

The Scottish Health Informatics Programme (SHIP) and related UK-wide initiatives



Cancer Outcomes Conference 2013:
Intelligence - the primary driver of cancer outcomes

Day 1, Workshop 2: Data processing, management and quality

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Health and administrative data: an untapped resource



- UK has some of the best health and administrative data in the world
- But we do not currently make best use of these resources for:
 - health care provision
 - research
 - public sector service planning

Recurrent challenges in the use of administrative data



- We must ensure the public support the use of their data and contribute to debates about what is in the 'public interest'
- Individual privacy must be protected and the law complied with
- The technical infrastructure must provide high end computing performance
- Overall, the arrangements must be efficient and not overly bureaucratic

A new dawn



Addressing the under-utilisation of data in Scotland (and elsewhere in the UK):

- Scottish Health Informatics Programme (SHIP)
- Information Gateway and Data Linkage Service for Scotland
- UK eHealth Informatics Research Centres (e-HIRCs)
- UK Administrative Data Taskforce (ADT)
- Administrative Data Liaison Service (ADLS)



Scottish Health Informatics Programme (SHIP)

- Scotland-wide research platform for the collation, management, dissemination and analysis of Electronic Patient Records (EPRs)
- Collaboration between the Universities of Dundee, Edinburgh, Glasgow and St Andrews and the Information Services Division (ISD) of NHS National Services Scotland
- Funded by the Wellcome Trust, the Medical Research Council (MRC) and the Economic and Social Research Council (ESRC)
- www.scot-ship.ac.uk



Aims of SHIP

- Provide access to a new **national research facility**, firmly embedded within and supported by NHS Scotland, providing the basis for numerous future studies using EPRs
- Create a **research portal** for EPRs already held by NHS Scotland that will **provide rapid, secure, access** to the type of data that clinical scientists require
- Develop and evaluate systems that work across institutional boundaries to allow linkage between large, federated, **third party** research datasets and the NHS research portal



SHIP Work Programme

- Core set of four generic activities (C1-C4): provisioning of datasets for research (C1); governance (C2); engaging researchers (C3); and engaging the public (C4).
- Support a related series of four work packages which will produce novel research using EPRs and major longitudinal cohort databases. These are: supporting clinical trials (RP1); national epidemiology (RP2); pharmacovigilance (RP3); and the linkage of EPRs to socio-economic, geospatial and environmental data (RP4).



Health and SHIP have led the way

- SHIP has provided:
 - Public consultation
 - Proportionate Information Governance
 - High end computing infrastructure
 - Development of networks between academics, the NHS and Scottish Government
- NSS is a key partner within SHIP
 - *SHIP was instrumental in helping to achieve e-HIRC's funding*

An empirical example: Insulin glargine and cancer



- International research suggested a possible link between increased cancer rates and use of Insulin glargine
- SCI-DC was linked to cancer registry to look at cancer rates in those using various types of insulin therapy.
- Overall, insulin glargine use was not associated with an increased risk of all cancers or site-specific cancers in Scotland over a 4-year time frame.

(Colhoun et al. *Diabetologia* 2009)

Making it happen in reality



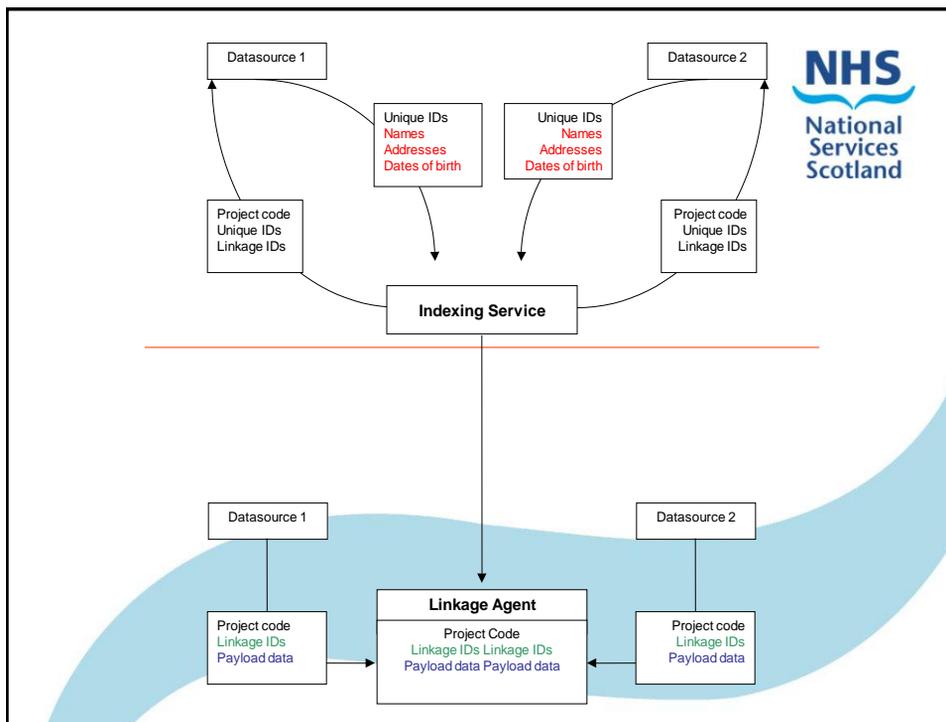
- Partnerships, networks and federated arrangements are the only way to maximise Scotland's administrative data
- Single organisations or individuals cannot achieve this in isolation
- But this raises new challenges around coordination: researchers need,
 - a single point of entry
 - help to navigate the system
 - to know what's possible

NSS's eData, Research and Innovation Service (eDRIS)



eDRIS is a new NSS service - it will:

- facilitate partnership working between the NHS, academics and industry
- provide coordination and expert advice to support researchers
- make research more efficient, easier, save time and encourage better research



What does this mean for researchers (and patients)?



- More and better research will lead to improvements in health and care
- On a practical level:
 - a single point of entry for health research
 - support from a named person to:
 - access networks of expertise
 - advise in key areas such as data quality, coding, terminology, feasibility of study design
 - secure data access and appropriate permissions
 - analyse data and interpret results (when required)

Going beyond linkages of health data: the Information Gateway and Data Linkage Service for Scotland (1)



- Lead development of data linkage IT and expertise, generating capacity for more and better data linkage for research and statistics across Scotland
- Develop and maintain methods for read-through between different individual referencing systems, and support the development and maintenance of a 'population spine'
- Provide a linkage service: conducting approved within and cross-sector data linkages where necessary and efficient, delivering improvements on the existing range of services available to potential users of linked data.

Information Gateway and Data Linkage Service for Scotland (2)



- Provide a trusted data-exchange service
- Provide support and encourage co-ordination across the network of data linkage facilities and safe havens that already exist, with a focus on collaboration in procurement and use of ICT and sharing of developments, good practice and methods for linkage
- Provide support and guidance on the development of linkable local and national sources in order to enhance the quality of strategically important data resources being shared and linked for statistical research purposes.

The SHIP infrastructure, which includes an indexing service and a 'state of the art' high performance database server and remote safe haven access, will form a crucial element of the technical capacity.



UK-wide initiatives

e-Health Informatics Research Centres (e-HIRCs)



- Research funders, led by MRC, and under the auspices of the Office for Strategic Coordination of Health Research (OSCHR), developed a Strategic Framework for Health Informatics in Support of Research (2009).
 - MRC called for applications for funding to establish e-Health Informatics Research Centres (centres of excellence)
 - Centres have been established in London, Manchester, Dundee*, and Swansea
 - Aspiration is to establish a UK network of e-HIRCs (Farr Institute)
 - www.mrc.ac.uk/Ourresearch/ResearchInitiatives/E-HealthInformaticsResearch/index.htm
- *Collaboration between universities and NHS NSS

UK Administrative Data Taskforce (ADT)



- Formed December 2011
- Aim: improve access to and linkage between government administrative data (eg, social security, tax, education records) for research and policy (social science focus)
- Led by the Economic and Social Research Council (ESRC) in collaboration with MRC and the Wellcome Trust
- Aspiration: to establish an Administrative Data Research Centre (ADRC) in each of the four UK countries, which in their entirety will create a UK Administrative Data Research Network.
- www.esrc.ac.uk/funding-and-guidance/collaboration/collaborative-initiatives/Administrative-Data-Taskforce.aspx

Administrative Data Liaison Service (ADLS)



- Funded by the Economic and Social Research Council (ESRC) to support administrative data based research in the UK
- Supports academic research by acting as an intermediary between academic researchers and data holding organisations
- Provides catalogue and metadata on potentially available data sets
- Managed by the University of St Andrews, in conjunction with the Universities of Oxford and Manchester
- www.adls.ac.uk/



Thank you for listening