

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

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**The Scottish Government**  
Riaghaltas na h-Alba

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

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

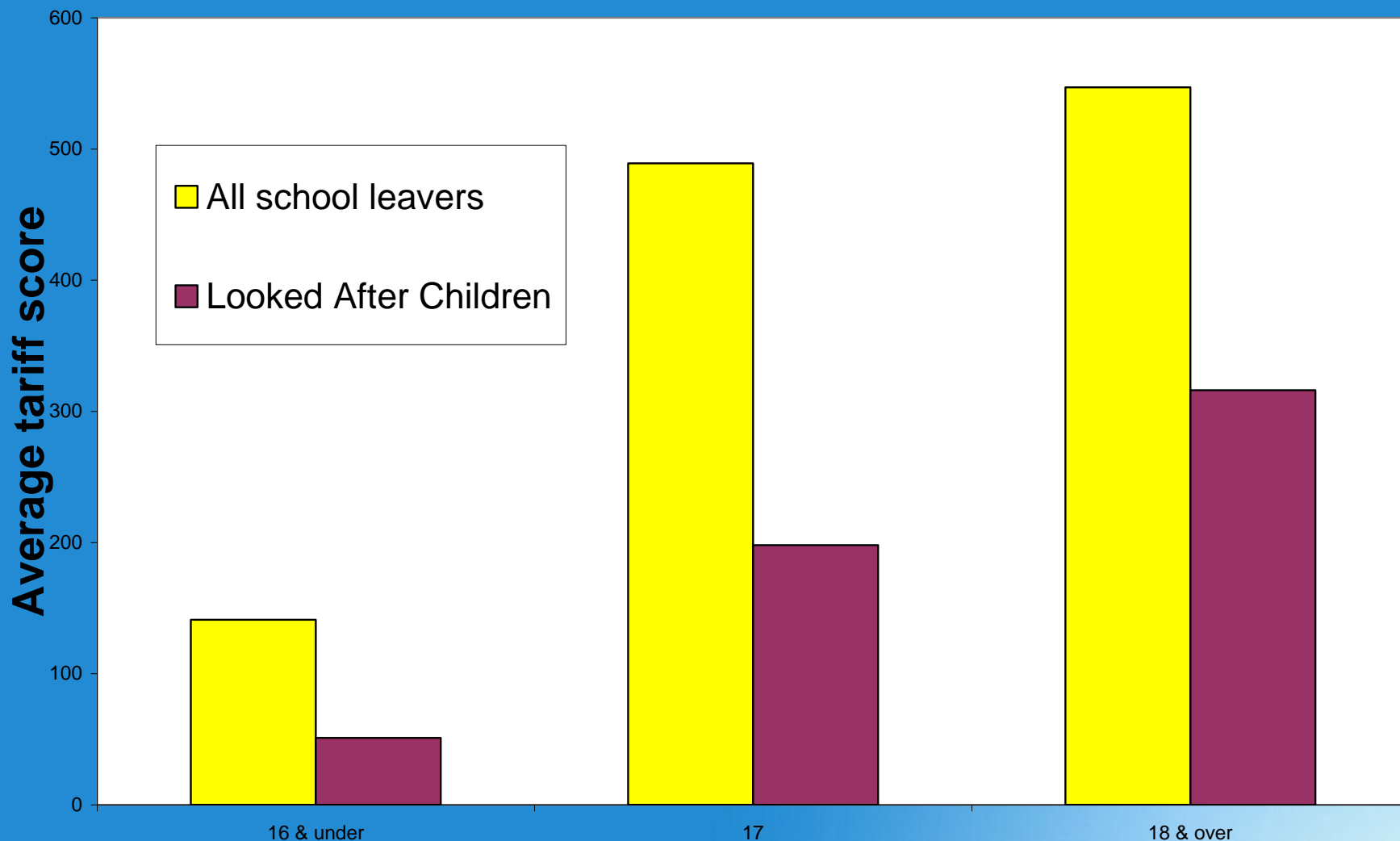
Our public services are high quality, continually improving, efficient and responsive to local people's needs

NATIONAL OUTCOMES



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# Increase power of official statistics



Statistics Publication Notice: Health and Care  
Series: Educational Outcomes for Scotland's  
Looked After Children, 2009/10



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# Allow low cost longitudinal research

SHeS self-report data on  
use of tricyclic antidepressants medication  
history of heart disease

linked with **8 subsequent years** of National Register data on  
CVD death  
non-fatal myocardial infarction  
coronary surgical procedures  
stroke  
heart failure

increased risk of Cardiovascular disease in adults taking tricyclic  
antidepressants was not explained by existing mental illness  
→ this medication is associated with an excess disease burden

Hamer, G. David Batty, Adrie Seldenrijk, and Mika Kivimaki  
Antidepressant medication use and future risk of cardiovascular disease: the Scottish Health Survey  
Eur Heart J (2011) 32(4): 437-442



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# Why a strategic framework?

1. Piecemeal developments
2. Nervousness about sharing data
3. Incomplete data



## **Premise**

it is in the public interest both to safeguard individual's right to privacy and to make efficient use of data for statistical and research purposes

## **Objectives**

help every-one involved in data linkage to balance these values

provide the public with assurance that personal data is being shared and used safely and appropriately

provide data owners with assurance that data can be shared when the appropriate safeguards are in place

increase capacity and efficiencies for linkages



# Emerging 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



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

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



Published today

[www.scotland.gov.uk/datalinkage](http://www.scotland.gov.uk/datalinkage)

Responses welcome by 15 June

Reporting September



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# 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?



# Framework timeline

## Next 6 months:

- Consultation on aims and principles
- Public acceptability testing
- Appoint programme manager to develop data linkage centre

## Next 2 years:

- Establish Data Linkage Centre
- Consult on Data Linkage Centre logistics and procedures
- Consult on Privacy Advisory Service
- Clarify investment needed – data, skills

## Longer-term:

- Legislation?
- Establish Privacy Advisory Service
- Invest in data

