Evidence in Policy Making

Scottish Government sponsored data linkage projects

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This presentation will cover:

- ✓ Who we are and our areas of expertise
- ✓ The service model for data linkage in Scotland
- ✓ The Scottish Government stream of linkage projects
- ✓ Our successes to date
- ✓ A case study – Out of Hospital Cardiac Arrest

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Who We Are:

- We're a team of statisticians and statistics policy leads
- Focus on Information Governance & application of data protection law to all data sharing and linkage for stats and research across Scottish Government (and more widely!)
- Co-ordinate all data linkage projects across Scottish Government & ADR-Scotland(in partnership) – now reporting to ESRC under Phase 2 data linkage investment
- Work with service partners to improve the system of data provisioning to make linkage more efficient and effective
- Strong networks with NHS Scotland's eDRIS team of Research Co-ordinators, NRS indexing team, University of Edinburgh computing infrastructure team, wider academic community

Digital Economy Act 2017

- Laying regulations under Part 5 of the Act covering the sharing of personal data for Public Service Delivery, Statistics, Research, Fraud & Debt
- Safeguards
  - Data Protection Law, Human Rights Law
  - Codes of Practice, setting out processes and guidance to be adopted in using each of the powers
- Statistics – provides legal framework that empowers statistical producers to collect and process data on which official statistics and statistical research are based. Working with ONS' Data As A Service Unit to prioritise key datasets and access to SG data.
- Research – powers to facilitate the linking and sharing of datasets for research purposes. Working with ONS to develop processes for Accreditation (People, Projects, Settings) that will work across all ADR partners

Data Linkage Framework in Scotland

- Built around the **Guiding Principles for Data Linkage,** published in 2012, following extensive public consultation
- Scottish Informatics Linkage Collaboration (SILC) – 4 partners
- Service model:
  i. NRS Trusted Third Party indexing function(probabilistic matching to spine)
  ii. NHS eDRIS Research Co-ordinators
  iii. University of Edinburgh EPCC computing infrastructure
  iv. Safe Haven – shared office space at Edinburgh BioQuarter

Data Linkage Framework in Scotland

Health data:

(formerly) Farr @ Scotland

Administrative data:

Administrative Data Research Centre - Scotland

Urban data:

UBDC

Government data:

Scottish Government

Scottish Informatics and Linkage Collaboration
(provides shared services to various research initiatives)

Shared office space at the Edinburgh BioQuarter

Shared computing resources at the University of Edinburgh (EPCC)

Shared indexing service at National Records Scotland (Trusted Third Party)

NHS Scotland eDRIS* Research coordination and advice

*electronic Data Research & Innovation Service

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Vision for Data Linkage in Scotland

Our aims

- **better access to statistics to support decision making**
- **infrastructure delivers more for less cost**

What we are doing

- **User-focused Service Design**
- **Common Formats for Publications**
- **Shared Ownership/ Governance**
- **Shared Training and Support**
- **Mobility of People**

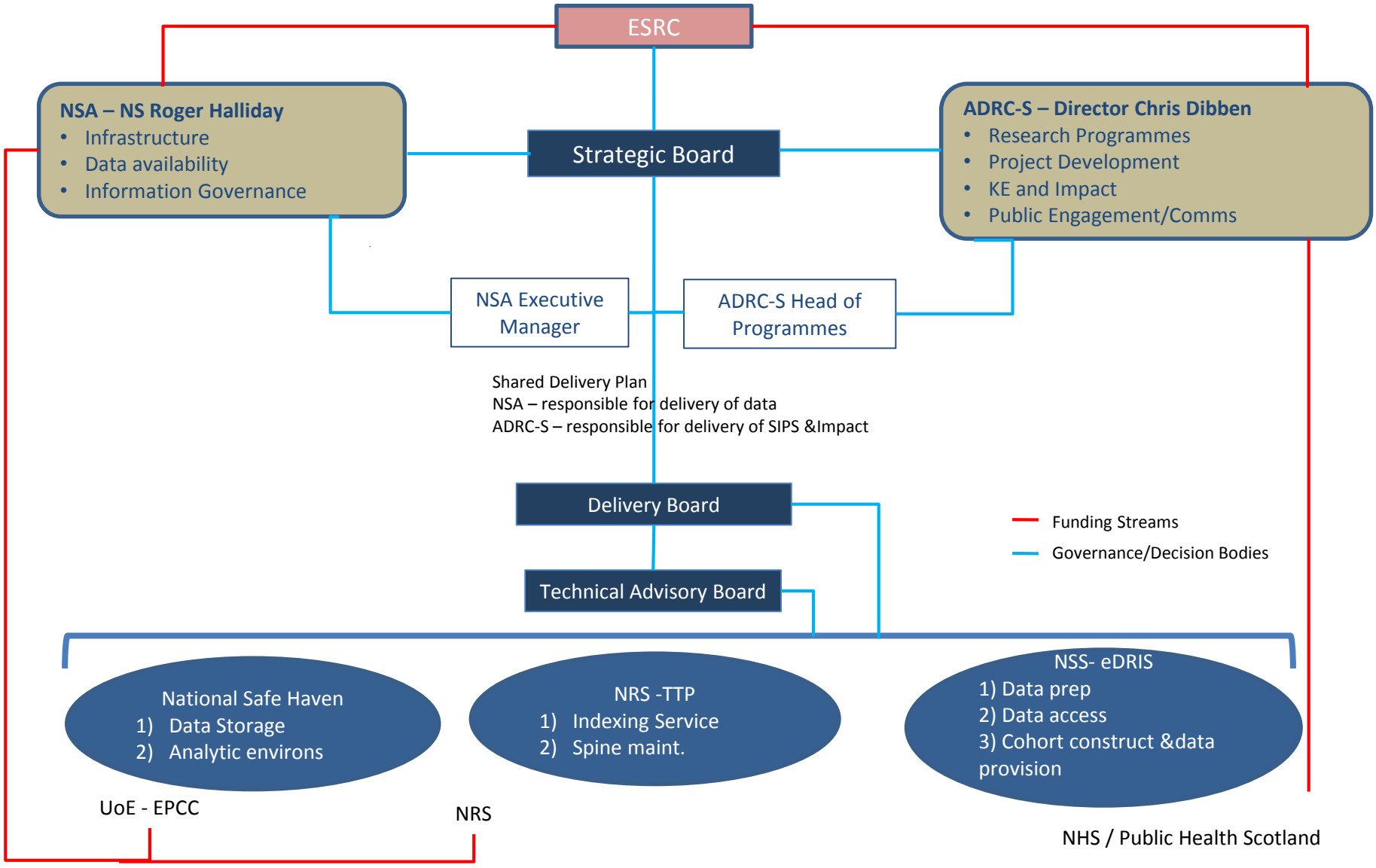
What's next

- Shared (software) Tools and Platforms
- Data Collection Processes
- Shared Analytical Processes
- Information Governance

Renewed partnership and services for Data Linkage in Scotland

- Admin Data for Research Phase 2 investment confirmed by ESRC – now a partnership between ADR-Scotland and Scottish Government
- Moving towards ‘research ready’ data sets, built around Strategic Impact Programmes (SIPs)
- Much more up-front prep of data; cleaning, indexing and hosting
- Exploring re-use of existing linkage studies
- University of Edinburgh to lead Health Data Research UK Scotland research programme
- Redesigning wider governance and IG covering all use of public sector datasets for data linkage for public benefit research

Scottish Administrative Data Research Partnership



Data Linkage in action

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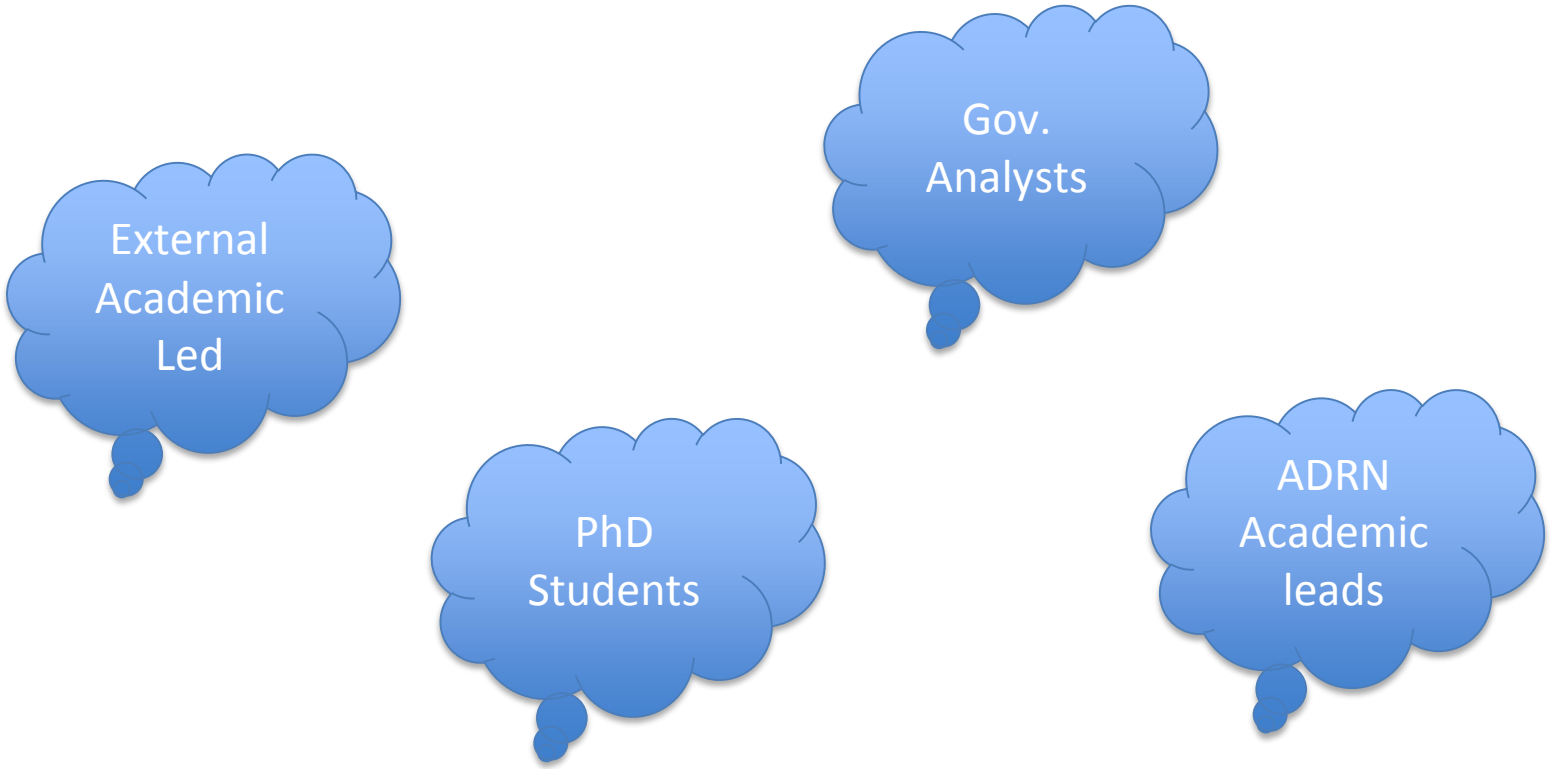
Not mutually exclusive – almost always a collaborative effort!

The application process – how do projects come to us?



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Currently under construction!

1. Application Process
(i) Submit project application form to Analytical Leadership Group / (ii) Draft Data Protection Impact Assessment (formerly PIA)
2. Approvals Process
(i) Public Benefit and Privacy Panels / (ii) Ethical Approval
3. Information Governance Documentation
(i) Data Sharing Agreements / (ii) Controller Processor Contracts (aka Data Processing Agreements)
4. Indexing & Linkage
National Records of Scotland (NRS) and eDRIS can index and link the data
5. Access to the linked data
Data can now be hosted and access via Safe Haven

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Is there ministerial support for this project?

Does the project tie in with the National Performance Framework – is there an associated national outcome?

What is the public benefit of this work?

ADR-SG Strategic Impact Programmes

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So far what have we used data linkage to achieve?

- ✓ To improve National Statistics e.g. linking pupil census and educational outcomes of looked after children – Education Analytical Services
- ✓ To evaluate Programmes or policies e.g. Family Nurse Partnership programme
- ✓ To address research questions e.g. Health and Homelessness project – Andrew Waugh, National Records of Scotland
- ✓ To provide localized linked data for informing policy development and resource allocation (statistical research)

What have been our successes to date?

- Out of Hospital Cardiac Arrest – Dr. Gareth Clegg (University of Edinburgh) and Ellen Lynch (Scottish Government)
- “Inequalities in the dental health needs and access to dental services among looked after children in Scotland: a population data linkage study” – Prof. David Conway (University of Glasgow)
- Health and Homelessness – Dr. Andrew Waugh, SG/NRS
- Growing up in Scotland – Dr. Ganka Mueller, SG
- Realigning Children's Services – Brendan Nisbet, SG

Case Study: OHCA

"Approx. 3,500 people in Scotland undergo attempted resuscitation each year after OHCA"

Two high level aims:

1. Increase survival rates (1,000 additional lives by 2020)
2. Equip an additional 500,000 people in Scotland with CPR skills by 2020

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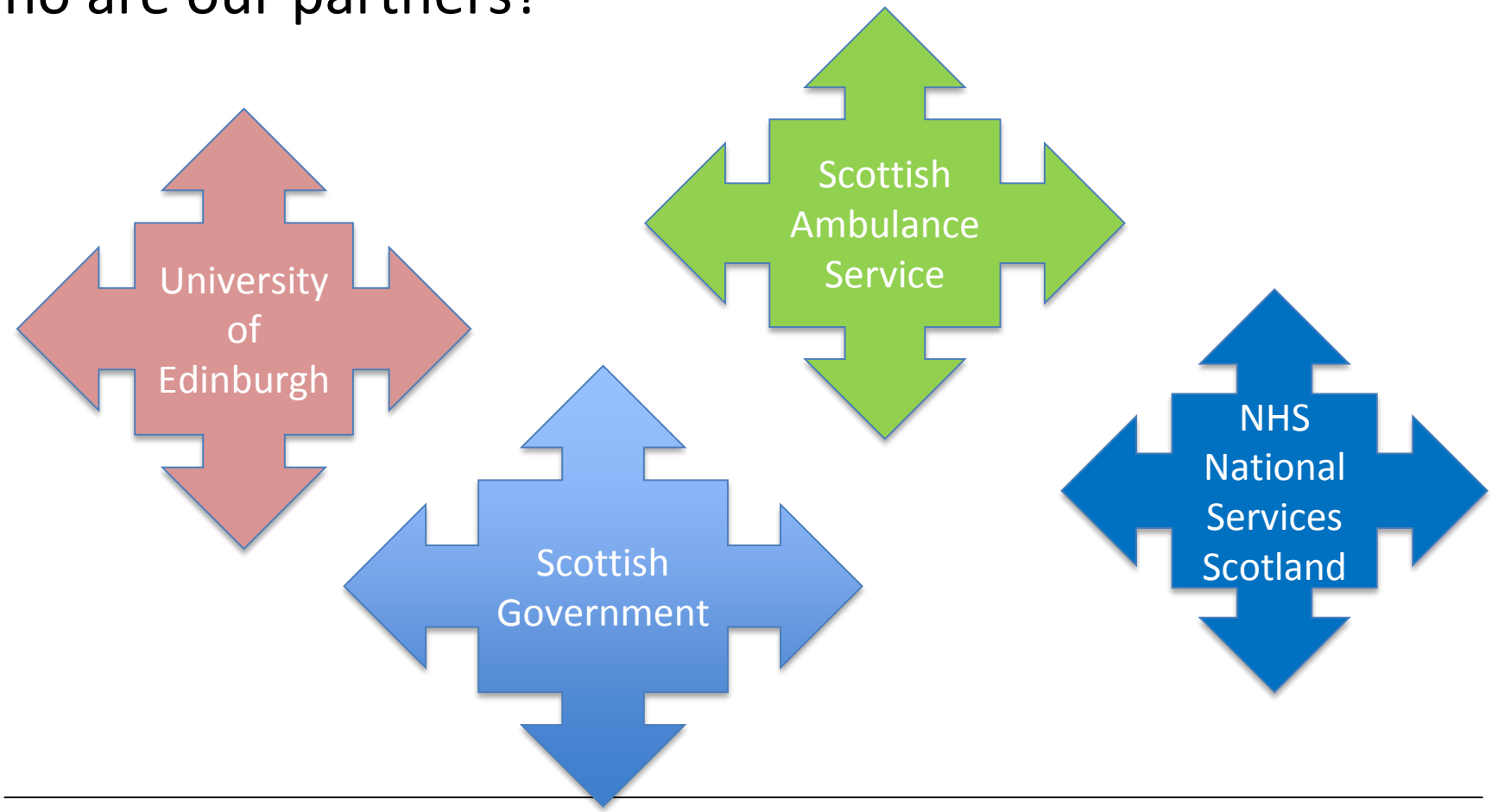
Case Study: Out of Hospital Cardiac Arrest

Who are our partners?



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How does the linkage lead to improved resource allocation, policy delivery and patient outcomes?

- Linking ambulance data with other clinical datasets in Scotland allowed patient outcomes to be tracked alongside monitoring of system performance and the impact of service changes.
  - The number of people in Scotland who had an OHCA, were resuscitated and were discharged from hospital alive
  - The number of patients who had an OHCA received bystander CPR
  - Explore existence and magnitude of geographical variations in survival rates following an OHCA.
  - Explore differences in care delivery systems around Scotland and their impact on survival rates following an OHCA
- The project considered several other factors as part of the analysis including, patient case-mix, geography, deprivation, healthcare delivery system (from initial 999-call through paramedic resuscitation, hospital care to return to the community).

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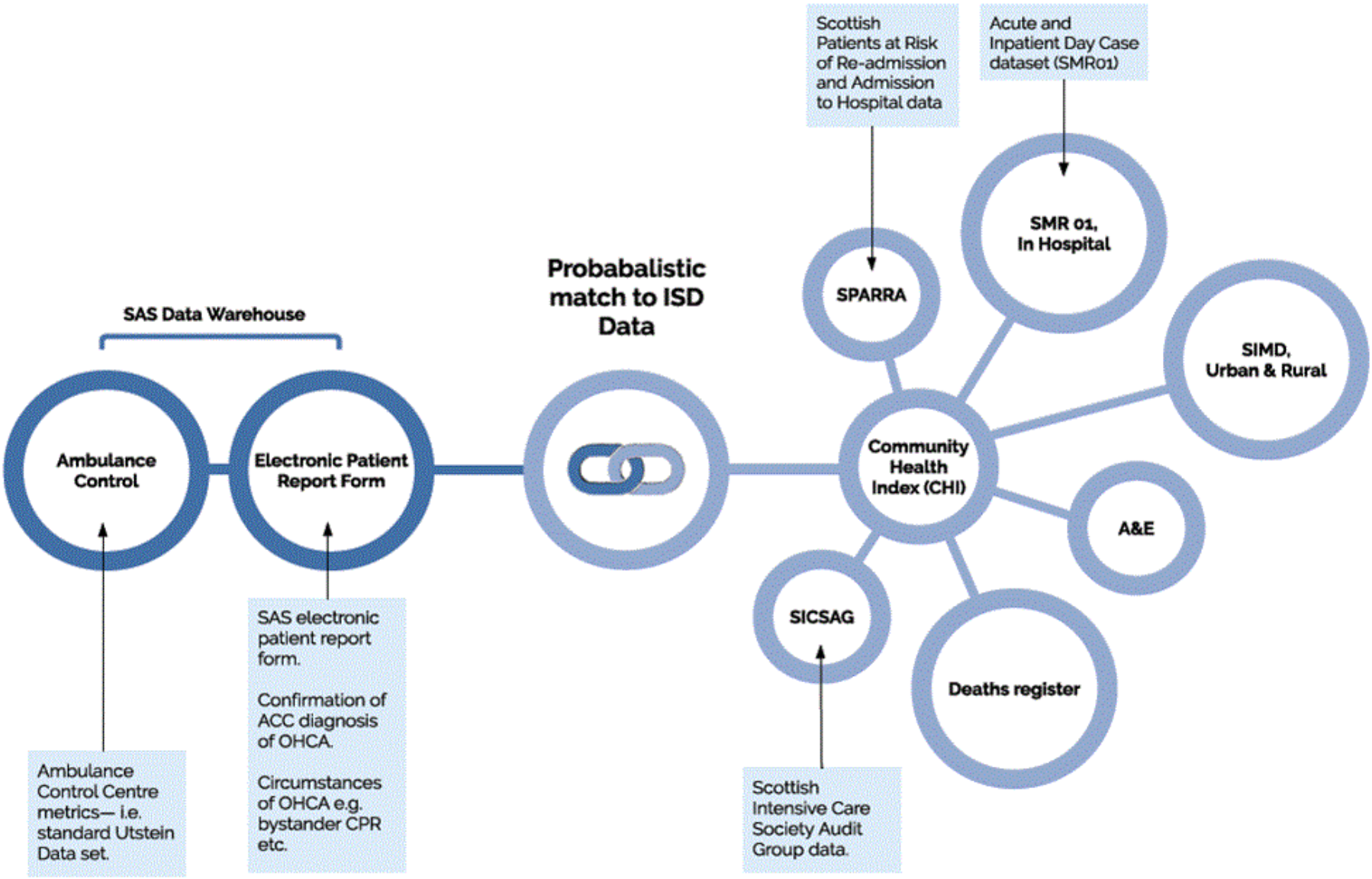

What outcomes have we seen so far?

- This project started in 2016, with two rounds of analysis already completed (next wave currently underway)

- The results have already fed into
  - a Scottish Government Strategy Report (which is published every 2 years)
  - As well as an Analytical Report (published annually)

- SG funding for an analyst sitting in Scottish Ambulance Service – will work on data management and data quality. Working towards new publications and enhanced data.

- Future work: engagement with the Fire Service and Police Scotland – building on successes to date

Lessons Learned

- **Explore data quality** and **availability** at the outset and schedule time to identify, prepare, clean and QA the data prior to linkage
- Ensure regular formal **communications** channels established at the outset – project teams, roles and responsibilities
- Adequate time to navigate permissions processes – **schedule time** to obtain approvals and anticipate questions
- Strong **Project Management** needed - to ensure actions, owners and timescales agreed, detailed specification of data provisioning to ensure correct datasets ready for linkage.
- **Preserve** the learning and linkage outputs where justified – to get the best from all the effort put into bringing the data together.
- An OHCA “epistry” (epidemiological registry) is being developed and we are now updating the linked dataset.

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What have been our challenges to date?

- **Data Quality** – this can vary widely
- Data discoverability – i.e. Is there **meta data**? Who are the data controllers? etc.
- Project complexity – scope creep
- Maintaining project momentum during times of upheaval (staff turnover, resourcing issues, etc.)
- Navigating **complex IG issues** and trying to find common ground for data sharing, reassuring data controllers
- Many layered permissions process and multiple scrutiny panels (Data access panels, Public Benefit and Privacy Panel, ethics committees, etc.)
- Underestimating work involved and hence resource

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In Summary

- **Scottish Government sponsored data linkage projects** often involve multiple stakeholders, requiring co-production and cross sectoral engagement by design and from project initiation.

- Challenging and labour intensive work, but high impact results and outcomes possible – a real capacity for enriching policy making and making change.

- Great opportunity to partner with ADR-Scotland who possess the necessary research skills - bringing this to those who know the data best and to policy makers

WHAT'S NEXT?

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Any questions?

You can also contact us at:

DataLinkage@scot.gov