

# ADR Scotland

## Public panel



2pm – 4pm Monday 25 November 2019

South Gallery Annex room, Dovecot Studios, 10 Infirmary Street, Edinburgh EH1 1LT

### Those present at the session:

Public panel members Nigel Mead, Hannah Tweed, Liz Elliott, Lauren Durell, Stephanie Davies, and Cathy Mitchell; Speakers Jackie Caldwell and Professor Susan McVie; and support staff Erin Gray, Harriet Barker and Colette McColl, from the Scottish Centre for Administrative Data Research. Apologies sent by four panel members who were unable to attend – Thomas Thomson, Michael Nicholson, Jacqueline Oliveros and Kevin Teviotdale.

### Session 1: Medical imaging data

*Jackie Caldwell, NHS National Services Information Services Division*

NHS Scotland is exploring the potential for the use of data from medical images across the NHS in Scotland for a range of purposes – including research and teaching. In this session Jackie Caldwell set out what is meant by medical image data, the plans for use of it in the future, and the safeguards in place. Panel members were asked about their views relating to the developments.

Two initial questions were asked, with participants asked to mark their responses on paper provided:

#### How do you feel about image data being used in this way?

Entirely Unacceptable:	0	Somewhat unacceptable:	0	Neither:	0	Somewhat acceptable:	0	Entirely acceptable:	4
------------------------	---	------------------------	---	----------	---	----------------------	---	----------------------	---

#### How do you feel about other data (not images) being used for similar purposes?

Entirely Unacceptable:	0	Somewhat unacceptable:	0	Neither:	0	Somewhat acceptable:	4	Entirely acceptable:	0
------------------------	---	------------------------	---	----------	---	----------------------	---	----------------------	---

Discussion points and queries raised by panel members included:

- The way gender bias will be factored in/controlled for was queried – given gender will be removed as part of the personal identifiable information, this may give rise to unintentional bias – particularly in algorithm development in later stages.
- This was also raised in relation to other characteristics – given certain conditions may be easier to detect within certain groups of the population than others, and that it is important to be aware of and address any unintentional bias. Access to information about how data was gathered was also highlighted as an important factor to prevent this.
- One member of the panel asked about commercial use/access to the data, and their concerns regarding this. Jackie Caldwell set out that NHS Scotland only provide direct access to approved researchers, but this could be indirectly used for commercial purposes. The panel member felt it important to clarify the specifics of how access to this data may be used for

- commercial purposes, as it would have a significant impact on how the public may feel about the work - and that for them personally, access for commercial use would not be appropriate.
- Another panel member asked how researchers would see the other variables which might relate to or cause issues raised in an image. Jackie said that the data could be linked to other datasets, which could include prescribing histories or other administrative data records. The absence of a tag to indicate that someone is a smoker, for example, was discussed.
  - Lastly, a member raised that there should be equitable access to data for research – including the third sector. They felt that the work set out was interesting and had potential, but that access should be equitable to ensure public benefit.

Panel members were invited to send any further points they might have regarding potential uses of medical imaging data, and how this might be communicated to the public, by email, since further time was not available for discussion in this session.

## Session 2: Violence and vulnerability in Scotland

*Professor Susan McVie, University of Edinburgh*

Professor McVie outlined some of the key sources and context for data on crime, justice and violence in Scotland, and a project she and her team are hoping to undertake using it, focused on violence and vulnerability in Scotland. Panel members were asked about their views on the project. Questions asked of the panel included:

- How do you feel about this project?
- What concerns might you have about it? Any potential risks to the public?
- What do you think about the benefits of the project? How might they be thought through or considered further?
- What (if any) further questions do you feel should be asked of the data?
- To what degree do you feel comfortable/not comfortable with this project taking place?

Discussion with panel members included the following issues and points raised:

- One panel member queried if the research might impact how safe people feel about calling 999 in future, as they may not understand (or the media may not make clear) the safeguards and context which ensure individuals are not identifiable in the research. The importance of effective communication about the research findings with this in mind, and to a range of audiences, was stressed.
- One panel member asked if there is evidence that other countries who have used data in this way have seen positive impacts. Professor McVie did not have a direct international comparison example to hand, but cited examples of the positive effects of administrative data research in similar areas, and stated this is an area to explore further.
- Another member asked if it might be more / equally useful to look at violence by area, rather than individual. Professor McVie said that geographical spread is critical, and that this would be explored within the project also (such as mapping against Scottish Index of Multiple Deprivation for common themes and overlaps); but that by looking at the individual, it is possible to note incidents in the data sets that took place for that individual before or after the violent incident, which makes the data more meaningful.
- Professor McVie was asked how big an impact people who 'walk in and walk out' of A&E (rather than arriving via the Ambulance Service, and being admitted to hospital) have on the data and research findings– since related violence is not likely to be recorded in their records in the same way. She stated that it is not possible to know how big an issue this would be; particularly given the persistent issues regarding data on domestic violence in particular. This issue would be acknowledged in the research findings, and can be used (as part of the

broader work of the Scottish Centre for Administrative Data Research and ADR Scotland) to work toward improvements in data quality in Scotland.

- One panel member said that it sounded highly useful, and queried how the full impact of the project and findings could be expected, unless all relevant stakeholders were fully engaged with the work. Professor McVie explained that both Police Scotland and the Ambulance Service were interested in the project, but the findings would be of most direct value to the Ambulance service as it involved detailed analysis of their data. It is hoped that as the research project develops and findings emerge, this may encourage other key stakeholders - including Police Scotland – to consider sharing data that would make the project more relevant to them.
- The way in which organisations involved define violence was queried (since it had been discussed that relevant organisations did not have a shared definition of 'vulnerability'). Professor McVie set out that Police Scotland use set Scottish Government crime codes, but that there is not a common way for other services to define violence, given it is not traditionally a core part of their service.
- Panel members said they felt positive about the project taking place, and that it seemed it would be of benefit to the public.