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Data Benefits: Attitudes and aspirations of benefit recipients in Scotland towards data sharing

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Objectives

The reuse of administrative data has the potential to transform public services. However, there remains limited evidence on the views of affected communities towards the sharing and linking of their data. Our research aimed to gather attitudes of one such group: those in receipt of benefits.

Methods

We ran seven deliberative focus groups at community centres in Edinburgh, speaking to 37 individuals in receipt of benefits. These focus groups discussed four data sharing scenarios that were co-produced with stakeholders from the public sector, academia and the third sector. Our four scenarios included three scenarios of data sharing for the administration of benefits (one of which currently happens), and one scenario based on sharing of Scottish social security data for academic research (i.e. for data linkage). These events were followed up by two community discussion events which were open to the general public.

Results

All participants were familiar with the idea of 'personal data', and spoke about various kinds of data sharing that already happens with their data. While some expressed trust, most participants strongly distrusted agencies and their ability to keep their data safe and use it in ways that would benefit them or be proportionate.

Despite this, when discussing the four scenarios, participants did outline some advantages. These were that data sharing could: help ensure those who were entitled to benefits received them; make benefits easier to receive; and facilitate research for the public good. Nonetheless, participants all expressed concerns about the data sharing scenarios. In particular, there was considerable concern about the lack of choice or consent, and that certain communities' data were being disproportionately used.

Conclusions

Our research demonstrates the importance of talking to affected communities in ways that are grounded in specific scenarios rather than general attitudes (as views often change depending on the context). It also highlights the interest these communities have in being consulted and involved in discussions around data sharing and linkage.



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