Clinical trials and administrative data: a marriage proposal

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Background

- Long term follow up is an essential component of clinical trials in chronic diseases including cancer
- Both benefits and adverse effects of interventions may take years to emerge
- Traditional clinical trial approach has been to follow patients actively, scheduling appointments at the relevant specialty centre

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Background

- Traditional approach is becoming challenging
  - Follow up care is moving to the community
  - Costs of bringing patients to a centre solely to obtain clinical trial data are substantial
  - Centres are unable to cover these costs and academic clinical trial sponsors can't afford them
- NCIC CTG must explore different options for long term follow up

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Could administrative databases in Ontario be used for long term clinical trial follow up?

Feasible?

Acceptable?

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ICES Probabilistic Data Linkage

Research question has two components

- Can we use identifiers held by NCIC CTG to link to individuals in ICES databases?
- If so, can we match trial outcome data?

Probabilistic Data Linkage

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- CO17 and CO20: randomized phase 3 clinical trials in patients with metastatic colorectal cancer

ICES

- CIHI-DAD, CIHI-SDS, CIHI-NACRS, OHIP, RPDB, OCR, OBSP

Using

- birth date*, patient initials*, gender, diagnosis site, date of diagnosis, histology

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Preliminary data presented on linkage results: publication to follow

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Survey of patient preferences around data linkage

- Self administered survey of cancer out-patients
- Based on hypothetical scenario of clinical trial participation
- University Hospital Network & Cancer Centre of Southeastern Ontario
- Goal to determine patient's attitudes to
  - Research access to administrative databases
  - Sharing identifiers to facilitate linkage

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Preliminary data presented on survey results: publication to follow

Conclusions

- Majority of cancer patients in Ontario
  - support linkage
  - would be willing to provide identifiers to facilitate
- Probabilistic linkage has 90% success rate
  - OHIP number would optimize
  - analyses ongoing

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Considerations

- Balance between
  - protecting patient privacy and
  - facilitating research to improve patient outcomes
- Possible to extend into other jurisdictions?
- Ready to incorporate ‘administrative follow-up’ into existing and future clinical trials?

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Thank you

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