



The role of ICT in the Scottish Cancer Registry

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Outline

- How cancer registration operates in Scotland
- Record linkage: computerized probability matching
- Recent enhancements in Scottish Cancer Registry computer system
- Future developments
- Expanding uses of cancer registry data
- Other ICT issues

How Scottish Cancer Registry data are collected

- Electronic capture and reformatting of 'raw' data
- Code conversions
- Probability matching to related incoming records and to previous registrations
- Application of multiple primary rules and rules to deal with metastatic disease
- Creation of 'best guess' provisional registrations
- Completion and validation by outposted staff in hospitals using medical records

Source data

- Hospital discharge records
- Pathology records (8 different lab systems)
- Mortality records
- Oncology records (currently 2/5 centres)
- Cancer audit data (not yet for all cancers)
- Other, eg, private hospitals

SWIFT

- SWIFT – Submission with Internet File Transfer
- Web-based application for secure transfer of data across the NHS net using 128 bit SSL (secure socket layer) encryption
- Currently used to obtain pathology, oncology, and cancer audit records

Record linkage

Record linkage

Can be used to examine

- risk factors (cohort and case-control studies)
- interval cancer rates (screening)
- patterns of referral
- post-operative mortality
- longer term survival outcome
- late effects of treatment, eg, second primaries, cardiac disease, etc.

Scottish Cancer Registry: computer system features

- ORACLE-10 on a UNIX server
- Web-based, JAVA “front-end” interface
- Central database, remote (encrypted) access
- Communications by VPN / NHSNet / ADSL
- 1,290,000 registrations on main table
- Data output/analysis via SQL, Business Objects and other packages

Recent developments

- Improved screen layouts
- More extensive validation
- Capture and archiving of full text of pathology report
- Staging data collected for a wider range of tumours
- 3rd edition of *International Classification of Diseases for Oncology: ICD-O(3)*

Future developments

- More systematic capture of cancer audit data
- Capture of radiotherapy data
- Capture of chemotherapy data
- Linkages to biological data/repositories
- Capture of recurrence data?
- Electronic patient records?

Why do we need cancer registration data?

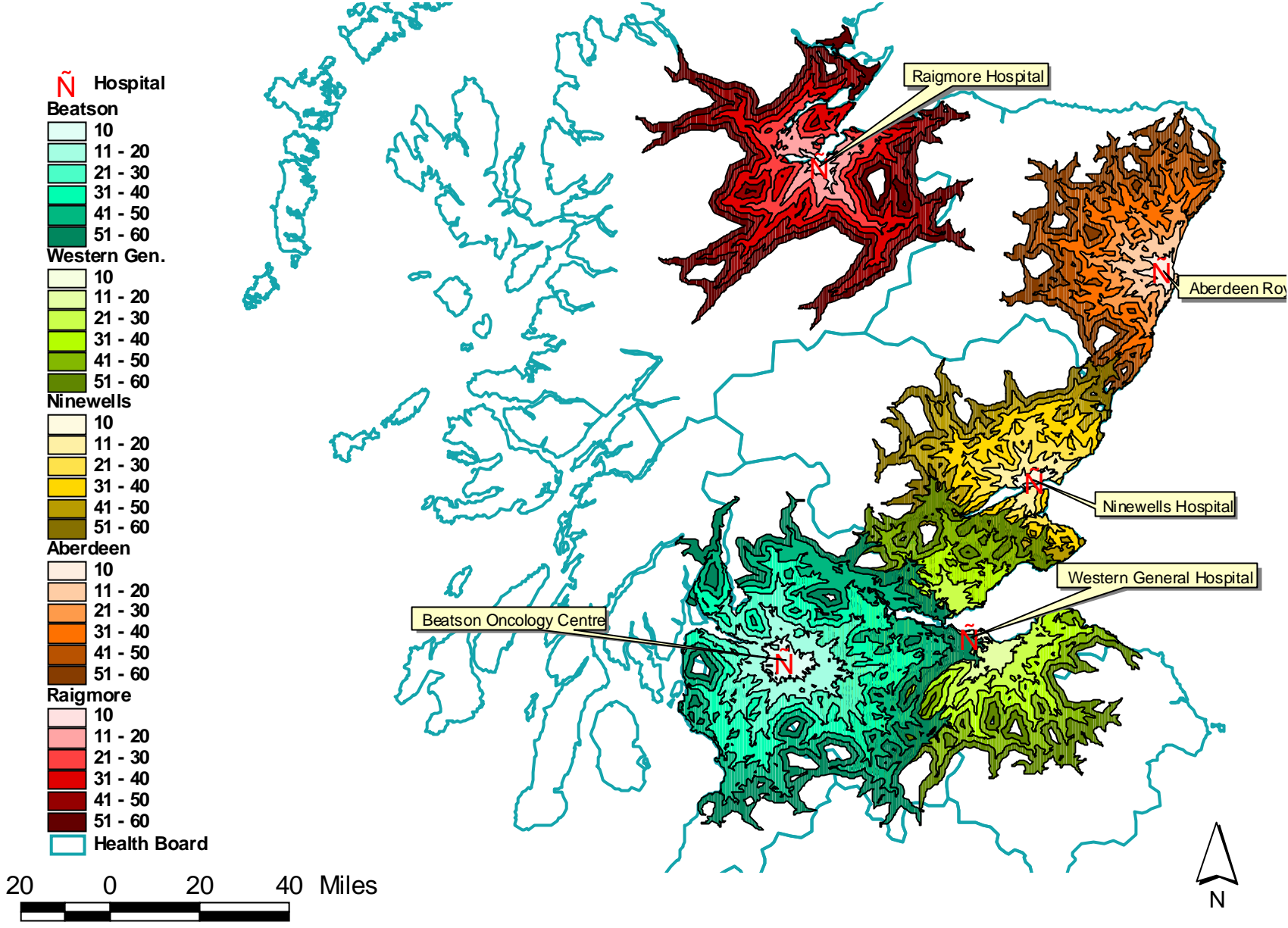
‘The cancer registry is an essential part of any rational programme of cancer control’

Jensen & Storm, 1991

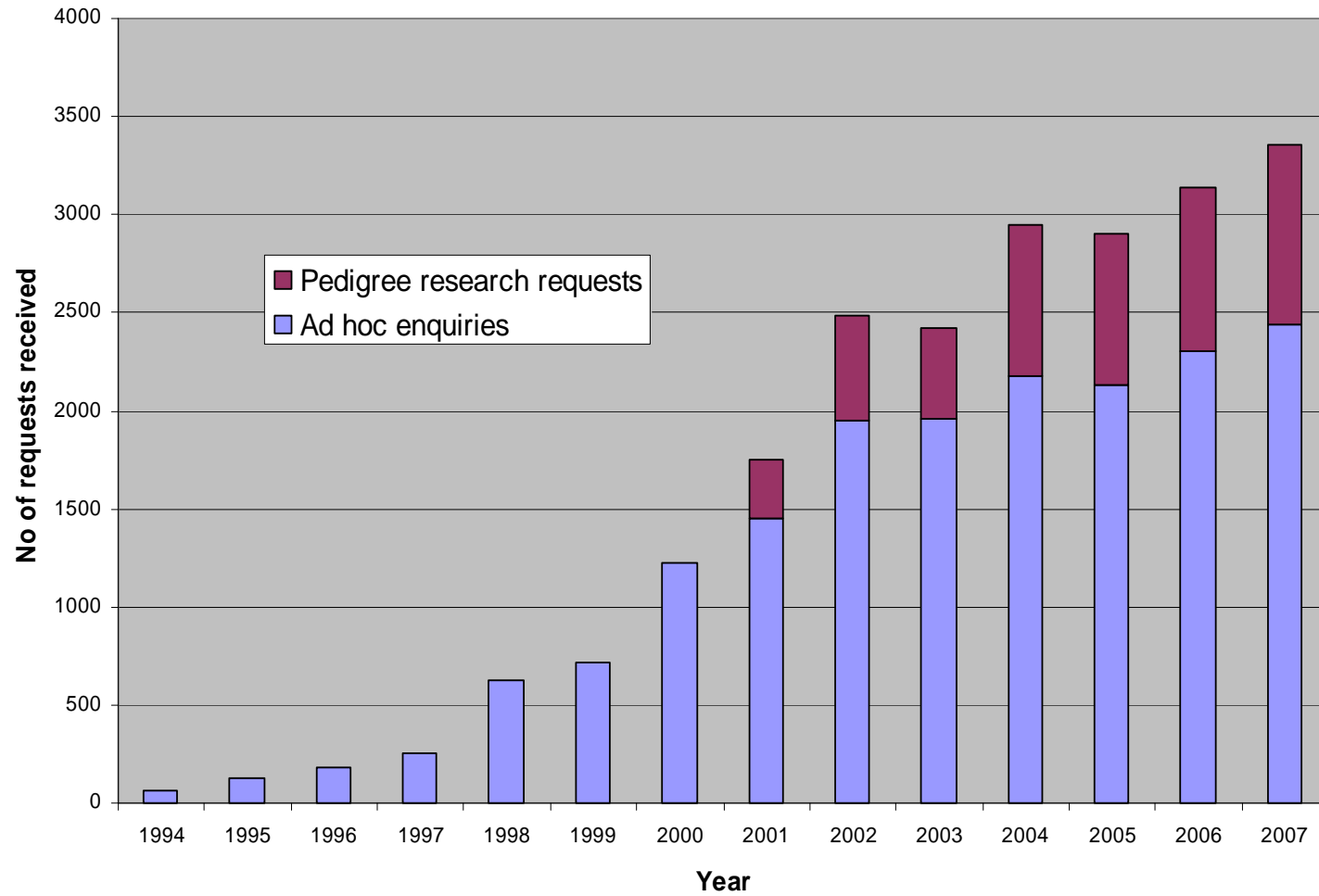
Uses of cancer registry data

- Public health surveillance
- Needs assessment, planning and commissioning cancer services
- Evaluating the impact of interventions
- Clinical audit and health services research
- Epidemiological studies aimed at determining the causes of cancer
- Information to support health promotion, cancer charities, patient notification exercises, genetic counselling, etc.

Travelling times for radiotherapy in Scotland



Increase in requests for information to support genetic counselling



Impact of cancer registry-based genealogy service

Prospective survey of 454 consecutive requests for pedigree research completed between 1 April 2002 and 31 March 2003

Results

- *Family history altered in 41% of cases*
- *Risk category altered in 30% of cases*
- *Management altered in 23% of cases*

Source: *Familial Cancer* 2004; 3: 139-41

Other ICT issues

- E-mail, tele-conferencing, etc
- Data security
- Analysis software, including GIS
- Web-based publication
- Etc.

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