



Knowledge Exchange Seminar Series (KESS)

...is a forum that encourages debate on a wide range of research findings, with the overall aim of promoting evidence-based policy and law-making within Northern Ireland



Public Attitudes to Data Sharing in Northern Ireland

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@ADRC_NI @ARK_info #datasharing

Background

- Effective linking and sharing of medical and other social data for research has great potential for public good (administrative data research → value)
- It also presents challenges in terms of protecting individual privacy
- Public confidence and engagement are critical to a careful advance in the use of these techniques

Northern Ireland Life and Times survey (NILT)

- Monitors the attitudes and behaviour of people in Northern Ireland annually
- Comprised of modules which vary from year to year
- In 2015 included a module of questions/vignettes relating to **data sharing**
 - derived mainly from the 'Dialogue on Data' report from ESRC and Ipsos Mori in 2014¹
 - related to the key theme of 'Public understanding and views of sharing of health data, data linking, and relevant safeguards'

<https://www.ipsos-mori.com/researchpublications/publications/1652/Dialogue-on-Data.aspx>



NILT Methods – Participants and Procedures

- Systematic random sample of addresses
 - *person to be interviewed randomly selected using the 'next birthday' rule*
- Interviews
 - *conducted, with adults aged 18 years or over, between 21st September and 22nd December 2015*
 - *carried out face to face in the respondent's home via Computer Assisted Personal Interviewing*

FINDINGS

Trust in Organisations

...to keep information or data that they have about people secure and use it appropriately

91%

GP Surgery

86%

The NHS

73%

Government Departments

72%

Academic Researches in a University

51%

Charities

41%

Commercial Organisations like Insurance Companies

FINDINGS

General concerns about use of data:

Of the roughly 4 in 10 respondents who expressed a concern, these were the main concerns expressed.



Government sharing data within health system

- An **Electronic Care Record** was introduced in Northern Ireland in 2013
- Overwhelming support
 - 98% find the system acceptable in an emergency situation
 - 96% find the system acceptable in a non-emergency situation

Sharing of GP records outside the NHS

What is this? Passing of information to another government department to help improve services

80% thought it would be acceptable to pass on information about people with a long-term **physical illness** to benefit offices so they could be encouraged or helped to apply for disability benefits



Linking health data for use by academic researchers

Some Definitions/Issues/Concerns involved

- Is the data Identified (names/dob/address) or de-identified (anonymous...stripped of identifying details)?
- What are the data security measures (how is it held/transferred/shared)?
- Is there individual informed consent? Is it feasible?
- Public benefit (how defined and communicated)



Scenario

Suppose some university researchers are studying the causes of Parkinson's disease. They are allowed to see bits of health records including medical information about patients as well as their age, sex and occupation. However they are not allowed to see names, addresses or postcodes. But the researchers are very keen to know roughly where patients live because some people think that there is a link between Parkinson's disease and living near fields where pesticides have been used.

87% YES: NHS staff link postcodes to agricultural data, remove postcodes, and pass data to researchers

60% YES: NHS staff pass patients' postcodes to **researchers** so they can link to agricultural data



The need for consent

Respondents were very divided on this issue

30%

It isn't necessary to ask for consent for linking data in these ways as long as there is a guarantee that nobody will be identified.

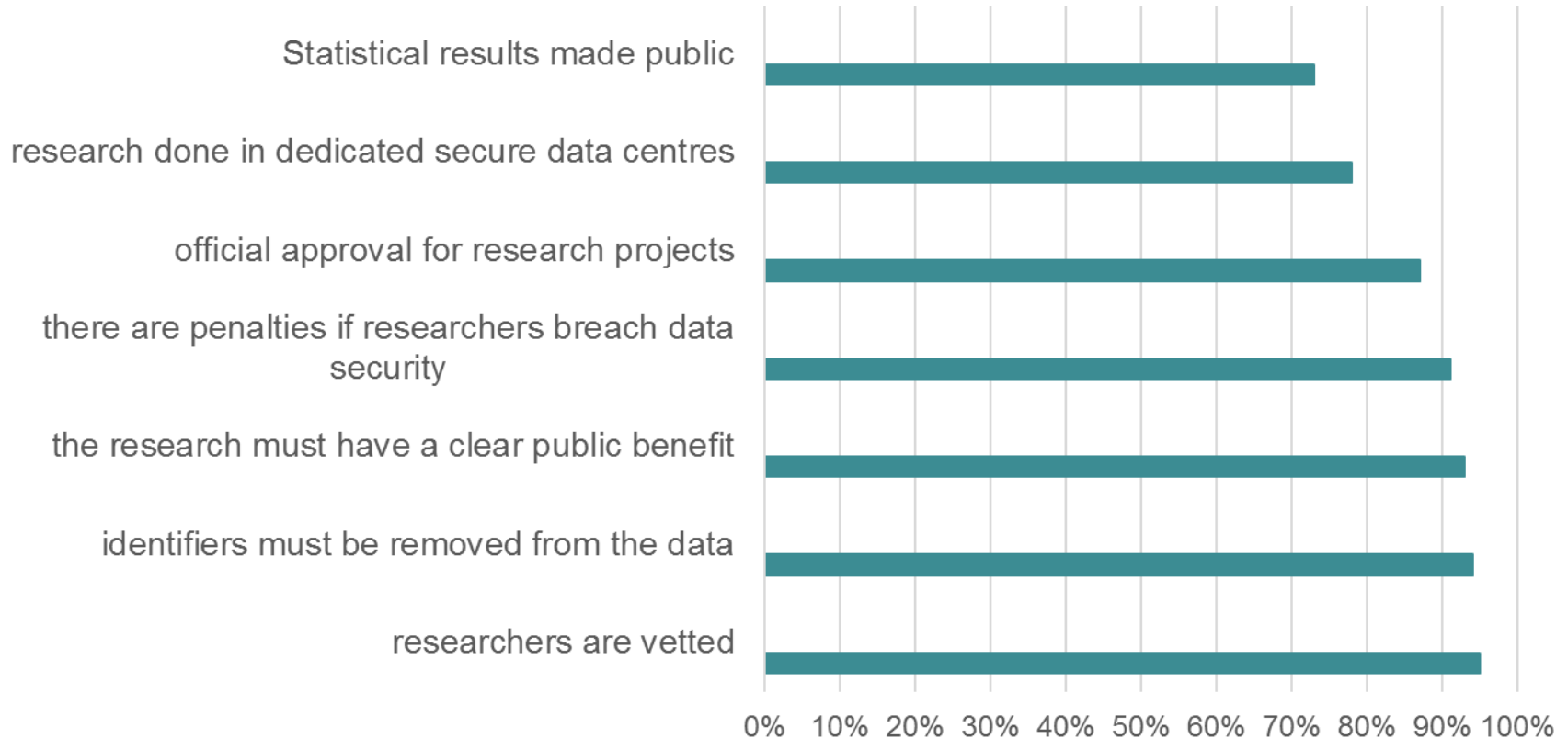
34%

You should always have try to get consent when you can but if the difficulties are too great important research should not have to be abandoned for this reason.

31%

You should always have to ask for each individual patient's consent before linking their data with anything else and you will have to abandon the research if there are difficulties contacting people.

Importance of safeguards for academic research



“if personal data can be made anonymous and a person’s right to privacy maintained, then the data should be used where there is a benefit to society”

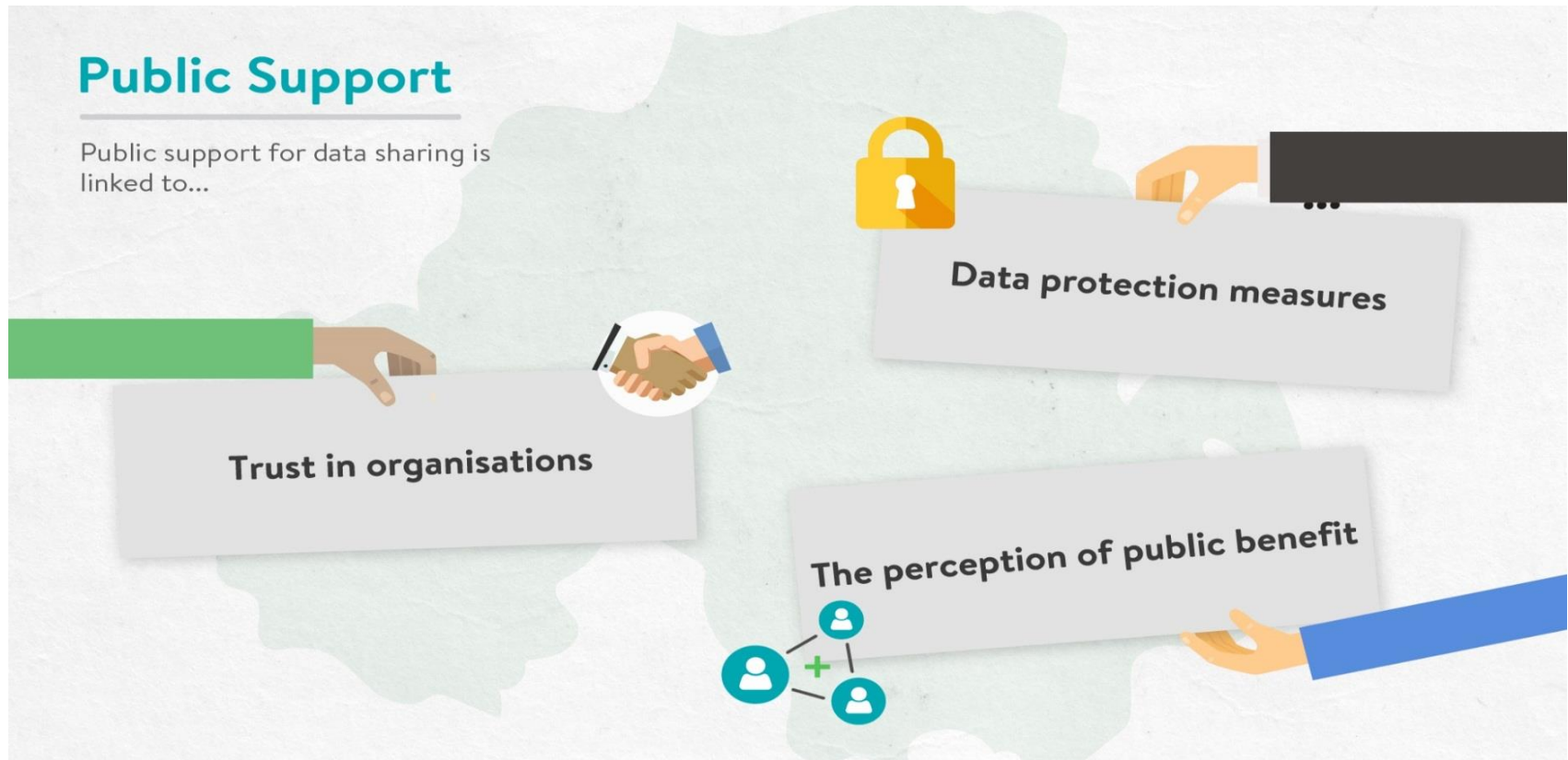
85% Agree



Pillars of Support

Public Support

Public support for data sharing is linked to...



Implications for MLAs

To increase public trust

- Educate constituents on data use/sharing
- Provide opt-out mechanisms where possible without imposing unworkable consent requirements (*remember consent is not always feasible with administrative data)
- Contact ADRC-NI researchers to learn more about their systems for protecting privacy and securing data.

Then, with your increased understanding of our work

- Take action in making more data available for research.
- Speak with your government department leadership and civil servants and encourage the data sharing process.





Northern Ireland
Assembly



Queen's University
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