Using secondary data to cross the quality chasm…
…dilemmas in implementation
.. don’t just rely technology + policy

Presented to
AMIA Secondary Use of Health Data Conference

Presented by
Simon de Lusignan

14th June 2007
Overview

• About me / Ground talk in “real” UK practice
  • How my practice collect clinical data + provides $2^0$ clinical data
  • Using $2^0$ clinical data in research

• Assumptions
  • There is a quality chasm in healthcare
    ▪ We want to cross!
  • Acknowledge there is a role for:
    1. Legislation
    2. Technical security measures

• Professionalism + ethical guidance
  • Human factors: Organisational culture, Personal + Professional
  • Caldicott Guardians + UKCHIP as exemplars

• Developing the White paper (Safran et al., JAMIA 2007)
  • First Law of Informatics & context

• Conclusions
About me

• GP in Guildford
  • 11,500 patient practice
  • 6.5 Whole time equivalent GPs
  • Computerised since 1990
  • PHCT >30 people “write” in the EPR
  • Health Service management – Surrey PEC

• Academic GP, St. Georges – University of London
  • Head of General Practice & Primary Care

• Informatics research + Teaching
  ▪ Research – using routinely collected data for QI – the consultation
  ▪ Teaching – First full-time undergraduate degree course in UK
• Chair PCI WG of EFMI
Secondary use of clinical data

Data provided to data bases

1. RCGP Spotter practice
   www.rcgp.org.uk/bru
2. Q-Research
3. Ad hoc research projects

Public Health Notification of disease
Prescribing + referral data

Health service management
QOF – Quality based payments

Inspection, appraisal & Re-validation
On-line GP quality scores
http://www.qof.ic.nhs.uk/

SEARCH FOR GP PRACTICE:

Search for your GP practice by typing in a single word: e.g., city, town or district name, practice name, street name, first part of the postcode or the practice code. For example: grantham, oakley or LS11.

Search for GP practice...

PRACTICES FOUND IN:

GUILDFORD (1)

Practices matching your search word have been found in the above location. The number in brackets following the location indicates the number of all the practices in that location.

Results summary  Practice results summary

Detail page: 1. DE LUSIGNAN S & PARTNERS of 1

TOTALS:

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<thead>
<tr>
<th>Percentage of total</th>
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<tbody>
<tr>
<td>Total Achieved Results</td>
<td>1,037.31 out of 1,050 points</td>
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<td>Total Clinical Results</td>
<td>533.73 out of 550 points</td>
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CLINICAL INDICATOR GROUPS:

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<tr>
<td>Asthma 7 indicators</td>
<td>67.83 out of 72 points</td>
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<td>Cancer 2 indicators</td>
<td>12.00 out of 12 points</td>
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<td>Chronic obstructive pulmonary disease 8 indicators</td>
<td>45.00 out of 45 points</td>
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<td>Coronary heart disease 12 indicators</td>
<td>100.92 out of 101 points</td>
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<td>Diabetes mellitus 16 indicators</td>
<td>97.55 out of 99 points</td>
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<td>Epilepsy 4 indicators</td>
<td>15.93 out of 16 points</td>
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<td>Hypertension 5 indicators</td>
<td>99.74 out of 105 points</td>
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Research using routine data

- Data quality completeness, accuracy, currency, fit for purpose?
- Data aggregation from one brand of GP system
  - EMIS – Q-research
  - IPS (originally VAMP Vision*) – GPRD
  - iSoft (originally AAH Meditel*, then Torex)
    - IMS + DIN
  *Initially part of a “Free computers for GPs” Scheme 1987
    http://www.primis.nhs.uk/informatics/jan97/jan2.htm
- International data collection networks
- Combining data from many systems
  - MIQUEST / HQL Common interface for multiple systems

For debate

- Assumptions

- Essential elements for implementation
Assumptions:

1. There is a “Quality chasm” we want to cross

2. Secondary use of clinical data can help

3. Legislation + policy provide useful frameworks

4. Investment in technology to enhance security is also useful
Implementation

• Human / professional aspects are important
  • Organisations – need to embed secure practice within its working practices
  • Personal – need to own responsibility + have increased awareness of risk
  • Professionalism (Trust) – senior clinicians + informaticians

• Exemplar
  • Caldicott Guardians (or Steward?)
    ▪ Similar but clinician centric – not patient consent
  • UK CHIP

Caldicott Guardians

• Caldicott report 1997
  • **Principals for use of identifiable data:**
    ▪ Justify – Necessary – Minimum – Access control – Personnel understand responsibilities – Legal compliance

• Senior clinician / person responsible for clinical governance in NHS
  • **Preceded Data Protection / Human Rights / Freedom of Information Acts**

• Strengthened by UK Caldicott Guardian Council 2005
• Extended to social care

Aim to ensure informatics professionals have an agreed Code of Conduct

Provides a publicly visible register

UKCHIP www.ukchip.org.uk

UKCHIP REGISTRATION

PUBLIC REGISTER

The UKCHIP online public register allows you to check that a health informatician is on our register. It is linked directly to our database, which means that any changes we make to a registrant’s information are shown immediately on the register.

Registration with UKCHIP is currently voluntary and inclusion on the register shows that a health informatician meets our standards for registration levels and agrees to work to our code of conduct.

You can search for a complete name or a string of letters, which will show all those names containing that string. You may also have to search for alternate spellings such as Clark/Clarke, Smith/Smythe, Potter-Harrop / Harrop to ensure all potential matches are found. If you do not find the person you are looking for then please email registrar@ukchip.net, with all the details you know, to check a registration.

The register shows the date each registrant’s current registration ends. Registrants have up to four weeks after the renewal date in which to renew their registration. The date does not indicate how long a registrant has been on the register in total. If you would like information regarding a registrant’s previous registration dates please email the Registrar on registrar@ukchip.net.

SEARCH CONSTRAINTS

Surname: [Input]
Forename: [Input]

To apply for registration with UKCHIP go to the online registration site.

RETURN TO UKCHIP HOME PAGE

14th June 2007
Developing the white paper
(Safran et al., JAMIA 2007)

- Understand context in which data is collected
Context is key

• **First Law of Informatics** (van der Lei J. Methods 1991)
  - “Data can only be used for the purpose for which it is collected”

• **Overcoming the first Law (Maybe a 2nd Law)**
  - Understand the context (Clinician using the system)
  - Know the technical details of how data are collected + recorded

• **UK examples about data quality/validity:**
  - Two versions of same computer system different drug dictionaries
  - Picking list read the same coding system differently
  - “Ballistic loading” accentuate inter-practice differences
  - Influence of being on the “QOF” list in a consultation

Variable views of the same clinical concept

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<th>Entry</th>
<th>MYOCARDIAL INFARCTION</th>
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<tr>
<td>Select option. &lt;Return&gt; to alter synonym :</td>
<td>MNL</td>
</tr>
<tr>
<td>A Acute myocardial infarction</td>
<td>G30</td>
</tr>
<tr>
<td>B MI - acute myocardial infarct</td>
<td>G30-5</td>
</tr>
<tr>
<td>C Inferior myocardial infarction NOS</td>
<td>G308</td>
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<tr>
<td>D FH: Myocardial infarction</td>
<td>12C5</td>
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<tr>
<td>E Anterior myocardial infarction NOS</td>
<td>G3012</td>
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<tr>
<td>F Old myocardial infarction</td>
<td>G32</td>
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<tr>
<td>G Other specified anterior myocardial infarction</td>
<td>G301</td>
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<tr>
<td>H H/O: myocardial infarct &gt;60</td>
<td>14A4</td>
</tr>
<tr>
<td>I ECG: myocardial infarction</td>
<td>323</td>
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<tr>
<td>J H/O: myocardial infarct &lt;60</td>
<td>14A3</td>
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<tr>
<td>K Silent myocardial infarction</td>
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**Keyword Search**

Search Text: MYOCARDIAL INFARCTION

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<td>ACUTE myocardial infarction</td>
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<td>Old myocardial infarction</td>
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<td>ECG: myocardial infarction</td>
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<td>Inferior myocardial infarction NOS</td>
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<td>Myocardial infarction aborted</td>
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<td>Coronary thrombosis not resulting in myocardial infarction</td>
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<td>Subsequent myocardial infarction</td>
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<td>Postoperative myocardial infarction</td>
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<td>[(Y)Observation for suspected myocardial infarction</td>
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<td></td>
<td>Myocardial infarction aborted</td>
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Page 1 of 5
Summary
Summary

• Legislation + policy are important in ensuring the safe secondary use of data

• However there is also a role for:
  • Trusted senior clinician to act as “Guardian” or “Steward” for these data
  • An accountable Informatician to minimise risk
  • Working within an appropriate ethical framework

• The wrong conclusions may be drawn from secondary data unless
  • Clinical context of recording is fully understood
  • Technical complexity is recognised
  • Understand the quality of the data
Conclusion

• Clinicians + informaticians are the mountain guides working within ethical frameworks

...To help us cross the quality chasm
The End – thanks for listening

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www.sgul.ac.uk/informatics/

14th June 2007