

# Out of Hospital Cardiac Arrest Data Linkage – Draft PIA (working document) Aug 2017

## Step one: Identify the need for a PIA

*Explain what the project aims to achieve, what the benefits will be to the organisation, to individuals and to other parties.*

### Project Aims

Out-of hospital cardiac arrest (OHCA) is a significant healthcare challenge in Scotland. In 2011/12 the Scottish Ambulance Service responded to approximately 8,900 adult OHCA calls, 3,058 of these resulted in resuscitation attempts. Although almost a third of these patients had a favourable 'shockable' heart rhythm, overall only 16.1% had return of a pulse before arriving in the Emergency Department. Having reached hospital, not all survive to leave hospital alive.

**This project aims to inform health improvement work to increase the chance of survival following an OHCA.**

Linking ambulance data with other clinical datasets in Scotland would allow patient outcomes to be measured alongside monitoring of system performance and the impact of service changes. The project will consider a number of 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). International comparisons show that foundational to all successful efforts to increase survival after OHCA is the collection of data to measure performance of the local system of care delivery.

(Examples of) Research questions:

How many people in Scotland who had an OHCA were resuscitated and were discharged from hospital alive?

How many patients who had an OHCA received bystander CPR

(Cardiopulmonary resuscitation)?

Are there geographical variations in survival rates following an OHCA? If so, quantify these.

Are there differences in care delivery systems around Scotland which impact on survival rates following an OHCA? If so, quantify these.

Does this research justify the routine linkage of data about the pathways of patients who have had an OHCA in order to lead to health improvements and increased survival rates?

### Benefits

This research will help inform policy decisions for example, how to manage public access defibrillators, where to target social marketing of health messages about OHCA. The research will also identify if there are variations in survival rates and what are the reasons for these variations. This will inform policy, service planners and practitioners in developing interventions and services to improve the outcomes for people who have had an OHCA.

This project is due to run from Aug 2015 – 2021 (approx.).

## Step two: Describe the information flows

*You should describe the collection, use and deletion of personal data here and it may also be useful to refer to a flow diagram or another way of explaining data flows. You should also say how many individuals are likely to be affected by the project.*

Most of the data which is being utilised in this project are already routinely linked to inform service delivery through the 'Unscheduled care data mart' which is held securely by NHS National Services Scotland. This includes Scottish Ambulance Service data, A&E data, unplanned hospital admissions data and deaths data. The additional data to be included are some further information from the Scottish Ambulance Service, SPARRA (Scottish Patients At Risk of Re-admission) and information about intensive care & high dependency care which is held internally by NHS National Services Scotland.

The data to be included in this project will be from 2010/11 – 2019/20.

Scottish Ambulance Service and NHS National Services Scotland already have existing data sharing agreements and secure data transfer methods in place. This project will utilise these existing arrangements for the additional data to be incorporated from the Scottish Ambulance Service.

The data linkage will be undertaken by NHS National Services Scotland who have expertise in data linkage as they routinely link NHS datasets.

Key features of using National Services Scotland data linkage service include:

- The linking of data is for statistical / research analysis only.
- Data will be securely transmitted and stored in line with NHS Scotland and Scottish Government data security requirements.
- Data sharing agreements are in place between the data controller and the organisation responsible for delivering the data linkage service.
- The data used for analysis will not contain patient names and CHI

numbers.

- Data is accessed through a secure safe haven<sup>1</sup> (and limited geographical data is accessed via the Scottish Government's Geography Team and Health & Social Care Analysis Division).
- No copies of the datasets are allowed to be made onto removable media.
- Data provided for the project will only include the data which is necessary and relevant to fulfil the research project aims.
- Access to data for analysis is only given to approved analysts for example, they have completed data protection training and they are directly involved in this project.
- The analysts must apply to the '*Public Benefit and Privacy Panel for Health and Social Care*' to gain access to the linked data.
- All analytical outputs are checked to ensure they comply with confidentiality requirements, for example by applying Statistical Disclosure Control<sup>2</sup>:
  - The aim of disclosure control is to ensure that any statistical analyses will not reveal the identity of an individual or any private information relating to them.
- The linked data from this project will be retained for the duration of the project, but will be reviewed at least annually by the analysts.

This pilot project will inform if there should be a long term commitment to link OHCA pathway data. If there is strong justification for an on-going data linkage, then there will be a new PIA and permission will be sought from the data controllers.

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<sup>1</sup><http://www.isdscotland.org/Products-and-Services/EDRIS/>

<sup>2</sup><http://www.scotland.gov.uk/Topics/Statistics/About/Methodology/Glossary>

## Consultation requirements

*Explain what practical steps you will take to ensure that you identify and address privacy risks. Who should be consulted internally and externally? How will you carry out the consultation? You should link this to the relevant stages of your project management process.*

*You can use consultation at any stage of the PIA process.*

The majority of the datasets have already been linked by the NHS as part of the 'Unscheduled care data mart' and therefore we have not undertaken an external consultation for this particular project. The additional datasets to be linked are also NHS datasets. This project will be conducted utilising the electronic Data Research and Innovation Service (eDRIS) and the data sharing and linkage infrastructure via the Scottish Informatics and Linkage Centre (incorporating the [Farr Institute Scotland](#) and [Administrative Data Research Centre](#) (ADRC)).

The Privacy Impact Assessment will be published on the Scottish Government's website. In addition, permission will be sought from the '*Public Benefit and Privacy Panel for Health and Social Care*' which includes representatives from the public, NHS and Scottish Government.

## Contact point for future privacy concerns

Health & Social care Analysis Division (HSCA)

Scottish Government

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