

**Presentation to the
Annual SHIP Retreat 2012**



**Opportunities for
Record Linkage Today
& Tomorrow**

***But will the
Obstacles Prevail?***

D'Arcy Holman



**THE UNIVERSITY OF
WESTERN AUSTRALIA**

“This morning I am speaking on behalf of a group concerned with record linkage in the North-East of Scotland ... I would like to deal with the practical problem of introducing record linkage into an existing service and particularly with the difficulty of making certain that the costs of record linkage are seen to be justified.

The immediate needs have been, firstly, a reorganization of patient identification on a regional scale making certain that enough information is being collected; secondly, an improvement in the methods of recording; and, thirdly, a study of the feasibility of linkage and its likely costs.

It would now appear that we have misjudged our priorities and are in danger of being accused either of proposing facilities we cannot fully justify or, if successful, of developing facilities we will be unable to exploit.

It would not be far from true to say that record officers, clinicians and administrators are neither willing, ready nor able to utilize record linkage, and this has very serious implications.”



THE INTRODUCTION OF RECORD LINKAGE IN NORTH EAST SCOTLAND

R. DEANS WEIR

THE first point that I must make is that this morning I am speaking on behalf of a group concerned with Record Linkage in the North-East of Scotland, and this includes many people outside the three research units which function in this area. I would like to deal with the practical problem of introducing record linkage into an existing service and particularly with the difficulty of making certain that the costs of record linkage are seen to be justified.

Certainly so far as Aberdeen was concerned there were few problems in convincing people about the ultimate benefits and need for record linkage, and the fact that this was coupled with a population of manageable size in an area with certain geographical and administrative advantages was encouraging. Plans for the phased introduction of linkage were produced and approved. It was agreed that the immediate needs were firstly, a reorganization of patient identification on a regional scale making certain that enough information was being collected; secondly, an improvement in the methods of recording and, thirdly, a study of the feasibility of linkage and its likely costs. No one knew what this would involve; initially it might involve more cost and perhaps no saving at all because if the system could then do more, more would be asked of it and as a result running costs would be even greater. Paradoxically the advantages of linkage were at the same time likely to be the greatest drawbacks to its introduction. Simply to argue that the system would be more efficient is not enough.

The means by which record linkage could be used and exploited seemed at that time obvious and therefore of less importance and their consideration was postponed. It would now appear that we have misjudged our priorities and are in danger of being accused either of proposing facilities we cannot fully justify or, if successful, of developing facilities we will be unable to exploit.

The purpose of record linkage is to bring together reliable and related items of information. Techniques to achieve this goal will very soon be available, and it will be possible to apply these techniques if wished on a national scale. Against this is the cost and the fact that we are not in a position to make use of such facilities. It would not be far from true to say that records officers, clinicians and

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Record Linkage in Medicine

Proceedings of the International
Symposium, Oxford, July 1967

Edited by

E. D. Acheson



E & S Livingstone Ltd

Dr RD Weir, Dept Pub Health & Soc Med, University of Aberdeen

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Program Handbook

2012

International Data Linkage Conference

2-4 May 2012

Perth, Western Australia

www.datalinkage2012.com.au

Hosted by



Government of Western Australia
Department of Health

Advancing knowledge
for better health and
social outcomes

The Gatherings

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E & S Livingstone Ltd

- **Oxford UK, 1967.**
- **Hosted by Oxford Regional Hospital Board.**
- **118 participants and 29 papers from 8 countries.**
- **Speakers incl. Acheson, Newcombe, Doll.**
- **2 Scottish papers (Weir, Heasman).**

Program Handbook

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Advancing knowledge
for better health and
social outcomes

- **Perth Australia, 2012 (45 years later).**
- **Hosted by Data Linkage Australia consortium (WA).**
- **365 participants and 132 papers from 13 countries.**
- **Speakers incl. Stanley, Martens, Goldacre, Ford.**
- **3 Scottish papers (Frank, McGilchrist, Sethi).**

1967: Today's Agenda



1. **Establishment**/development of data linkage systems 8
2. Methods of data **matching** (probabilistic, deterministic) 7
3. Epidemiologic **applications** to health problems 5
4. **Genealogical** data linkage (pedigrees, families/sibships) 5
5. **Confidentiality** and legal issues 3
6. Extending data linkage to **education** sector 1

Total papers = 29



1967: Tomorrow's Aspirations

(One interpretation)



- ❑ Prove **utility** of data linkage to inform policy & practice and also assist in health service operations [eg, identifying high risk individuals; early warning of ADRs].
- ❑ Use in **aetiologic** research [eg, cohort studies for chronic disease; disease correlation studies; twin and other genetic studies].
- ❑ Use in disease **surveillance** [eg, birth defects, chronic diseases].
- ❑ **Automation** of data linkage to reduce manual processes.
- ❑ Enabling **legislation** to mandate national data linkage.



1997: The Obstacles

(One interpretation)



- ❖ Lack of **credibility** and interest due to little or not track record.
- ❖ Some politically **hostile** clinicians and service administrators.
- ❖ **Confidentiality** interests [eg, doctors' fears of litigation].
- ❖ **Non-existence** of data [eg, beyond hospitals, births & deaths].
- ❖ **Paper records**; not 'machine-coded' data.
- ❖ **Poor quality** data [identifiers, key clinical fields].
- ❖ Inadequate **computing** power [eg, 40K RAM was a boast!].
- ❖ Clunky, ad hoc **software**.
- ❖ Unaffordable **cost** [eg, £30,000 + £7,000 pa in NE Scotland].



2012: Today's Agenda

1. Epidemiologic applications to health problems	44
(CVD, cancer, diabetes, aging, pharmaceuticals, injury)	
2. Governance and security (controls, anonymisation, delivery)	19
3. Early childhood education, protection & health	16
4. Quality of data & links (missing, coding, linkage errors)	12
5. Development of (mostly) national data linkage systems	10
6. Privacy and legal issues	7
7. Benefits of successful data linkage systems	6
8. Ancillary methods (ascertainment algorithms, visual)	5
9. Methods of data matching (cyphers, encrypted, ecological)	5
10. Consumer/community participation	4
11. History	2
12. Housing and health	1
13. Training	1

Total papers = 132



2012: Tomorrow's Aspirations

(One interpretation)



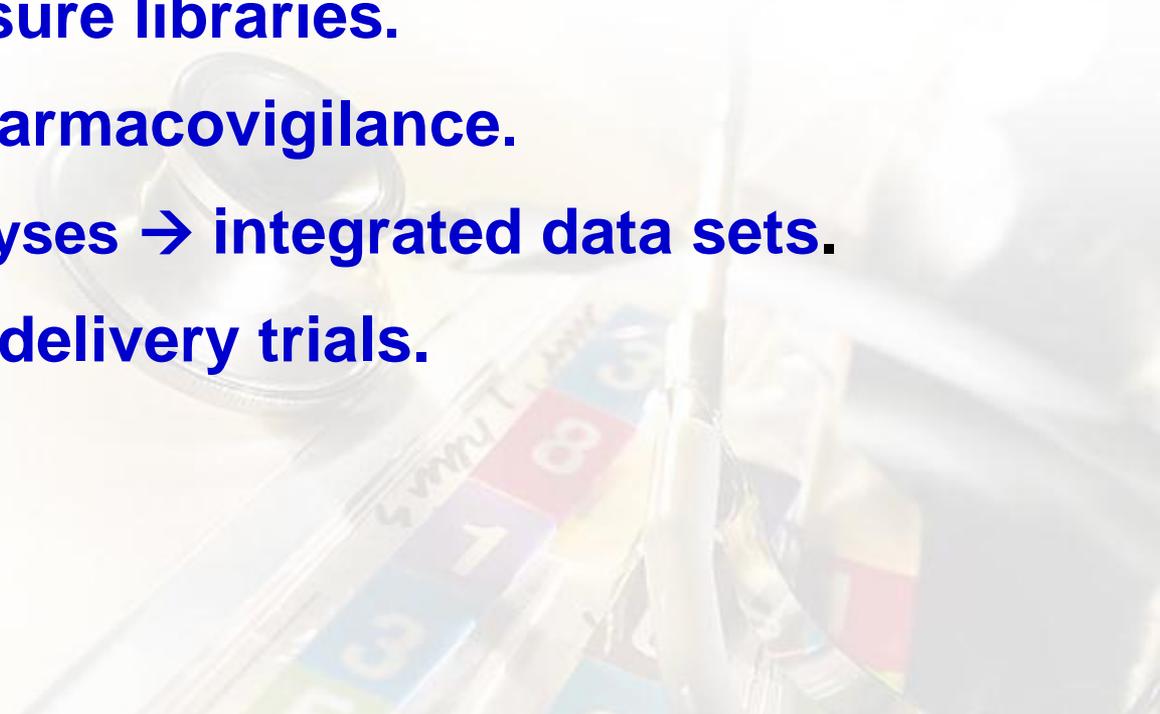
- ❑ Further **inter-sectoral** extensions of data linkage.
- ❑ Inter-generational, intra-uterine and **life course** research.
- ❑ Integration with **human genome** and other biomarker research.
- ❑ Integration with research using **spatial analysis**.
- ❑ Use of **new study designs** and multi-level modelling.
- ❑ **International** research collaborations and knowledge transfer.

Were there any glaring omissions?

- ❑ ? Support for **intervention research** in design, selection and outcome ascertainment.



Tomorrow's Aspirations: ***A more local view in WA***

- ❑ Inter-sectoral extensions: **Vulnerable populations.**
 - ❑ Inter-generational & life course: **Family Connections System.**
 - ❑ Biomarker research: **Busselton family cohort and others.**
 - ❑ Spatial analysis: **Exposure libraries.**
 - ❑ New study designs: **Pharmacovigilance.**
 - ❑ International: **Meta-analyses → integrated data sets.**
 - ❑ Interventions: **Service delivery trials.**
- 



2012: The Obstacles

(One interpretation)



- ❖ Tensions between government transparency and **secrecy**.
- ❖ Some politically **hostile** govt officials and data custodians.
- ❖ **Conservative** legal interpretations of regulatory frameworks.
- ❖ Focus on ‘one-legged’ **governance** [data security without regard to research functionality].
- ❖ **Timeliness** failure due to complex system issues.
- ❖ Lack of **expert** system architects and data analysts.

BUT

- ✓ **Computing** hardware and software are up to task & inexpensive.
- ✓ **Data** are machine readable and generally of adequate quality.
- ✓ The track record of **benefits** has become difficult to refute.



2057: Today's Agenda

PROGRAM SCREENBOOK AND SYNOPSES

2057

Nuuk &
Cyberspace
31 May 2057

**7TH WORLD ASSEMBLY OF
INTEGRATED HUMAN AND EARTH
DATA JURISTS**



Thank you

