A care system support organisation

North East and North Cumbria Secure Data Environment programme

Health data sharing: Equality Impact Assessment

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2 Summary

2.1 Key points

- **Overall NENC is more open to data sharing than England**
- **The less deprived are less likely to share data**
- **GPs are important stakeholders to engage with**
- **Support for data sharing inside the NHS is much higher than sharing with outside organisations**

2.2 Abstract

This report looks at the perception and actions of people in the North East and North Cumbria around their healthcare data. It examines the historical context of attempts at NHS data collection from GP Practice systems. Then breaks down the demographics publicly available data of the National NHS data Opt-Out and looks at published survey data as it applies to North East England. The conclusions it finds is that demographics has an impact on people's perception and action of data sharing. Those who live in Opt-Out rate is higher among women, the most affluent, the most educated, and those aged 30 to 59. The North East is in general more open to data sharing, and as a lower level of data Opt-Out than the country as a whole.

3 Introduction

3.1 Background

Data held by the NHS and other care organisations has a previously untapped potential for supporting research by NHS analysts, academia, and industry. *The Goldacre Review* (Goldacre & Morley, 2022) described how *Trusted Research Environments* (TREs) could achieve this potential without compromising the privacy of individual people. *The Department of Health & Social Care* made this policy for England in October 2023 (Department of Health and Social Care, 2023) with a network of *Secure Data Environments* (SDEs).

3.2 Objectives and Scope

The purpose of this report is to look at available data on public actions or views on healthcare data sharing, participation in medical research, and digital privacy with particular focus on people living in the *North East and North Cumbria* (NENC) *Integrated Care Board* (ICB). This is to enable better communication with the public and better support for the *Secure Data Environments* (SDEs) in engagement activities.

3.3 Data bias

When analysing data pertaining to people who may have concerns or objections regarding the utilization of their personal data, it is imperative to acknowledge that a subset of these individuals will have proactively excluded themselves from data collection processes or opted not to participate in surveys. This introduces inherent bias to any data and must be considered in the interpretation of the results presented in this report.

4 Key Events

4.1 care.data

As part of the *Health and Social Care Act* (UK Public General Acts, 2012) there was a requirement under section 259(5) for GPs to allow the *Health and Social Care Information Centre* (HSCIC) to extract data when requested. The was a plan to extract data from all English GP care records in Spring 2014 under a programme named care.data (*pronounced: care dot data*). The programme was initially supported by various healthcare organisations and union. However, it gained negative responses from both public and in particular GPs (Sterckx, et al., 2016) (Ford, et al., 2020).

A leaflet was sent to all households in England '*Better information means better care'* (HSCIC, 2014) however this was poorly received with 23% remembering receiving the leaflets and 45% did not understand the care.data scheme (Medical Protection Society, 2014). In January 2014 a survey of 600 GPs showed that 80% of them did "not believe they have a good understanding of how patient data will be used in the care.data system" (Medical Protection Society, 2014), and another survey reported that 41% of GPs saying they personally intend to opt-out (Pulse Today, 2014).

The objections of both public and GPs both revolved around lack of information about the programme, uses of the data, and perceived a risk of if the data were sold onto commercial interests (Sterckx, et al., 2016) (Ford, et al., 2020).

The planned extraction was stopped in May 2014 and in October 2014 reduced to only 'pathfinder' areas in six specific Clinical Commissioning Groups (CCGs). The programme was officially closed in 2016 after a review by Dame Fiona Caldicott which stated "In the light of the Review, the Government should consider the future of the care.data programme" (National Data Guardian for Health and Care, 2016).

4.2 General Data Protection Regulation

On 25 May 2018, the national data opt-out was launched, alongside the new General Data Protection Regulation (GDPR). The opt-out affects other NHS organisations who may want to use confidential patient information for planning as well as researchers and commercial organisations who use patient data to provide research and analysis expertise to the NHS. According to (Evans, 2018), the consequences will depend on opt-out rates. If they remain low, there will be less impact. Even a low rate of opt-out has a potentially detrimental impact on some types of analysis. As of Feb 2024, the national opt-out rate is 5.4% (NHS Digital, 2024).

4.3 Covid-19 Pandemic

Information was critical to the response to COVID-19. The National Data Guardian conducted polling (2,114 adults in England) to gauge public opinion on the use of data during the COVID-19 coronavirus pandemic (National Data Guardian, 2020):

More than half of survey respondents (56%) agreed that during the coronavirus pandemic, they have learned more about how health and care data can be used to monitor public health and for research.

Nearly two thirds (63%) agreed what they have learned during the pandemic has made them more accepting of the need for sharing health and care data.

A majority (64%) said that they would trust government agencies to use information about them such as coronavirus test results. However, a further 17% did not agree

with this and 19% were not sure, showing that it is essential that there is an ongoing focus to build public trust in the use of their information to manage the pandemic.

Around 60% agree that after the pandemic, organisations such as local authorities, university and hospital researchers, and private companies should be allowed to carry on using health and care data to improve care.

4.4 GP Data for Planning and Research

The *GP Data for Planning and Research* (GPDPR) programme is a national initiative to update how GP data is collected for secondary use (not direct care), mainly service planning and research. It was launched in 2021, after being delayed by the Covid-19 pandemic, but there was an attempt to deliver the changes rapidly. The public and NHS staff felt that timelines were rushed, there was insufficient communication and insufficient data privacy protections and, as a result, the initiative was paused (NHS Digital, 2023).

5 National Opt-Out

5.1 Background

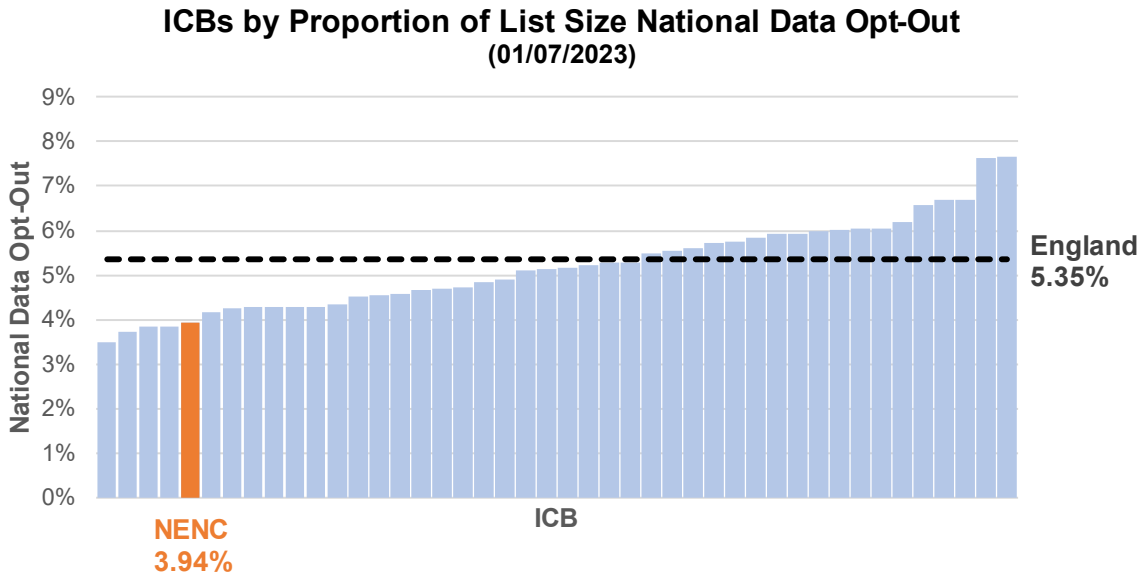
The *NHS National Data Opt-Out* was introduced in May 2018 following recommendations from the National Data Guardian based on. UK's implementation of *General Data Protection Regulation* (GDPR) (UK Public General Acts, 2018).

Reporting on data opt-outs is published by *NHS Digital* (NHS Digital, 2024) and is available through a public dashboard[1] (NHS Digital, 2024). The dashboard updates weekly, whereas published data is updated once a year or when the national-opt out proportion changes by more than 0.1 per cent. The denominator used to calculate the proportion of out-outs is the GP registered list size, less known deaths.

The level of opt-out is the best available metric of public confidence in NHS data privacy as it represents real numbers of people actively choosing to remove their data from existing NHS data sources. This data source will be therefore less effected by the bias of these individuals proactively excluding themselves from data collection processes and surveys.

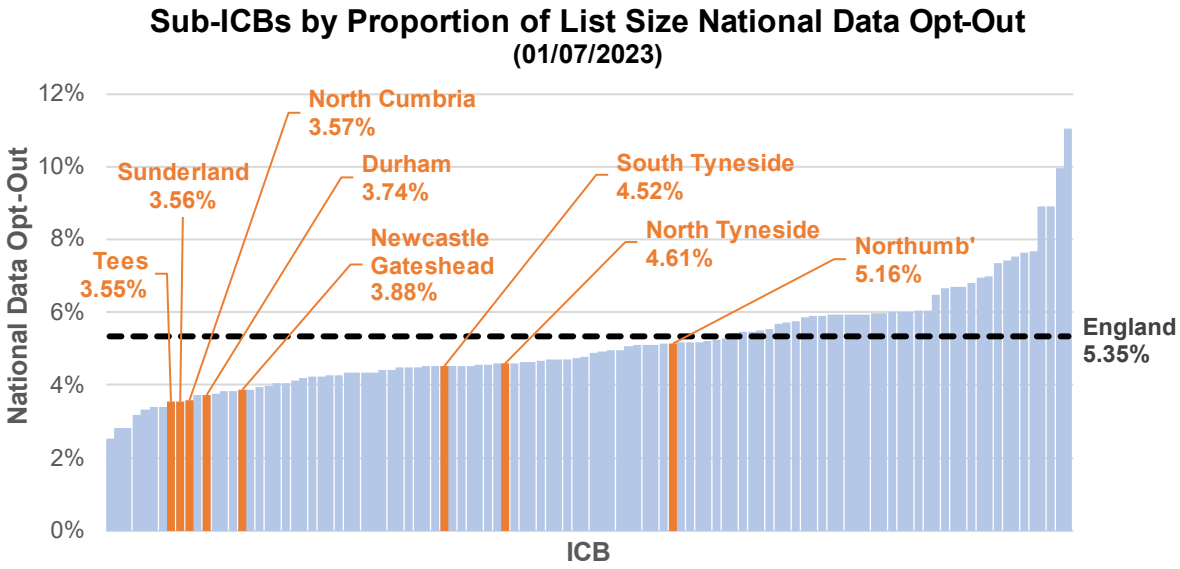
5.2 Place Opt-Out

In the latest published figures (NHS Digital, 2023) *NHS North East and North Cumbria Integrated Care Board* (NENC ICB) the 5th lowest proportion (3.94%) of opt out across England, and considerably lower than the overall national proportion (5.35%).



All NENC sub-ICBs, previous clinical commissioning groups (CCGs), have opt-out below the national proportion. The highest being Northumberland (5.16%) and the lowest being Tees Valley (3.55%), Sunderland (3.56), and North Cumbria (3.57%).

[1] https://digital.nhs.uk/dashboards/national-data-opt-out-open-data



This table shows the Opt-Out proportions for the North East and North Cumbria ICB and its constituent sub-ICBs.

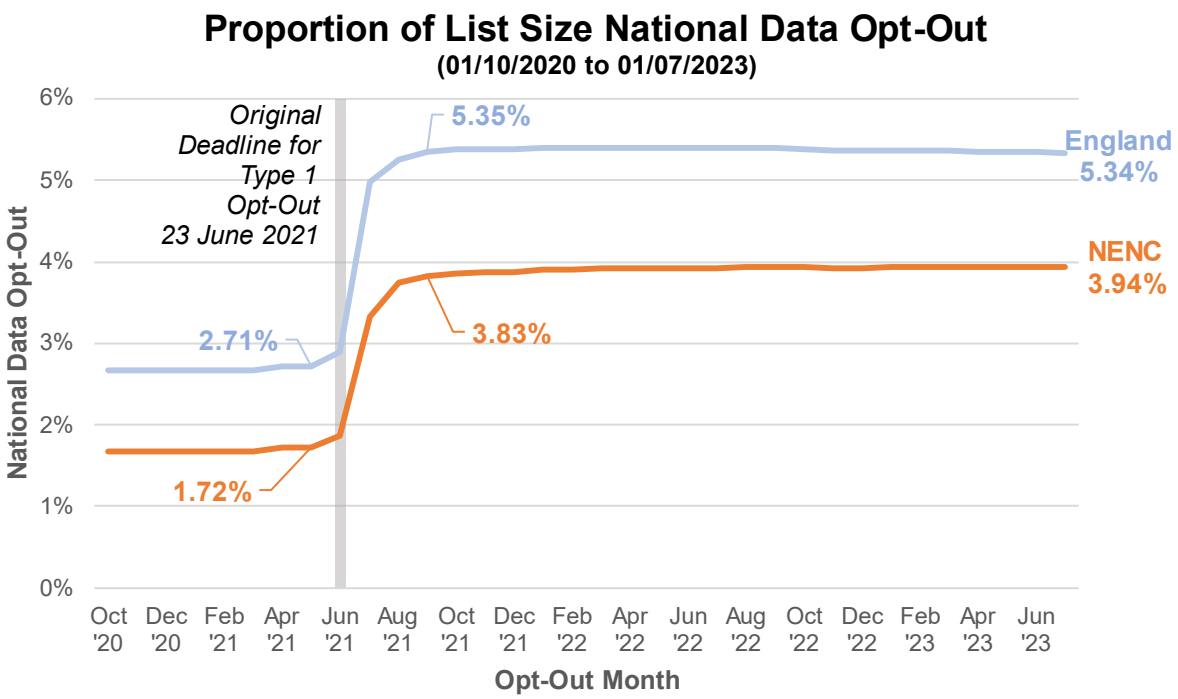
NENC Sub-ICBs by Proportion of List Size National Data Opt-Out

ODS Code	Sub-ICB	Opt-Out July '23	List Size Population	Opt-Out %
16C	Tees Valley	26,000	727,000	3.55%
00P	Sunderland	10,500	290,500	3.56%
01H	North Cumbria	12,000	333,000	3.57%
84H	Durham	21,000	563,500	3.74%
13T	Newcastle Gateshead	21,500	547,500	3.88%
00N	South Tyneside	7,000	159,500	4.52%
99C	North Tyneside	10,500	226,500	4.61%
00L	Northumberland	17,500	336,500	5.16%
QHM	**NENC ICB**	**108,000**	**2,847,000**	**3.79%**
	England	**3,506,000**	**65,553,500**	**5.35%**

Population numbers in table rounded to nearest 500

5.3 Change over Time

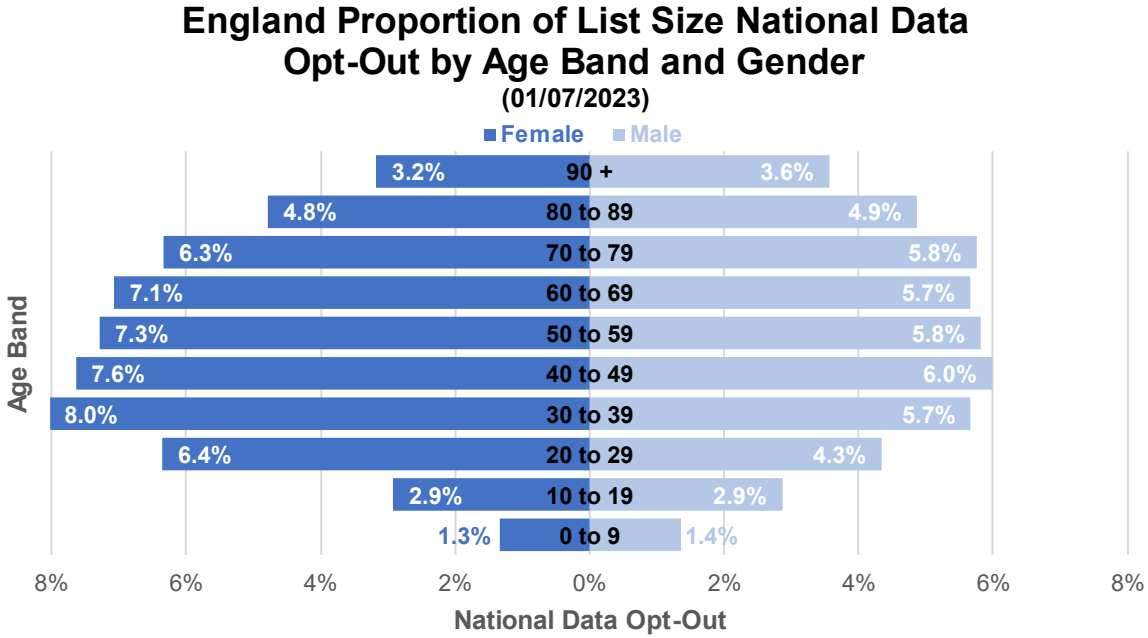
Opt-Out proportions have remained relatively constant over time apart from a spike in June-September 2021. The spike caused a percentage point increase of 2.1 per cent from 1.72% to 3.83% of the population. The increase was caused by an initial deadline for people to opt-out of an extract of GP practice systems, known as a *Type 1 opt-out* (NHS Digital, 2021). There was some misinformation on social media "…told your GP to hand over your health data, including mental & sexual health, to third parties for payment" (Rahman, 2021). There was coverage in in national news (Hinde, 2021) (Murgia, 2021) and lifestyle articles (Savin, 2021) which highlighted the misinformation but also reported on how to opt-out of data sharing and why people might want to opt-out. Following this national interest the deadline was first extended to September 2021, then to no fixed date (NHS Digital, 2021), with a number of criteria needing to be met including when a "Trusted Research Environment is available."

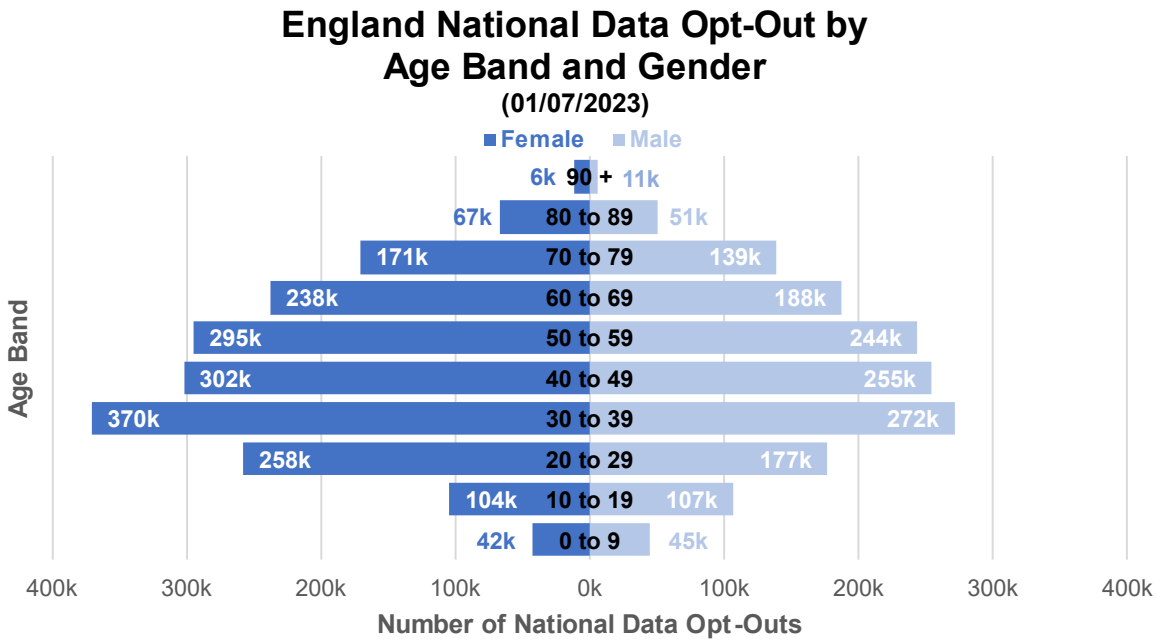


5.4 National Demographics

5.4.1 Age-Sex

Data in the *National Opt-Out* is not available at individual level. Demographic characteristics are only accessible at the national level, precluding any direct investigation into *North East and North Cumbria ICB* sub-populations.

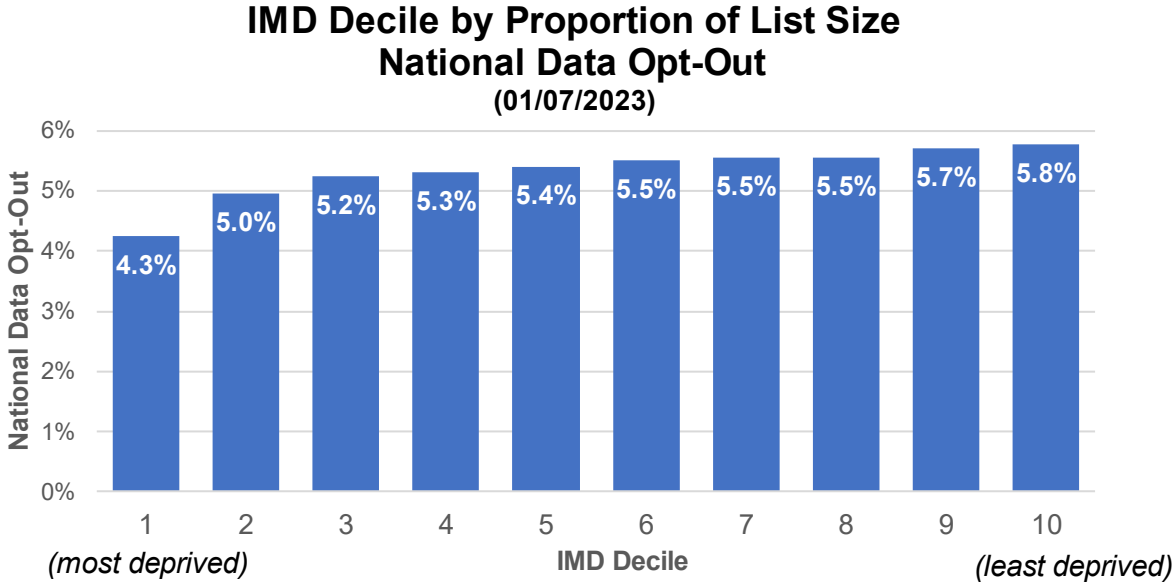




In England overall the largest group of opt-outs is in female people aged 30 to 39 (8.0%, n=~370,000). Females generally exhibit higher opt-out proportion than males across age bands, the exception being people aged 80 and over. In age there is a peak at 30 to 39, decreasing over age bands for females but remaining relatively static for males.

5.4.2 Deprivation

Index of Multiple Deprivation (IMD) 2019 decile (Noble, et al., 2019) provides a relative measure of deprivation for *Lower-layer Super Output Areas* (LSOAs) across England, based on seven different domains. The decile divides all the LSOAs into ten equally sized groups based on their deprivation rank. Deciles range from 1; most deprived; to 10; least deprived.



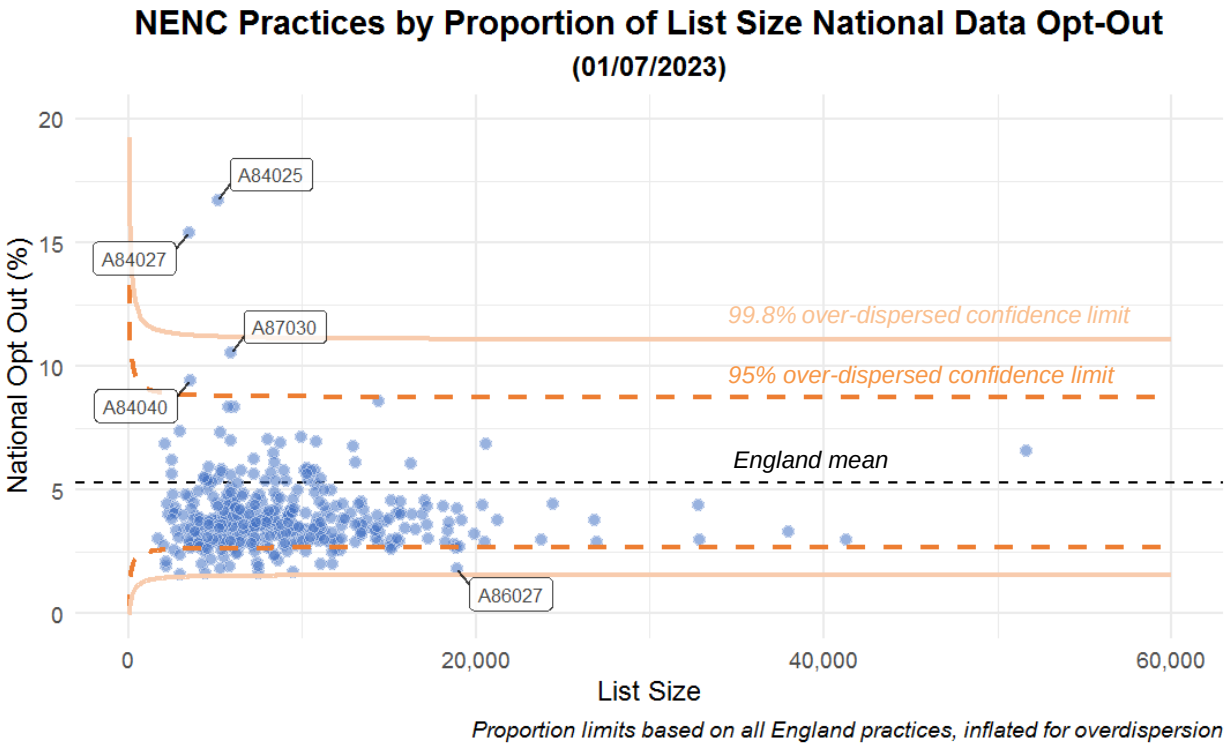
The published *National Opt-Out* summary notes that there are some areas not included in the IMD data as the IMD-LSOA lookup was made in 2019 and any

geography changed in the 2021 census LSOA update will not be mapped to an IMD decile (NHS Digital, 2023).

5.5 GP Practices

National Opt-Out proportions are available for each practice within England. The practice opt-out proportions were evaluated using a funnel plot. Funnel plots aim to account for the effect that greater variance is expected in smaller sized institutions. This analysis was performed using the *R* (R Core Team, 2023) statistical package *FunnelPlotR* (Mainey, 2023). The package implements methods developed by Prof Sir David J. Spiegelhalter to compare institutional performance, with particular reference to the NHS (Spiegelhalter, 2005) (Spiegelhalter, 2005) (Spiegelhalter, et al., 2012). The results were observed to be exhibiting over-dispersal (ϕ = 48.40), indicating there may be factors outside of practice policy that contribute to variation in list size opting out. Correction for over-dispersion was applied to the 95% and 99.8% Poisson funnel limits.

Practices with more opt-outs than their list size or with total list size less than one thousand were excluded from analysis. The total number of practices used in the analysis was 6,318 points of which 854 were outliers. The funnel plot below only shows the 345 practices in NENC of which 37 are outliers.



Only four practices in NENC are high outliers, these are highlighted in the plot (A84025, A84027, A87030, A84040). One larger practice with significantly lower than the England mean opt-out value is also highlighted (A86027). The table below shows details of the practices that are highlighted on the funnel plot. Three of the high outlier GP Practices are in *Northumbria* Sub-ICB place, the three practices do not belong to the same *Primary Care Network* (PCN). Northumbria has the highest proportion of National Data Opt-Out of all NENC Sub-ICB places (5.16%) it remains the highest proportion even excluding these three high outlier practices (16,000 / 324,000 = 4.82%).

NENC Practices Funnel Plot Highlighted Outliers of List Size National Data Opt-Out

Practice	Code	**A84025**	**A84027**	**A87030**	**A84040**	**A86027**
	Name	Cramlington Medical Group	Bellingham Practice	Redburn Park Medical Centre	Humshaugh & Wark Medical Group	Newcastle Medical Centre
	Postcode	NE23 6QN	NE48 2HE	NE29 6HT	NE46 4BU	NE1 7XR
Sub-ICB	Code	00L	00L	99C	00L	13T
	Name	Northumberland	Northumberland	North Tyneside	Northumberland	Newcastle Gateshead
July `23	Outlier	U99.8%	U99.8%	U95%	U95%	L95%
	Opt-Out	855	535	625	335	345
	List Size	5,110	3,460	5,900	3,560	18,885
	Opt-Out %	**16.7%**	**15.4%**	**10.6%**	**9.4%**	**1.8%**
95% Limit	Lower	2.6%	2.6%	2.6%	2.6%	2.7%
	Upper	8.8%	8.8%	8.8%	8.8%	8.8%
98.8% Limit	Lower	1.5%	1.5%	1.5%	1.5%	1.5%
	Upper	11.2%	11.3%	11.2%	11.3%	11.1%

Population numbers in table rounded to nearest 5

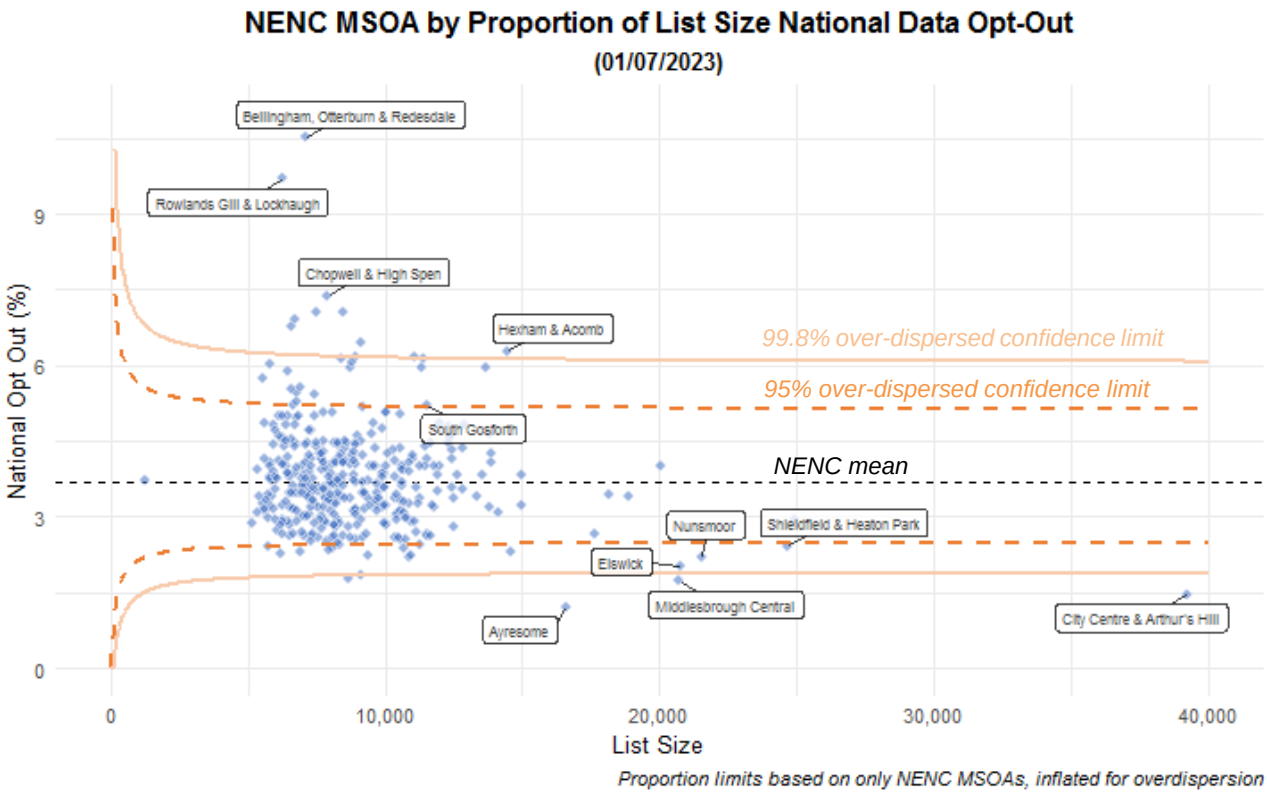
5.6 Middle-Layer Super Output Areas

National Opt-Out numbers are published at *Lower-layer Super Output Area 2011* (LSOA) level, but without a GP practice registered list size to use as a denominator. The LSOAs can then be aggregated into the larger *Middle-layer Super Output Areas 2011* (MSOA). To derive an Opt-Out proportion an estimate denominator was derived using a pseudo-anonymised feed of the *Personal Demographic Service* (PDS) data supplied by *North of England Commissioning Support* (NECS) data services.

PDS (NHS Digital, 2024) is the national master database of all NHS patients in England, Wales and the Isle of Man. It is required for patient facing NHS organisations to use to maintain correct basic patient details such as name, address, date of birth, post code, registered GP, nominated pharmacy and NHS number. The version supplied by NECS and used for this analysis contained no directly identifiable personal data. Data recording the LSOA of residence of individuals in NENC was available for analysis but would exclude anyone who had opted out of national data. The denominator used for each LSOA is equal from the total of the PDS residents registered with a GP practice in NENC plus the number of National Opt-outs.

The LSOAs were aggregated to MSOAs and recognisable names were added (House of Commons Library, 2022). The same method for GP practices was applied to the MSOAs to identify outlier areas. The results were observed to be exhibiting over-dispersal ($\phi = 12.34$), correction for over-dispersion was applied to the 95% and 99.8% Poisson funnel limits.

Data from analysis of MSOA outliers shows that Northumberland is significantly different to other areas of NENC. Areas around in Morpeth, Cramlington and Hexham have National Opt-Out proportions higher than other areas of NENC. The Northumberland MSOA *Bellingham, Otterburn & Redesdale* (E02005727) has the highest Opt-Out across NENC at 10.5%. This MSOA is the location of *Bellingham Practice* (A84027) which has the second highest proportion of Opt-Outs of GP practices in NENC (15.4%).



Rural areas of Gateshead around *Chopwell Woodland* also have some of the highest Opt-Out proportions in the ICB; *Rowlands Gill & Lockhaugh* (E02001703, 9.7%) and *Chopwell & High Spen* (E02001705, 7.4%).

Areas which have a significantly lower Opt-Out rate than other MSOAs tend to be very high population, over the 15,000 which is the upper end for MSOA population size. This means that it is likely that these areas have undergone significant population growth since the 2011 MSOA boundaries were set. They tend to be dense urban areas, for example *Ayresome* in Middlesbrough (E02002498, 1.2%), *City Centre & Arthur's Hill* in Newcastle (E02001731, 1.5%), or *Millfield* in Sunderland (E02001801, 1.8%).

NENC Sub-ICBs MSOA Outliers for National Data Opt-Out

ODS	Sub-ICB	Upper 99.8%	Upper 95%	Not Outlier	Lower 95%	Lower 99.8%	Total MSOA
84H	Durham	-	-	65	2	-	67
13T	Newcastle Gateshead	2	1	48	5	1	57
01H	North Cumbria	-	-	37	3	-	40
99C	North Tyneside	-	4	26	-	-	30
00L	Northumberland	9	8	23	-	-	40
00N	South Tyneside	-	2	21	-	-	23
00P	Sunderland	-	-	33	2	1	36
16C	Tees	-	-	84	2	3	89
QHM	**NENC ICB**	**11**	**15**	**337**	**14**	**5**	**382**

Proportion limits based on all NENC MSOAs, inflated for overdispersion

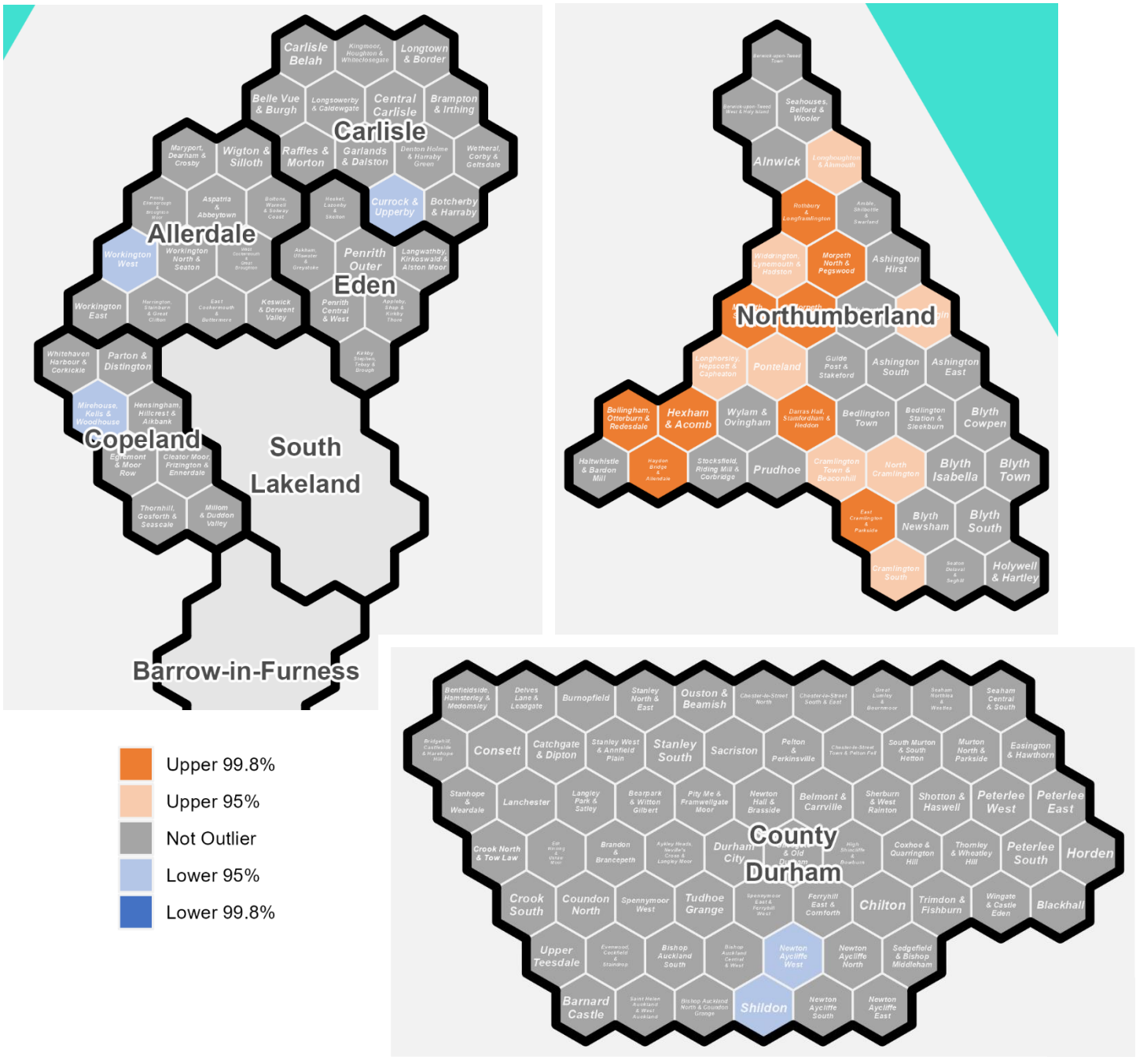
MSOAs are designed to have 2,000 to 6,000 households and have a usually resident census population of 5,000 to 15,000 people and are entirely fitted within Local

Authorities (Office for National Statistics, n.d.). This means that MSOA vary in size with population density, with larger rural areas and smaller urban areas. To geographically visualise MSOAs and look for trends in outliers the results of the funnel plot analysis were applied to a *hex cartogram* (Baker & Lowe, 2023).

A cartogram is a type of map that represents geographical regions abstractly. This hex cartogram represents each MSOA as a hexagon of equal size that "are arranged approximately geographically within the wider local authority shape, according to the relative position of their "population-weighted centroid" (Baker & Lowe, 2023). This means that a rural MSOA with a large area will be the same size on the diagram as a small area MSOA from a city centre, and the spatial relationship between them will be broadly maintained. In this diagram five areas have been separated to tesselate on the page (Cumbria, Northumberland, Tyneside & Sunderland, County Durham, Teesside).

MSOA by Proportion of List Size National Data Opt-Out

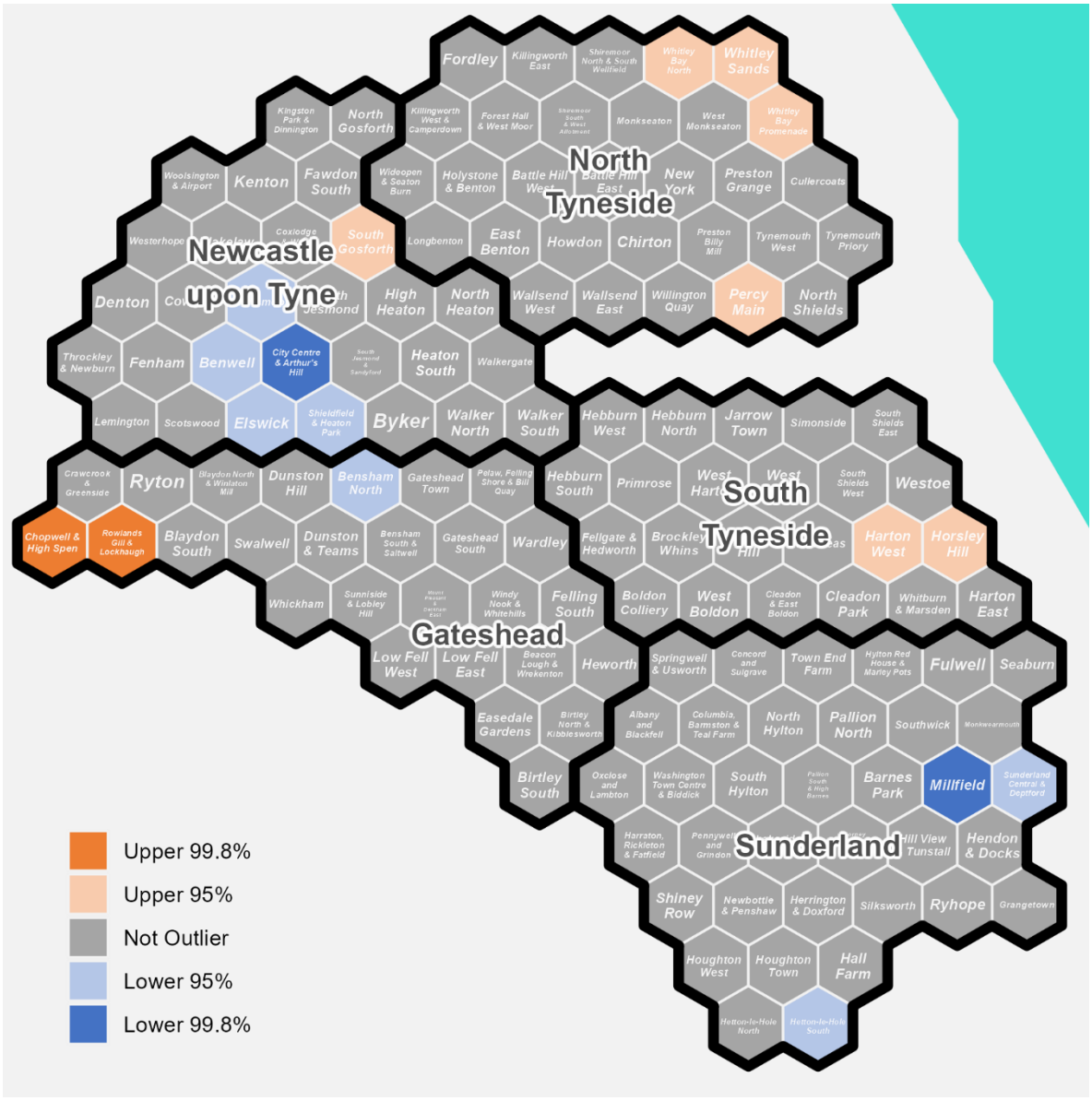
(01/07/2023) Cartogram with MSOAs as Hexagons

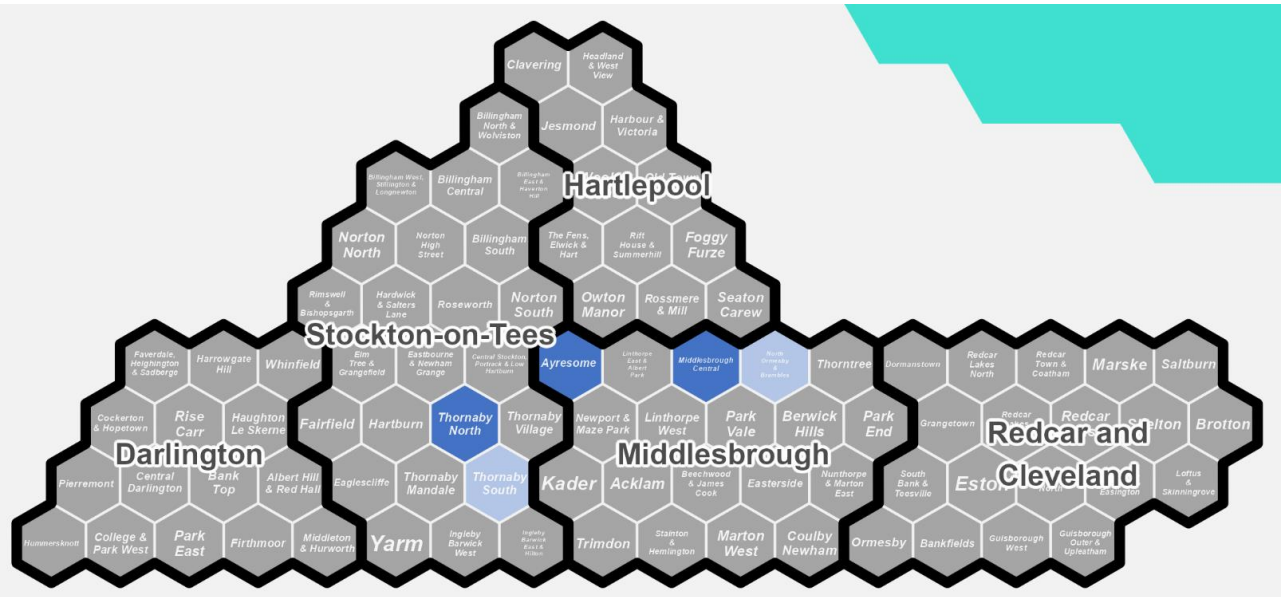


Proportion limits based on all NENC MSOAs, inflated for overdispersion

MSOA by Proportion of List Size National Data Opt-Out

(01/07/2023) Cartogram with MSOAs as Hexagons





Proportion limits based on all NENC MSOAs, inflated for overdispersion

6 Estimated Acorn Demographics

6.1 Problem

Data for NHS data National Opt-Out is not available broken down by demographics characteristics at anything other than a England level. There is little additional information that can be gained how groups in society react differently to engagement or social change.

6.2 Method

6.2.1 Population data

The basis of the analysis is the pseudo-anonymised feed of the *Personal Demographic Service* (PDS) data supplied by *North of England Commissioning Support* (NECS) data services. PDS supplies demographic information such as *Lower-layer Super Output Area* (LSOA) of residence, gender, and age (NHS Digital, 2024). It is also linkable to other datasets provided by NECS data services that share a common pseudo-anonymised NHS Number key. The population used was extracted February 15th 2024 and consisted of 3,306,710 individuals (rounded to nearest ten).

6.2.2 Acorn

Acorn is a geodemographic segmentation tool developed by *CACI Limited* (Limbu, 2023). Every UK postcode is grouped into a hierarchy of *Category*, *Group*, and *Type*, In the hierarchy there are 7 *Categories*, 22 *Groups*, and *65 Types.*

The 2023 version of Acorn is linked to individuals in the PDS data via a pseudo-anonymised postcode provided by NECS data services. Any individuals where a link could not be made were grouped into a category of "*Unknown"*.

Further information on each geodemographic segment is available from the Acorn website [2] (CACI Ltd, 2023), including data on media preferences, finance, and shopping habits.

6.2.3 National Opt-Out

The proportion of National Data Opt-Out (NHS Digital, 2024) was set by the latest LSOA of residence of each individual in the PDS. Where a link to LSOA was not available the Out-Out proportion from the person's registered GP practice was used as a proxy value. The Opt-Out rate for each individual was then weighted based on the percentage difference between the England Opt-Out for their age-sex and the overall England proportion.

$$OptOut_{weighted} = OptOut_{lsoa} \times \left(1 - \frac{\left(OptOut_{england} - OptOut_{agesex}\right)}{OptOut_{england}}\right)$$

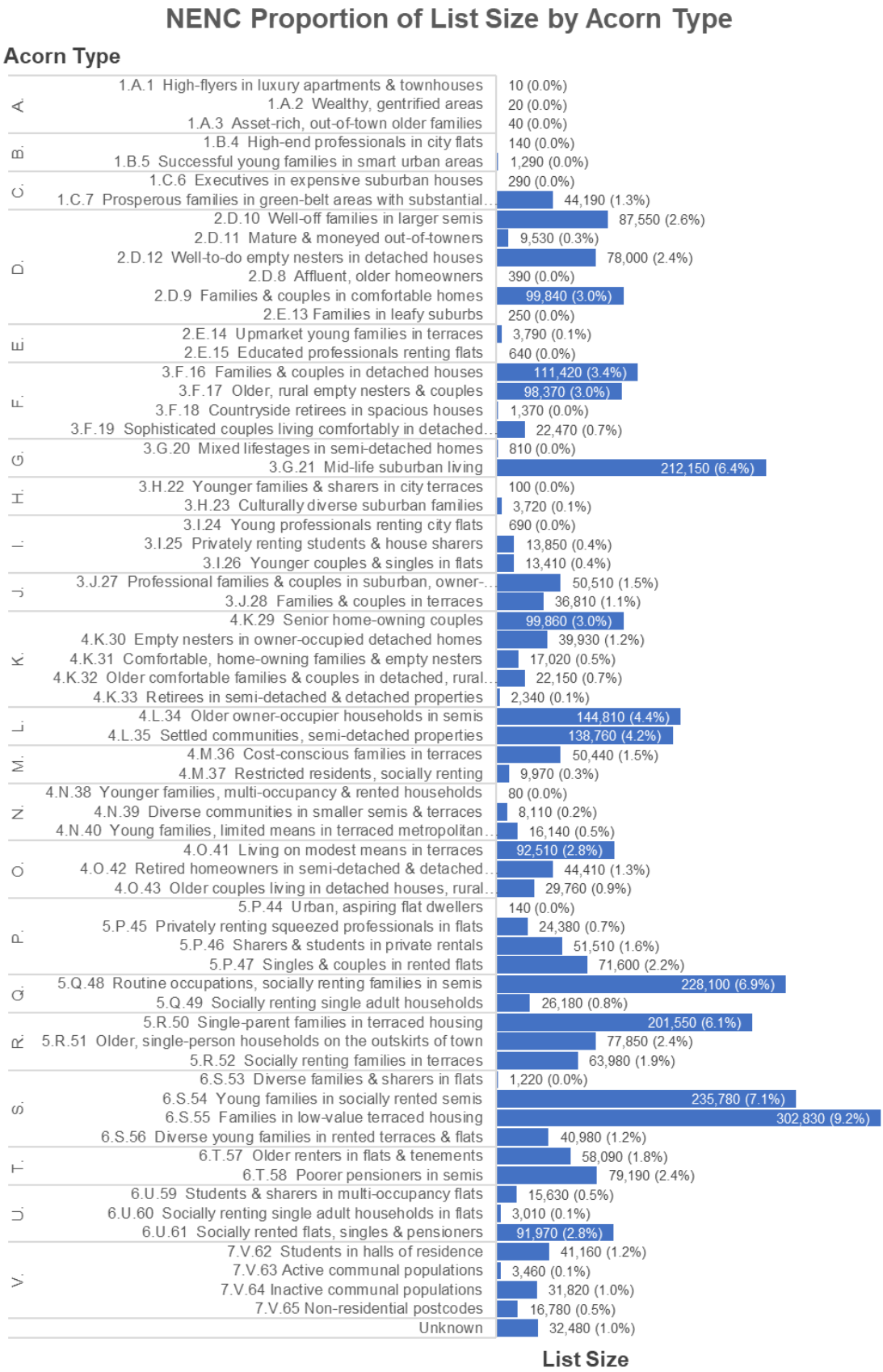
There is an issue with this approach, in that it assumes that the demographics of the population who did not Opt-Out are the same as the population that did Opt-Out.

[2] May require sign-up https://acorn.caci.co.uk/report

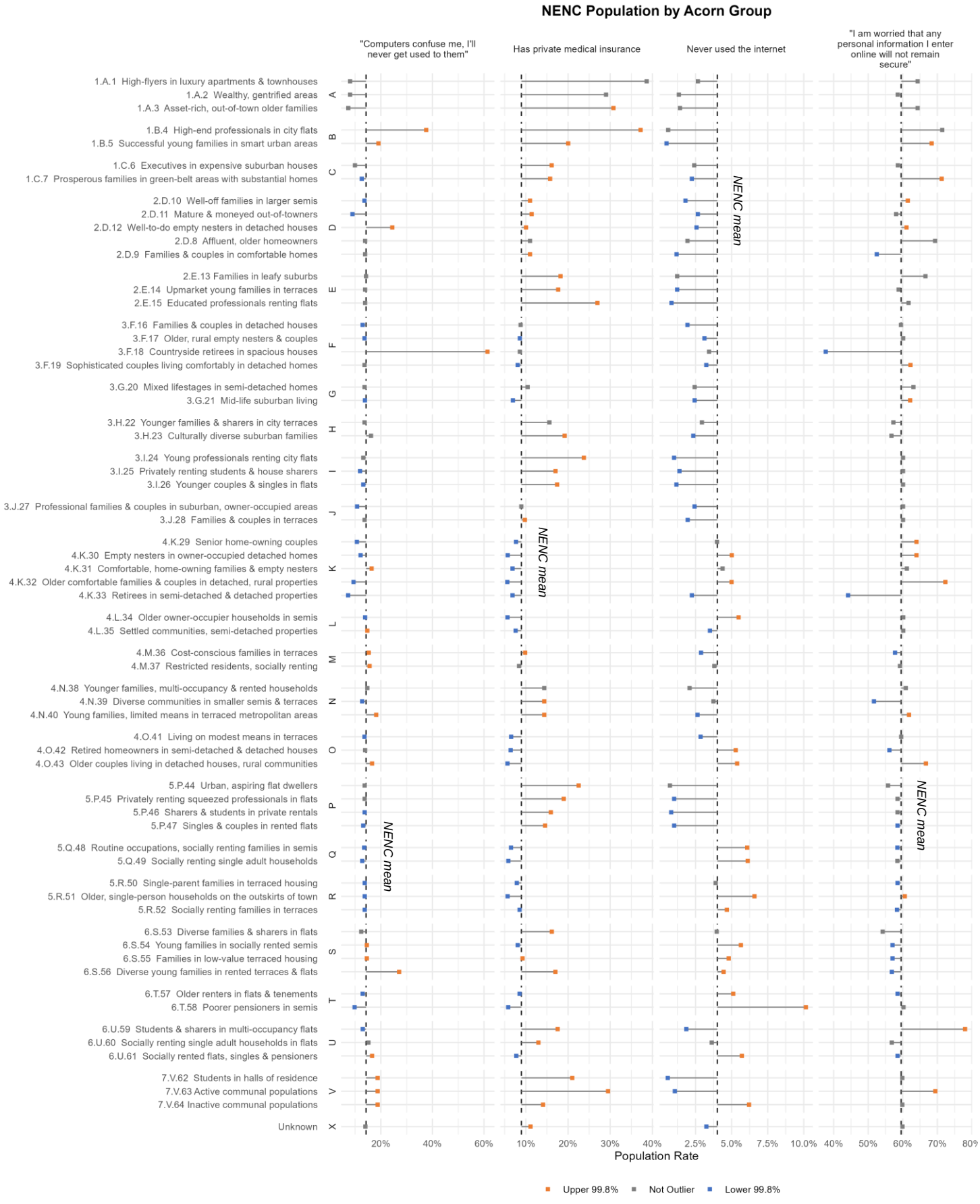
6.3 Results

6.3.1 Acorn Population data

The chart below shows each of the 65 Acorn Types, plus *Unknown*, and the proportion of the *North East and North Cumbria Integrated Care Board* (NENC ICB) that is assigned to that segment. The largest two Types are both from the Group *S. Cash-Strapped Families.* They are *6.S.55 Families in low-value terraced housing* (9.2%, n=302,830) and *6.S.54 Young families in socially rented semis* (7.1%, n=235,780).



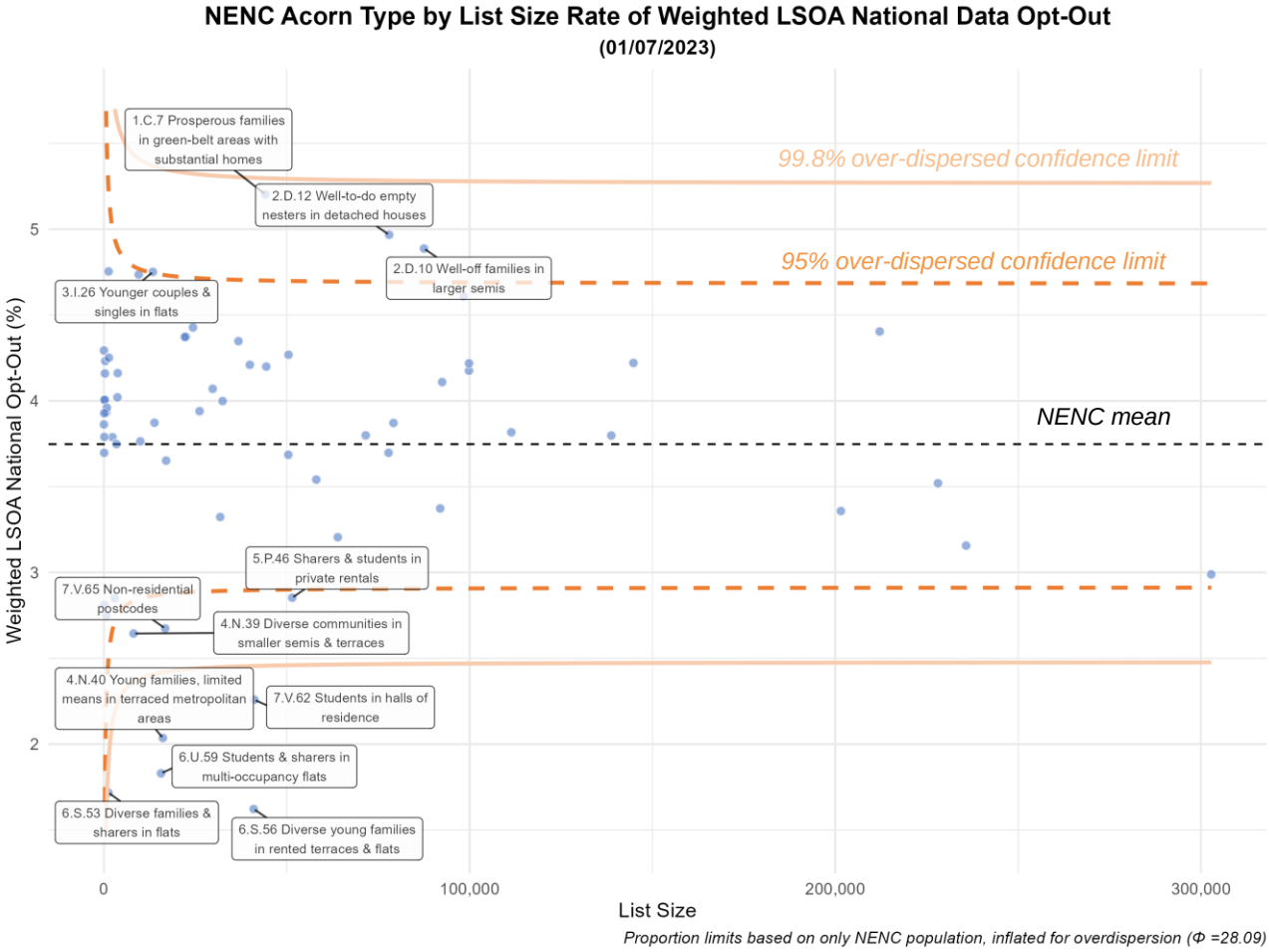
This chart shows the 65 Acorn Types, plus *Unknown*. It shows four variables taken from the Acorn data (CACI Ltd, 2023) and whether there is a significant difference from the NENC mean. The variables were selected to be most relevant to the topic of sharing medical data. The numbers are as presented in the Acorn data, but the NENC mean is weighted to the segment makeup of the NENC population.



The data shows that *3.F.48 Countryside retirees in spacious houses* are much more likely that any other group to state that "*Computers confuse me, I'll never get used to them*", and that the types in group *5.P44-47 Tenant Living* are all more likely to have private medical insurance and less likely to have never used the internet. The group that is most concerned about the lack of security of their online data is *6.U.59 Students & sharers in multi-occupancy flats*.

6.3.2 Acorn Type National Opt-Out

Examination of the Opt-Out rate used the same funnel plot methodology as GP Practices. The results were observed to be exhibiting over-dispersal (ϕ = 28.09), correction for over-dispersion was applied to the 95% and 99.8% Poisson funnel limits.



Patterns in the outlier data suggest that Opt-Out of National NHS data collection is something done by those with the means to do so. For example, those with access to higher education (43%+ have a degree) and higher household income (above national average) are in the high outlier groups (CACI Ltd, 2023). The lower outlier groups tend to be types which are more diverse families or student residences. The table below shows details of the four high outliers, and one low outlier for comparison. The images are extracted from the Acorn Segment Summary dashboard[3] (CACI Ltd, 2023)

[3] May require sign-up https://acorn.caci.co.uk/report/explore/segment-summary/

NENC Acorn Groups Funnel Plot Outliers Highlights of List Size LSOA Weighted National Data Opt-Out Rate

Acorn Code	1.C.7	2.D.12	2.D.10	3.I.26	6.S.56	-
Acorn Type	Prosperous families in green-belt areas with substantial homes	Well-to-do empty nesters in detached houses	Well-off families in larger semis	Younger couples & singles in flats	Diverse young families in rented terraces & flats	UK
Opt-Out %	**5.2%**	**5.0%**	**4.9%**	**4.8%**	**1.6%**	**5.4%**
Opt-Out	2,300	3,875	4,280	635	665	-
List Size	44,185	78,005	87,550	13,410	40,980	-
Opt-Out Outlier	U95%	U95%	U95%	U95%	L99.8%	-
Adult in household has a degree	45%	51%	43%	45%	8%	22%
Just managing to make ends meet	15%	16%	19%	22%	31%	25%
Mean Gross Household Income	£79k	£66k	£68k	£58k	£27k	£48k
Computers confuse me, I'll never get used to them	13%	14%	24%	27%	27%	14%
I am worried that any personal information I enter online will not remain secure	72%	62%	61%	56%	57%	60%
Never used the internet	2.3%	1.8%	2.6%	1.2%	4.5%	3.0%
Has Private Medical Insurance	16%	11%	10%	17%	17%	11%

Population numbers in table rounded to nearest 5

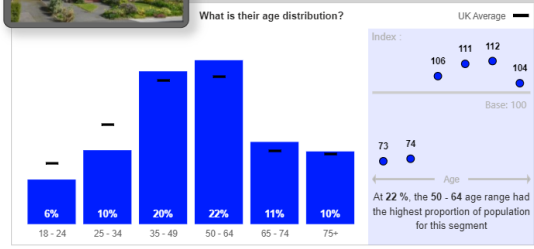
Acorn Summary Dashboard

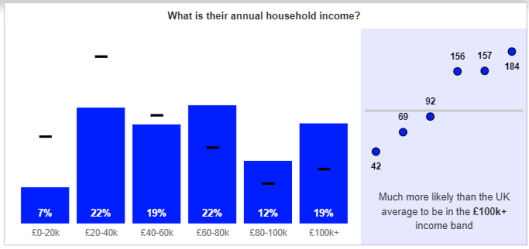
Acorn Summary Dashboard

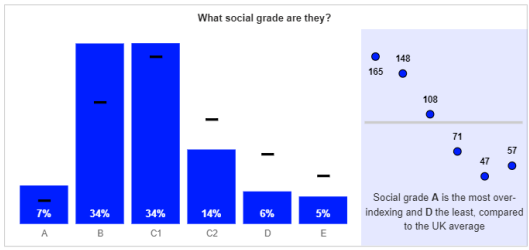
Well off families in larger semis make up **1.2%** of the UK population

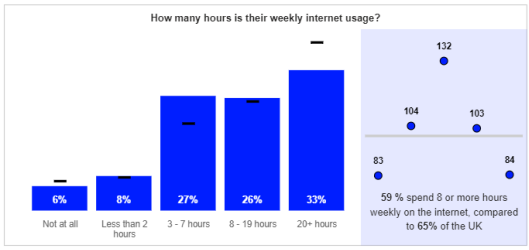
More likely :

£ House value 500k - 750k | Semi-detached house | Children at home: 1 | Number of cars: 2 | Director / managerial





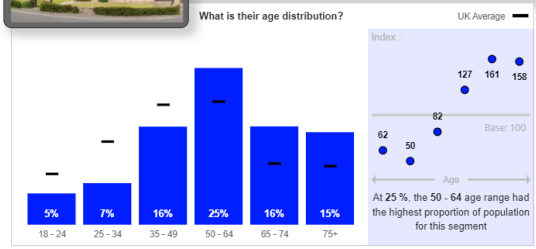


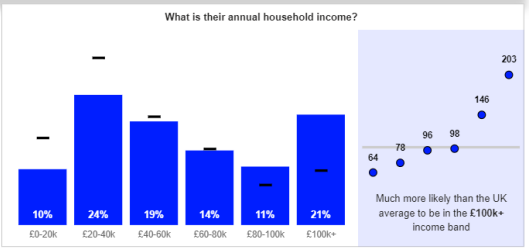


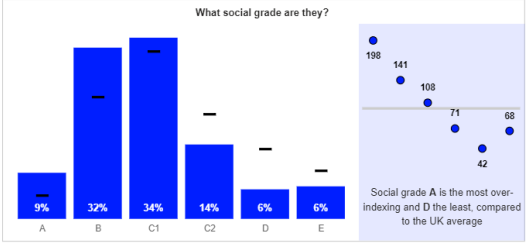
Well-to-do empty nesters in detached houses make up **2.1%** of the UK population

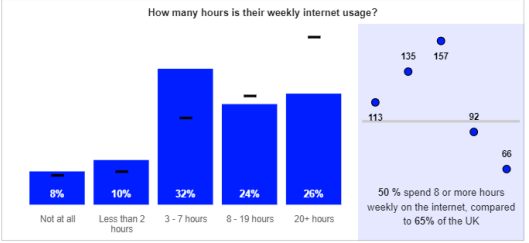
More likely :

£ House value 750k - 1m | Detached house | Children at home: 0 | Number of cars: 3+ | Director / managerial





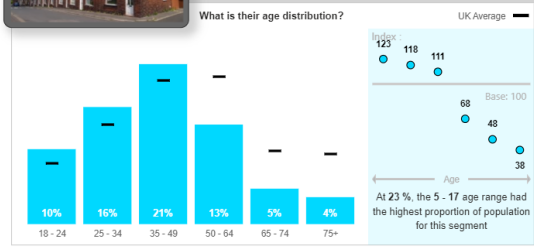


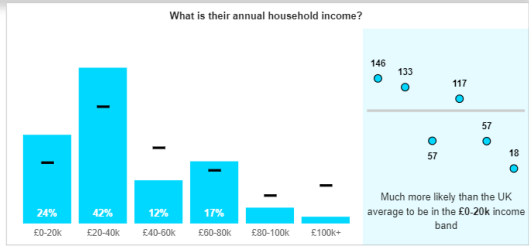


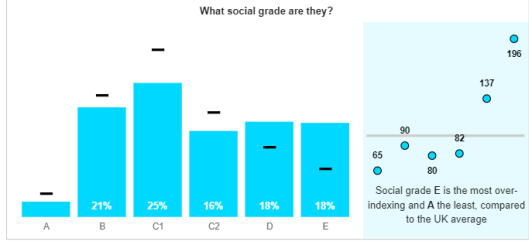
Diverse young families in rented terraces and flats make up **0.8%** of the UK population

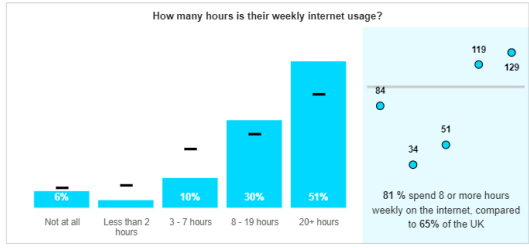
More likely :

£ House value up to 100k | Terraced house | Children at home: 3+ | Number of cars: 0 | Unemployed









7 Healthcare Data Surveys

7.1 Background

In June 2015, *The Wellcome Trust* commissioned *Ipsos MORI* to conduct a study investigating the public attitudes towards the commercial access to healthcare related data. For this study, *Ipsos MORI* conducted survey across UK interviewing 2,017 adults (76 responses from North East) aged 16 and over (Ipsos MORI, 2016).

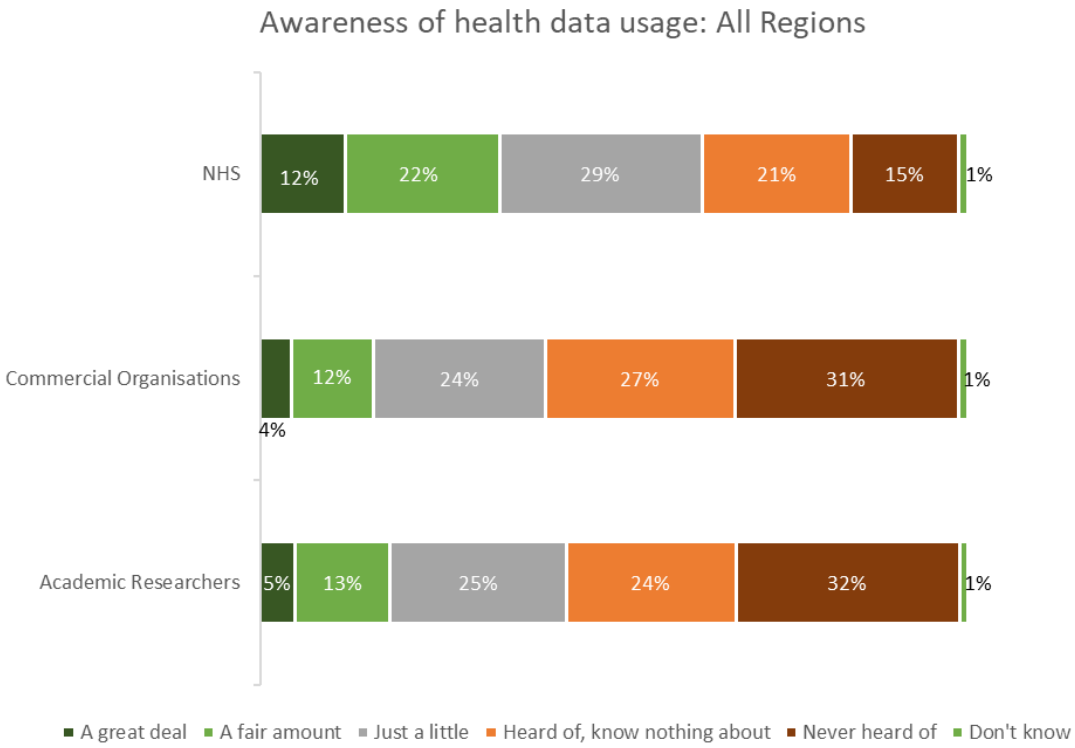
Similar healthcare data survey in England was conducted by *BCG* in 2023 to understand the public perception around access and use of healthcare data (BCG, 2023). The article published in *Lancet Health Digital* surveyed adults (aged 18 and over) in United States (1,114 respondents) and United Kingdom (2,080 respondents) to examine the public views about health data sharing (Dael, et al., 2020).

Sharing data has become easier than ever due to technological advancements. As per the *Office for National Statistics* (ONS) report, focus groups with people aged 18 to 24 years showed that this age group tend not to question or spend time worrying about data sharing. This is because they have been sharing data their whole lives. They cannot see what difference it would make to share just that little bit more, as so much is already out there (Office for National Statistics, 2023).

This section covers the outcomes of these surveys to better understand the public perception of healthcare data sharing.

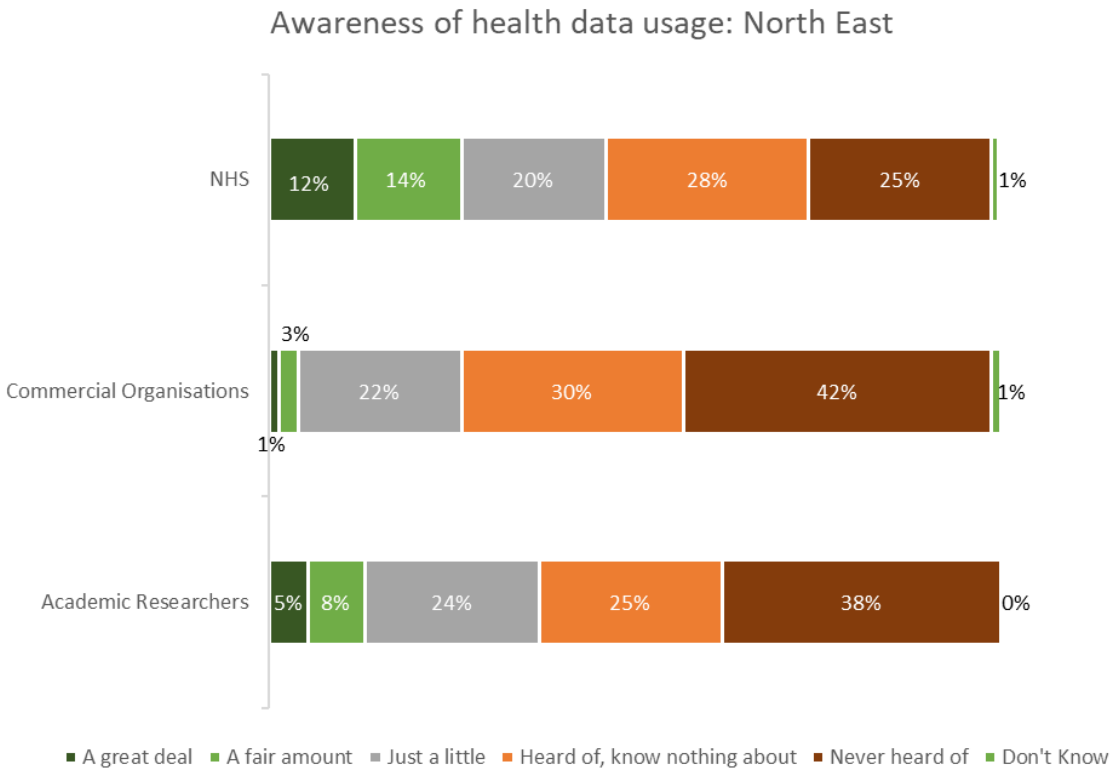
7.2 Awareness of healthcare data usage

The *Ipsos MORI* survey tried to assess the awareness of the healthcare data usage by three different organisation types: NHS, commercial organisations, and academic researchers.



Around 84% have at least heard of data usage in the *NHS* while the proportion of people saying that they have at least heard of data usage by commercial organisation and academic researchers is lower (67% each).

Among the survey respondents in the North East region, 74% have at least heard of data usage by the NHS, 56% heard of data use by commercial organisations and 62% have heard of data usage by academic researchers.



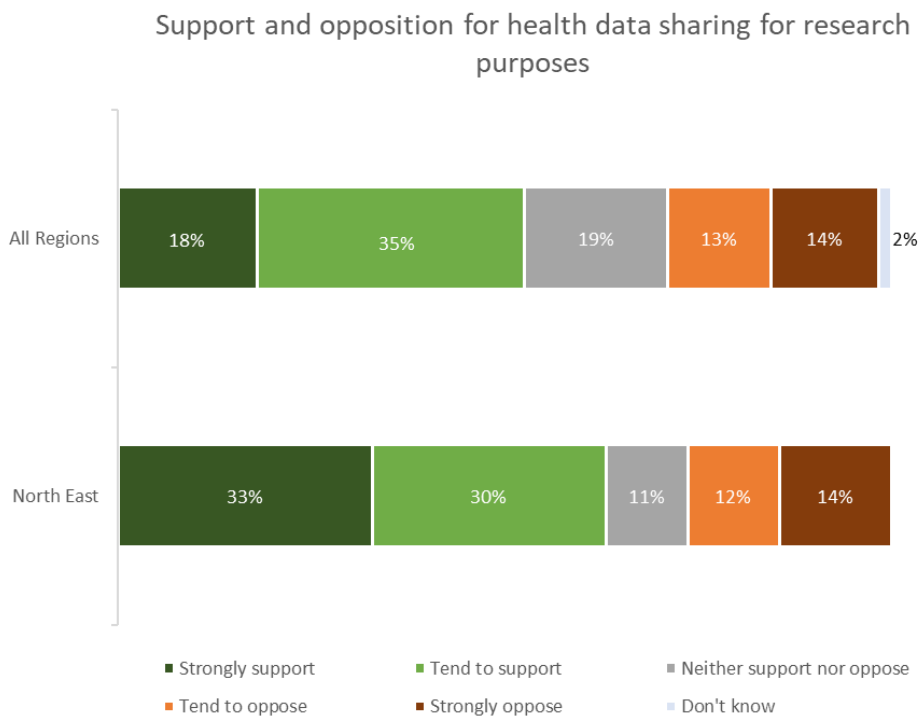
Even though most of the respondents have heard of data usage by different organisations, the detailed understanding of data usage is low.

This study observed that the heath data use awareness among the people with educational attainment and with internet access is higher.

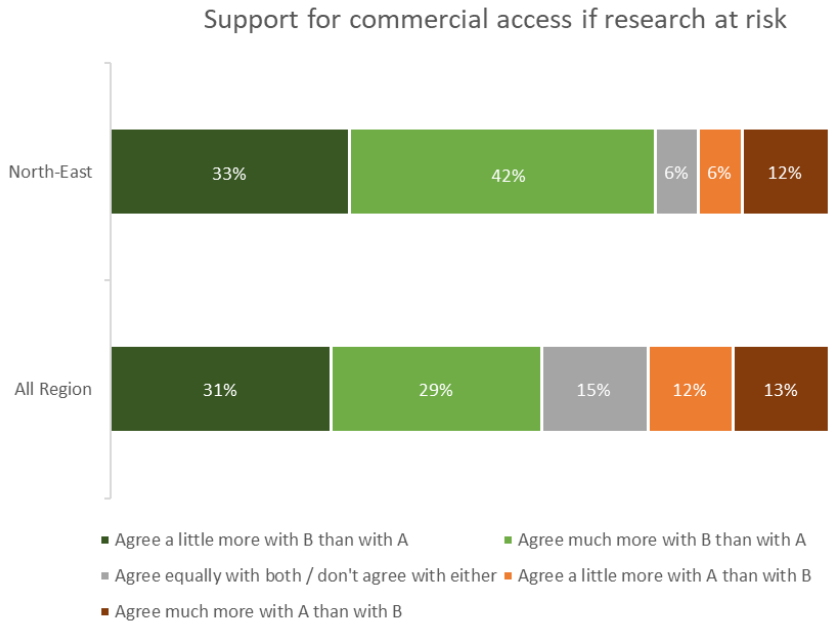
7.3 Data access for health research

7.3.1 Data sharing with commercial organisation for research

In *Ipsos MORI* survey, asked the respondents to what extend they support data access by commercial organisations for health research. Over half (53% nationally and 63% North East) support access by commercial organisations for health research purposes. More than quarter of the respondents (27% nationally and 26% in North East) oppose the access by the commercial organisations. While 19% national respondents and 11% North East respondents do not support or oppose commercial access to health data.



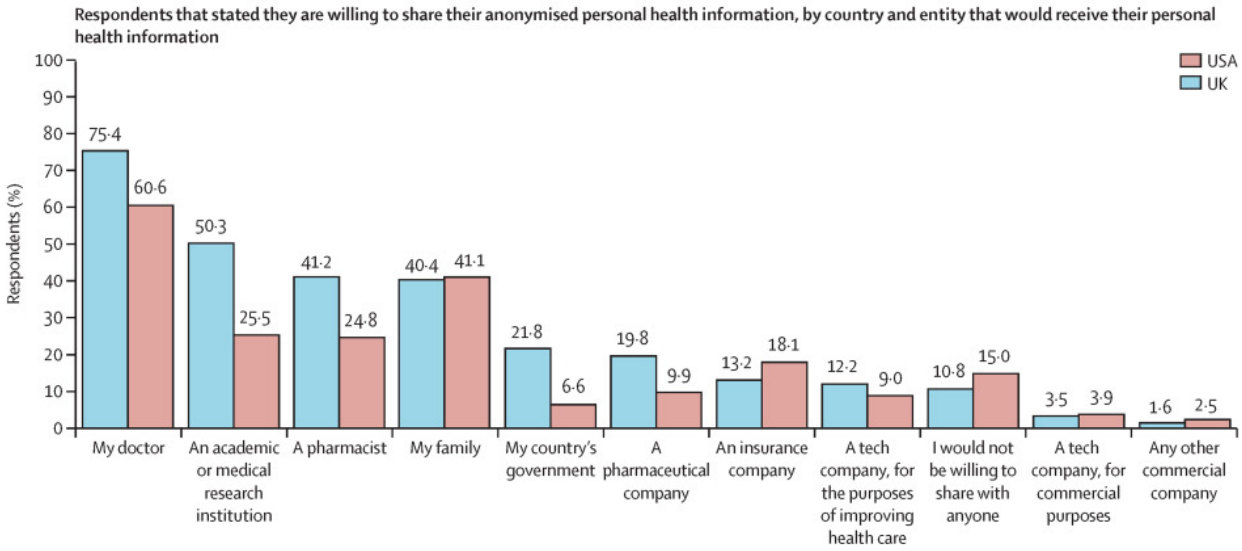
In the North East 18% of the respondents (25% national) don't want commercial organisations to access health data even if that means research does not take place. While 75% of North East (60% national) respondents support research by commercial organisations if there is possibility of developing new treatments for diseases. (Ipsos MORI, 2016).



A. I would not want commercial organisations to have access to anonymised health data, even if this means the research does not take place.

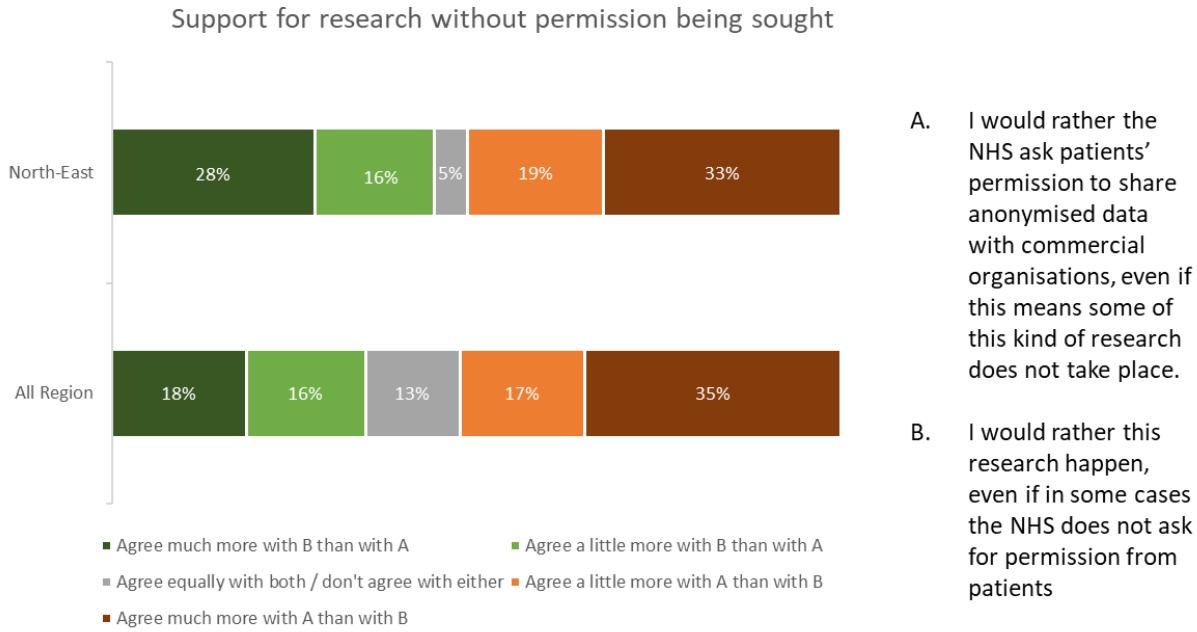
B. The research should be conducted by commercial organisations if there is a possibility of new treatments for diseases being developed.

Survey published in Lancet Health Digital journal observed that more than 75% UK respondents were willing to share their electronic health records (EHR) with their doctors while more than 50% were fine with academic or medical research institute using their EHR (Dael, et al., 2020):



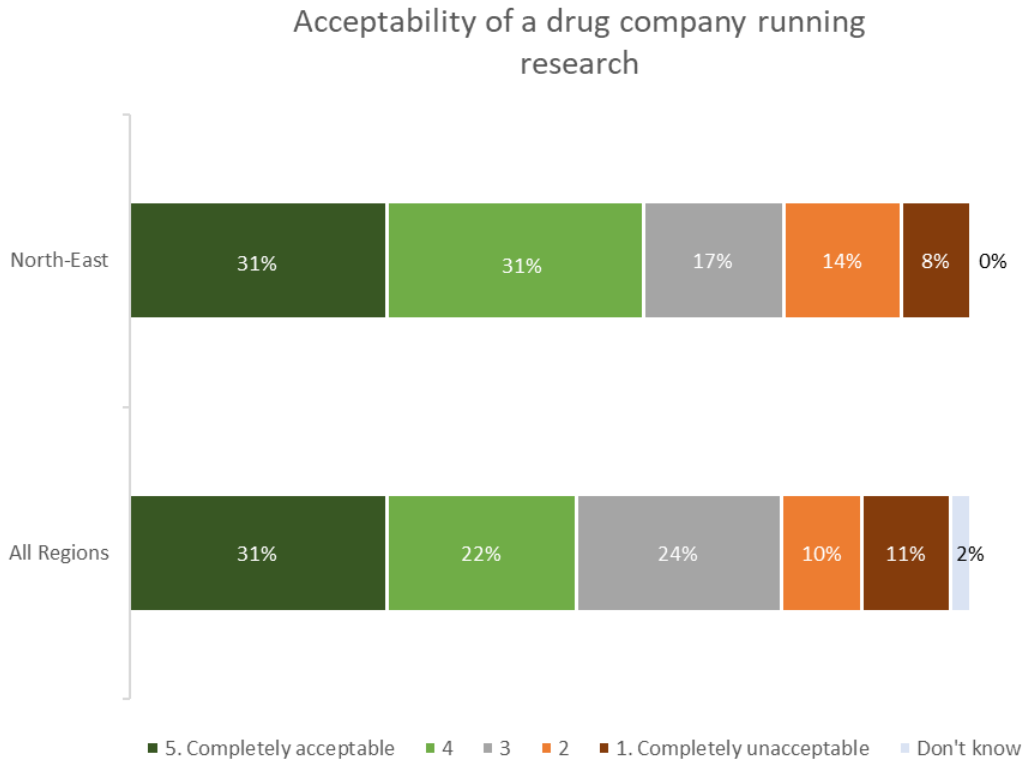
7.3.2 Patients' Permission for data use

Even though many respondents support data sharing for research, most of them (52% in both North East and nationally) want NHS to seek patient's permission to share the data with commercial organisation. (Ipsos MORI, 2016)

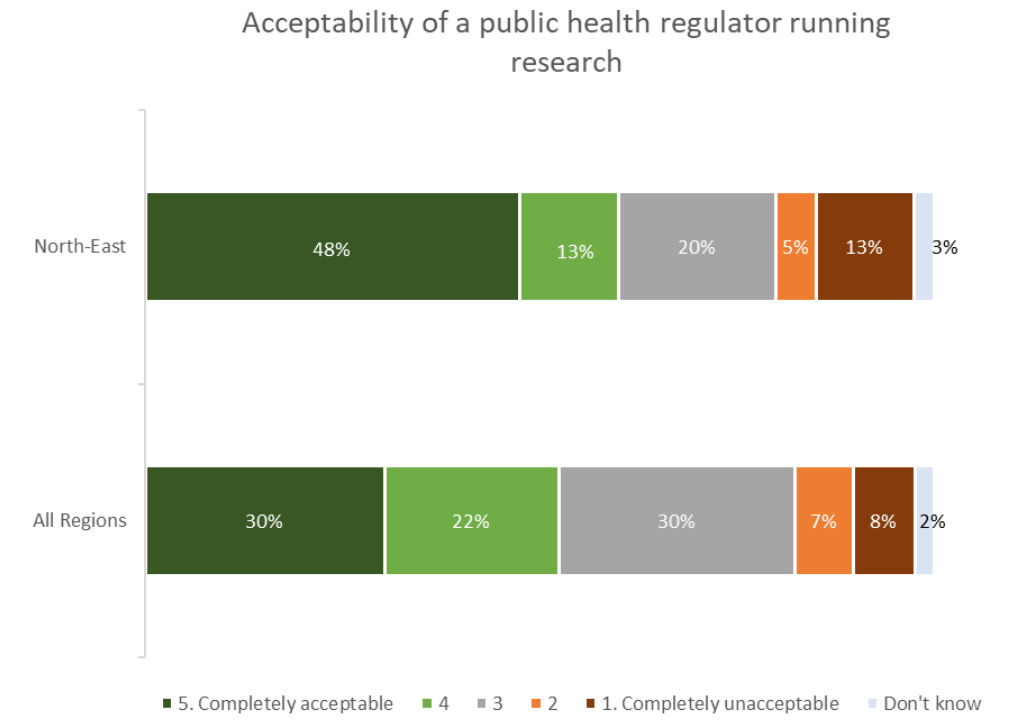


7.3.3 Drug companies vs. public health regulator

Based on the *Ipsos MORI* survey, a pharmaceutical ('drug') company conducting research is overall equally acceptable to a public health regulator accessing the data to conduct research. However, in the case data being used by public health regulators the levels of complete acceptability are higher, and complete unacceptability are lower.

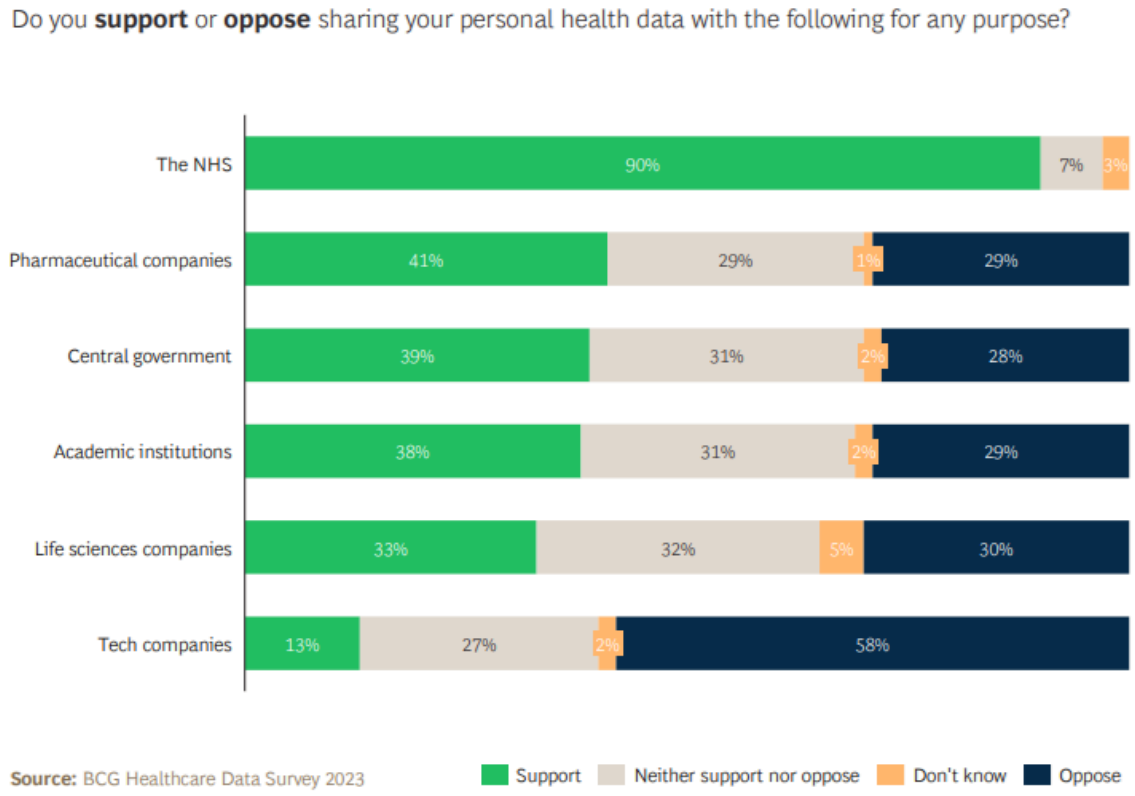


In the North East 61% respondents say drug companies using data for research is acceptable, with the same proportion (61%) of respondents saying that public health regulators using data for research is acceptable. Responses from all regions the percentage differs slightly with 51% accepting pharmaceutical research and 52% saying public health regulator use is acceptable (Ipsos MORI, 2016).



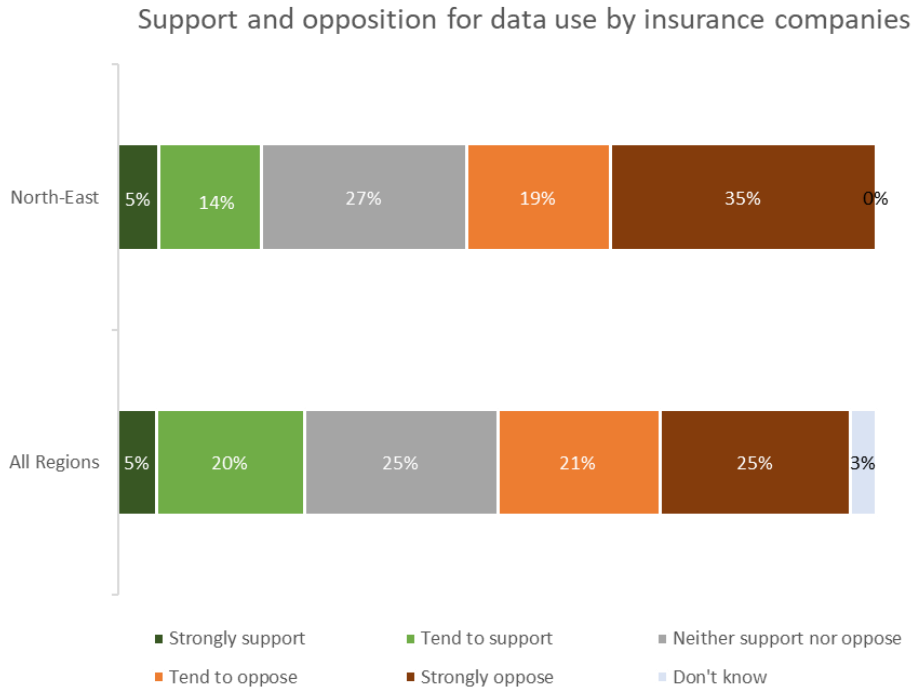
7.3.4 *Other organisation types*

According to the *BCG* survey, 90% respondent support the data sharing within the *NHS* for any purpose. While the support for the other organisations is lower, there is still more support than opposition except in the case of Tech Companies: (BCG, 2023)



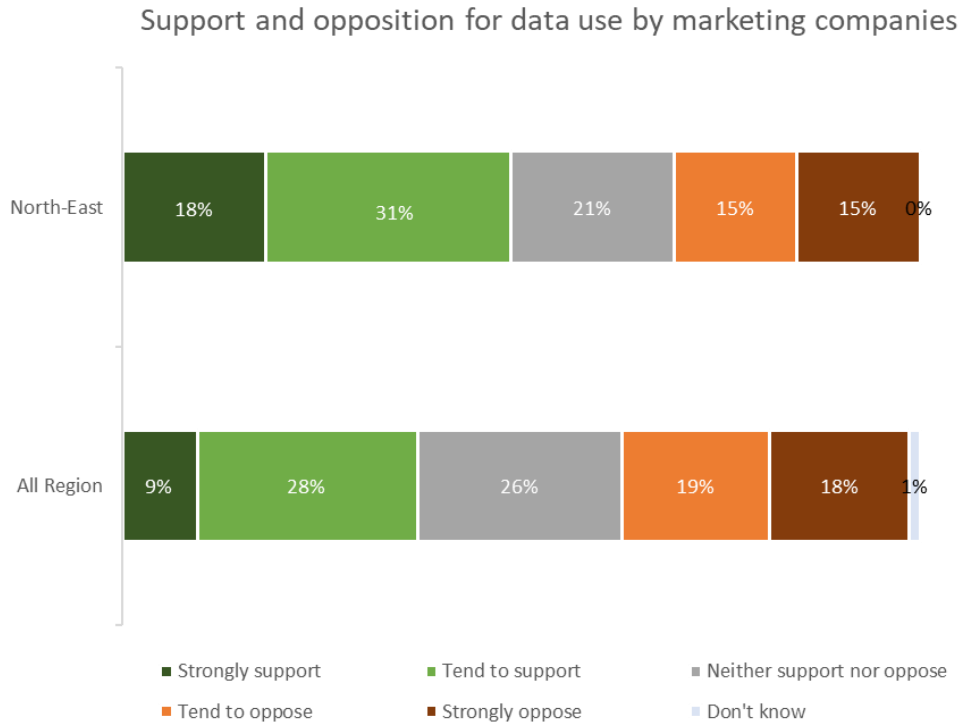
7.3.5 *Insurance and marketing companies*

The Ipsos MORI survey randomly allocated participants to one of two questions about support for health data being used for different commercial purposes. Half of the sample was asked about their support for insurance companies using health data from the NHS to develop their insurance pricing. The other half of the sample was asked to their opinion on using health data for marketing purposes.



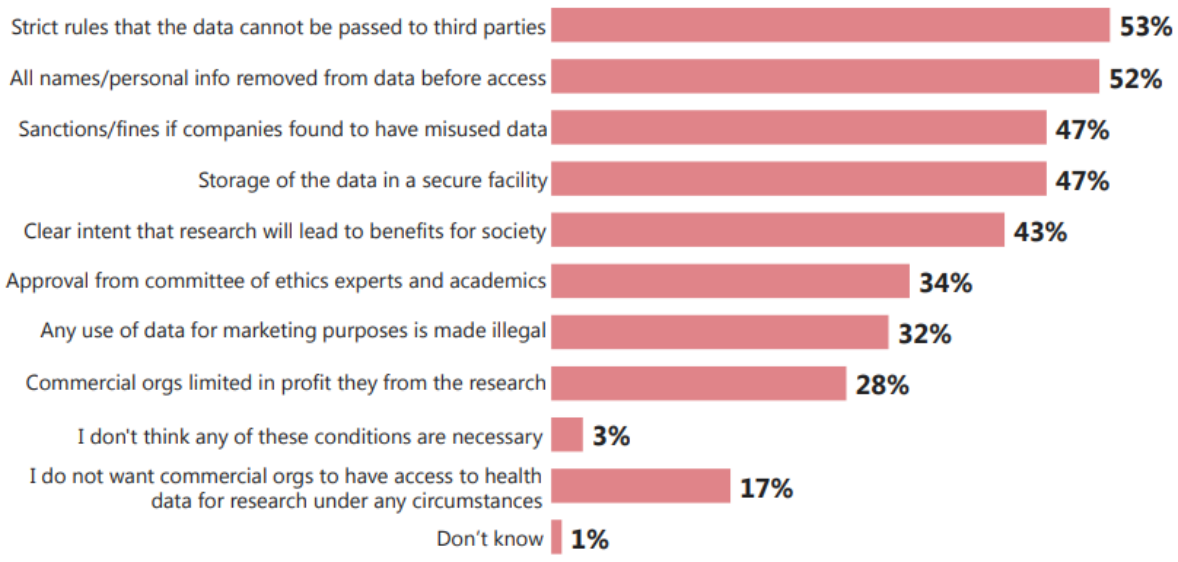
Most of the respondents in North East (54%) and nationally (46%) oppose data sharing with insurance companies to develop their pricing. Though one-in-five (19%) North East respondents and a quarter (25%) of respondents from all regions support data sharing with insurers.

The support for data use for marketing purposes is higher than for insurance. Around 49% of North East respondents and 37% of national respondents supported data use by marketing companies. (Ipsos MORI, 2016).



7.3.6 Conditions for sharing with commercial organisations.

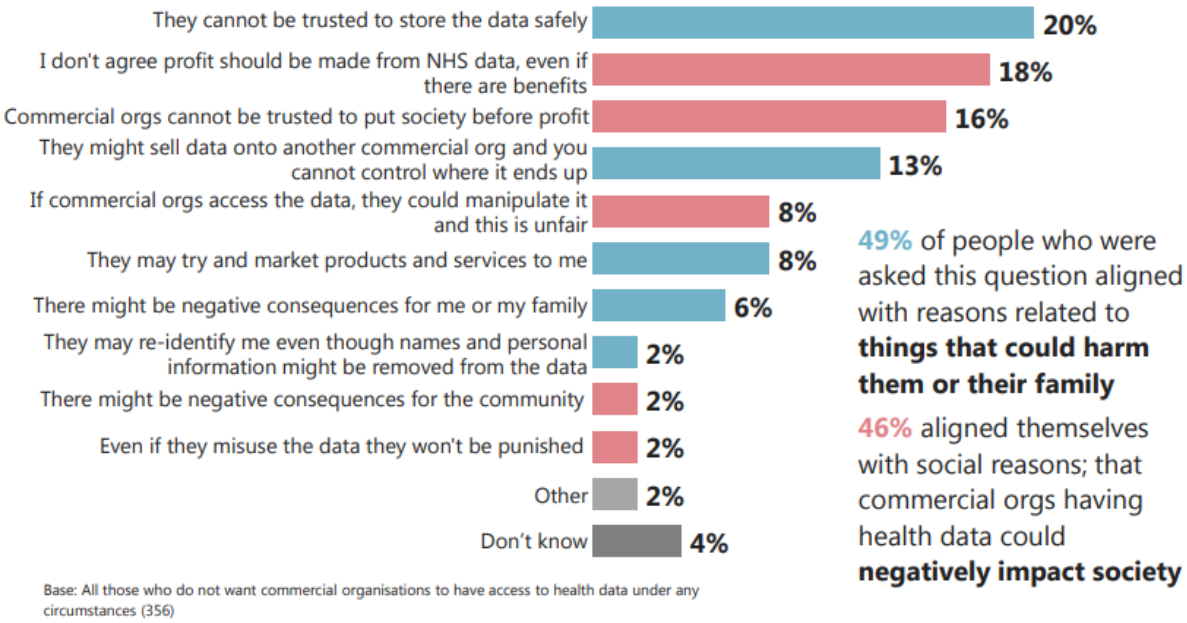
More than half of the respondents wants data to be anonymised (52%) and strict rules in place to prevent data being passed to third parties (53%). Just under half (47%) want data to be store in secure facilities and sanctions or fines if companies misuse data. There are 17% respondents who don't want commercial organisations to have access to health data under any circumstances (Ipsos MORI, 2016).



7.3.7 Reasons for opposing commercial organisation access to health data

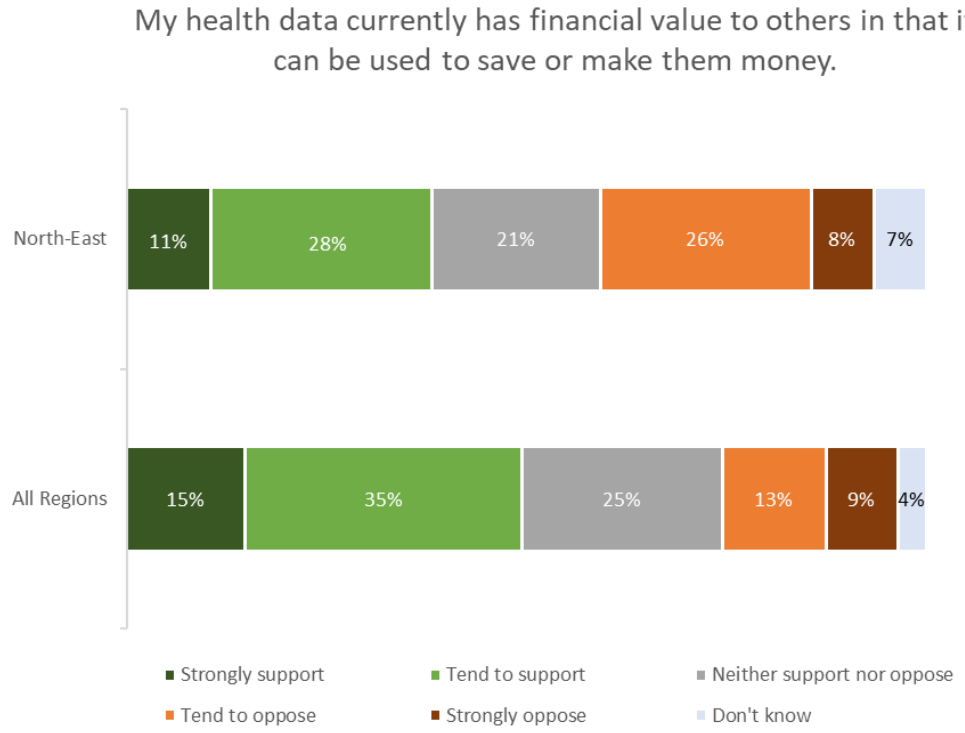
About half of people (49%) who opposed commercial organisation access to health data selected a reason classed as potential harm them or their family. Most of these respondents are concerned about the safe data storage.

The other main reason (46%) people give for opposing is that they think giving data access to commercial organisations could negatively impact society. Most of these respondents think that NHS data should not be used to make profits. There is also concern about whether commercial organisations can be trusted to put society before profits.



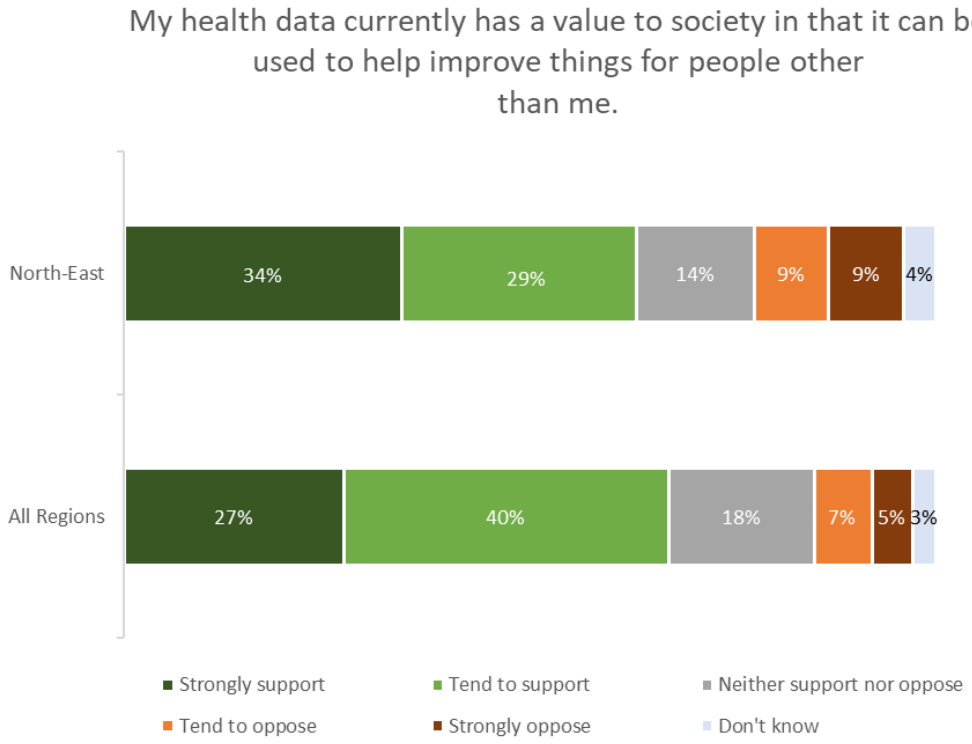
7.4 Perception of value in health data

Respondents were asked about their views regarding financial and societal value of health data.

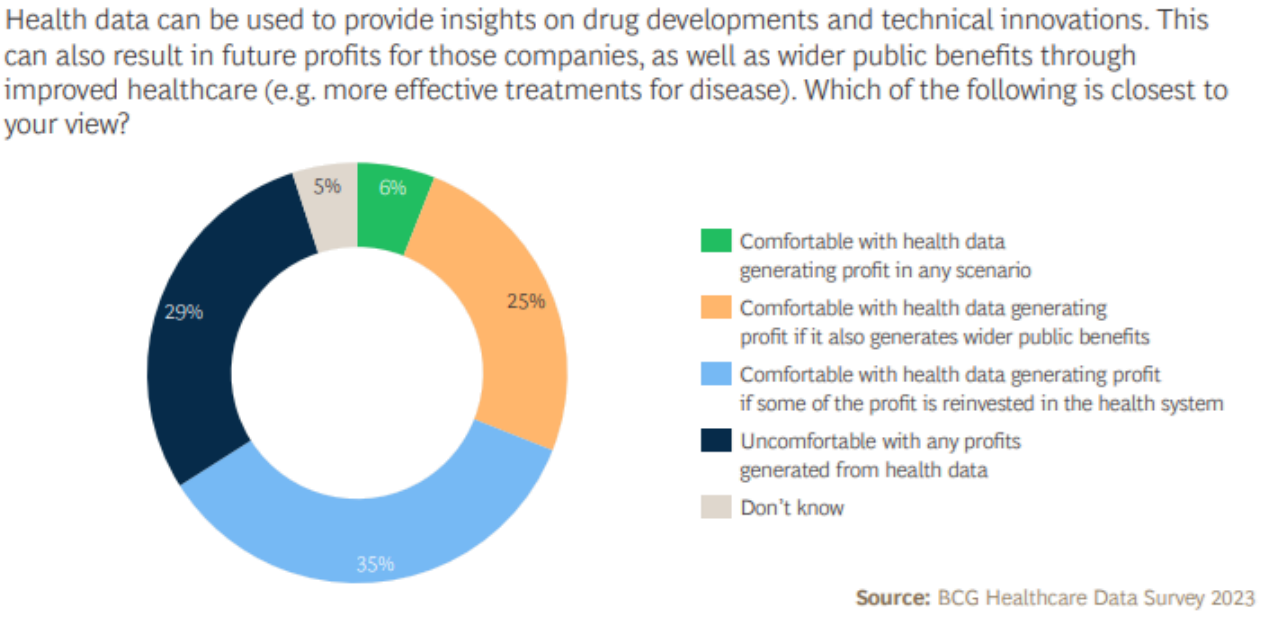


Half of the national respondents (50%) agree that their health data has a financial value and can be used to save or make them money. Of the North East residents 49% agree that their health data has financial value while 34% disagree that health data has financial value.

Around 63% North East and 67% national respondents agree that their data has a value to society, and it can be used to help improve things for people other than themselves. (Ipsos MORI, 2016).



According to BCG health data survey, 35% survey responders are comfortable with health data generating profit if some of the profit is reinvested back into health services. Some (29%) are uncomfortable with any profits generated from health data. A quarter (25%) are comfortable with health data generated profit if it also generates wider public benefits and 6% are comfortable with health data generating profit in any scenario. (BCG, 2023).



8 Conclusions

People living in the North East and North Cumbria (NENC) Integrated Care Board (ICB) have a lower (3.94%) than England (5.35%) proportion of people Opting-Out for National NHS data collection (NHS Digital, 2023). The Opt-Out proportion is a good indication of how strongly certain demographic groups feel about data sharing with the NHS. Nationally the Opt-Out rate is higher among women, the most affluent and those aged 30 to 59.

The Opt-Out rate varies with GP Practice, with certain practices having much higher proportions of their list removing themselves from data collection. This may in part be the demographics of the area the practice covered, but GPs are very powerful as data controllers of their records (Ford, et al., 2020).

Results of analysis of Acorn (CACI Ltd, 2023) geodemographic segmentation in terms of Opt-Out rates show that those who are likely to be more educated, more affluent, and live in more rural areas are more likely to object to their data being used. Those people who are living in diverse household who are struggling to make ends meet, or people who are students are less likely to Opt-Out. This suggests that Opting-Out of national data reporting is something that is done, or able to be done, by those with a higher degree of privilege and stability in their lives.

Surveys (Ipsos MORI, 2016) (BCG, 2023) have been published that look at how the public perceives data use by the NHS. One (Ipsos MORI, 2016) suggests that among the survey respondents in the North East England fewer have heard of data usage by the NHS or other organisations than in the rest of the country. People in North East England in general are more positive about sharing data across different metrics, including with pharmaceutical companies.

People in North East England were less likely to see financial value in their health data, and more likely to see use in their health data being used to help others. The differences between England as a whole and the North East may be to do with underlying demographic differences rather than an overall difference in culture.

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