Cross-Party Group on Health Inequalities

12.30- 2pm, 21 February 2024

Minute

Present

MSPs

Brian Whittle MSP, Carol Mochan MSP

Invited guests

Lauren Blair, Voluntary Health Scotland
Judith Connell, Kidney Care UK
Anna Cowan, Waverley Care
Sarah Curtis, Universities of Edinburgh and Durham
Nancy Dear, Stroke Association
Alan Eagleson, Terrence HigginsTrust Scotland
Paula Fraser, VOX Scotland
Rob Gowans, Health and Social Care Alliance Scotland (the ALLIANCE)
Josh Hill, Blood Cancer UK
Susan Hunter, Befriending Networks
Roisin Hurst, Scottish Community Link Worker Network
Laura Jones, RNIB Scotland
Gabrielle, King, Waverley Care
Donna, Lawrie, MECOPP
Una MacFadyen, Children's Health Scotland
Samantha MacKinnon, Chest Heart & Stroke Scotland
Lewis MacLeod, Chest Heart and Stroke Scotland
Ian McCall, Paths for All
Joe, McCready, Carers Scotland
Kira McDiarmid, Breast Cancer Now
Agnieszka Morrison, Feniks
Stephanie Morrison, Robert Gordon University
Justina Murray, Scottish Families Affected by Alcohol and Drugs
Susan Rarity-Middleton, Chest Heart and Stroke Scotland
Helen Reilly, QNIS
Anne Renwick, Salvesen Mindroom
Bushra Riaz, Kidney Research UK
Tilly Robinson-Miles, Food Train
Arvind Salwan, Care Inspectorate
Stuart Smith, Terrence Higgins Trust
Tom Steiner, Obesity Action Scotland
Claire Stevens, Voluntary Health Scotland
David Stewart, Fedcap Scotland

KellieThomson, Voluntary Health Scotland
Robert Thomson, Care and Repair Scotland
SheilaThomson, Community Renewal Trust
Tom Wightman, Pasda
Kirstin Worsley, The Breastfeeding Network

Non-MSP Group Members

Eilidh Guthrie , Research Data Scotland
Gemma Ingram, Scottish Government - Population Health Directorate
Andrea Lenssen, Scottish Government
Fiona McIntyre, Royal Pharmaceutical Society
Sarah Murray, Royal Voluntary Service
Katherine O'Sullivan, DaSH
Vanessa Paynton, Art in Healthcare
Layla Robinson , Research Data Scotland
Rosie Seaman, Research Data Scotland
Richard Simpson
Lucy Wharton, Association for the Study of Medical Education

Apologies

Emma Harper MSP

Agenda item 1

Approve Minutes from 6th October CPG meeting. Proposed by Tilly Robinson-Miles and seconded by Alan Eagleson.

Agenda item 2

Approved new members:

Robert Gordon University

Breastfeeding Network

Cyrenians

Blood cancer UK

Carers Scotland

Agenda item 3

Discussion topic- Data and Health inequalities

Presentations from:
- **Rosie Seaman, Data Sourcing Manager and Layla Robinson Partnership and Strategy Director at** [Research Data Scotland.](#)
- **Kate O'Sullivan, Operational Lead, Grampian Data Safe Haven (DaSH)**

Research Data Scotland (RDS) is a not-for-profit charitable organisation established in 2021 and presented alongside Grampian Data Safe Haven (DaSH), sharing work from the West of Scotland regional Safe Haven.

RDS aims to advance health and social wellbeing in Scotland by simplifying and scaling access to public sector data for research that will deliver public good. Work that can improve society by filling gaps of knowledge – generating evidence allowing policymakers and others to build a picture through analysis. RDS presented on two examples of data being used for public good in the regional safe havens. These are cross-sector data linkages projects that provided contemporary evidence for policy to reduce health inequalities in two regions of Scotland. An example from the West of Scotland provided evidence of co-occurring homelessness, justice involvement, opioid dependence, and psychosis. An example from Grampian provided evidence for inequalities in children's mental health care.

Both projects were completed in the two regional safe havens. Safe havens are Trusted Research Environments (TREs). In practice, these are highly controlled, powerful computing environments. TREs are independently governed and independently accredited. Data used by researchers in Scotland's safe havens can be considered functionally anonymised and have been fully approved for research purposes only. In regional safe havens, pseudonymisation takes place, which is critical to be able to maintain patient confidentiality whilst also ensuring reproducibility of research findings. Only fully trained and accredited researchers can access the safe havens and all outputs are formally checked before they can be released.

Linking data, that is routinely collected, from across different organisations provides the opportunity to understand the predominance of overlapping experiences. This linkage demonstrated the type of 'real-world' evidence needed to inform policy making across multiple sectors to improve population health and reduce health inequalities, an endeavour often referred to as healthy public policy.

This type of data linkage offers entirely new possibilities for evaluating the health impacts of social policies (such as welfare reform or homelessness prevention), through natural experiment designs and policy decision modelling.

More information on the case studies can be found via the Powerpoint presentation.

Agreeing the Data Sharing / Governance of both projects was the most challenging part. The bureaucratic burden is demanding for all organisations involved, at every step of the way the process is resource intensive. Both projects were delivered under the traditional "create and destroy model" for cross-sector data linkage. This means if you need these projects up-dated with the most contemporary data you need to start

again with the multiple application forms and multiple years of waiting. The create and destroy model is inefficient for everyone and outdated for the scale and quality of research policy needs to deliver contemporary change for public good.

Researchers across the regional safe havens have demonstrated time and time again the feasibility of cross-sector linkage and the ultimate policy impact. Now we need to be using data in Scotland at pace and at scale to deliver public benefit across the country, not just project by project, region by region, application after application. The true public good of data can only be realised by changing to a "research ready and re-use model".

RDS is leading that change.

They advocate for the policy changes that will enable Scotland to realise the full potential of cross-sector data linkage in safe havens across the country. They argued that we need policy change to scale and speed up data access so, when our society is faced with challenges, we can respond in real time - not three years later when the information governance paperwork has been signed off for only one local authority.

RDS cannot achieve all of this alone, but said they were proud to be at the heart of Scotland's research data ecosystem.

Questions and discussion

Q. Brian Whittle MSP- Who owns the data?
A. Rosie Seaman - Not about ownership but understanding that the research and data are for public benefit and looking at the scale that is needed to make the change. The safe havens have had no data breaches - they are working at level 10 but can hopefully be more confident and work with the data controllers to reduce to 8. There is a legal basis for sharing data for this purpose. Working with organisations to realise the potential of the data is key. Change the perspective of fear and worry in data breaches to confidence - high standards needed.

Q. Brian Whittle MSP- Looking at trends in data to enhance understanding for individuals- are we talking just about general trends?
A. Kate O'Sullivan- its two-fold to understand the general trends but that provides a way to analyse the data to look at trends for individual patients, to understand what is happening and be able to respond to help an individual.
A. Layla Robinson- it is mainly doing population research but we work to make it easier to allow professional researchers to get access to this information to allow other organisations the ability to change. Safeguarding is key.

Q. Tilly Robinson-Miles, Food Train – the data is not there for malnutrition in the community. It's great to use existing data sets but how do we get the data that third sector organisations hold? However, they are not part of the data sharing pool. How can third sector organisations get their important data used to inform policy?

A. Rosie Seaman- RDS is there as a research service provider to take data, anonymise the data and bring it in to the data picture. Speak to RDS to be part of their

data sourcing strategy. There is fear at allowing data to be shared but RDS also working to help organisations understand how they can share the confidence to do it safely.

Q. Sheila Thomson, Community Renewal Trust - who is involved?There is a need to get others rather than just the statutory organisations. Will those third sector organisations who share get to see benefits?
A. Kate O'Sullivan - how do we facilitate that at national level? There is a duty of care to ensure individuals are not identified- but it is a challenge to bring organisations together. It is a big concern and it is a valid point as data controllers need to agree to data sharing. Early intervention is a key benefit of data sharing but also needs to have the funding and resourcing of the data sharing.
A. Rosie Seaman- statutory organisations have tested and tried this system- this now allows other organisations to have confidence to be involved.

Q. Sarah Curtis, Universitiesof Edinburgh and Durham- is there scope for public and wider debate on this? There is an ethical principle underlying all the obstacles to this. That is something that representatives of government need to review and public perception is key. It would be good to open the debate and include academia in the discussions. We are making it impossible to move quickly.
A. Rosie Seaman - third sector can use the safe haven data- it's not just academics, services can be provided by RDS to access this.

Q. David Stewart, Fedcap- the reality is third sector can't afford to access this. Data only fulfils its potential if you do something with it. How can third sector get involved more easily or access funding to allow this to happen?
A. Rosie Seaman- safe havens are the place to achieve this and they will work with you to achieve this through linking on other data sets already there. RDS will bring the data set into the safe haven, the research is where the cost comes in. It is no longer enough to have just statutory services providing the data sets, the bigger picture is more important to understand what is missing and that's where the third[d] sector comes in.

Q. Justina Murray, Scottish Families Affected by Alcohol and Drugs - is AI a consideration in this?
A. Rosie Seaman – short answer is yes.

Agenda item 4

No other business raised- the next meeting date will be confirmed shortly.