Use of routinely collected electronic healthcare data – lessons learnt

ENCePP Plenary

25 November 2014

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Strategic Data

Alison Bourke, CSD Medical Research UK

Some things I know about collection of primary care data in the UK

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Agenda

→ History

→ Lessons learnt
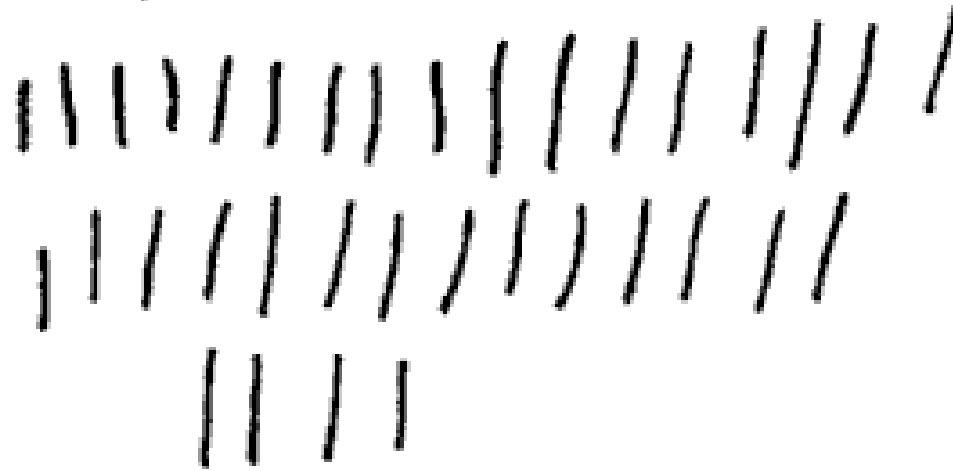
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History

→ Early 1980s – Start of GP computerisation

→ 1984 – Capoten PMS using teletext at Squibb

→ 1987 – Launch of VAMP "no cost option scheme"

   – Collection of pseudonymised GP data for research

→ 1993 – VAMP Research Bank moved to DoH & became GPRD (General Practice Research Database)

→ 1994 – EPIC formed by Alan Dean (former founder of VAMP)

→ 2002 – THIN established

→ 2005 – EPIC became part of Cegedim which also owns INPS (formerly VAMP)

Summary – Same data, same aims, same people

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YEARS

LESSONS LEARNED

| | | | | | | |

- Data
- Infrastructure

Lessons Learnt about Data

- ✓ Quality – data provider motivation
- ✓ Format – flexibility
- ✓ Completeness – context sensitive
- ✓ Quality – subjective ie need to be able to describe:-
  - Completeness
  - Consistency
  - Accuracy/validity

Lessons Learnt about Infrastructure

✓ People/staff – focus on quality 1st and client expectation 2nd

✓ Programming/Code lists – multidisciplinary

✓ Testing – rigorous testing & QA

✓ Documentation – clear & detailed for transparency & reproducibility

✓ Confidentiality – vital but "identifiability" is not absolute, benefit/risk

"Quality is in the eye of the beholder"

Any questions?

Thank you
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