



Public Attitudes to Data Sharing in Northern Ireland

Gillian Robinson and Helen Dolk



Introduction

When organisations gather information about people (whether it be medical data, tax information, benefits, or criminal justice records) guarantees are generally made to client groups that the data will be kept confidential and that it will not be passed on to any other organisation. However, increasingly debate has centred around the potential public good if some of these administrative data could in fact be shared or combined. This may be on an identified basis for service provision, or on a de-identified basis for research. At

the heart of this debate is the need to protect individual privacy against the benefits that data sharing or linking could reveal in terms of discovering factors in disease prevention or social policy and improving medical practice and more efficient services generally across a range of areas.

This summary paper reports on a survey of public attitudes to data sharing in Northern Ireland with an emphasis on health issues, carried out as part of the 2015 **Northern Ireland Life and Times survey** (NILT). Effective sharing and linking of medical and other social data

is potentially a game-changer in advances in health and social wellbeing but public confidence is critical to a careful and judged advance in the use of these techniques.

Trust in organisations

While very high numbers of respondents trust their GP surgery and the NHS in general to keep information or data that they have about people secure and use it appropriately, slightly smaller percentages are prepared to trust government departments and academic researchers.

Table 1: Percentage of respondents who 'definitely' or 'probably' trust different organisations

	%
The NHS	86
Government departments	73
Your GP surgery	91
Commercial organisations like insurance companies	41
Academic researchers in a university	72
Charities	51

However trust plummets when it comes to commercial organisations like insurance companies where only two fifths say that they trust these

organisations. Charities are also viewed with scepticism with only half of respondents prepared to trust charities in their use of data.

Overall, 42% of respondents said that they had had particular concerns about how these organisations used the information about people that they kept. The two most common concerns were that the information kept would be used for other purposes that the respondents would not be told about and that the information might be hacked. Other concerns less frequently mentioned included that the information might be lost by accident. A smaller number of respondents (one fifth) felt that the information might be used to actively discriminate against the respondent. When respondents mentioned other concerns they tended to be about persistent phone calls.

The Electronic Care Record

In 2013, Health and Social Care (HSC) in Northern Ireland introduced a new computer system that brought together every patient's care record so that health and social care staff could quickly access all relevant information even if treatment had been in a different hospital or another part of the service. The Northern Ireland Electronic Care Record (NIECR) contains details of lab tests, x-rays, referrals, investigation requests, appointments and discharge letters from various HSC systems. Two questions in the survey were included to measure the level of public acceptance of this system and the results show overwhelming support with 98% finding the system 'definitely' or 'probably' acceptable in an emergency situation and 96% finding it acceptable in a non-emergency situation.

Sharing GP records

Sharing of GP records outside the NHS is not as palatable to the public as is the Electronic Care Record. Respondents were presented with a number of different scenarios, the first of which involved the routine passing of information to benefit offices about people with a long-term physical illness so that those people could be encouraged or helped to apply for disability benefits. While close to 80% of respondents found this to be 'definitely' or 'probably' acceptable, a fifth of respondents were not prepared to accept this kind of routine information sharing.

When the scenario was changed from a physical to a mental illness, rather more respondents pulled back from this routine sharing of information with just over a quarter feeling that this should not be allowed routinely. When the scenario was changed to one where GP information could be routinely shared with schools in relation to health conditions like diabetes or asthma there was again a slight increase in public unease with around 27% of respondents finding this unacceptable. All in all, there are

Table 2: Consent to data linking

Some people think that you should not be allowed to link data in these ways unless you have the consent of each individual patient - even if this means that the research might have to be abandoned because of difficulties contacting patients. Other people think that consent is not necessary in cases like these. Which of these three statements comes closest to your own view?

	%
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 <u>always have to ask for each individual patient's consent</u> 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

still large numbers of people (at least two thirds) who find each of these types of data sharing acceptable but there is a substantial minority of people who would not be happy with this.

Linking data

The NILT module also explored public attitudes to the linking of health data – specifically for use by academic researchers. Very high percentages (87%) of people believe that academic researchers should be allowed to use data that has already been linked to other data by 3rd parties. The first scenario presented to respondents suggested that patient addresses could be *linked by NHS staff* to other data and the latter could then be passed on to the researchers.

However there is a clear drop in support when it is suggested to respondents that the patients' postcodes could be passed to the researchers and then the researchers do the linking. Overall around 60% of respondents think that this should be allowed but just over a third feel that this should not be allowed.

The need for consent

None of the questions on data linking addressed specifically the issue of consent, however, once the context had been set and the concepts of linking explained via the scenarios, a specific question was asked to measure the extent to which respondents felt that consent was necessary. Table 2 shows that respondents were very divided on this issue. A third felt that the researchers should try to get consent for linking where possible, 30% felt that consent wasn't necessary as long as nobody will be identified and about 30% felt that consent was vital and the research could not proceed without it.

Table 3 shows the percentages of different groups who believed that consent was vital and the research could not proceed without it. Young people appeared particularly likely to feel that consent was so important that the research could not proceed without it. However multivariate analysis did not confirm this finding.

Table 3: Percentages who believe that individual consent to data linking is vital according to sex, age and religion.

	%		%
Men	34	18-24	39
Women	29	25-34	29
		35-44	26
Catholic	34	45-54	30
Protestant	31	55-64	32
No religion	23	65+	32

Commercial research

Public attitudes to commercial research using administrative data are twofold. Certainly results of the first question on this survey affirmed that public trust in commercial

organisations like insurance companies to use data appropriately was less than impressive.

Nonetheless when examples are used where there is a clearly apparent public benefit to research carried out by commercial companies, people are much more accepting than might have been thought. Respondents were given the following scenario:

There are many commercial organisations such as drug companies who could be allowed to use some NHS patient information under the same strict regulations as university researchers. Suppose a company has developed a new drug that could be used to cure Alzheimer's disease. They have asked the NHS for access to some patient information - without names or addresses - so that they could work out which kinds of patients might benefit the most. This kind of information would help the company to apply for the drug to be made available for the most appropriate patients. How much do you agree or disagree with each of these?

Respondents were then given a series of statements to consider and while this issue was not explored exhaustively there are strong indications of where public sympathy

lies. The first question (Table 4) was simply in relation to access given the potential public good.

A full three quarters of respondents felt that a drug company should be allowed to use de-identified data under the same conditions as academic researchers if they were working on a drug that might cure Alzheimer's disease. Only 13% of respondents were prepared to disagree with this. So in a clear unequivocal case of potential public benefit there is strong public support for commercial access. However whether public sentiment would really accept 'the same conditions as academic researchers' is a moot point. About half of respondents indicated in a different survey question that they were in favour of stricter controls for commercial research than academic research.

When the notion of paying for this access was introduced, this was not greeted with universal support. Given possible public perceptions of wealthy drug companies and the fact that new drugs will generate profit, it was conceivable that public sentiment would demand payment for access. Although 57% of respondents did agree that a fee should be paid for access this was by no means overwhelming support. Just

Table 4: Public support for commercial access to NHS patient information in the search for a cure for Alzheimer's disease

I would like them to get access to patient records because we will all benefit if they can find a cure for Alzheimer's disease

Agree	Neither agree nor disagree	Disagree	Don't know
%	%	%	%
75	8	13	3

over a fifth of respondents disagreed explicitly. It may be that the example given (a potential cure for Alzheimer's disease) was so potent that some people were not prepared to put blocks in the way of this. However whether public sentiment would really accept 'the same conditions as academic researchers' is a moot point. About half of respondents indicated in a different survey question that they were in favour of stricter controls for commercial research than academic research.

Conclusion

Public support for data sharing is

linked to trust in organisations; data protection measures and the perception of public benefit. The difficult balance that regulators have to negotiate is in the potential enormous public benefit from linking administrative datasets against the right to privacy of the individual. This balance is reflected in the final set of survey results which illustrate that there is huge public goodwill to achieve the potential benefits but an unwavering acknowledgement of the right to privacy. The overwhelming majority of respondents (83%) agree that *The right to privacy has to be respected over everything else.* An

equally impressive 85% maintain that *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.* Despite the difficulties in achieving a balance between individual privacy and the public good, the level of public support gives this task a fair wind at the very least. The views of a significant minority must be taken into account but this very visible groundswell of opinion should motivate regulators to work through these difficulties in a fair, respectful and pragmatic way.

Key points

- Public support for data sharing is linked to trust in organisations; data protection measures and the perception of public benefit.
- People in Northern Ireland are much less willing to trust commercial organisations to keep their data secure and use it appropriately than they are to trust their GP or the NHS.
- The vast majority of people support personal data sharing within the health service and in particular the Electronic Care Record.
- Nearly one third of people believe that data should only be shared for research if there is explicit consent, even if the practical difficulty of getting consent means that the research has to be abandoned. Though this attitude is less often expressed where it is clear that the data will be anonymised.

Gillian Robinson is a Professor of Social Research within the School of Criminology, Politics and Social Policy at Ulster University.

Helen Dolk is a Professor of Epidemiology and Health Services Research within the Institute of Nursing and Health Research at Ulster University.

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The **Northern Ireland Life and Times survey** (NILT) is carried out annually and documents public opinion on a wide range of social issues. NILT is a joint project of the two Northern Ireland universities and aims to provide an independent source of information on what the public thinks about the social issues of the day.

In collaboration with Queen's University Belfast and Ulster University

Magee campus, Ulster University
Northland Road, Londonderry BT48 7JA
Tel: 028 7167 5513
E-mail: info@ark.ac.uk

School of Social Sciences, Education and Social Work
Queen's University Belfast, Belfast BT7 1NN
Tel: 028 9097 3034
E-mail: info@ark.ac.uk