

A Scotland-wide data linkage framework for statistics and research



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DATA LINKAGE FRAMEWORK

| | | WEALTHIER & FAIRER | SMARTER | HEALTHIER | SAFER & STRONGER | GREENER | | |
|-------------------|--|--|---------|-----------|---------------------|---------|--|-------------------|
| NATIONAL OUTCOMES | | We live in a Scotland that is the most attractive place for doing business in Europe | | | | | | NATIONAL OUTCOMES |
| | | We realise our full economic potential with more and better employment opportunities for our people | | | | | | |
| | | We are better educated, more skilled and more successful, renowned for our research and innovation | | | | | | |
| | | Our young people are successful learners, confident individuals, effective contributors and responsible citizens | | | | | | |
| | | Our children have the best start in life and are ready to succeed | | | | | | |
| | | We live longer, healthier lives | | | | | | |
| | | We have tackled the significant inequalities in Scottish society | | | | | | |
| | | We have improved the life chances for children, young people and families at risk | | | | | | |
| | | We live our lives safe from crime, disorder and danger | | | | | | |
| | | We live in well-designed, sustainable places where we are able to access the amenities and services we need | | | | | | |
| | | We have strong, resilient and supportive communities where people take responsibility for their own actions and how they affect others | | | | | | |
| | | We value and enjoy our built and natural environment and protect it and enhance it for future generations | | | | | | |
| | | We take pride in a strong, fair and inclusive national identity | | | | | | |
| | | We reduce the local and global environmental impact of our consumption and production | | | | | | |
| | | Our people are able to maintain their independence as they get older and are able to access appropriate support when they need it | | | | | | |
| | | Our public services are high quality, continually improving, efficient and responsive to local people's needs | | | | | | |

Aims

| | |
|---|---|
| → | Speed up cycles of improvement through the delivery of a higher quality cross-sectoral evidence base to inform public policy and strategic spending decisions |
| → | Enable better use of existing data to develop efficient and reliable methods of producing demographic and census-type statistics |
| → | Increase the power of statistics available to all |
| → | Allow relatively low cost longitudinal research to be conducted both retrospectively and prospectively, informing preventative spend |
| → | Increase the capacity to robustly evaluate the costs, benefits and risks of new health, social, educational and associated programmes |
| → | Provide exemplars of research excellence, enhancing Scotland's reputation and attracting investment and job creation to Scotland |

Why a strategic framework?

1. Capitalise on synergies in existing programmes
2. Co-ordinated and systematic attack on the challenges:
 - Uncertainty about the legalities and public acceptability of data sharing and linkage
 - Incomplete data, or data that cannot be linked
 - Limited capacity for secure exchange and access to data
 - Limited capacity of public sector organisations to analyse and make use of linked data

The framework

STEERING GROUP

DATA LINKAGE CENTRE

PRIVACY ADVISORY
COMMITTEE / SERVICE

PRINCIPLES

PRINCIPLES

Based on SHIP Guiding Principles

(Laurie and Sethi, Edinburgh Law School)

1. Public Interest
2. Governance and Public Transparency
3. Privacy
4. Removal of names and direct identifiers
5. Consent
6. Security
7. Access and Personnel
8. Clinical Trials
9. Data sharing agreements and sanctions

**A Scotland-wide Data Linkage
Framework for Statistics and Research**

**Consultation Paper on the Aims and
Guiding Principles**



www.scotland.gov.uk/datalinkage

Responses welcome by 15 June

Reporting by September

Consultation Questions

- Are there other benefits of data linkage for statistical and research purposes?
- Are there other challenges or barriers preventing more effective and efficient data linkages?
- **Are the guiding principles sufficient and appropriate?**
- Are the objectives set out for a Privacy Advisory Service the right ones?
- Are the functions that will be led by the National Data Linkage Centre the right ones?

Public acceptability testing

- Ipsos MORI, Sarah Cunningham-Burley and Claudia Pagliari
- 3 deliberative citizen engagement events to
 - Identify particular concerns re within and between sector linkage
 - Any sector-sector linkage esp sensitive
 - Test reassurance of the Guiding Principles
 - Identify safeguards that could maximise public confidence
- Reporting August

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