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Public Attitudes to Data Sharing in Northern Ireland: Findings from the Northern Ireland Life and Times Survey 2015.

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MOTIVATION FOR THE RESEARCH

We live in a society where government and other organizations routinely collect information on individuals during the course of providing services (health, education, tax, social benefits, electoral registry, driver and vehicle licensing, etc.) This information is called **administrative data**. When researchers analyse these data sets (alone or when linked to each other), **meaningful information and insights can emerge about trends in the population. Value emerges.**

MLAs may then use research insights to shape more effective social policy for their constituents; grassroots organizations can use research insights to advocate for their members or develop tailored resources or initiatives. The efforts of researchers to use these administrative data for the public good exists in a wider context where there are critical legal and ethical considerations. The government seeks to act in the public interest by: protecting individual privacy rights; ensuring data are secured and shared appropriately; ensuring consent is part of the equation; being cost-effective; and, ensuring transparency throughout all these processes. When MLAs or civil servants create and implement policies and programmes, the public's trust is fundamental because the public is at the centre of all these activities.

Since the public are at the centre of all aspects of data collection and sharing—providing the data, paying for the research, and as the beneficiaries of research impact—public dialogue in this process is essential. Researchers with the Administrative Data Research Centre of Northern Ireland (ADRC-NI)¹ conducted investigations to better understand the public's attitudes toward sharing and linking government data sets, especially with regard to sharing health data. Broadly, researchers sought insight into local public opinion, wanted to provide a baseline for future assessment of the public's attitudes, and provide information that can inform the public debate on this issue.

¹ The ADRC-NI is a coalition of researchers (at Queen's University Belfast and Ulster University) and data acquisition and protection specialists (at the Northern Ireland Statistics and Research Agency (NISRA)) who focus on conducting research on NI administrative data sets with the collaboration of various government departments and community sector groups. The centre is one of 4 centres (others are in Wales, Scotland, and England) under the Administrative Data Research Network that is funded by the Economic and Social Research Centre. www.adrn.ac.uk

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In 2015, the ADRC-NI secured funding from the Northern Ireland Health and Social Care Research and Development Division (HSC R&D Division) of the Public Health Agency to include a module of questions on attitudes to data sharing in the well-established Northern Ireland Life and Times (NILT) survey, an annual survey that looks at social attitudes toward a wide range of issues.

DETAILS ON NILT SURVEY

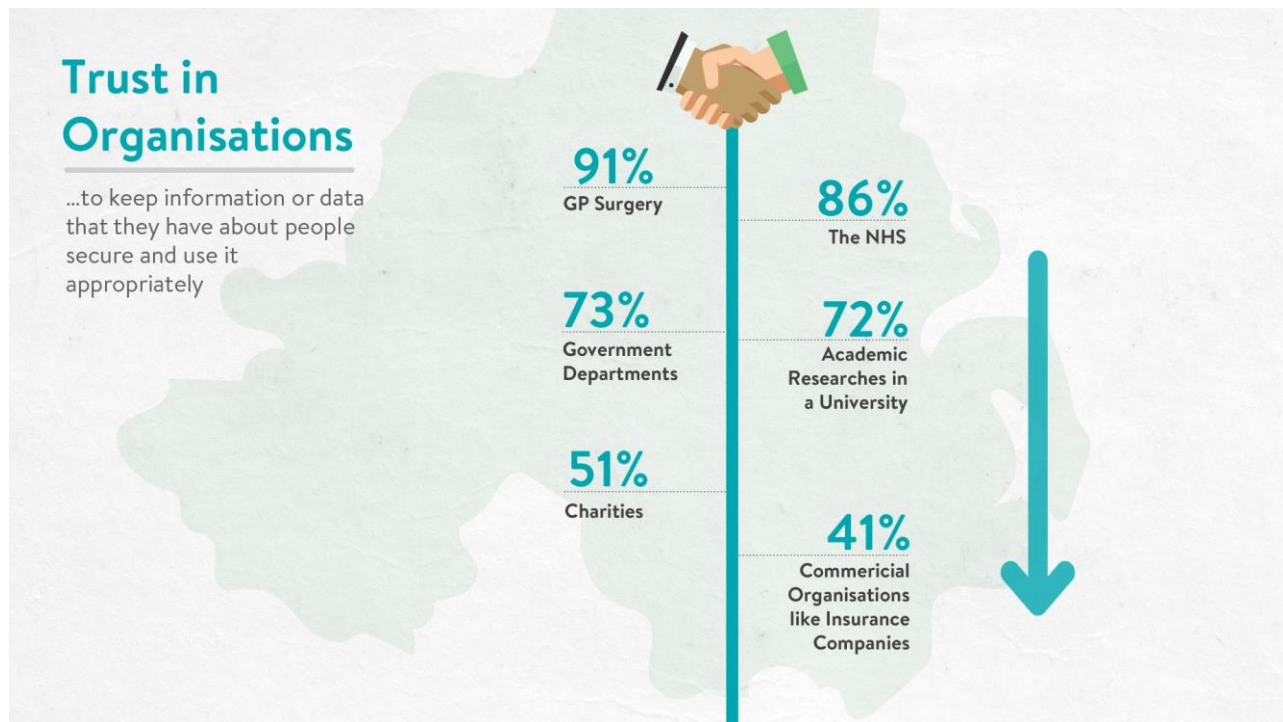
The NILT 2015 survey included interviews with 1202 respondents aged 18 or over, sampled via a systematic random sample of addresses taken from the Postcode Address File. The response rate was 55% and the module on data sharing included approximately 50 items. Full details of the NILT survey methods are available at <http://www.ark.ac.uk/nilt/2015/tech15.pdf> and the full dataset and lay friendly tables are available online <http://www.ark.ac.uk/nilt/results/datashare.html>. A short research update is available <http://www.ark.ac.uk/publications/updates/update108.pdf> and a fuller report is awaiting publication.

FINDINGS

The questions posed to survey participants first tried to assess how much people trust government and organisations to keep their data secure and to use it appropriately. Then, more specifically the lines of questioning fell into two categories. The first category related to what people think about the government sharing the public's data across its own departments in order to improve its services (where people's identities are known). The second category concerned whether government departments should make their data (stripped of identifying information such as name and address) available to researchers so that those researchers can investigate particular problems or look for societal trends that can then later influence government action.

Trust in Organisations to Keep Data Secure and Use it Appropriately

Who Does the Public Trust with Their Personal Data? The survey asked respondents, "How much do you generally trust each of these organisations to keep information or data that they have about people secure and use it appropriately?" See the chart below for the organizational choices and breakdown of responses. Respondents most trust their GP Surgery and the NHS.



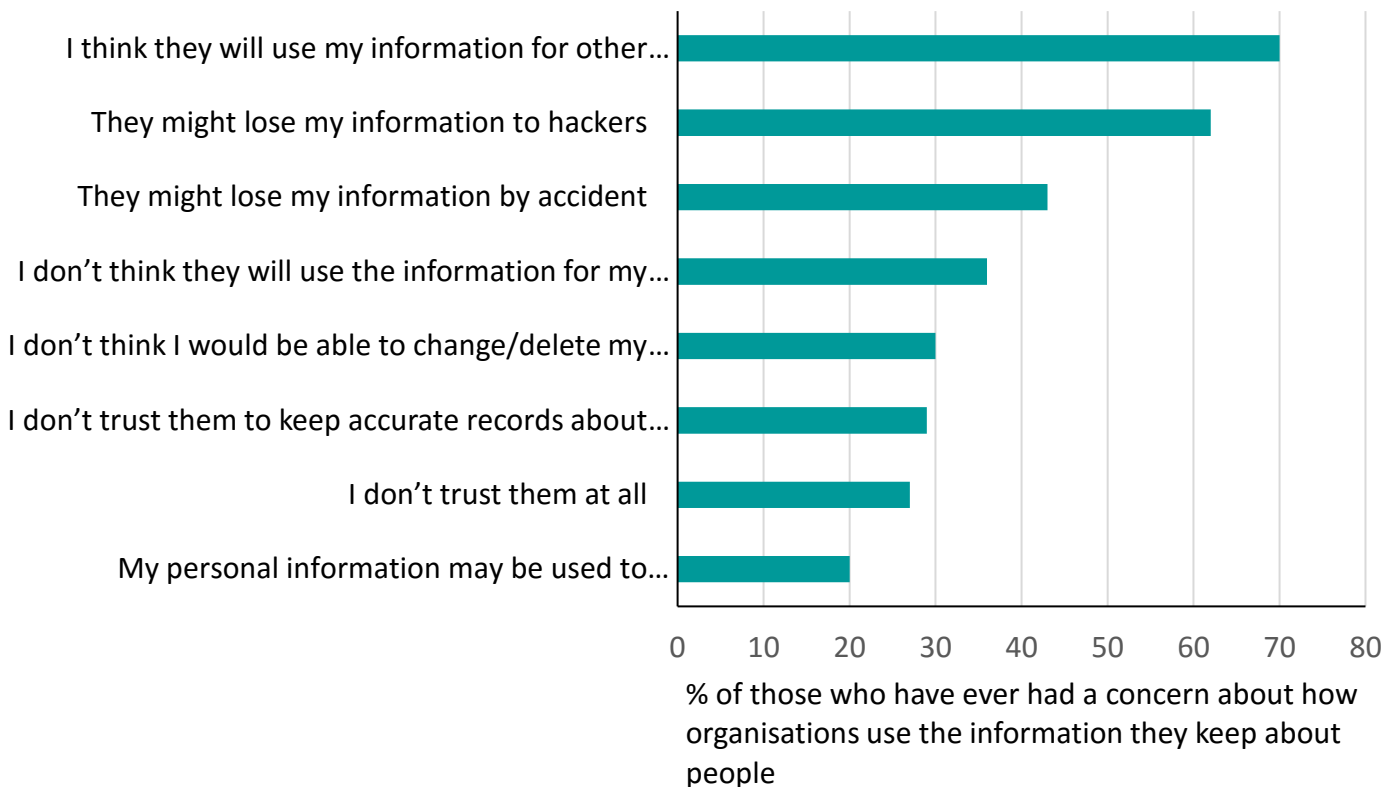
When the Public Does Express Concerns, what are those Concerns?

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42% of respondents said they, at some point in time, had a concern about how any of these organizations use the information that they hold. See the graph below for a breakdown of the types of concerns they expressed.

General concerns about use of data:

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



Attitudes Toward Government Sharing Information to Improve Its Own Services

Does the Public Support the Concept of the Electronic Health Record (data shared among various health system providers)?

Over 96% of respondents support this concept.

The Health and Social Care (HSC) introduced the Electronic Care Record (NIECR) as a way of sharing a patient's care record (i.e. details of lab tests, x-rays, referrals, etc. from separate health service providers) so that all of an individual's relevant personal health information is in one place. When the scenario of sharing a person's data involved emergency treatment, that level of support rose to 98%.

Does the Public Think Personal Information Should Be Linked across Government Departments?

80% of people were in favour of health information being shared ("linked") to improve access to services provided by other government departments, with that support decreasing when the scenario involved sharing information about children or about a person's mental health.

Attitudes Toward Government Sharing Information with Researchers

Does the Public Support Sharing Personal Health Data Outside the NHS?

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Public support and tolerance for sharing data is nuanced; unsurprisingly, support can be complicated or situation dependent.

Three pillars – trust in organisations, data protection measures, and public benefit—support data sharing for research purposes. If any of these are reduced or taken away, public support falls, and conversely if energy is put into one of these domains but not in others, then it will not be enough to secure public support.

When administrative data is used for research, the public may be concerned about whether consent has been given, whether that data contains information that identifies actual individuals, and whether the purpose of the research is to contribute to solving a particular problem (the research has a clear social benefit they deem significant).

The survey questions not only asked broad questions to ascertain the public's general attitude toward data sharing, but also then presented real-world scenarios for what data sharing might involve and what a researcher might investigate. Embedded in the scenarios were issues about how data might be "linked" or brought together (e.g. health records linked to educational records or social security records in order to uncover trends). These scenarios did not include wording that spelled out whether consent was obtained. However, some did address the issue of whether the data being shared was "identified"—meaning it contained individual traits such as name, date of birth, address, postcode—or whether the data was stripped of those characteristics before the data was analysed ("anonymised").

Some of the findings include:

85% of people agree that "if personal data can be made anonymous and a person's right to privacy maintained, then the data should be used [by researchers] where there is a benefit to society."

Very high percentages (90%) of people believe that academic researchers should be allowed to use data that has already been linked to other data by the NHS. For example, this 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.

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. There is an easy way that the NHS staff could link the postcodes of their patients to other agricultural data held to see how close the nearest fields are. Should the NHS staff be allowed to pass on the distance to the nearest fields while still keeping postcodes private?

When respondents were given the option of researchers linking the data there is a clear drop in support to around 60%. (and when asked about a third party linking the data around 73% of respondents would find this acceptable.)

What did the Public Say About the Issue of Consent when Using Data for Research?

None of the general questions directly addressed the issue of consent²—whether active or passive consent. A small number of respondents mentioned this spontaneously in their 'other' answers. Realistically we cannot assume that respondents made the assumption that consent would or would not be sought in these scenarios.

² When conducting administrative research, individual consent is not feasible. The best one can do is to have overall consent. ADRC-NI Researchers can provide the MLAs with further information on the types of consent systems and the feasibilities of those as well as the protections built into the research process to ensure individual identities are never known.

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However, once the context had been set and the concepts of linking data sets explained **via the scenarios**, a **specific question was asked to measure the extent to which respondents felt that consent was necessary**. Respondents were **very divided** on this issue. See below the scenario and graphic displaying the results.

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?



Nearly one third of respondents insist that data should only be shared for research if there is explicit consent, even if this means you will have to abandon the research if there are difficulties contacting people. **The 31% who indicated consent must always be given were less likely to trust organisations including the NHS and government departments with their personal data.** However, future research is recommended to investigate the extent to which anonymization of data would address this concern.

What do the Results tell Us about how Researchers Must Safeguard People's Personal Information?

There is a high level of support for data protection measures which are already implemented by the ADRN, particularly: making the data anonymous; checks and penalties for researchers; and, making sure research is of public benefit. Other measures also have high support (e.g. researchers only gaining access in centres dedicated to holding and securing that data, and making results public).

IMPLICATIONS

It was clear that the answers to survey questions depended on the complex details of particular scenarios, and that the general "abstract" questions can have quite different answers from more specific scenario-driven questions. It goes without saying that follow up research will continue to grow the body of knowledge around data sharing issues.

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A very high proportion of respondents (83%) felt that the “right to privacy has to be respected over everything else.” At the same time, 85% felt “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.” To these researchers, this suggests that the anonymization and other data protection measures as they together ensure privacy, coupled with research that has a clear potential public benefit, is an endeavour highly likely to be supported by the general public.

Given that data exists which can inform social policy and given that we all must ensure protections for and engagement by the public, we recommend that in order to maintain and raise support, MLAs should take measures to increase trust in government through

- Educating their constituents as to what their data may be used for, what sharing looks like, and the benefits and potential risks of sharing data.
- Providing opt-out mechanisms where possible without imposing unworkable consent requirements. [Remember that when using administrative data, full consent is not feasible in all cases because the data was not collected primarily for research purposes, it was collected in the course of administering programs. Building in mechanisms that inform individuals that their information might be shared at a later date, in aggregate and stripped of their personal details for research and programmatic improvement efforts creates transparency and a passive consent mechanism.]
- Contacting ADRC-NI researchers to learn more about their systems for protecting privacy and securing data.
- Ensuring that public opinion is regularly monitored on this topic.

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.

For more detailed information on the NILT survey results (including further details on breaking down these results along various lines of gender, age, religion, etc.), please see <http://www.ark.ac.uk/nilt/results/datashare.html> contact Gillian Robinson at gm.robinson@ulster.ac.uk

INDEX TERMS: Data Sharing, Attitudes, Privacy, Health Data