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

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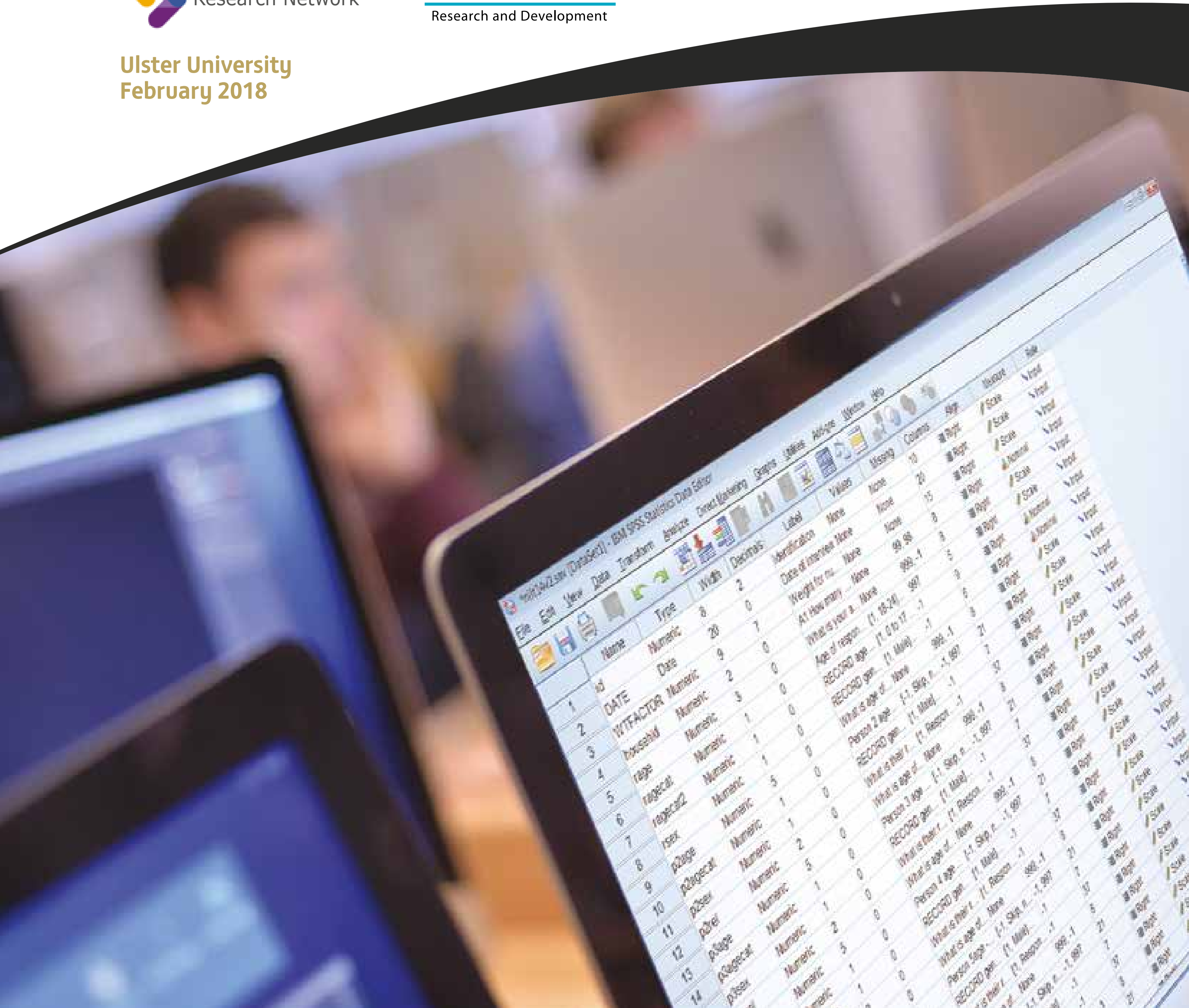

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This report reflects the views of the research team and not necessarily those of the Northern Ireland Health and Social Care Public Health Agency Research and Development Office.

Executive Summary

A module of questions on attitudes to data sharing was included on the 2015 Northern Ireland Life and Times survey (NILT). The NILT 2015 survey included interviews with 1202 respondents sampled via a systematic random sample of addresses taken from the Postcode Address File. The research was funded by the Northern Ireland Health and Social Care Public Health Agency Research and Development Office.

High proportions of respondents trust their GP surgery (91%) and NHS (86%) to keep information or data secure and use it appropriately. Slightly smaller proportions trust government departments (73%) and academic researchers (72%) and trust in charities (51%) and commercial organisations (41%) is much lower. Overall, 42% said they had ever had particular concerns about how any of those organisations used the information they kept.

The majority of Northern Ireland (NI) residents support the concept of sharing of identified health data in order to improve services. Over 95% were in favour of sharing data within the health service by means of the electronic care record, and over two thirds of people were in favour of health information being shared to improve access to services provided by other government departments, with information about mental health or children seen as more sensitive.

Regarding sharing data for research, eighty-five percent 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 where there is a benefit to society”.

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”. It was striking that this attitude toward needing consent is associated with low trust in organisations including the NHS and government departments. However, future research is recommended to investigate the extent to which anonymization of data would address this concern.

There is a high level of support for data protection measures, particularly de-identification, checks and penalties for researchers, and making sure research is of public benefit. Other measures also have high support e.g. data access in dedicated secure data centres, and making results public.

The lower level of trust in commercial organisations to keep data securely and use it appropriately is reflected in less support for data sharing with commercial organisations and 50% believe the data protection safeguards implemented for academic researchers should be greater for commercial organisations. However, there was evidence that where there is great public benefit, there is more support for commercial access to data.

In conclusion, public support for data sharing sits on three pillars – trust in organisations, data protection measures, and public benefit. 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. A repeat survey in three years’ time is recommended to reflect the progress that has been made.

1. Introduction

With the increasing computerisation of health records and other administrative data, access to administrative data to improve services, conduct research, and inform policy has become an important but controversial issue. The potential public benefits of use of these data must be balanced against concerns about data security and consent. Since the public are implicated in all aspects – providing the data, paying for the research or research processes, and being the beneficiaries of research impact - it is obvious that public engagement in this process is crucial.

Several distinctions need to be made to analyse public attitudes. Data on individuals may be identified or de-identified (anonymised), and may or may not be linked to other data (e.g. health records linked to social security records). Identified data is needed for operational uses to improve service provision to individuals, or to share data about an individual with another part of the health service or outside the health service for "joined up" services. For research purposes and to improve systems of service provision or inform policy, data about individuals can be de-identified at the earliest opportunity. For such purposes, data only need to be identified as long as this is required for linkage between records, and encryption methods can ensure that de-identification even precedes linkage. Currently, initiatives such as the Administrative Data Research Network (www.adrn.ac.uk), and the Northern Ireland Honest Broker Service (www.hscbusiness.hscni.net), provide "safe havens" where secure linkage is performed where required, and access is then given to researchers to de-identified data.

A further distinction can be made between data (identified or de-identified) used with or without individual informed consent. Consent can be given once (with potential renewal) for general purposes, or for each use of the data. Consent can be given on an opt-in basis (the data cannot be used unless the individual expressly gives consent) or an opt-out basis (the data can be used unless the individual expressly refuses consent). It is often easier to ask for consent for operational service use than for research use, but even for service use there may be problems e.g. sharing data in emergency situations, and complex consent mechanisms impose considerable burden which may impede good service provision. While opt-in individual consent for research is desirable where possible, for large population research studies it is very (usually prohibitively) expensive to ask everyone for informed consent, impractical to trace and contact individuals (especially when data from the past are being used), the consenting process may itself risk confidentiality, and inability to gather consent from selective parts of the population may invalidate the research or its representativity. The need for consent may moreover be less clear when data are de-identified. A balance must therefore be struck between public benefit and need for consent, and public engagement in these issues is required to strike this balance optimally.

Public engagement is also needed to determine what is considered to be for the public benefit and who decides. Public benefit may be for current or future generations, concern health or welfare or economic benefits, and be realised by small or large sectors of the population. Research provides evidence for, but does not dictate, the policy response, which may not be felt by all to be of benefit, thus emphasising the need for public access to research evidence. Attitude to research for profit by commercial companies is a particular issue.

The Northern Ireland Life and Times Survey is conducted each year to survey public attitudes to a range of social issues. In 2015, a module was included in the survey to gauge public attitudes to data sharing. The survey, funded by the NI Health and Social Care Public Health Agency Research and Development Office, was associated with the public engagement programme of the Administrative Data Research Centre Northern Ireland (ADRC-NI) , funded by the Economic and Social Research Council. The survey focused particularly, but not uniquely, on health data, and covered both sharing of data for service provision and for research, with more focus on the latter.

2. Previous surveys and research on public attitudes to data sharing

Our survey on public attitudes to data sharing is the first to be conducted in Northern Ireland, but a substantial literature has grown up in the United Kingdom (UK). Studies have been either surveys of representative samples of the population or special populations (e.g. hospital patients), or qualitative studies such as focus groups. The advantage of a survey is that one can gauge the frequency of different opinions held in the population and the demographic characteristics of those who hold different opinions, and track these through time with repeated surveys. One can also gauge the "gut reaction" that might be expected to a public announcement. However, respondents may not understand the issues well, and may have given different responses had they had more prior information and understanding. This would be particularly true in the complex area of data sharing. Focus groups and other qualitative methods are particularly good for exploring the informed opinions of members of the public, as time can be taken to discuss in depth. Thus, both types of research are necessary for a rounded picture of the situation.

Previous surveys and research have revealed the following:

A 2007 report by the General Medical Council (GMC) highlighted areas of public concern as personal risk from disclosure; ability to control the risks; trust/distrust- in actors and in systems; sense of "rights or autonomy". Office of National Statistics (ONS) (2014) categorised public concerns as being about security and confidentiality; privacy and anonymity; transparency control, consent and trust; and public and personal benefits. It was concluded that in order to gain public acceptance of data usage the government should (i)communicate what it is doing with the data, and potential benefits of data use (ii) ensure that safeguards are put in place and communicated to the public.

Surveys and research have revealed great variation in opinions, based on personal history, values and circumstances (Singleton et al 2007, Bartlett 2012). Moreover, the assessment of public attitudes is "dependent on framing of the subject, particularly as to whether a practical or theoretical choice is being forward" (Singleton et al 2007). Bartlett (2012), in research about both administrative and commercial data, proposed the following clusters of British adults: 30% non-sharers; 22% sceptics who show low trust for government and companies, and want control over their data; 20% pragmatists who prefer efficient services to complete privacy; 19% value hunters who seek value for sharing; 8% enthusiastic sharers.

Low awareness in the population of data retention and sharing practices (Page 2006, Nair et al 2004, Scottish Consumer Council 2005, ONS 2014, Hopkins van Mil 2015), and of what the data are used for ONS 2014, Ipsos Mori 2014, Ipsos Mori 2015) has been widely demonstrated. Lack of awareness of legal and ethical rights (Sankar et al 2003) may lead to both overestimation and underestimation of current data protection practices. A number of studies have shown that greater awareness leads to greater willingness to share de-identified data (Riordan et al 2015, Hill et al 2013, Perera et al 2011, Ispos Mori 2014). A proportion of people believe that data is already being shared more widely than it actually is (Scottish Consumer Council 2005, Eldridge 2000, Ispos Mori 2014) or that there exists a central government database (Ipsos Mori 2014). Research by Ipsos Mori (2015) has revealed that people are not clear about the difference between use of data for operational purposes and its secondary use for research purposes, and have low awareness of social research. High awareness has however been found of use of data in the private sector (Hopkins van Mil 2015, Bartlett 2012).

The public trust the National Health Service (NHS) and General Practitioners (GPs) more regarding retention, use or sharing of personal data (Whiddet et al 2006 Buckley et al 2011) than other government agencies (Singleton et al 2007), and the commercial sector is least trusted (ONS 2014). Nevertheless, some scepticism is expressed regarding the ability of the NHS to safeguard personal information (Papoutsi 2015, Greenhalgh et al 2010). Eldridge (2000) found that general concern was not about government departments' use of data but rather about the possibility that government collected data could later identify individuals to those in the private/commercial sectors. Trust in academics depends on their relationship to commercial organisations.

Bartlett (2012) found that three quarters of people were worried about governments or companies losing data, and the same proportion were concerned about third party access. Some less frequently voiced concerns involved worries about receiving unwanted marketing phone calls, spam text messages/emails (Bartlett et al 2012). In an Office of National Statistics Survey (ONS 2014), approximately three quarters of the public in England and Wales trusted ONS to protect the confidentiality of their data, and when provided with reassurance on privacy processes, the majority supported ONS reusing administrative data for statistical purposes. A survey by the NI Statistics and Research Agency (NISRA) found 9 out of 10 people believed personal data provided to NISRA would be kept confidential, and 76% of people expressed trust in NISRA, similar to the level of trust for the civil service in general.

Concerns about data security are common. In a survey of health service patients in London, 79% of participants reported concerns about security of their health record if this became part of a national record system and 71% thought the NHS was unable to guarantee the security of their data (Papoutsi et al 2015). There was also a recognition that “no system is failsafe” in relation to hacking or human error (Papoutsi et al 2015, Ipsos Mori 2014). The Scottish Consumer Council (2005) reported that the most commonly expressed concerns were about security and a desire for the public to have some level of control over who has access to their records. Bartlett (2012) reported that losing control of personal information was the most significant concern among British survey respondents. This related to data being used without consent, being accidentally lost (or stolen as part of ID theft) or being shared with third parties. Ipsos Mori (2014) found in more in depth discussions that the processes of linkage and de-identification were not well understood and therefore not at first trusted, and there were concerns about the possibility of re-identification.

There is a high level of support for data sharing for the public good, if data security can be assured (Ipsos Mori 2014). Support for data exchange within the NHS to improve care is particularly high. General support of data sharing for public benefit has been found to be outweighed by data security concerns (Eldridge 2000, Singleton et al 2007), and tempered by lack of awareness of the role of research (Singleton et al 2007). Papoutsi et al 2015 found that the majority of participants were happy for datasets to be shared if it meant better understanding of the causes of disease, led to more effective treatments and better resource allocation. However, the focus group research of Ipsos Mori 2014 also showed that people were concerned about the “value for money” of publicly funded research and research infrastructure, and while they supported the general concept of public benefit, they were not always convinced about the value of individual research areas or were surprised at the cost of research.

The public varies greatly in attitudes to the need for consent. Attitudes range from expecting consent for each use of data, to being satisfied with a one-off indication of consent, to those happy to allow their data to be used without consent. However, these attitudes can be scenario-specific in relation to other data security requirements, whether the data are de-identified, and levels of transparency and control. Riordan et al (2015) showed in a survey of primary and secondary care NHS patients that the overwhelming majority (91%) expected to be asked for explicit consent for access to identifiable data, but this fell to less than half (49%) for de-identified data. Consent expectations for use of de-identified data varied with sociodemographic characteristics – women, ethnic minorities and people with lower educational qualifications were more likely to expect to give explicit consent. Where research involves children’s data or other vulnerable populations, attitudes to consent are stricter (Knoppers 2002, Helgesson 2005). While people expect to be told about the possibility of linkage at the time that data is collected, they may also accept that it is not always possible to predict future data uses (Eldridge 2000, Ipsos Mori 2014). Some cynicism has been expressed about the efficacy of opt-out consent mechanisms (Ipsos Mori 2014).

Bartlett (2012) found that many people believe that personal access to data, and the ability to refuse or withdraw access by others, is an important aspect of ownership of their own data. Respondents particularly favoured measures such as the ability to withdraw data (73%) and see what information is held on me (70%), while other measures were supported by a minimum of 62% - clear statement on how information is used, system of fines for misuse of data, online dashboard to control my data, legal protections, and knowing exactly what data is held on me.

The public are more guarded about commercial use of data. For commercial access or profit, the public desire greater control of their data, including consent, and may see data sharing as “being taken advantage of” or exploitation (Willison et al 2009). Lack of understanding has been exhibited as to why the NHS would want to allow commercial access to data and how this sector currently contributes to healthcare (Ispos Mori 2015). Eldridge (2000) found access to individual level data by commercial organisations to be a concern that surfaced throughout discussions. Others, while understanding that the data would not identify individuals, pointed out that there could still be an adverse effect if the data identified their area as having an undesirable attribute such as a high rates of crime. Some voice concerns that the government already sells their data to commercial companies (Ipsos Mori 2014). On the other hand, where data collected within the commercial sector are concerned, there is considerable awareness of how data is used (e.g. shopping history) (Bartlett 2012) and some people are fatalistic about their ability to control their data: “At the end of the day, there is no way you can opt out of giving data unless you live like a hermit in the middle of an island. You’ve got no choice. The genie is out of the bottle, you can’t do anything about it. It’s just the way we live.” (Hopkins van Mil 2015).

During the qualitative stage of Ipsos Mori (2015) research, participants were introduced to hypothetical case studies (including deliberately provocative and controversial ones) in which the sharing of health data took place. The conclusion reached from the research was that most of the general public tended to accept commercial sharing of health data, as long as there was clear adherence to four ‘key tests’, each of which must be passed before the public would accept commercial access to health, biomedical or genetic data:

(i) Why: Does the activity’s outcome have a provable and sufficient public benefit?

(ii) Who: Can the organisations doing this be trusted to have public interest at heart?

(iii) What: How anonymised and aggregated is the data?

(iv) How: Does the safeguarding, access and storage protocol reassure me that the data will be safe?

Ipsos Mori (2015) revealed a hierarchy of acceptability of commercial organisations with companies working alongside the NHS deemed most acceptable. Least acceptable were retail and pharmaceutical sectors where the public found it difficult to recognise how these groups would have public value as an objective: “Big Pharma...Are they doing it with my consent, looking at a group to identify, make progress, come up with treatments, understand conditions more- I’d be comfortable with that. Or are they just given free rein on my daughter’s medical records so they can stabilise business, play entrepreneurs, gamble on it- no, that’s not ok”.

3. Northern Ireland Life and Times survey 2015: Methods and Results

Methods

Survey sample

The survey took the form of a module of questions included on the 2015 Northern Ireland Life and Times survey (NILT). A design group was set up to develop the questions for each module and the group consulted widely on draft questions. 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. Response rate was 55% and the module included approximately 50 items. The main stage of the fieldwork was undertaken during the period 21th September 2015 to 22nd December 2015. Full details of the NILT survey methodology are given at Appendix 3.

Statistical Analysis

Responses to all questions were first analysed on a univariate basis, and then differences in responses by age and sex were considered.

Other sociodemographic variables were chosen from other modules of the survey which, on the basis of the literature reviewed, might influence attitudes to data sharing in the population. The composition of the sample in terms of these variables is shown in Appendix 1.

Attitudes, as expressed in question responses, were explored in both univariate and multivariate analyses. Multivariate analysis was done by backwards logistic regression. Variables were entered into the backwards logistic regression model if they were significant on univariate analysis at $p<0.1$ and retained if they made a significant contribution to the final model ($p<0.05$) or if any individual values of the variables were significant ($p<0.05$). Differences in question responses for each sociodemographic characteristic are reported in the results only where they remain significant in a multivariate model. Attitudes were grouped into categories for multivariable models e.g. grouping “definitely trust” and “probably trust” categories together and ‘unknown/don’t know’ responses were treated as missing.

Table 1 Percentage of respondents who ‘definitely’ or ‘probably’ trust different organisations by sex

	Men	Women	All
	%	%	%
The NHS	83*	89*	86
Government departments	67*	78*	73
Your GP surgery	89*	94*	91
Commercial organisations like insurance companies	36*	46*	41
Academic researchers in a university	71	74	72
Charities	49	52	51

*difference between men and women statistically significant

Results

Trust in organisations to keep data securely and use data appropriately

While very high numbers of respondents trust their GP surgery (91%) and the NHS in general (86%) 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). However, trust plummets when it comes to commercial organisations like insurance companies where only two fifths say that they trust these organisations and only half of respondents trust charities. Five percent of respondents did not trust any of the organisations listed, and 29% probably or definitely trusted all of them.

The level of trust within different sociodemographic groups carried across organisations. For example, women tend to have more trust in organisations than men (Table 1), except in relation to academic researchers in a university or charities – where there is little difference between the sexes. Protestants tend to be more trusting than both Catholics and those of no religion, except in relation to academic researchers and charities (Table 2).

Interestingly, older people (aged 55 or more) tended to be less trusting of commercial organisations while the ‘older young’ (aged 25-44) had more faith in academic researchers. There were no other significant age-related differences in trust in NHS, government departments or GP surgery (Appendix 2).

Perhaps unsurprisingly, faith in big British institutions varied with political identity (Table 3). Strong nationalists (although based on small numbers) were markedly less likely to trust NHS and government departments, with 62% reporting that they would trust the NHS and 31% stating that they trust government departments to keep information or data that they have about people secure and use it appropriately (compared to 72% of those with no political identity and 77-80% of unionists). Perhaps reflecting a general mistrust of a system that others assume to be benign. ‘Not very strong’

Table 2 Percentage of respondents who ‘definitely’ or ‘probably’ trust different organisations by religion

	Catholic	Protestant	No religion
	%	%	%
The NHS	83*	91*	85*
Government departments	67*	82*	63*
Your GP surgery	89*	96*	88*
Commercial organisations like insurance companies	38*	48*	28*
Academic researchers in a university	74	72	69
Charities	53	49	45

* differences by religion statistically significant

In addition to the differences in trust described above by political identity trust in Charities also varied across a number of sociodemographic factors. Those in the youngest (18-24) age group were more likely to report that they trusted Charities (63%) than those in the other age groups (42-57%). Trust in Charities also varied by marital status with single people more likely to trust charities (56%) than was the case for married or divorced groups (44-52%).

Table 3 Percentage of respondents who ‘definitely’ or ‘probably’ trust different organisations by political identity

	Strong Nationalist	Fairly strong Nationalist	Not very strong Nationalist	Neither	Not very strong Unionist	Fairly strong unionist	Very strong unionist
	%	%	%	%	%	%	%
The NHS	62	80	94	86	92	89	91
Government departments	31	68	78	72	77	80	80
Your GP surgery	82	93	95	89	93	96	99
Commercial organisations like insurance companies	26	37	45	40	46	39	50
Academic researchers in a university	67	70	79	75	67	70	75
Charities	33	46	62	53	46	48	52

nationalists tended to express greater trust across a range of organisations. Unionists (other than strong unionists) were less likely to express trust in academic researchers.

Housing executive tenants expressed less trust than owner occupiers in all organisations while people living in the suburbs were more likely to trust government departments than those living in any other urban or rural areas. Rural dwellers were more likely to trust academic researchers than those living in urban areas (Appendix 2).

One finding which perhaps raises a particular concern is that respondents who reported caring responsibilities were less likely to trust their GP surgery to keep data securely and handle it appropriately.

In general, trust in organisations appeared to be unaffected by respondents’ education, religiosity (measured by church attendance), health or disability - once the factors discussed above had been taken into account. Respondents who had lived outside Northern Ireland for 6 months or more did evidence a slightly greater trust of academics, possibly reflecting the views of those who had attended university in other parts of the UK or Ireland.

General concerns about use of data

Overall, 42% of respondents said that they had ever had particular concerns about how any of those organisation used the information about people that they kept. Consistent with the previous findings on trust, the same groups of people tended to have concerns. Men (46%), those of no religion (59%), and those of strong nationalist political identity (71%) were more likely to say that they had had particular concerns. Perhaps reflecting doubts over intentions as well as competencies of different organisations. However, graduates emerged as a group with a higher level of concern (49%) while those living on a farm or in the country were markedly less likely to express concerns (33%).

Respondents were shown a list of possible concerns and asked which, if any, they had themselves (see Table 4):

"Here are some of the concerns that other people have mentioned. Which, if any, of these concerns have you had yourself? (asked of those who said they had a concern)".

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.

Table 4 Percent of respondents reporting specific concerns amongst those who stated they concerns about the use of their data

	%
I think they will use my information for other purposes they won't tell me about	70
They might lose my information to hackers	62
I don't think they will use the information for my personal benefit	36
They might lose my information by accident	43
I don't trust them to keep accurate records about me	29
I don't think I would be able to change/delete my information if it is wrong	30
I don't trust them at all	27
My personal information may be used to discriminate against me	20
Something else	1
Don't know	2

Sharing identified data for service purposes

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 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.

"Suppose GPs were to be allowed to share information about patients to help improve services provided by another government department. For example, if they routinely passed on information about all people with a long-term illness like severe arthritis to the benefit offices so that those people could be encouraged or helped to apply for disability benefits. Do you think that this should be allowed?"

Table 5 Acceptability of GP sharing records of people with a long-term illness to help improve services provided by another government department

	%
Yes definitely	45
Yes probably	33
No probably not	10
No definitely not	10
Other answer	1
Don't know	2

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. A small number of respondents remarked specifically that this would be acceptable if there was consent, and there may be ambiguity as to whether respondents assumed that data sharing would require individual consent in the various scenarios presented.

Young people, Catholics and strong nationalists were significantly more disapproving of the possibility of GPs sharing information with other government departments.

A high proportion of those aged 18-24 (30%) felt that this kind of data sharing should not be allowed compared with only 16-22% of other age groups. Opinions also varied by religion with 24% of Catholics against this idea compared to 16% of Protestants and 20% of those with no religion. There was no difference in terms of general political identity but when strength of political identity was considered in addition, there was a marked difference with 44% of strong nationalists and 30% of fairly strong nationalists stating that this should not be allowed compared to 11-20% among the other political identity groups.

While carers were noted earlier to display less trust in their GP surgery to keep data safe and use it appropriately, there is nonetheless more appetite among this group for data sharing that could benefit the individual. Those with caring responsibilities were less likely to be against this type of data sharing (15% vs. 21%). Other results indicated that those living in the suburbs were also much less against this type of data sharing (12% vs. 19-23% for other areas).

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. Given public perceptions of the sensitivity of mental illness over physical illness this is perhaps unsurprising.

"What if the long-term illness was a mental illness – do you think GPs should be allowed to routinely pass this information on to the benefit offices so that these people should be encouraged or helped to apply for disability benefits?"

Table 6 Acceptability of GP sharing records of people with a mental illness to help improve services provided by another government department

	%
Yes definitely	38
Yes probably	33
No probably not	12
No definitely not	14
Other answer	1
Don't know	4

There was a similar pattern of variation, with young people more likely to think it unacceptable (40% of 18-24 year olds). Catholics and those with no religion were also more likely to find it unacceptable (29% and 33% respectively compared to 20% of Protestants). Strong nationalists again are particularly against such data sharing (53% vs 21-31%) while graduates are a little more disapproving (30% vs others 21-25%). However, those with caring responsibilities are less against the idea (16% vs 27%). Again while some carers may have lost some faith in their GPs in general, their sense of advocacy may spur them to embrace new ways of improving the lives of those they care for.

When the scenario was changed to one of GP information being routinely shared with schools in relation to everyday 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 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.

"What about allowing people outside government departments to see health information. For example, should GPs be able to routinely pass personal health information on to schools about health conditions like diabetes or asthma that might affect a child during the school day? Do you think that this should be allowed?"

Table 7 Acceptability of GP sharing records with schools

	%
Yes definitely	37
Yes probably	30
No probably not	11
No definitely not	16
Other answer	1
Don't know	5

In this example it was interesting that young people did not emerge as one of the most concerned groups. In this case it is possible that one of the most uneasy groups may have been parents with school age children and in fact 36% of those aged 45-54 found this idea to be unacceptable compared with 23-31% in other age groups. Again religious differences were apparent with 32% of Catholics and those with no religion finding this unacceptable compared to 23% of Protestant's. Graduates (35% vs 24-25%) and those living in a big city (34% vs 20-30%) were also more likely to find this unacceptable.

Sharing de-identified data for research

Academic research - linking data

The NILT module also explored public attitudes to the linking of health data – specifically for use by academic researchers. Very high percentages 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. Only 10% overall see a problem with this kind of linking and there are no significant differences in the views of respondents by sex, age or religion or any other variable, Table 8.

"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?"

Table 8 Acceptability of data linking by NHS staff

	Definitely or probably should be allowed
	%
Men	88
Women	86
18-24	86
25-34	88
35-44	85
45-54	85
55-64	88
65+	89
Catholic	88
Protestant	88
No religion	84

However, there is a clear drop in support whenever it is suggested to respondents that the patients' postcodes could be passed to the researchers and then the researchers do the linking. Table 9 shows the results for different groups. Overall around 60% of respondents think that this should be allowed but just over a third feel that this should not be allowed. This did not vary significantly by any of the personal characteristics.

"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?"

Table 9 Acceptability of data linking by researchers

	Definitely or probably should be allowed
	%
Men	63
Women	58
18-24	52
25-34	65
35-44	55
45-54	63
55-64	62
65+	62
Catholic	60
Protestant	62
No religion	58

A third scenario was presented to respondents which, like the first, involved linking carried out by a 3rd party but was a little more complicated. Table 10 shows the results and about 73% of respondents overall would allow this particular scenario. It is considered more acceptable than the scenario where researchers themselves carried out the linking but less acceptable than the first scenario. In this case possibly the explicit wording – hospital records linked to school records may simply ring warning bells for some respondents who might have assumed that this referred to targeting individual children. It is also possible that people are keener to protect data about children, less aware of what is held in school records, less keen to link data between different domains (health and education), or find less potential public benefit in the research.

"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?"

Table 10 Acceptability of data linking by the people who keep hospital records

	Yes (Definitely or probably)
	%
Men	74
Women	71
18-24	68
25-34	75
35-44	71
45-54	75
55-64	74
65+	71
Catholic	71
Protestant	76
No religion	67

The only significant difference seen was in relation to whether or not the respondent had a long term physical or mental health condition. Those who had a condition which reduced their ability to carry out day-to-day activities were more likely to be against such data sharing (24-25%) compared to 20% of those who had no long term condition.

Data sharing for research – whether consent is necessary

None of the questions on linking or data sharing addressed specifically the issue of consent, although 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. 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 11 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.

"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?"

Clearly these results highlight the crux of the dilemma as to the way forward in using administrative data. If 31% of people feel that important research should be abandoned if consent is not obtained, then this is a significant minority of the public whose views must be taken seriously. Of course the question did not define the nature of the research except to refer to the preceding questions so we do not know if responses would be different if respondents felt, for example, that a cure for Alzheimer's disease or Parkinson's disease was the explicit purpose

Table 11 Need for consent to link data

	%
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

of the research study in question. Nor is it clear if the same response would be given if respondents were sure that the data would be de-identified. Nonetheless it is important to look more closely at the characteristics of respondents who gave this response to reach a better understanding of the groups of people most likely to hold this view, Table 12.

In general, men, strong nationalists, those with no qualifications and those with a health condition themselves were more likely to feel that consent was vital while owner-occupiers and those with no religion were less likely to feel that consent was vital. It was noteworthy that some groups tended to prefer the middle option (you should try to get consent if possible but research should not be abandoned if you can’t). This included graduates and those who have lived outside Northern Ireland or 6 months or more.

The figures themselves were often quite striking. Strong nationalists were much more likely to state that you should not do research without consent (50% compared to 34% among those with neither political identity and 22-35% among unionists and 28-31% among the other nationalists). Those with no qualification were also much more likely to state that you should not do research without consent and this decreased with increasing education level (38% among those with no qualification, 32% among those with school level qualifications and 26% among those with graduate level qualifications). The figures for men were 34% compared with 29% for women. There were also differences for those affected by long term health conditions although this may be affected by small numbers. Those with a health condition which reduced their ability to carry out day-to-day activities a little or a lot were more likely to state that you should not do research without consent (40% and 42% respectively) than those who had no illness (30%) or whose illness did not reduce their ability to carry out day-to-day activities (15%).

Those with no religion were less likely to state that you should not do research without consent (24% among those with no religion compared to 31% of Protestants and 34% of Catholics). There was a difference by tenancy with owner occupiers less likely to state that you cannot do research without consent than those in the ‘other’ or housing executive tenancy categories (29% vs. 39% and 37%).

However, while all these variables contributed significantly to a multivariate model, the model itself explained little variance (<10%) and correctly classified only 69.6% of responses, suggesting that these variables in combination do not strongly predict the response. Clearly this is not the whole story.

Table 12 Percentage of respondents who believe that you should always have to ask for individual patient consent before linking their data with anything else and you will have to abandon the research if there are difficulties contacting people*

	It isn't necessary to ask for consent	If the difficulties are too great important research should not be abandoned due to lack of consent	You will have to abandon research if there are difficulties gaining consent
	%	%	%
Males	28	33	34
Females	31	35	29
Catholic	25	33	36
Protestant	36	34	34
No religion	34	31	24
Strong nationalist	18	28	50
Fairly strong nationalist	31	40	27
Not very strong nationalist	28	40	31
Neither	29	32	34
Not very strong unionist	35	37	22
Fairly strong unionist	33	37	29
Strong Unionist	27	32	35
No qualifications	27	27	38
School level	33	32	32
Graduate	28	44	26
Owner occupier	32	37	29
Other	24	29	39
Housing executive tenant	29	26	37
No health condition	30	36	30
Health condition – ability to carry out day-to-day activities not affected	31	54	15
Health condition – ability to carry out day-to-day activities reduced a little	26	27	42
Health condition – ability to carry out day-to-day activities reduced a lot	31	19	40

*in multivariate analysis the first two categories were combined

The relationship between the attitude to consent and trust in organisations

Is it the case that attitudes to consent are linked to trust in organisations? Certainly some of the same groups of respondents came to notice in responses to both sets of questions. In fact, analysis revealed strong relationships between the attitude to consent (not always necessary vs always necessary), and trust in organisations to keep data securely. Those who felt you should not do research without consent were more likely to state that they did not trust the NHS (20% vs. 9%), the government (35% vs. 20%), their GP practice (11% vs. 5%), commercial organisations (63% vs. 54%) and academics (29% vs. 19%). The only non-significant result was for trust in charities. Conversely, a high proportion of those who did not trust the NHS felt that you should not do research without consent (53%), with other organisations shown in Table 13.

Table 13 Proportion who feel that you should abandon research if there are difficulties gaining consent among those who do not trust organisations to keep the data they have about people secure and to use it appropriately

Organisation not trusted	You should abandon research if there are difficulties gaining consent
	%
The NHS	53
Government departments	46
GP surgery	49
Commercial organisations	37
Academic researchers	43
Charities	35
Total	31

There was no relationship between ever having had concerns about how these organisations may use the data they have on people and opinions in terms of the need for consent.

Academic research - safeguards

Certain specific safeguards and principles in the use of administrative data for research purposes have already been agreed by the Administrative Data Research Network (ADRN). Respondents to the survey were asked about the importance of each of these. All of these safeguards are considered important by large majorities of respondents and four in particular are endorsed by over 90% of people. Most important appears to be that the researchers are vetted, and that identifiers must be removed from the data. Also particularly important is that the research must have a clear public benefit and that there are penalties if researchers breach data security, see Table 14.

“How important are each of these safeguards for using this kind of personal information for academic research by university researchers?”

Table 14 Importance of safeguards when using personal information in research by academics

	Important	Neither important nor unimportant	Unimportant	Don't know
	%	%	%	%
The research must have a clear public benefit	93	4	1	2
Names and other things that could identify someone must always be taken off	94	4	1	2
The researchers must go through checks to ensure that they are properly trained and working for an approved organisation	95	3	<1	2
Every project must have official approval	87	8	2	3
The researchers have to go to one of the dedicated secure data centres to do their analysis	78	11	5	6
The statistical results of the research must be made public	73	16	7	4
There are penalties if researchers breach data security	91	5	1	4

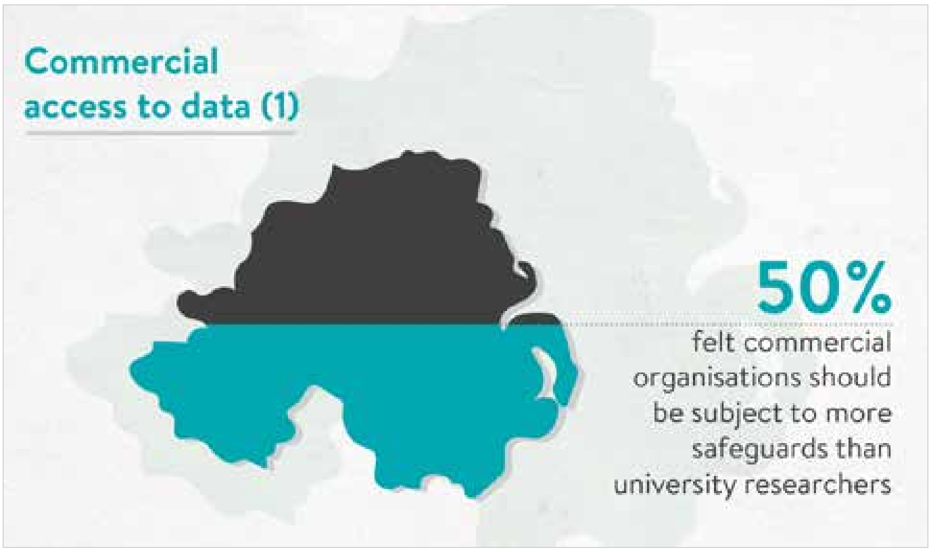
Commercial research

Public attitudes to commercial research using administrative data are twofold. Much of the previous qualitative work on attitudes to data sharing indicated a high level of suspicion of commercial organisations when it came to personal data. Certainly results of the first question on this survey reiterated that public trust in commercial organisations like insurance companies to use data appropriately was less than impressive. Further, when respondents were asked about the necessary safeguards if research using personal information was being carried out by commercial organisations half of them felt that there should be even more safeguards applied to commercial organisations, see Table 15.

"And supposing the research using personal information was

Table 15 Safeguards necessary when commercial organisations use personal information in research

	%
Same safeguards	46
More safeguards	50
Less safeguards	1
Other answer	0
Don't know	4



being carried out by commercial organisations, should they be subject to the same safeguards as university researchers, more safeguards or less safeguards?"

Belief that there should be more safeguards was higher both in those with graduate level education (56%) and no qualifications (53%) compared to school level education (45%). Those living in the suburbs were less likely to feel that commercial companies should have more safeguards (41%) compared to 48-58% among those living in other areas.

Nonetheless when examples are used where there is a clearly explained 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 exhaustively explored there are strong indications of where public sympathy lies. The first question (Table 16) was simply in relation to access given the potential public good.

Table 16 Commercial access to NHS patient information in research 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'

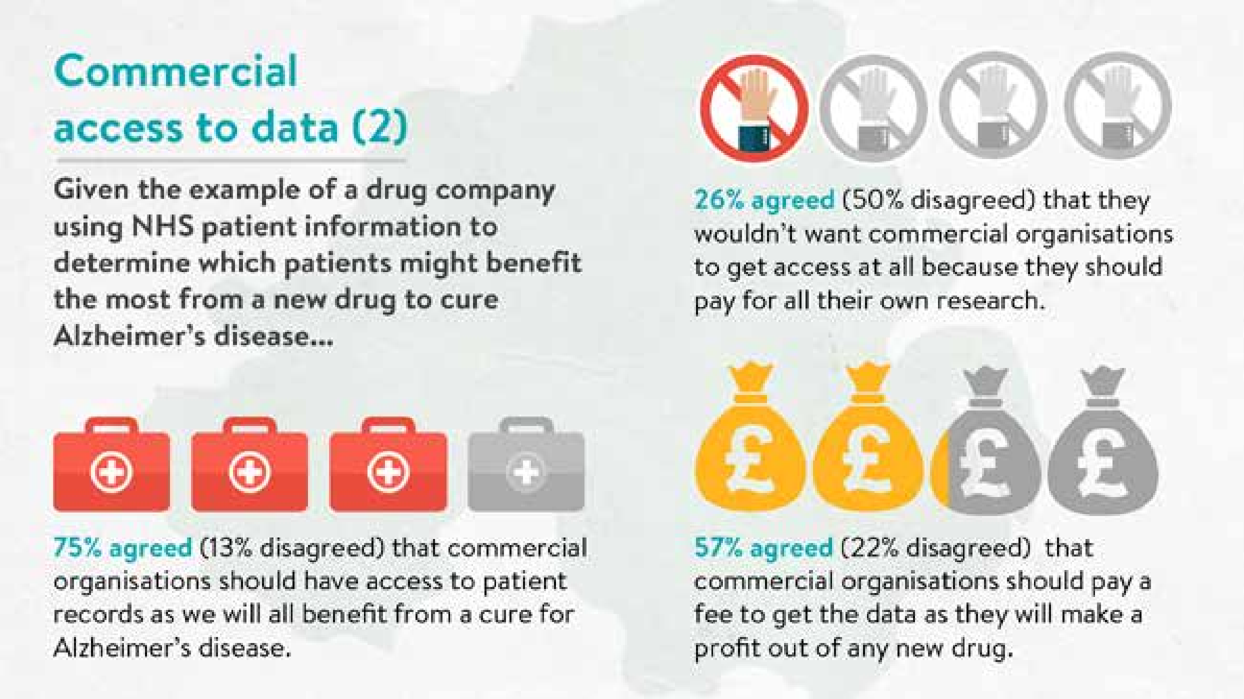
Agree strongly/ Agree	Neither agree nor disagree	Disagree strongly/ Disagree	Don't know
%	%	%	%
75	8	13	3

"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."

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 suggesting that when there is a clear unequivocal case of potential public benefit there is strong public support for commercial access. However, this varied according to age, with younger age groups more likely to disagree, and political identity, with strong nationalists more likely to disagree, see Table 17.

Table 17 Percentage of respondents who disagreed that commercial access to NHS patient information in research for a cure for Alzheimer's disease should be allowed

	Disagree strongly/ Disagree
	%
18-24	21
25-34	18
35-44	13
45-54	11
55-64	7
65+	12
Strong nationalist	45
Fairly strong nationalist	14
Not very strong nationalist	11
Neither	13
Not very strong unionist	8
Fairly strong unionist	13
Strong Unionist	9



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.

When the notion of paying for this access was introduced, this was not greeted with universal support (Table 18). Given some public perceptions of wealthy drug companies and the fact that new drugs will generate profit, it was possible that public sentiment would demand payment for access. Although 57% of respondents did agree that commercial organisations should be granted access and that a fee should be paid this showed that introduction of a fee for access does not increase support. Just 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.

"I would like them to get access to patient records but they should pay a fee to get the data as they will make a profit out of any new drug."

Table 18 Commercial access to NHS patient information in research for a cure for Alzheimer's disease: 'I would like them to get access to patient records but they should pay a fee to get the data as they will make a profit out of any new drug'

Agree strongly/ Agree %	Neither agree nor disagree %	Disagree strongly/ Disagree %	Don't know %
%	%	%	%
57	15	22	7

Finally, a statement was included to tap into potential public disapproval of such access by commercial companies – though again linking this with monetary issues. A quarter of respondents were prepared to agree that they didn't want such companies to get access at all because they should pay for all their own research and trials. Half of those questioned actively disagreed with this statement, Table 19.

I don't want them to get access at all because they should pay for all their own research and trials.

Table 19 Commercial access to NHS patient information in research for a cure for Alzheimer's disease: 'I don't want them to get access at all because they should pay for all their own research and trials'

Agree strongly/ Agree	Neither agree nor disagree	Disagree strongly/ Disagree	Don't know
%	%	%	%
26	17	50	8

Significant predictors of agreement with this statement were political identity (strong nationalists being much more likely to agree), educational level (graduates being less likely to agree) and caring duties (those without caring duties more likely to agree), Table 20.

Table 20 Percentage of respondents who agreed with the statement that 'I don't want them to get access at all because they should pay for all their own research and trials'

	Agree strongly/ Agree
	%
Strong nationalist	59
Fairly strong nationalist	28
Not very strong nationalist	27
Neither	26
Not very strong unionist	14
Fairly strong unionist	24
Strong unionist	26
No qualifications	29
School level	29
Graduate	22
With caring duties	19
Without caring duties	28

General attitudes to the use of personal data, privacy and the public good

Weighing privacy against public benefit

While respondents are not generally willing to allow their data to be used by just anyone there is nonetheless an acceptance that their data may be used where it is not possible to identify themselves. Only a fifth of the sample said that they didn't care who used data about them (see Table 21) but almost three quarters were happy enough that their data could be used if it was anonymised. Further, only 16% of respondents said that they didn't want university researchers to be able to use their personal data at all. However, this figure rose to 39% in relation to commercial organisations.

Opinion was divided on whether data could ever actually be completely de-identified. Forty-six per cent of respondents felt that even if data were anonymised it would probably still not be completely de-identified (Table 22). There was considerable uncertainty around this though with a further 35% sitting on the fence and 20% actively disagreeing.

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. The final set of survey results (Table 23) illustrate that there is huge public goodwill to achieve the potential benefits but an unwavering

Table 21 General willingness for own personal data to be used

	Agree strongly/ Agree	Neither agree nor disagree	Disagree strongly/ 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

Table 22 Perception that data can be de-identified

	Agree strongly/ Agree	Neither agree nor disagree	Disagree strongly/ Disagree	Don't know
	%	%	%	%
Even if you take the names off files of patient information you can often still tell who it is from all the other information that is there.	46	24	20	11

Table 23 The balance between the right to privacy and the public good

	Agree strongly/ Agree	Neither agree nor disagree	Disagree strongly/ 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

acknowledgement of the right to privacy. Eighty-three per cent of respondents 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 overall 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. As the debate progresses it would probably be helpful to repeat this survey at two or three yearly intervals in order to monitor changing public opinion.

4. Discussion and Conclusions

Strengths and Limitations of this Survey and its Interpretation

The great strengths of this survey were that we consulted a large representative sample of the NI population and collected extensive data about their sociodemographic characteristics. The limitations should also be borne in mind.

The results of this survey represent the expressed attitudes of people given their current experience and knowledge of these issues, without further explanation. This is a different approach to qualitative research which seeks to hold in depth discussions with people to gauge what their attitudes would be if they fully understood the issues. It was clear in this survey that the answers to survey questions depended on the complex details of particular scenarios, and that general "abstract" questions can have quite different answers from more specific scenario-dependent questions, and this needs to be borne in mind when comparing with other surveys. A particular problem in this survey was addressing multifaceted scenarios involving de-identification, consent, data protection and public benefit. For example, people who insisted that consent should always be asked before using data for research may have done so far with identified rather than de-identified data in mind, as indicated by the large proportion generally supported the notion of using anonymised data for public benefit. Trust in organisations to hold data securely and use it appropriately also was expressed in the light of public knowledge of what is done with their data, and might be lower or higher if people were better informed.

The response rate to the survey was 55% which is usual for these surveys. While this leaves an opportunity for respondents to have been biased with respect to their attitudes to data sharing compared to non-respondents (particularly as they were themselves sharing anonymised information), this bias is unlikely to be great since the sample respondents were very similarly distributed to the NI population in terms of age and sex, and the survey covered multiple topics apart from data sharing.

We conducted many statistical analyses, and some apparently "statistically significant" results may have been chance differences between population subgroups.

We did not tackle a number of areas of potential importance. For example, we did not explore the level of public knowledge about social and health research, and we did not explore the public's attitude to different forms of consent (e.g. opt-in or opt-out). We also did not explore the extent of public knowledge about the funding, public and commercial, of academic research, and how this influences attitudes to academic research.

In general terms, our results reflect those in the literature (see section 2), for example the importance of trust in institutions, of autonomy, and of culture and values. We are not able to compare our research directly with that of other surveys carried out elsewhere. However, general comparisons suggest that the perception of public benefit of data sharing may be particularly high in Northern Ireland, while on the other hand distrust of institutions may be particularly high in some population subgroups in NI, particularly with regard to political orientation. Political orientation has to our knowledge not been explored in surveys elsewhere. Geographical scale may influence attitude – it is possible that the relatively small population of NI may improve support for data sharing for operational purposes (where it can readily be seen to be practically necessary) but on the other hand may pose more data confidentiality concerns.

Relevance to Policy

We found that public support for data sharing depends on three "pillars" – data protection, public benefit, and trust in organisations. If any one of these is reduced, then public support falls. Conversely, if all the resources are put into one of these domains but not in others, then it will not be enough to secure public support.

Public support and confidence is critical to moving forward in this area. In this respect, policymakers should heed the findings that 83% of people agree that "the right to privacy has to be respected over everything else" and 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 where there is a benefit to society."* The views of a significant minority who show little support for data sharing, particularly without individual consent, must be taken into account, but the survey findings should motivate regulators to work through difficulties in a fair, respectful and pragmatic way.

We did not explore the sources of public distrust of institutions and more research is needed into the sources of public distrust, particularly among sociodemographic groups most likely to show distrust. Our survey is the first in the UK to investigate the degree to which political opinions influence trust, in particularly finding that the small group of strong nationalists surveyed showed least trust and least support for data sharing. Previous research shows that the minimum requirements for public trust relate to transparency (having access to information about exactly what data are held and what is done with it) and data protection (handling it securely). Improvement of practices and transparent communication to the public about these areas should eventually help improve trust.

Our survey presented a number of scenarios to participants, and it was clear in the responses that attitudes expressed to data sharing are very scenario-specific, reflecting the complexity of the issues involved. Factors influencing public support for any given scenario might include perceived public benefit of answering the research question, the population groups concerned (e.g. children vs adults, or those with mental vs physical health problems), knowledge about the type of administrative data available, and the degree of linkage of different domains about the same individual (e.g. health to education).

The NI population was split evenly between those who did not think it necessary to ask for consent as long as nobody could be identified, those who thought need for consent should be balanced against practical difficulties of obtaining it, and those who thought consent always necessary, even if research might have to be abandoned due to practical difficulties. It was striking that although there were some sociodemographic and cultural differences in response to this question, these factors, while statistically significant, explained little of the variation in the population of views on consent, suggesting that other factors (perhaps including personal experience) influence attitudes to consent. While the majority of the public prefer consent to be asked, this is not always practical. We did not include questions in our survey about opt-in or opt-out consent, or right to withdrawal of data or access to own personal data. Other research has suggested that need for consent for each data use can be balanced against full transparency and autonomy. This balance could be addressed in future surveys of public attitudes.

Nevertheless, there was a significant minority who expressed concerns. Thirty percent of the population felt that consent should always be asked before using data for research, even if difficulties in obtaining consent meant abandoning the research. There was some sociodemographic variation in the proportion of people expressing this view – it was more likely to be expressed by males, less likely to be expressed by those of no religion, more likely to be expressed by those of no or strong political opinions, less likely to be expressed by owner occupiers, and more likely to be expressed by people with health conditions which reduced their ability to carry out day-to-day activities a little. However, these factors, while statistically significant, explained little of the variation in views on consent, and future public engagement should explore the origin of these concerns in more depth. Meanwhile, organisations handling health data should take these concerns into account, for example by providing opt-out mechanisms.

We found that three quarters of the population thought the types of data protection measures employed by the NI Administrative Data Research Centre were important, including data de-identification, vetting of researchers, provision of secure data centres, and disclosure control. This validates the considerable resources being devoted to data protection measures, and the need for this type of centre to be funded sustainably.

Commercial use of data is clearly seen to be more problematic than academic use. Our findings suggest that commercial data users should be subject to all the requirements, if not more, regarding de-identification, data protection, and public benefit, as academic data users now are subject to in contexts such as the Administrative Data Research Centre. More public engagement is needed regarding an appropriate fee structure for commercial use of data, and to understand more fully what types of commercial use of health data the public would support.

Since the public are implicated in all aspects of data sharing – providing the data, paying for the research or research processes, and being the beneficiaries of research impact - it is obvious that public engagement in this process is crucial. Previous research has shown that the public have limited knowledge about how data are or can be used for research, or the potential cost-effectiveness of linkage of administrative data for research. Measures to increase public awareness of potential public benefit of research, as well as data protection measures currently in place are needed. The public also need a voice and role in deciding what is of public benefit, and how different considerations should be weighed. Our findings however reinforce other research showing that the

public are extremely diverse in their attitudes to data sharing and this needs to be respected and taken account of.

We recommend that this survey be repeated in 3 years' time, to measure the progress that has been made.

Conclusions

We found a generally positive attitude in the community to sharing of health data, both identified data for operational purposes and de-identified data for research, given adequate measures for confidentiality.

Nevertheless, there was a significant minority who expressed concerns. Future public engagement should explore the origin of these concerns in more depth. Meanwhile, organisations handling health data should take these concerns into account, for example by providing opt-out mechanisms and mechanisms to see the personal data held.

The public are less positive about the use of their health data by commercial companies for research. Nevertheless, we found that if the perceived public benefits were strong enough, the majority were in favour, suggesting that mechanisms to assess public benefit, with lay representation, should be a prerequisite for allowing commercial access. Half of those surveyed also felt that stronger data protection mechanisms should be in place for commercial than academic access to data.

Attitudes to data sharing were strongly linked to trust in organisations to keep data securely and use it appropriately. Improved levels of trust should result from organisations achieving higher standards of practice and communicating these to the public.

In summary, we found that support for data sharing sits on three pillars – trust in organisations, data protection measures, and public benefit. If any of these are reduced, 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.

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Appendix 1 Demographic characteristics of the sample (weighted)

Characteristic	Categories used	%
Age	18 – 24	12.0
	25 – 34	14.6
	35 – 44	14.3
	45 – 54	17.8
	55 – 64	15.0
	65 and over	25.8
	No answer/refused	0.6
Sex	Male	46.5
	Female	53.5
Marital Status	Single	31.4
	Married/Civil Partnership	51.4
	Separated	3.7
	Divorced	4.7
	Widowed	8.5
	No answer/refused	0.3
Religion	Catholic	38.9
	Protestant	40.6
	None	15.8
	Other/ Refused/Don't know	4.7
Political identity	Strong Nationalist	3.2
	Fairly strong Nationalist	10.6
	Not very strong Nationalist	9.2
	Neither	39.0
	Not very strong Unionist	12.2
	Fairly strong Unionist	13.9
	Strong Unionist	5.5
	No answer/refused	6.4
Highest educational level achieved	No qualification	18.6
	School level	46.2
	Graduate level	30.7
	No answer/refused	4.5

Demographic characteristics of the sample (weighted) continued

Caring responsibilities	Yes	17.1
	No	82.9
Place lived	Big city	14.8
	Suburbs or outskirts of a big city	18.1
	Small city or town	34.9
	Country village	14.0
	Farm or home in the country	18.2
Ever lived outside NI for 6 months or more	Yes	30.1
	No	69.8
	No answer/refused	0.1
Tenancy	Owner occupier	67.2
	Other	17.4
	Housing executive tenant	14.2
	No answer/refused	1.3
Physical or mental health condition, lasting or expected to last for 12 months or more, and how much it reduced their ability to carry out day-to-day activities	No health condition	78.7
	Health condition – ability to carry out day-to-day activities not affected	2.2
	Health condition – ability to carry out day-to-day activities reduced a little	7.0
	Health condition – ability to carry out day-to-day activities reduced a lot	11.3
	No answer/refused	0.8
Disclosed their income	Yes	69.4
	No	30.6

Appendix 2. Results of Multivariate Analyses

Table 2.1 Multivariate models showing the % who definitely/probably trust each organisation and ORs and 95% CIs for those variables which predict trust in the organisation

	NHS		Government departments		GP surgery		Commercial organisations		Academic researchers	
	Definitely/probably trust									
	%	OR (95% CI)*	%	OR (95% CI) *	%	OR (95% CI) *	%	OR (95% CI) *	%	OR (95% CI) *
Sex										
Female	90.7	1.69 (1.14-2.49)	79.9	1.87 (1.38-2.53)	94.8	1.87 (1.14-3.05)	48.3	1.40 (1.07-1.82)	79.6	
Male	84.7		68.7	1.0 Ref	90.6	1.0 Ref	36.9	1.0 Ref	75.5	
Age										
18 – 24	89.5		73.8		93.8		41.8	1.78 (0.99-3.20)	75.7	1.04 (0.61-1.78)
25 – 34	91.2		72.5		92.9		36.4	1.28 (0.78-2.11)	84.5	2.13 (1.22-3.72)
35 – 44	91.1		79.2		91.7		48.8	1.84 (1.15-2.94)	84.2	2.07 (1.18-3.62)
45 – 54	85.4		75.9		91.5		47.1	1.50 (0.99-2.28)	73.2	1.03 (0.66-1.60)
55 – 64	84.4		69.9		92.7		39.4	0.95 (0.62-1.45)	76.9	1.18 (0.73-1.90)
65 and over	88.1		76.3		93.8		42.8	1.0 Ref	74.6	1.0 Ref
Highest educational level										
No qualification	85.2		69.3		90.8		44.4		75.1	
School level	89.1		76.8		94.4		43.9		76.8	
Graduate level	88.6		75.1		90.8		39.9		80.3	
Marital status										
Single	89.3		73.7		92.9		39.3	0.89 (0.60-1.30)	77.4	
Married/Civil Partnership	87.1		76.3		92.0		43.4	1.0 Ref	78.0	
Separated	84.1		63.6		93.3		33.3	0.69 (0.42-0.93)	75.0	

Table 2.1 continued

Divorced	87.7		71.4		94.7		47.3	1.44 (0.77-2.71)	83.0	
Widowed	89.0		75.0		96.0		54.3	1.97 (1.17-3.30)	75.3	
Religion										
Catholic	84.1	1.0 Ref	69.0	1.0 Ref	90.0	1.0 Ref	39.9	1.0 Ref	78.5	1.0 Ref
Protestant	91.8	2.17 (1.14-4.13)	82.8	2.47 (1.50-4.09)	95.9	3.02 (1.37-6.66)	49.8	1.98 (1.28-3.04)	77.3	1.03 (0.73-1.44)
None	86.6	1.27 (0.70-2.31)	64.7	0.86 (0.54-1.37)	90.3	1.37 (0.70-2.69)	28.7	0.60 (0.38-0.95)	73.9	0.62 (0.40-0.96)
Political identity										
Strong Nationalist	61.5	0.37 (0.17-0.81)	30.8	0.29 (0.13-0.64)	81.6	0.71 (0.28-1.83)	26.3	0.71 (0.32-1.58)	68.4	
Fairly strong Nationalist	81.1	0.82 (0.45-1.49)	69.6	1.12 (0.67-1.88)	93.7	2.40 (1.03-5.61)	37.6	0.97 (0.60-1.57)	74.8	
Not very strong Nationalist	94.5	3.73 (1.40-9.93)	79.6	1.81 (1.02-3.21)	95.4	3.37 (1.24-9.14)	47.2	1.37 (0.84-2.24)	82.1	
Neither	87.4	1.0 Ref	73.5	1.0 Ref	90.5	1.0 Ref	42.3	1.0 Ref	79.8	
Not very strong Unionist	92.5	1.27 (0.58-2.77)	78.9	0.78 (0.45-1.35)	93.8	0.89 (0.36-2.16)	48.9	0.81 (0.51-1.30)	73.1	
Fairly strong Unionist	89.2	0.85 (0.43-1.69)	80.1	1.09 (0.63-1.88)	96.4	1.77 (0.65-4.86)	39.4	0.55 (0.35-0.86)	76.0	
Strong Unionist	90.9	1.07 (0.41-2.80)	80.3	1.06 (0.51-2.22)	98.5	3.68 (0.32-1.02)	50.0	1.09 (0.60-1.98)	78.1	
Caring responsibilities										
Yes	90.3		77.2		90.8	0.57 (0.32-1.02)	48.5		76.0	
No	87.5		74.1		93.2	1.0 Ref	41.6		78.1	
Place lived										
Big city	86.9		72.3	0.50 (0.30-0.86)	93.2		36.6		76.6	1.32 (0.80-2.18)

Table 2.1 continued

Suburbs or outskirts of a big city	91.7		83.8	1.0 Ref	94.5		46.4		71.1	1.0 Ref
Small city or town	87.9		73.4	0.49 (0.31-0.79)	92.4		43.8		75.2	1.21 (0.80-1.83)
Country village	88.0		72.7	0.52 (0.30-0.92)	95.2		44.4		86.5	2.76 (1.52-5.04)
Farm or home in the country	85.1		70.8	0.39 (0.23-0.66)	89.8		41.3		82.9	1.89 (1.15-3.11)
Ever lived outside NI for 6 months or more										
Yes	85.5		71.5		90.1		44.3		81.6	1.40 (0.98-2.01)
No	88.9		75.9		93.9		42.2		76.0	1.0 Ref
Tenancy										
Owner occupier	88.4	1.0 Ref	77.2	1.0 Ref	93.3		45.8	1.0 Ref	78.1	1.0 Ref
Other	91.0	1.75 (0.96-3.18)	72.7	0.79 (0.52-1.20)	93.5		36.8	0.67 (0.45-1.00)	82.5	1.23 (0.76-2.00)
Housing executive tenant	83.1	0.72 (0.44-1.19)	66.9	0.53 (0.35-0.81)	89.9		36.3	0.63 (0.42-0.93)	68.9	0.64 (0.42-0.97)
Physical or mental health condition, lasting or expected to last for 12 months or more, and how much it reduced their ability to carry out day-to-day activities										
No health condition	89.2		76.2		93.2		44.8		78.0	
Health condition – ability to carry out day-to-day activities not affected	84.6		77.8		88.5		42.3		87.5	

Table 2.1 continued

Health condition – ability to carry out day-to-day activities reduced a little	85.2		72.0		93.9		35.0		81.3	
Health condition – ability to carry out day-to-day activities reduced a lot	80.3		64.9		89.4		34.4		72.3	
% of total variance explained by model										
Cox and Snell		4.5		9.0		3.4		7.1		4.6
Nagelkerke		8.6		13.2		8.2		9.6		6.9

* If the variable was not a significant predictor in the model no OR is given.

Table 2.2 Multivariate model showing the % stating ‘you should not do research without consent’ and ORs and 95% CIs for those variables which predict opinion on the need for consent

	% stating you should not do research without consent	OR (95% CI)*	P value for variables contribution to the final model
Sex			**0.079**
Female	30.4	0.78 (0.59-1.03)	
Male	35.9	1.0 Ref	
Age			
18 – 24	41.3		
25 – 34	31.7		
35 – 44	27.3		
45 – 54	30.6		
55 – 64	32.8		
65 and over	33.9		
Highest educational level			
No qualification	41.3		
School level	32.8		
Graduate level	26.7		
Marital status			
Single	35.3		
Married/Civil Partnership	31.6		
Separated	26.2		
Divorced	38.5		
Widowed	32.6		
Religion			**0.001**
Catholic	36.0	1.0 Ref	
Protestant	31.4	0.94 (0.61-1.46)	
None	25.4	0.46 (0.28-0.74)	
Political identity			**0.004**
Strong Nationalist	54.1	1.36 (0.64-2.89)	
Fairly strong Nationalist	28	0.58 (0.35-0.96)	
Not very strong Nationalist	31.2	0.71 (0.42-1.18)	
Neither	36.2	1.0 Ref	
Not very strong Unionist	23.7	0.40 (0.30-0.85)	
Fairly strong Unionist	29.3	0.54 (0.33-0.87)	
Strong Unionist	37.1	1.14 (0.62-2.11)	
Caring responsibilities			

Table 2.2 continued

Yes	31.2		
No	33.4		
Place lived			
Big city	28.6		
Suburbs or outskirts of a big city	28.3		
Small city or town	36.2		
Country village	37.9		
Farm or home in the country	32.2		
Ever lived outside NI for 6 months or more			
Yes	35.5		
No	31.8		
Tenancy			**0.013**
Owner occupier	29.4	1.0 Ref	
Other	42.1	1.66 (1.14-2.42)	
Housing executive tenant	40.1	1.45 (0.97-2.15)	
Physical or mental health condition, lasting or expected to last for 12 months or more, and how much it reduced their ability to carry out day-to-day activities			**0.035**
No health condition	31.0	1.0 Ref	
Health condition – ability to carry out day-to-day activities not affected	15.4	1.43 (0.93-2.20)	
Health condition – ability to carry out day-to-day activities reduced a little	43.8	1.64 (1.00-2.70)	
Health condition – ability to carry out day-to-day activities reduced a lot	43.9	0.44 (0.15-1.34)	
% of total variance explained by model			
Cox and Snell		5.3	
Nagelkerke		7.4	

* If the variable was not a significant predictor in the model no OR is given.

Table 3 Multivariate models showing opinions relating to commercial access to administrative data for research and OR and 95% CIs for variables which predict opinion

	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		I don't want them to get access at all because they should pay for all their own research and trials	
	Disagree/disagree strongly		Agree/agree strongly	
	%	OR (95% CI)	%	OR (95% CI)
Sex				
Female	12.1		26.5	
Male	14.3		26.1	
Age				
18 – 24	20.8	2.12 (1.19-3.78)	22.9	
25 – 34	17.6	1.38 (0.78-2.45)	29	
35 – 44	12.8	0.89 (0.47-1.69)	24.6	
45 – 54	11.2	0.91 (0.51-1.63)	29.4	
55 – 64	6.7	0.54 (0.27-1.09)	26.3	
65 and over	12.3	1.0 Ref	24.8	
Highest educational level				
No qualification	10.3		28.6	0.92 (0.62-1.35)
School level	14.2		28.6	1.0 Ref
Graduate level	13.6		22	0.64 (0.45-0.90)
Marital status				
Single	17.2		25.3	
Married/Civil Partnership	9.7		25.8	
Separated	24.4		38.6	
Divorced	16.1		26.3	
Widowed	11.7		28.2	
Religion				
Catholic	15		31.8	1.0 Ref
Protestant	10		20.5	0.47 (0.34-0.65)
None	17.4		28.4	0.82 (0.54-1.23)
Political identity				
Strong Nationalist	44.7	6.48 (3.17-13.26)	59	

Table 3 continued

Fairly strong Nationalist	14.1	1.19 (0.66-2.16)	28.1	
Not very strong Nationalist	10.9	0.96 (0.49-1.86)	27.3	
Neither	12.6	1.0 Ref	26.5	
Not very strong Unionist	7.5	0.63 (0.31-1.27)	14.3	
Fairly strong Unionist	13.2	1.19 (0.69-2.05)	24	
Strong Unionist	9.1	0.84 (0.34-2.05)	25.8	
Caring responsibilities				
Yes	8.3		18.9	0.61 (0.40-0.92)
No	14.2		27.8	1.0 Ref
Place lived				
Big city	11.8		12.4	0.33 (0.18-0.59)
Suburbs or outskirts of a big city	11.9		26.1	1.0 Ref
Small city or town	13.8		28.2	1.10 (0.73-1.66)
Country village	15.4		34.3	1.39 (0.86-2.26)
Farm or home in the country	12.8		28	1.12 (0.71-1.78)
Ever lived outside NI for 6 months or more				
Yes	15.2		29.6	1.46 (1.06-2.02)
No	12.3		24.9	1.0 Ref
Tenancy				
Owner occupier	11.8		25.4	
Other	15.8		26.8	
Housing executive tenant	15.2		29.4	
Physical or mental health condition, lasting or expected to last for 12 months or more, and how much it reduced their ability to carry out day-to-day activities				
No health condition	13.3		26.2	1.0 Ref

Table 3 continued

Health condition – ability to carry out day-to-day activities not affected	0		3.7	0.07 (0.01-0.98)
Health condition – ability to carry out day-to-day activities reduced a little	9.5		26.2	1.16 (0.66-12.00)
Health condition – ability to carry out day-to-day activities reduced a lot	14.7		29.6	1.02 (0.64-1.62)
% of total variance explained by model				
Cox and Snell		4.2		7.2
Nagelkerke		7.9		10.6

* If the variable was not a significant predictor of in the model no OR is given.

Appendix 3
Northern Ireland Life and Times survey: Survey Methods

Please see the Northern Ireland Life and Times survey website for full technical details:
www.ark.ac.uk/nilt/2015/tech15.pdf

The overall design

The 2015 Northern Ireland Life and Times survey involved 1202 face-to-face interviews with adults aged 18 years or over. The main interview was carried out using computer assisted personal interviewing (CAPI) and the respondent was then asked to complete a self-completion questionnaire.

The self-completion questionnaire was completed using the following three methods:

- CASI method – the respondent completed the self-completion on the iPad.
- CAPI method – the interviewer completed the self-completion on the iPad.
- Traditional pen and paper method – the respondent completed the self-completion on paper booklet.

Survey content

The survey consists of a number of different modules, each based on a specific topic. The modules included in the 2015 survey were:

- Introductory questions
- Informal care
- Social care
- Community relations
- Minority ethnic groups
- Data sharing and privacy
- Political attitudes
- Background

Pilot and mainstage fieldwork

All interviews were conducted by Perceptive Insight interviewers in the respondents' homes. Pilot interviews with 30 respondents were carried out during 22nd August – 6th September 2015. The main stage of the fieldwork was undertaken during the period 21th September 2015 to 22nd December 2015. Respondents were asked to complete a CASI (Computer Assisted Self-Interviewing) questionnaire. On agreeing to complete the CASI questionnaire, the respondent was shown how to use the interviewer's iPad to enter answers by completing some example questions. If a respondent did not wish to complete the self-completion questionnaire on the iPad they were given the option to complete a paper version. The paper self-completion questionnaire was completed and handed back to the interviewer at the time of the main interview. If a respondent could not complete the self-completion questionnaire on the iPad or by paper, due to literacy or health issues, the interviewer completed the self-completion questionnaire on the iPad where consent was granted by the respondent.

Advance Letter

An advance letter was issued by Perceptive Insight to all sampled addresses prior to the interviewer calling at each address. The letter explained the purpose and rationale for the survey as well as contact details for the Perceptive Insight staff managing the project.

Sampling design

The sample for the 2015 survey consisted of a systematic random sample of addresses selected from the Postcode Address File (PAF) database of addresses. Private business addresses were removed from the database prior to sample selection. A total of 2,350 addresses were selected for interview.

The Postcode Address File (PAF) provides a good sampling frame of addresses, but contains no information about the number of people living at an address. Further selection stages were therefore required to convert the listing of addresses to a listing of individuals from which one person (the 'selected respondent') is chosen to complete the questionnaire.

The person to be interviewed was randomly selected using the ‘next birthday’ rule. The interviewer asked the householder to list the birthdays of all members of the household eligible for inclusion in the sample: that is, all persons aged 18 or over living at the address. The person with the next birthday, at the time of the call, was the person with whom the interview was to be conducted. Where the selected respondent was not available, an appointment was made to call back to interview them at a more suitable time.

Response rate

Table 3.1 shows the status of addresses, and the number of addresses in scope.

Table 3.2 shows the breakdown of response

Table 3.3 shows the response rate for the self-completion questionnaires.

Table 3.1 Status of addresses

Total addresses issued	Ineligible (e.g. vacant/ derelict/ commercial)	Total in scope
2350	176	2174

Table 3.2 Breakdown of response

	Number	%
Total co-operating	1202	55
Fully co-operating	1202	55
Partially co-operating	0	0
Refusal to co-operate	574	26
Non-contact	398	18
Total	2174	

Table 3.3 Completed self-completion questionnaires

Number of main stage interviews	1202
Number of self-completion achieved	1202
% of self-completion achieved	100

Sampling errors and confidence intervals

Table 3.4 sets out sampling errors and confidence intervals at the 95% confidence level relating to a Systematic Random Sample design as used in the survey. Note that the margin of error for all sample estimates is within the parameters of + 2.8%.

Table 3.4 Sampling errors and confidence intervals for key variables (unweighted data)

		%	Margin of Error	95% Confidence Limits
Age	18 – 24	8.7	1.59	7.1-10.3
	25 – 34	14.4	1.98	12.4-16.4
	35 – 44	15.2	2.03	13.2-17.2
	45 – 54	15.1	2.02	13.1-17.1
	55 – 64	14.2	1.97	12.2-16.2
	65 and over	31.4	2.62	28.8-34.0
Sex	Male	44.8	2.81	42.0-47.6
	Female	55.2	2.81	52.4-58.0
Marital Status	Single	32.1	2.64	29.5-34.7
	Married/Civil Partnership	41.5	2.78	38.7-44.3
	Separated	5.3	1.27	4.0-6.6
	Divorced	6.7	1.41	5.3-8.1
	Widowed	13.9	1.96	11.9-15.9
Religion	Catholic	37.5	2.74	34.8-40.2
	Protestant	40.1	2.77	37.3-42.9
	None	16.8	2.11	14.7-18.9
	Other	1.6	0.71	0.9-2.3
	Refused/Don’t know	4.0	1.11	2.9-5.1

Table 3.5 Comparison of household characteristics

		NILT 2015*	CHS 2014/15	Northern Ireland Census 2011
Characteristics of sampled households			All households	
Tenure	Owned outright	40	37	32
	Owned with mortgage/co-ownership	22	31	35
	Rented Local Authority	17	11	12
	Rented other***	18	20	18
	Rent free	2	1	3
	Refused	1	-	-
Base=100%		1,202	2,521	703,275

* Household characteristics are based on unweighted data from the NILT survey

*** 'Rented' includes rented from a housing association and rented privately

Table 3.6 Comparison of individual characteristics (weighted data)

		NILT 2015	CHS 2014/15	Northern Ireland Census 2011
			%	
Individual characteristics			18+	
Sex	Male	47	47	49
	Female	53	53	51
Age	18-24	12	10	13
	25-34	15	17	18
	35-44	14	17	18
	45-54	18	18	18
	55-64	15	16	14
	65 and over	26	22	19
Base=100%	n		4,670	1,380,100
			18+	
Marital Status	Single	31	29	36
	Married/Civil Partner	51	56	48
	Widowed	9	6	7
	Divorced/Separated	8	8	9
	Refused/ Don't know	-	-	-
Base=100%	n	1,202	4,670	1,431,540

Table 3.7 Individual characteristics – NILT 2015 (weighted data)

	18-24	25-34	35-44	45-64	65 and over	All
	%					
Single	95	57	34	15	7	32
Married/Civil Partner	4	38	55	69	57	51
Divorced/separated/ widowed	1	5	11	16	36	17
Base=100%	146	176	170	393	310	1202

Table 3.8 Individual characteristics – CHS 2014/15

	18-24	25-34	35-44	45-64	65 and over	All
	%					
Single	99	54	25	13	7	29
Married/Civil Partner	1	43	66	70	63	56
Divorced/separated/ widowed	-	3	9	17	31	15
Base=100%	485	780	815	1560	1030	4,670

Table 3.9 Stated religious denomination

	NILT 2015 (weighted)	CHS 2014/15**	Northern Ireland Census 2011
	%		
Protestant	41	47	48
Catholic	39	42	45
Other or no religion*	17	9	6
Missing/refused	3	1	1
Base=100%	1,202	6,216	1,108,63

* Include ‘no religion’ and religion not stated

** Supplemented from household membership

Appendix 4. Results by survey question

Table A1: Trust in the NHS

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? (The NHS)

	%
Definitely trust them	46
Probably trust them	40
Probably don’t trust them	7
Definitely don’t trust them	5
Don’t know	2

Table A2: Trust in Government Departments

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? (Government Departments)

	%
Definitely trust them	32
Probably trust them	41
Probably don’t trust them	15
Definitely don’t trust them	10
Don’t know	3

Table A3: Trust in your GP surgery

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? (Your GP surgery)

	%
Definitely trust them	53
Probably trust them	38
Probably don’t trust them	5
Definitely don’t trust them	2
Don’t know	1

Table A4: Trust in Commercial organisations like insurance companies

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? (Commercial organisations like insurance companies)

	%
Definitely trust them	12
Probably trust them	29
Probably don’t trust them	29
Definitely don’t trust them	25
Don’t know	5

Table A5: Trust in academic researchers in a university

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? (Academic researchers in a university)

	%
Definitely trust them	24
Probably trust them	48
Probably don’t trust them	14
Definitely don’t trust them	7
Don’t know	7

Table A6: Trust in Charities

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? (Charities)

	%
Definitely trust them	14
Probably trust them	37
Probably don’t trust them	25
Definitely don’t trust them	19
Don’t know	6

Table A7: Concern about data usage

Have you ever had any particular concerns about how any of these organisations use the information or 'data' about people that they keep?

	%
Yes	42
No	55
Don't know	3

Table A8: Specific concerns about data usage

Here are some of the concerns that other people have mentioned. Which, if any, of these concerns have you had yourself? (asked of those who said they had a concern)

	%
I think they will use my information for other purposes they won't tell me about	70
They might lose my information to hackers	62
I don't think they will use the information for my personal benefit	36
They might lose my information by accident	43
I don't trust them to keep accurate records about me	29
I don't think I would be able to change/delete my information if it is wrong	30
I don't trust them at all	27
My personal information may be used to discriminate against me	20
Something else	1
Don't know	2

Table A9: Acceptability of NHS electronic care record (1)

At the moment some of the information that your GP has about you can be passed to any other part of the NHS. So for example if you have an accident and arrive in hospital as an emergency the hospital can quickly check on their computer for blood tests or medications you are taking so that they know how to treat you best. Do you think that passing on information like this throughout the NHS is acceptable or unacceptable?

	%
Definitely acceptable	77
Probably acceptable	20
Probably unacceptable	1
Definitely unacceptable	<1
Other answer	0
Don't know	1

Table A10: Acceptability of NHS care electronic record (2)

Suppose it wasn't an emergency but you were seeing a consultant and they were able to look up on their computer the results of some blood tests that you had in your GP surgery three months before. Do you think that passing on information like this throughout the NHS is acceptable or unacceptable?

	%
Definitely acceptable	75
Probably acceptable	21
Probably unacceptable	2
Definitely unacceptable	2
Other answer	0
Don't know	1

Table A11: Acceptability of GP sharing records outside NHS (1)

Suppose GPs were to be allowed to share information about patients to help improve services provided by another government department. For example, if they routinely passed on information about all people with a long-term illness like severe arthritis to the benefit offices so that those people could be encouraged or helped to apply for disability benefits. Do you think that this should be allowed?

	%
Yes definitely	45
Yes probably	33
No probably not	10
No definitely not	10
Other answer	1
Don't know	2

Table A12: Acceptability of GP sharing records outside NHS (2)

What if the long-term illness was a mental illness – do you think GPs should be allowed to routinely pass this information on to the benefit offices so that these people should be encouraged or helped to apply for disability benefits?

	%
Yes definitely	38
Yes probably	33
No probably not	12
No definitely not	14
Other answer	1
Don't know	4

Table A13: Acceptability of GP sharing records outside NHS (3)

What about allowing people outside government departments to see health information. For example, should GPs be able to routinely pass personal health information on to schools about health conditions like diabetes or asthma that might affect a child during the school day? Do you think that this should be allowed?

	%
Yes definitely	37
Yes probably	30
No probably not	11
No definitely not	16
Other answer	1
Don't know	5

Table A14: Acceptability of data linking (1)

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?

	%
Yes definitely	51
Yes probably	36
No probably not	6
No definitely not	4
Other answer	0
Don't know	3

Table A15: 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?

	%
Yes definitely	28
Yes probably	32
No probably not	18
No definitely not	17
Other answer	<1
Don't know	5

Table A16: Acceptability of data linking (3)

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?

	%
Yes definitely	36
Yes probably	37
No probably not	10
No definitely not	10
Other answer	<1
Don't know	7

Table A17: 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 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

Table A18: Importance of safeguards when using personal information in research by academics

How important are each of these safeguards for using this kind of personal information for academic research by university researchers?	Important	Neither important nor unimportant	Unimportant	Don't know
	%	%	%	%
The research must have a clear public benefit	93	4	1	2
Names and other things that could identify someone must always be taken off	94	4	1	2
The researchers must go through checks to ensure that they are properly trained and working for an approved organisation	95	3	<1	2
Every project must have official approval	87	8	2	3
The researchers have to go to one of the dedicated secure data centres to do their analysis	78	11	5	6
The statistical results of the research must be made public	73	16	7	4
There are penalties if researchers breach data security	91	5	1	4

Table A19: Safeguards when using personal information in research by commercial organisations

And supposing the research using personal information was being carried out by commercial organisations, should they be subject to the same safeguards as university researchers, more safeguards or less safeguards?

	%
Same safeguards	46
More safeguards	50
Less safeguards	1
Other answer	0
Don't know	4

Table A20: Safeguards when using personal information in research by commercial organisations

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?

	Agree strongly	Agree	Neither agree nor disagree	Disagree	Disagree strongly	Don't know
	%	%	%	%	%	%
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	35	41	8	10	4	3
I would like them to get access to patient records but they should pay a fee to get the data as they will make a profit out of any new drug	24	33	15	18	4	7
I don't want them to get access at all because they should pay for all their own research and trials.	13	13	17	41	9	8

Table A21: General attitudes to privacy and data-sharing

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Disagree strongly	Don't know
	%	%	%	%	%	%
I don't care who uses data about me	3	17	10	41	28	1
The right to privacy has to be respected over everything else	40	42	12	3	<1	2
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	22	51	8	13	3	2
Even if you take the names off files of patient information you can often still tell who it is from all the other information that is there.	11	35	24	18	1	11
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.	30	55	8	4	1	3
I don't want university researchers to be able to use my personal data at all	3	12	16	54	10	4
I don't want commercial organisations to be able to use my personal information at all	14	25	21	29	7	5

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