td>-</td>
</tr>
<tr>
<td>20+ y</td>
<td>1.5 (1.2-2.0)</td>
<td>-</td>
</tr>
</tbody>
</table>

(Journal of Public Health 2010, 32, 565-571)
Risk of breast cancer in women following discharge from hospital with benign breast disease, by months from BBD discharge –

Number of observed and expected cases, and rate ratios

<table>
<thead>
<tr>
<th>Months after BBD</th>
<th>Obs.</th>
<th>Exp.</th>
<th>RR</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;1 month</td>
<td>299</td>
<td>44.1</td>
<td>7.7</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>(6.8-8.7)</td>
</tr>
<tr>
<td>1-11 months</td>
<td>612</td>
<td>151.6</td>
<td>4.5</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>(4.1-4.9)</td>
</tr>
</tbody>
</table>

(Journal of Public Health 2010, 32, 565-571)
What happened?*

1. Woman discharged knowing she had breast cancer, wrongly recorded in the case notes as BBD?

2. Woman discharged without diagnosis, BBD assumed for case notes at discharge, woman told very soon after discharge?

3. Woman discharged having been told she had BBD, only to be re-called?

* It would be good to find out, by going back to the case notes, GP or indeed the woman, but not possible
‘Volume of care’ studies, adding up time spent in care in successive episodes of care
Volume of care study (1):
Use of health care by the elderly

- The elderly are heavy users of health care
- Regardless of age at death, care in the last few months of life tends to be heavy
- Increased use of health services by the elderly may result from their being closer to death than young people
- Which is the more powerful determinant of use of hospital care – age or proximity to death?*

*Hospital care for the elderly in the last year of life. BMJ 1990, 301: 17-19
*Does time spent in hospital in the final 15 years of life increase with age at death? BMJ 1999, 319: 1338-1339
Cumulative use of hospital care (converted into mean costs per person): people in the 365 days before death, and use of care (and costs) in a 365 day period by those of the same age, at the same time, who did not die.

(Source: Scottish record linkage. Evidence to the Treasury Review of Health Trends)
Summarising on ageing:

- Typically, there is a ‘high cost’ of dying

- Proximity to death is a stronger determinant of hospital use, and costs, than age

- Elderly people are heavy users of hospital care, but this is largely because most people now die in old age

- The increase in longevity itself may place less of a burden on hospital services than expected
Volume of care study (2): Time spent in hospital in the last year of life, comparing heart failure patients with cancer patients*

- Setting: ORLS area, 3 year period

- Mean total number of bed-days in the last year of life

  Heart failure: 20.2 days per person
  Cancer (all): 20.5 days per person
  Lung cancer 15.9 days
  Bladder cancer 30.4 days

Weaknesses and strengths of routine data

Weaknesses

• may not include the data you want
• may be issues about reliability
• will be issues about referral biases in hospital data; and lack of data on confounding

Strengths

• available
• enhanced by linkage, systems may become incredibly versatile
When we reflect upon the great number of institutions for the treatment of disease which exist in this country, the gratification arising from the thought of how much suffering might be saved and affliction relieved by them, is mingled with regret that so vast a source of information on the history of disease and the results of therapeutical treatment should be lost to mankind.
Landmarks in vital statistics

• Systematic recording in individual records
• Routine aggregation and analysis of records
• Linkage of records
• Unprecedented power in affordable information processing and dissemination