ARK Northern Ireland
ACCESS RESEARCH KNOWLEDGE

Administrative Data Research Centre Northern Ireland

An ESRC Data Investment

Public Attitudes to Data Sharing

Professor Gillian Robinson and
Professor Helen Dolk

7 September 2016

Belfast campus, Ulster University

#datasharing #NILT2015

Ulster University

HSC Public Health Agency
Research and Development

Queen's University Belfast

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Public Attitudes to Data Sharing
WELCOME

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Background

- Effective linking and sharing of medical and other social data for research has great potential for public good
- 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

- Aims to monitor the attitudes and behaviour of people in Northern Ireland annually
- Comprised of modules which vary from year to year
- 2015 survey included a module of questions and vignettes relating to data sharing
    - derived mainly from the 'Dialogue on Data' report from ESRC and Ipsos Mori in 2014[1]
    - 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

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

Survey Sample

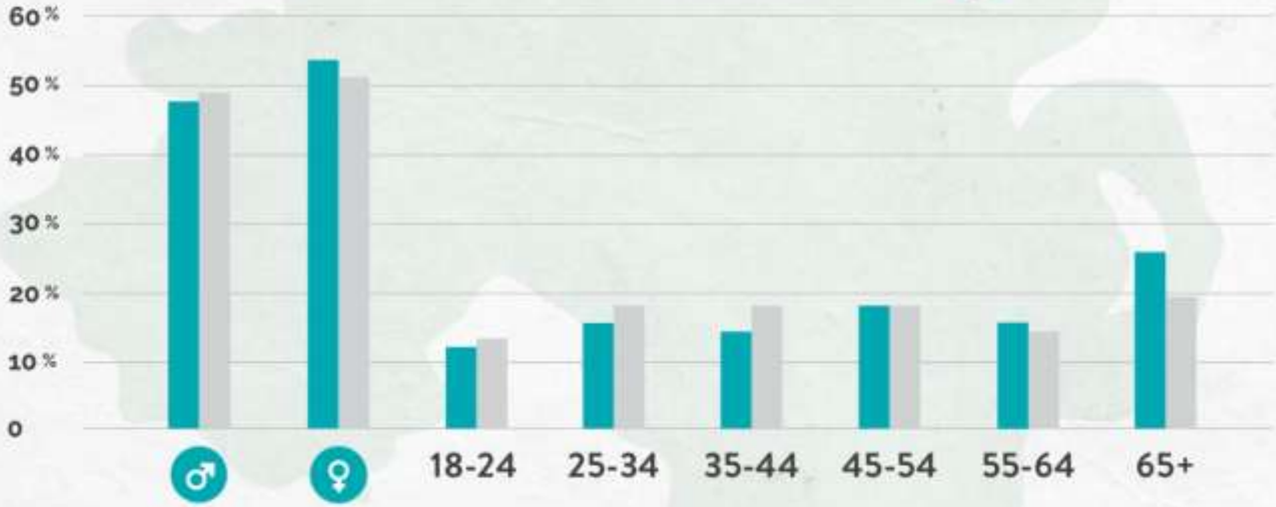
Base = 100%

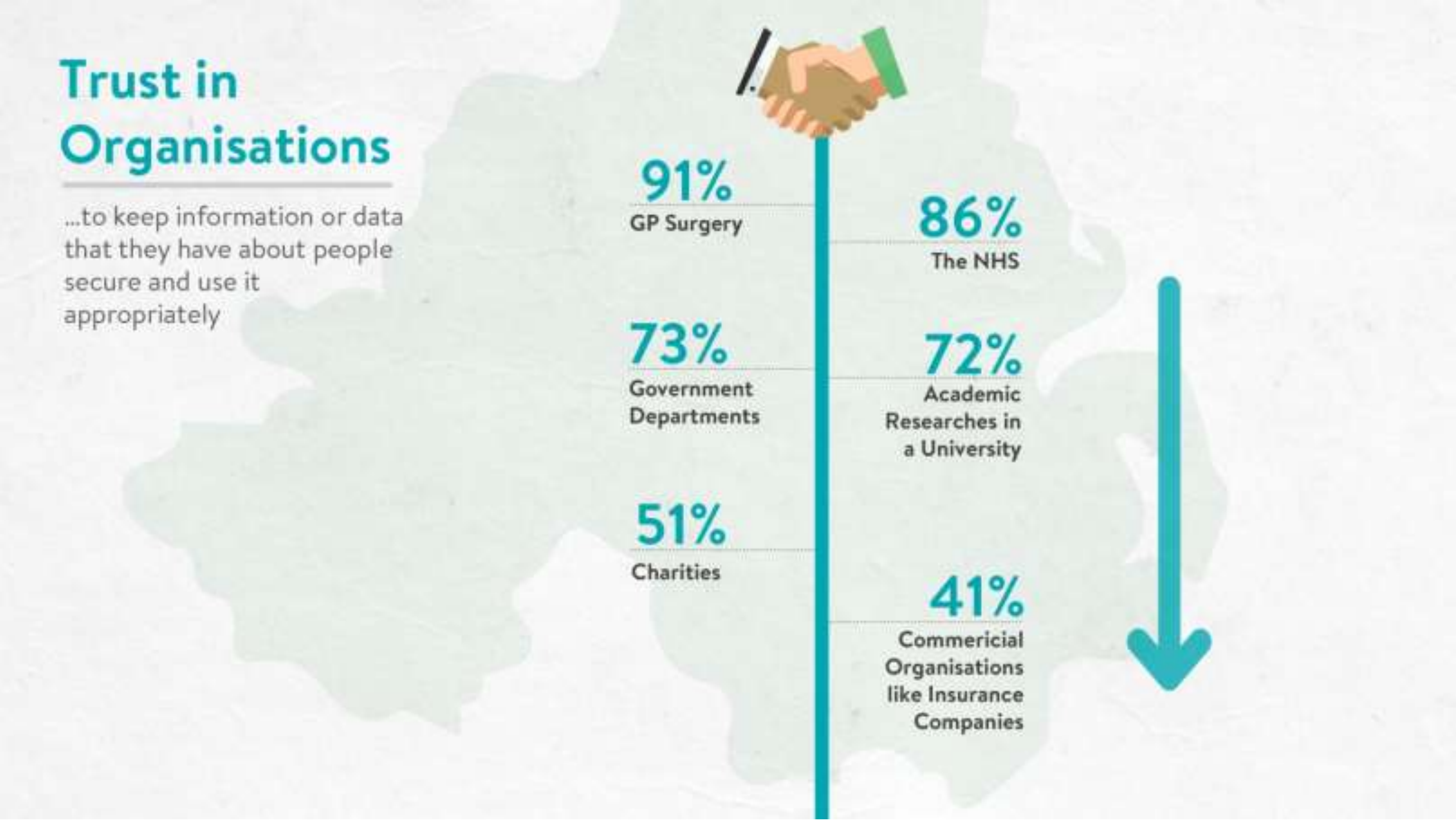
NILT 2015 (weighted)	1,202
NI Census 2011	1,431,540

✓ **55% Response rate**

✗ **26% Refusal**

18% No contact





Trust in Organisations

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

91% GP Surgery

86% The NHS

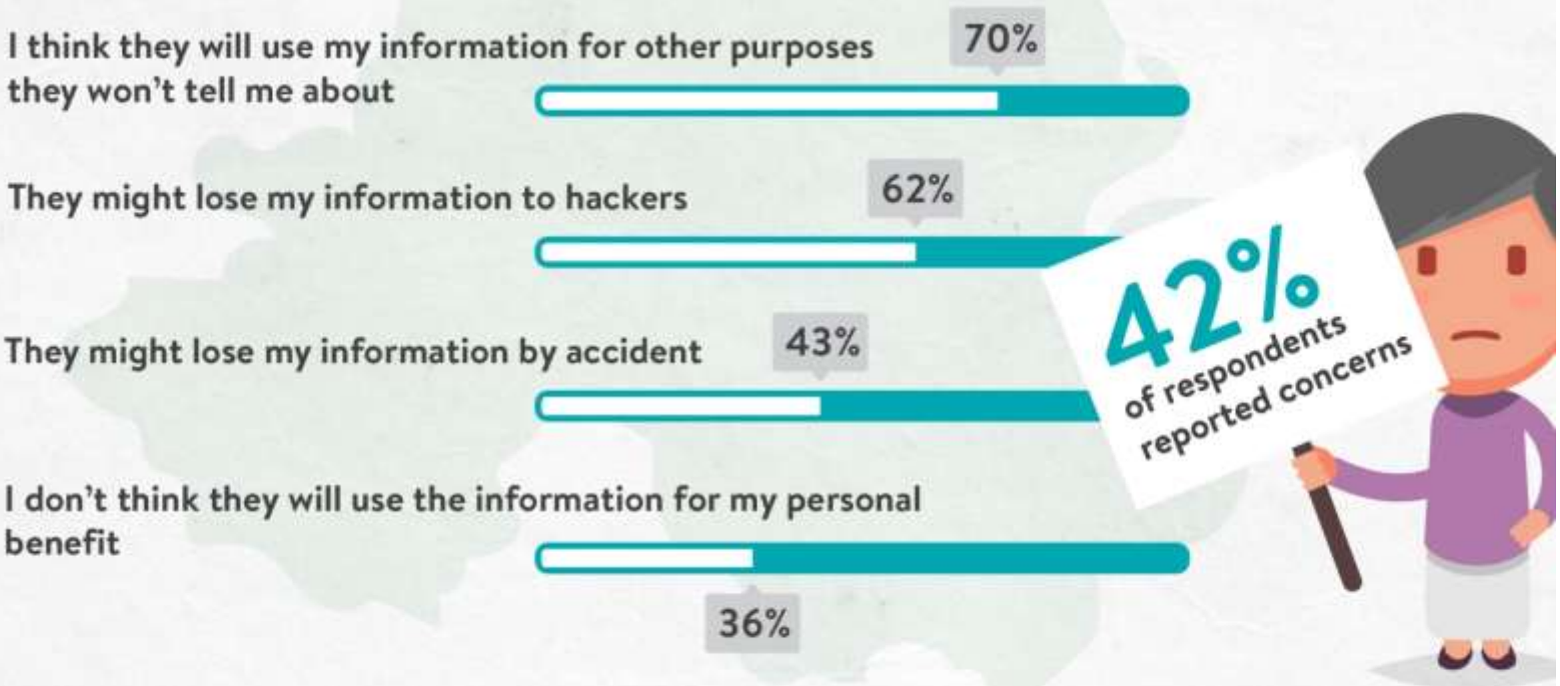
73% Government Departments

72% Academic Researches in a University

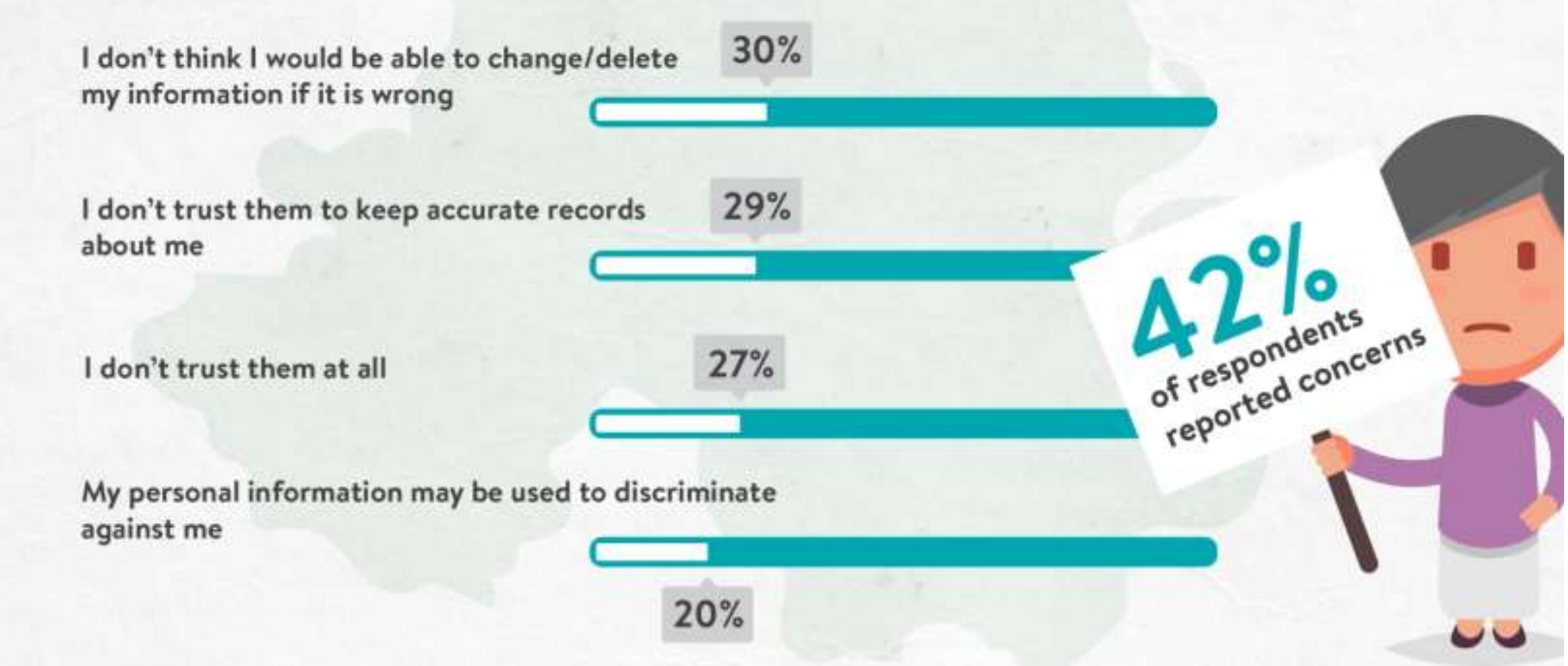
51% Charities

41% Commericial Organisations like Insurance Companies

Concerns about how these organisations use the information they keep about people (1)



Concerns about how these organisations use the information they keep about people (2)



- 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

- 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
  - 71% thought it would be acceptable to do this for those with a long-term **mental illness**
- Passing of information outside government departments
  - 67% thought it would be acceptable to pass information **to schools** about health conditions that might affect a child during the school day

Linking health data for use by academic researchers

- Identified or de-identified (anonymised)
- Other data security measures
- With or without individual informed consent
- Public benefit

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

And suppose researchers wanted to find out if babies born prematurely did less well at school so that in future such children should automatically be considered for extra help in the classroom. If the people who keep hospital records link them to school records and pass the researchers this data without names or addresses or other identifiers then the researchers can look at the patterns in the data. Do you think that this should be allowed?

……**Hospital records staff** link hospital records about premature babies to school records and pass de-identified data to researchers **73% YES**

The need for consent

Respondents were very divided on this issue

30%

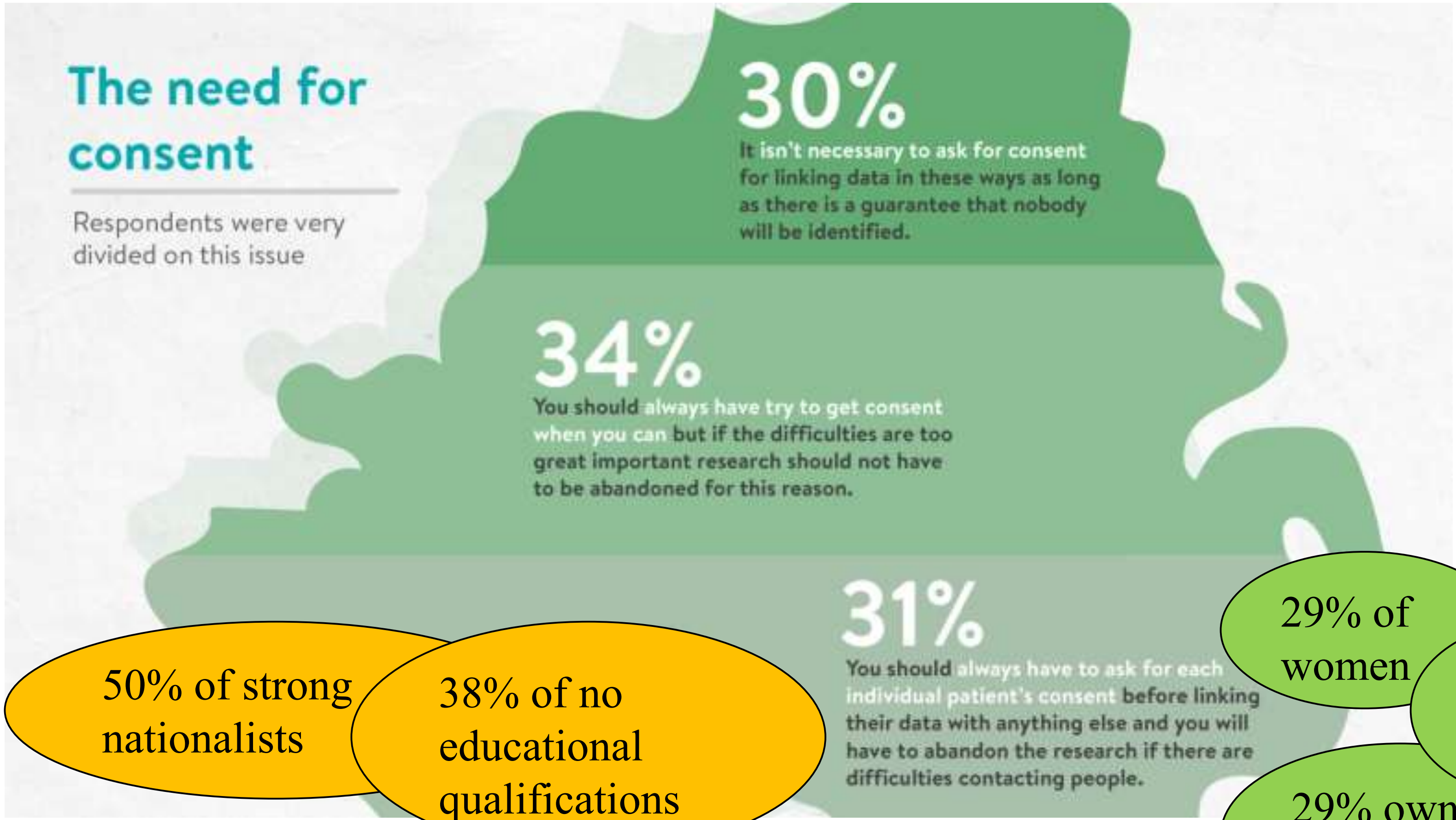
It isn't necessary to ask for consent for linking data in these ways as long as there is a guarantee that nobody will be identified.

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.



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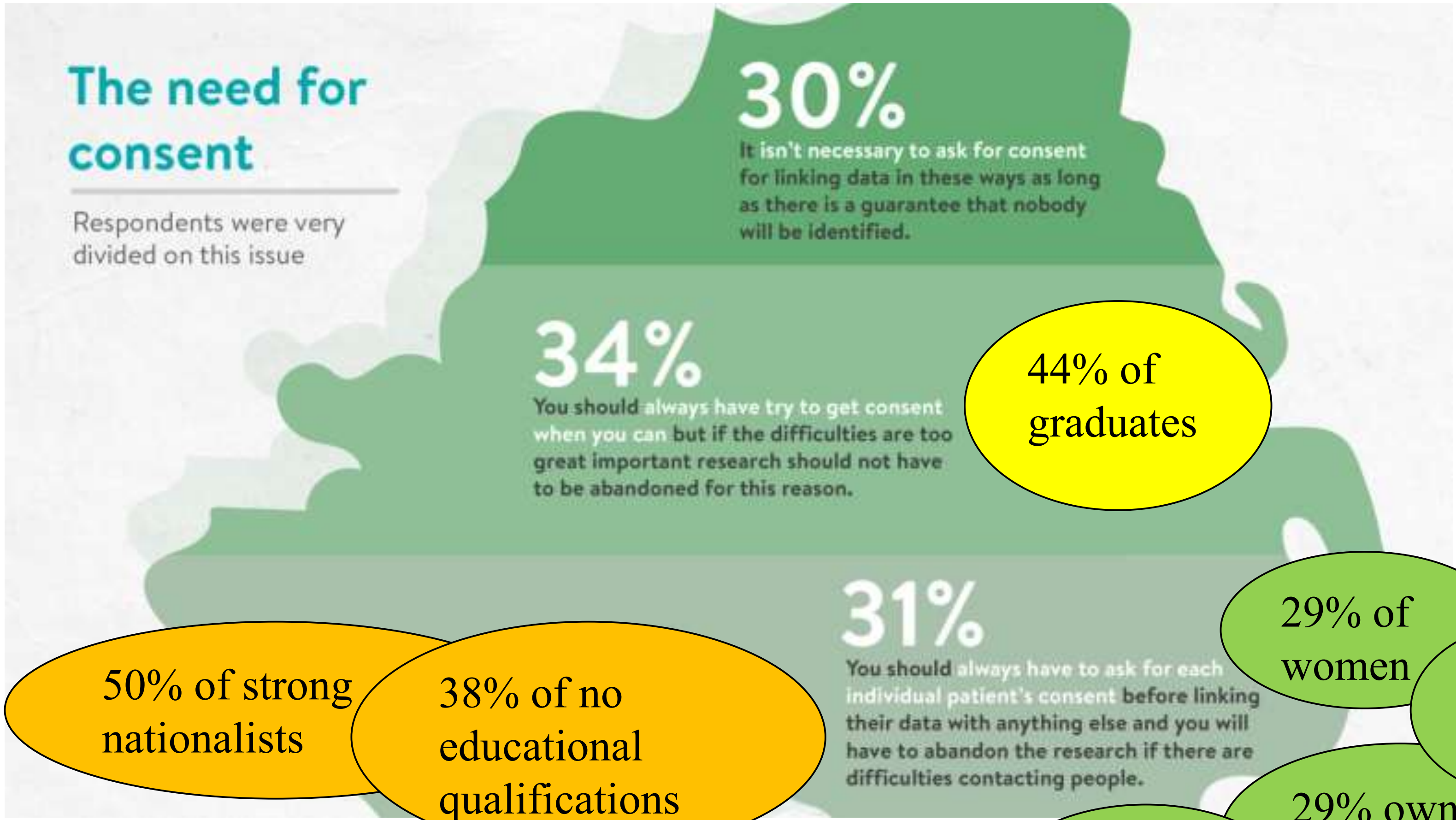
50% of strong nationalists

38% of no educational qualifications

29% of women

24% no religion

29% owner occupiers



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44% of graduates

50% of strong nationalists

38% of no educational qualifications

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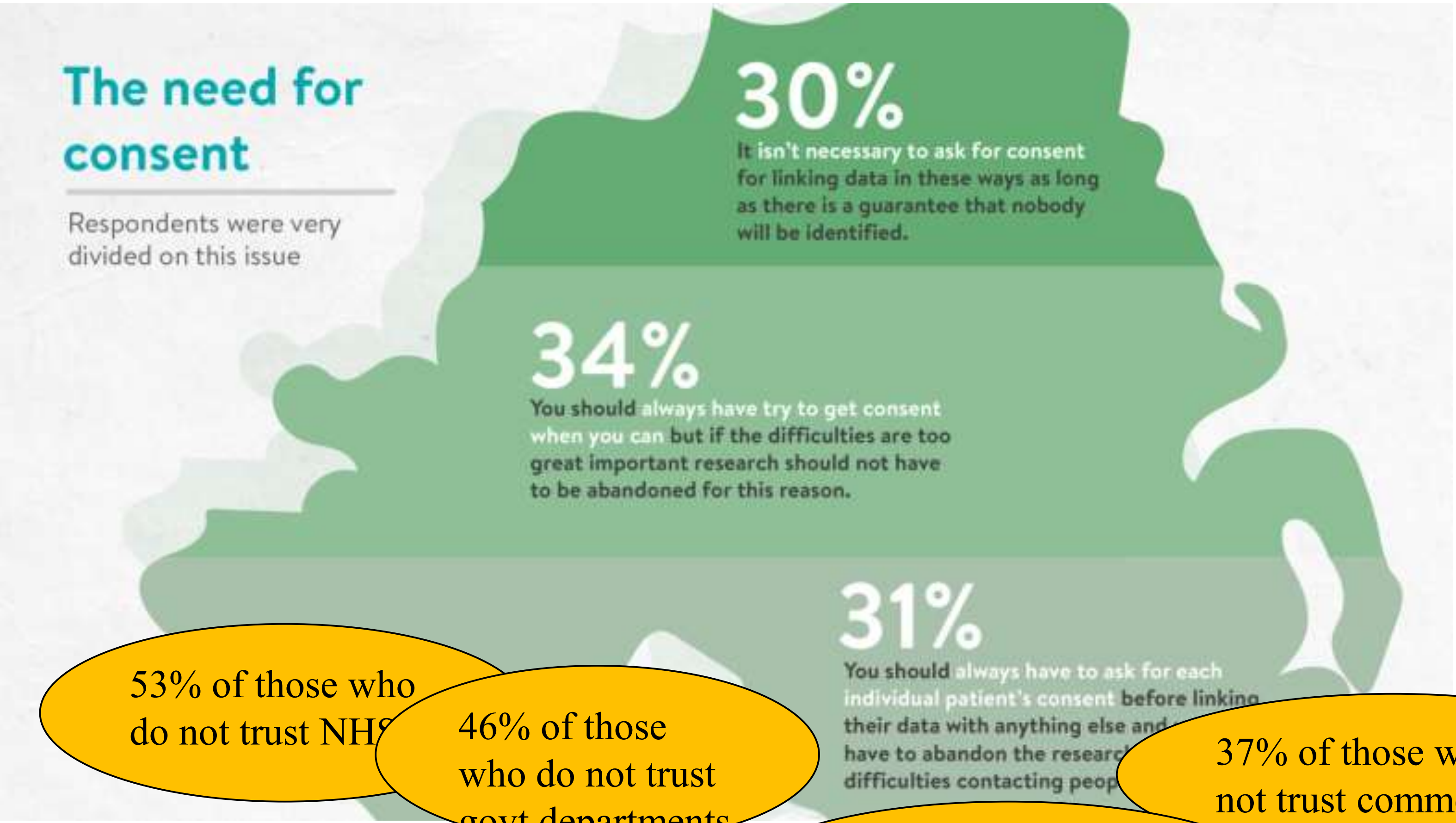
24% no religion

29% owner occupiers

26% of graduates



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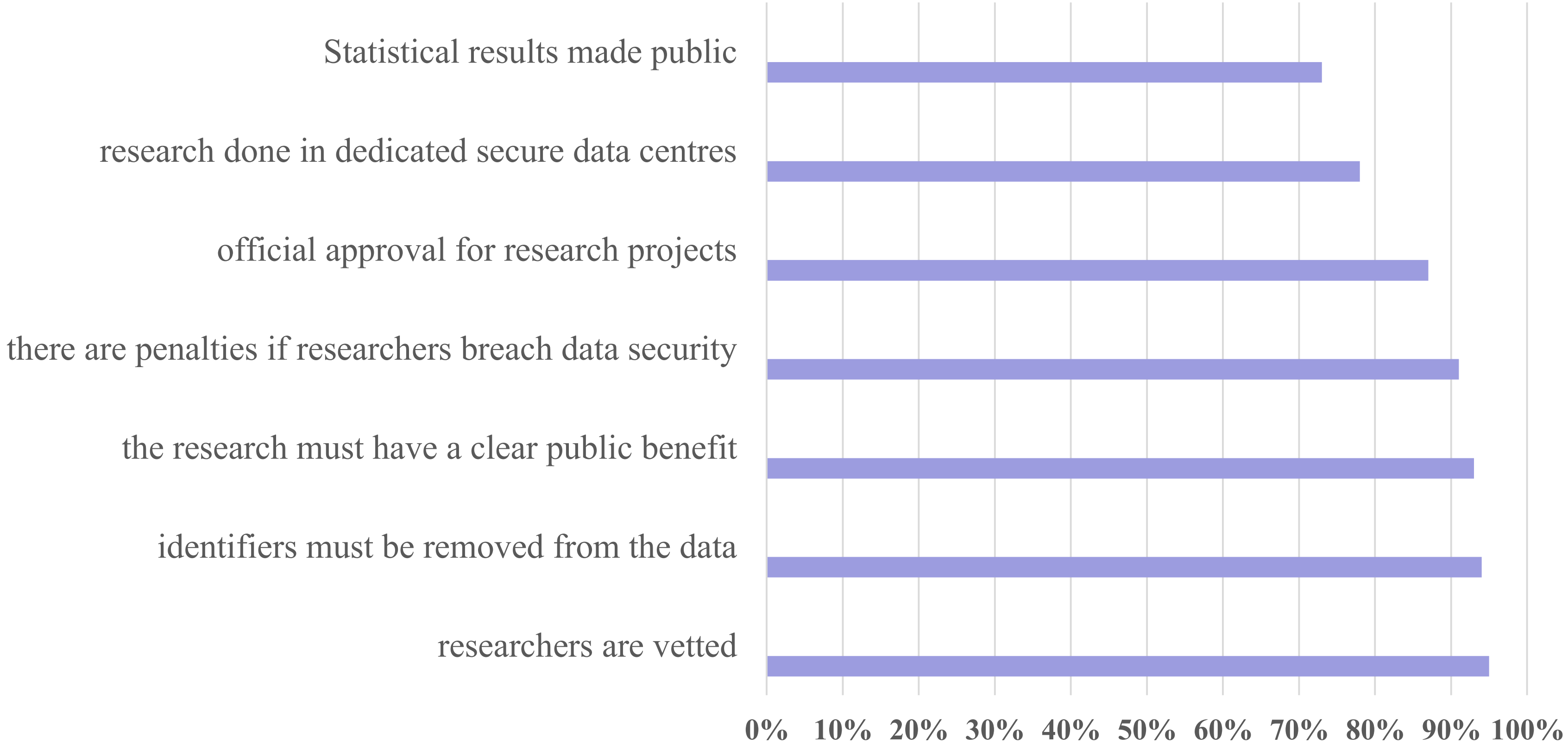
53% of those who do not trust NHS

46% of those who do not trust govt departments

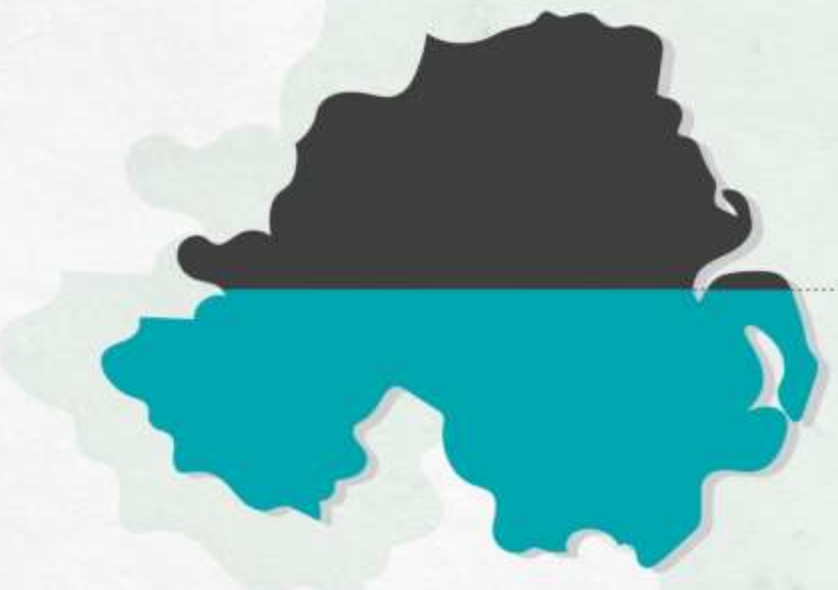
37% of those who do not trust commercial

43% of those who do not trust academics

Importance of safeguards for academic research



Commercial access to data (1)



50%

felt commercial organisations should be subject to more safeguards than university researchers

Commercial access to data (2)

Given the example of a drug company using NHS patient information to determine which patients might benefit the most from a new drug to cure Alzheimer's disease...

75% agreed (13% disagreed) that commercial organisations should have access to patient records as we will all benefit from a cure for Alzheimer's disease.

26% agreed (50% disagreed) that they wouldn't want commercial organisations to get access at all because they should pay for all their own research.

57% agreed (22% disagreed) that commercial organisations should pay a fee to get the data as they will make a profit out of any new drug.

“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

Conclusion

Public Support

Public support for data sharing is linked to...

- Data protection measures
- Trust in organisations
- The perception of public benefit

Public Attitudes to Data Sharing in Northern Ireland

-findings of the NILT 2015 survey

Response
by
Roy McClelland
Chairman Privacy Advisory Committee
(N Ireland)

Public Attitudes to Data Sharing in Northern Ireland

- the findings
- the context of this report

Public Attitudes to Data Sharing
Direct Care

Trust - within our trusts (86%)

in primary care (91%).

Unease - sharing information outside the HSC family with charities, academic and community organisations.

- sharing of sensitive information

Public Attitudes to Data Sharing
Secondary Uses

Awareness of the potential benefits of the uses of health information for health and social care research.

Support for allowing such uses. But with clear caveats.

Control and security. Personal identifiable information should not be used for such research, however worthy,

in the absence of consent,
in the absence of high standards of security,
in the absence of strong sanctions for accidental or willful breaches.

Use of de-identified data. A substantial number of people would wish to have a consenting arrangement for use for linking data sets for research- *even of anonymised information* .

Public Attitudes to Data Sharing Secondary Uses

Table 10 Consent and Data sharing	%
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	30
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	34
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	**31**
Don't know	5

Public Attitudes to Data Sharing
Secondary Uses

Table 9: Acceptability of data linking
without names or addresses or other identifiers (3)

	Yes (Definitely or probably)
	%
Men	74
Women	71

Public Attitudes to Data Sharing Secondary Uses

Table 8: Acceptability of data linking (2)

Do you think that the NHS staff should be allowed to pass on the patients' actual postcodes to the researchers and let them link it with the agricultural data?

	Definitely or probably should be allowed
	%
Men	63
Women	58

Public Attitudes to Data Sharing Secondary Uses

Table 17: General willingness for own personal data to be used

	Agree	Neither agree nor disagree	Disagree	Don't know
	%	%	%	%
I don't care who uses data about me	20	10	69	1
I don't mind how data collected about me is used, as long as names and addresses are taken off and there is a guarantee not to identify me	74	8	16	2
I don't want university researchers to be able to use my personal data at all	16	16	64	4
I don't want commercial organisations to be able to use my personal information at all	39	21	35	5

Public Attitudes to Data Sharing
Secondary Uses

Table 19: The balance between the right to privacy and the public good

	Agree	Neither agree nor disagree	Disagree	Don't know
	%	%	%	%
The right to privacy has to be respected over everything else	83	12	4	2
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	8	**4**	3

Public Attitudes to Data Sharing
Context

In NI:

Code of Practice on Protecting the Confidentiality of Service User Information

Personal Data Guardians

Privacy Advisory Committee

Honest Broker Service

HSC (Control of Data Processing) Act

Nationally:

National Data Guardian - Review of Data Security, Consent and Opt-Outs

Underpinning all:

DPA, HRA, Common Law Duty of Confidentiality

Public Attitudes to Data Sharing Context

The National Data Guardian’s report

“The case for data sharing still needs to be made to the public”

“There should be a new consent/opt-out model”

“The public is broadly content for their anonymized information to be used for health and social care purposes beyond direct care”

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The right to privacy has to be respected over everything else	83	12	4	2
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**	8	4	3

Public Attitudes to Data Sharing Context

HSC (Control of Data Processing) Act (NI)

The committee must arrange for the ***dissemination*** (in such form and manner as it considers appropriate) ***of such information*** as it may appear to it appropriate to give ***to the public about the operation of this Act*** (and any other relevant matter, and) ***in particular about the <u>rights</u> of relevant persons regarding the processing of confidential information*** of those persons.

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The circumstances in which the committee may ***authorise the processing of confidential information*** of a relevant person ***<u>shall not</u> include*** circumstances ***where that person has made representations*** to the committee ***that the relevant person's confidential information should <u>not</u> be disclosed or processed***.

Public Attitudes to Data Sharing Going Forward

For any and all uses of patient health data:

"public confidence is critical"

For any proposed uses of patient data for health and social care purposes not directly related to their care:

"the right to privacy has to be respected over everything else"

Questions / Comments