DATA PEOPLE ACTION ecda

Essex Centre for Data Analytics

Exploring citizen attitudes towards data sharing and analytics within the public sector

Essex County Council

} Contents

A note of thanks

} Foreword

Too often, need is only identified when a crisis occurs: a vulnerable child is excluded from school for disruptive behaviour; a young adult reaches breaking point before receiving mental health support; a family reaches financial hardship following unemployment; or, police are called out to a domestic abuse incident within a home.

The Covid-19 crisis has exacerbated the vulnerabilities and harm that many people are experiencing. Demand for critical services is escalating and the disadvantage, poverty and inequalities gap has widened even further.

The data we hold about how people access our services is knowledge at our fingertips. And the ever-increasing volume of data available to us is giving us more knowledge than we have ever had. As such, data has become one of our most important assets in protecting people and preventing them from harm. Yet data remains the biggest untapped potential in the public sector.

Working across Essex, councils, police, health, voluntary services and education providers deliver services to 1.8 million people living, learning and working in Essex, but alone, each organisation has only one piece of the jigsaw.

} Joining our data together has significant potential to deepen our shared understanding on some of our most challenging issues, so that we can intervene early and prevent people from reaching crisis.

The Essex Centre for Data Analytics (ecda) recognises that in entrusting their data for the provision of services, the people of Essex have a fundamental stake in the development and application of data science techniques that enable us to design services to meet their needs. It is, therefore, imperative that Essex citizens have a voice in deciding how and why we should use data.

Open and honest conversations with our citizens enable us to explore their views on using data for social good and create a reflective, practical and critical understanding to shape our policies and practices and begin to build trust.

This report provides valuable new understanding of people's beliefs and attitudes towards joining and analysing data across public sector organisations. It presents a fresh perspective on engaging everyone in a meaningful conversation about data and analytics. Most significantly it highlights the significant opportunity to create roles for citizens to help shape the future data ecosystem for public services.

Essex Centre for Data Analytics

Executive Summary

Overview

ecda worked collaboratively with Revealing Reality and Essex County Council's Research and Citizen Insight team to understand citizen attitudes in Essex towards the joining and analysis of data between public sector organisations to inform preventative and early interventions. This research involved in-depth interviews and focus group sessions with a range of individuals experiencing a variety of vulnerabilities, conditions, and life circumstances.

Themes and tensions

- **Personal experience of receiving support helps people see the benefits of data sharing.**

  Those who had experienced vulnerability were often more open-minded about benefits of data sharing.

- **Fear of 'exposure' exacerbates distrust in joining data.**

  For those who had previous contact with public services and viewed these interactions as negative, and deemed themselves as having "something to hide", the fear of future discrimination outweighed the perceived benefits of joining data.

- **The term 'data sharing' can be toxic.**

  Most people had an initially negative view about the concept of 'data sharing' – with the term associated with abuse of power, lack of privacy and commercialising individuals. Due to such preconceptions, there is a risk that they take more resistant positions.

- **Big data scandals have left people wary about whether they can trust anyone with their data.**

  People worried about the practical management of their data, and that this would fall into the 'wrong hands'.

- **People feared not having a choice of how their data is used, and what the interventions might be.**

  Participants recognised that we share millions of bits of our own data every day with commercial companies, whether that is searching for a restaurant on Google or logging in to social media, and that public services collect and analyse data to a much lesser extent than the private sector. However, participants said they do not feel that they have the same level of knowledge and control over how public services use the information held about them, nor where their data is ultimately held.

- **Labelling an area 'bad' can have real and enduring consequences.**

  People could clearly understand the wide-ranging implications of publishing evidence-based insight and were aware that negative labelling of a place could become a 'self-fulfilling prophecy'.

- **People feared being profiled negatively by their data.**

  Even those who understood that individual identification was not possible worried that they would be stereotyped negatively if their data is fed into an insight profile considered 'at risk'.

- **Third party anonymisation of data is a tricky concept to understand.**

  It was particularly hard for participants to understand the concept of pseudonymising data and to disentangle 'personally identifiable' data from the concept of public sector organisations joining and analysing non-identifiable datasets.

- **It is difficult to engage citizens in data science beyond the most civically minded.**

  It is challenging to start a conversation with citizens about public services if they are less interested in local issues and the workings of their local institutions and, particularly, if they feel their ability to influence local decisions is limited.

- **People say they want to be informed 'on an ongoing basis', but in reality, they do not.**

  There was a tension between participants wanting to 'know more' about how their data is being used and not wanting to proactively seek out information available online.

Cathy is a married mum of two young children, who has previously accessed services for depression and recreational drug use. Lockdown has exacerbated her worries around data sharing, explaining that

"her family, friends and work don't know about her past"

and she doesn't trust public services with her personal information.
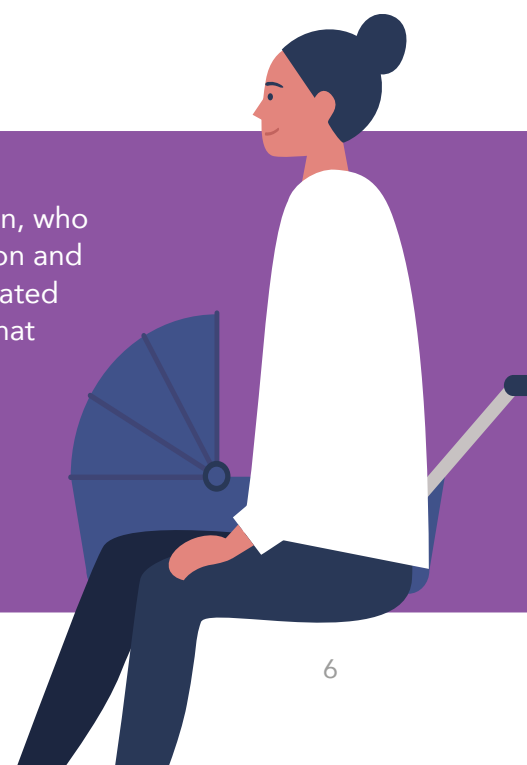
Reconciling the risks of data sharing

} Fear on the part of the public sector and citizens is standing in the way of collaboration.

While many concerns are valid, fear is often based on misconceptions that have stemmed from a lack of clarity in discussing data in general.

Citizens often react negatively initially to the idea of sharing data. They presume that local government will share personally identifiable data and that there will be no limits on who in the organisation will see any data.

People are unclear on the benefits of joining data and the safeguards that are in place. Many citizens do not know where the information sharing stops.

The public sector is not confident in its ability to combat citizen reluctance to sharing data. While some sectors have made progress on the data sharing process, many are naturally concerned that people do not want data sharing to happen.

Civic support for data collaboration

} The research concluded that people are relatively open to the idea of data-sharing when it is explained to them but have some concerns that need addressing.

Some of their concerns can be more easily tackled through better communication and collaboration, as set out in the practical recommendations in this report. While others require longer term work across the Essex system and support nationally through the involvement of citizens in the development of data technologies and data ecosystems within government.

The citizens that took part in this research clearly articulated the minimum standards and conditions that they expected to be in place to guide data joining and analytics between public sector organisations.

This meant that people were generally willing to look for solutions that enabled data joining and analytics to be carried out in a safe and secure way, protecting their personal rights.

What's the opportunity?

From enabling our rapid response to Covid-19 to informing how we support our communities to recover, ecda is in no doubt that joining data together to identify trends and behaviours, and extract knowledge and insights, can lead to better-informed business decisions.

However, there is an absence of consistent public involvement with emerging data technologies in policymaking, and insight from data analysis alone is not enough to inform our decision making.

Throughout our 2021-22 work programme, ecda is committed to:

- Exploring the role of citizens to play a part in our work

- Identifying the many ways that the people of Essex would like to engage with ecda

- Collaborating with citizens to shape opportunities for them to contribute and influence ecda's work.

Citizens' unique perspective on the purposes, design and application of system data analytics will contribute significant social and technological robustness to our practices. From project selection to gaining insight from their experiences, from ethical governance to co-commissioning services and evaluating impact, only by truly working together with our citizens do we have an opportunity to:

- Generate a deeper understanding on the most challenging issues to improve people's lives, organisation productivity and practice

- Target resources where they are needed most and support prioritisation of activity

- Forecast future demand, trends and emerging issues, including introducing early warning systems

- Model different scenarios to optimise decisions

- Embed evidence-led decision-making across a range of key challenges for public services, including service integration

- Grow capability and capacity within the public sector to support future opportunities

- Foster a data culture and ecosystem that we want for the public sector.

} Introduction

ecda is a partnership between Essex County Council, Essex Police and the University of Essex, bringing together people and data, to help generate valuable new insight that informs future planning.

The application of data science technology within the public sector is still relatively new and there is limited research on public engagement around data sharing. The application of 'data technologies' can be defined as everything from tracking public health trends using social media data to building early warning tools to prepare services for future demand. It was specified in our research as the joining of data held by public sector organisations within Essex to apply predictive analytics and generate insight that can be used to inform decisions about how we deliver services to those most in need.

This research was commissioned by ecda to discover and explore current attitudes in Essex towards the joining and analysis of data between public sector organisations to inform preventative and early interventions. Our research has included in-depth interviews and focus group sessions with Essex residents.

ecda's Citizen Research and Engagement Programme builds on:

- Research from the University of Bath Department of Psychology and Institute for Policy Research (included in appendix 1, page 31)

- Revealing Reality and the UK Regulator's Network research - Reimagining Vulnerability Data

- Results of Essex County Council's 2020 residents' survey (included in appendix 2, page 35).

Graham is a consultant and described himself as a

"data analyst at heart".

He felt that a joined up approach to tackling problems in the community was key and he was surprised that this wasn't already happening.

Research objectives

The key aim of this research was to identify levers of change around data joining and analysis for citizens in Essex, to help ecda refine its policy, practices and inform future public engagement.

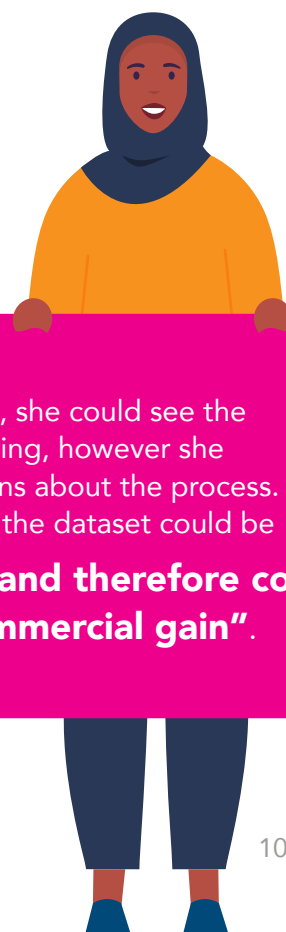There were also several more specific research objectives, to:

- Understand current attitudes of citizens around data joining between public service providers in Essex

- Explore any tensions or negative opinions that residents may have about this and identify potential levers of change that can be taken forward

- Explore to what extent citizens trust public service providers, and where they may need greater reassurance and changes in practice, including data ethics and governance

- Inform ecda's future public engagement.

Robbie had been homeless for over 15 years and also accessed drug and alcohol services. He thought that vulnerable people might be reluctant to share too much information as there was a fear that

"the little they did have, might be taken away from them,"

especially those who had previous criminal convictions.

Melissa is a scientist, she could see the benefits of data sharing, however she had some reservations about the process. She recognised that the dataset could be

"very valuable and therefore could be used for commercial gain".

10

} Methodology

The topic of data sharing can be a tricky and complex subject, with varying levels of public understanding and perception. To conduct research that captured meaningful insight, it was necessary to breakdown the different elements of data joining and analytics, and give people an opportunity to discuss and consider the topic at various stages.

We adopted a deliberative approach, conducting facilitated online focus groups and in-depth interviews. This approach allowed us to provide information about ecda, data analytics and data joining in general, talking through different phases to help build on the participants' existing knowledge and understanding. As the sessions progressed, participants were presented with new information, giving them opportunities to reflect, discuss and provide an informed view.

} Our research engaged a range of people from different life circumstances.

We engaged with a range of individuals. The 40 citizens that participated were geographically spread across the county, and experienced a variety of vulnerabilities, conditions and life circumstances. Our approach to the research was intended to be continuously evolving, seeking a community-created view. It was not intended to be exhaustive, but to be sufficiently informative to identify priorities and guide ecda's work.

Susanna lives with her grown up son and has Parkinson's disease.

She felt strongly that data should be shared to help more vulnerable people, saying that sharing more data

"can only be a good thing".
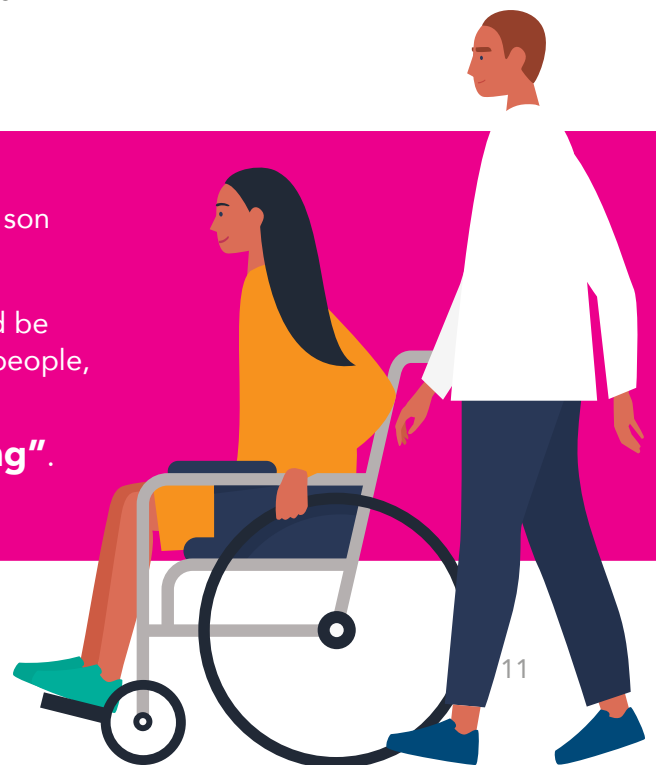
Research approach:

There were two phases of primary research:

Phase 1

Remote focus groups

- Group 1: Older and more affluent

- Group 2: Older and less affluent

- Group 3: Younger and less affluent

- Group 4: Younger and more affluent

Collaborative session with key partners

- This collaborative session involved members of the ecda Operational Management Board to get their feedback on the key issues and inform phase 2.

Following insight gathered from Phase 1, and through discussions during the collaborative session, we identified a need to conduct further research with specific vulnerable cohorts, specifically those who may be impacted through ecda projects, both now and in the future.

Phase 2

Remote focus groups with specific cohorts including:

- Young people (aged 13 to 18)

- Adults with learning disabilities and/or autism

- Adults receiving mental health support

- Carers both unpaid and paid.

One-to-one in-depth interviews with specific cohorts including:

- Adults who have experienced homelessness

- Adults receiving treatment for drugs and alcohol

- Adults with previous criminal convictions

- Adults with physical disabilities.

Phil works in the ambulance service and was strongly in favour of data being used for preventative action.

However he had concerns about people being stigmatised as a result saying

"there's a fine line between persecution and support".

Research materials

It was quite challenging to think about how best to articulate quite complicated concepts to a range of people, all with different levels of understanding and needs. We needed to ensure all of our research materials were easily understood and accessible to all. For both phases of the research we produced a range of different research materials, including an easy read toolkit in phase 2.

} We developed a toolkit to engage the public using examples to bring the topic to life.

As part of our discussion with citizens, we focused on:

- The value of data sharing and predictive analysis, collecting information on the benefits and risks that people perceive in data being used in this way

- Explaining key concepts to enable a dialogue that went beyond the basic understanding and knee-jerk reactions to data sharing and predictive analytics

- Introducing a range of different scenarios so participants could see how the concepts apply in various situations

- Collecting structured data around how perceptions on data sharing and predictive analytics shift in response to new information

- Developing an understanding of how people understand different concepts, including language and terms used to define different elements of the process

- Different scenarios which showed the ecda process, and tested how participants felt about different aspects of data sharing throughout.

Example stimulus content:

Qualitative Findings

Attitudes to
data sharing

Key Finding 1

} Personal experience of health vulnerability helps people see the benefits of data sharing

- Those who had experienced vulnerability were often more open-minded about benefits of data sharing

- Many factors influenced more vulnerable citizens' openness to data sharing. These included eliminating the need for them to repeat themselves to different organisations and instilling the feeling of having a safety net to support them should a condition or life circumstance worsen

- Those who had not had these experiences themselves found it harder to see the benefits, and were more likely to have reservations

- Those with reservations did empathise at a societal level, and with more detailed explanation, could envisage the benefits available from joining data to support vulnerable individuals and society more generally

- When the benefits were understood, some even advocated for individual identifiability to ensure that the advantages of data sharing were more fully realised. Some citizens felt it was our duty to help vulnerable people if we had identified that they were at risk.

" If you have data about a vulnerable person you have a responsibility to do something with it. "

Susanna (a person with Parkinson's)

Key Finding 2

} Fear of 'exposure' exacerbates distrust in data sharing

- People who had previous contact with public services and deemed themselves as having "something to hide", for example, they might have received drug and alcohol treatment or have a criminal conviction, expressed concerns about future discrimination and negative perceptions of their peers should their data be shared. This fear was exacerbated if individuals considered the experience of receiving those public services as negative or ineffective

- Some expressed specific concerns about the impact on their employment, housing, benefits, and childcare responsibilities, if data was shared with the "wrong" organisation

- For others, Covid-19 and related initiatives such as the Test and Trace app, Operation Shield and the vaccination programme, have exacerbated their existing anxiety around how data is recorded, stored and shared. Most participants in the phase 2 research had resorted to providing minimal personal information or giving false data so that their information could not be traced back to them

- There were increased concerns with this group around big data scandals and fraud, with most having had at least one negative experience of data sharing within public services

- Those who had experienced having their personal data shared by councils under a statutory obligation for safeguarding have a high distrust of public services and data sharing

- When discussing the benefits of data sharing and how this can help vulnerable people in the future, most agreed that this was a good thing, with a detailed explanation of the anonymisation process and information about when, and how, their data was being used.

" Although I'm fine now, I live in fear that one day someone might share something from my past, so I don't trust anyone with my data. **"**

Cathy (married mother of two)

Key Finding 3

} The term 'data sharing' can be toxic

- 'Data' is a loaded word; people were reactionary because they do not trust it. We observed a physical reaction – a shake of the head, crossing of arms - to citizens hearing the word 'data'

- Most people had an initially negative view about the concept of 'data sharing' – with the term associated with abuse of power, lack of privacy and commercialising individuals - and with such preconceptions, there is a risk that they take more resistant positions

- This negative association could be overcome with additional explanation focusing on specific applications of data sharing, for example, tackling domestic abuse

- However, people's views about different applications of data sharing varied wildly, with some areas having far greater concern, for example, obesity was considered more sensitive than domestic abuse

- Colleagues and partners note anecdotally that there has been a change in public opinion during the coronavirus outbreak – with people's opinions initially swaying in favour of data sharing – and later in opposition to it, as they feel jaded by the Government's use of data elsewhere.

" ...you should add something to it, like collaborative data sharing, or data sharing for good. Get people to think about the positives and not the negative associations. **"**

Jacob, 16

Key Finding 4

} Big data scandals have left people wary about whether they can trust anyone with their data

- Although most participants felt that local organisations should be collecting and using data in the way ecda is advocating, people worried about the practical management of their data, and that this would fall into the 'wrong hands'

- People are not clear on who, within an organisation, has access to their data; one person, several teams, whole organisation – and they are worried about this

- Some had questions around the 'third party data platform' and the process and people involved in removing identifiable information from the dataset

- Others were concerned that the data set would be valuable, and that ecda may not be able to guarantee its safety in years to come

- Most people are sceptical about the public sector being held to account.
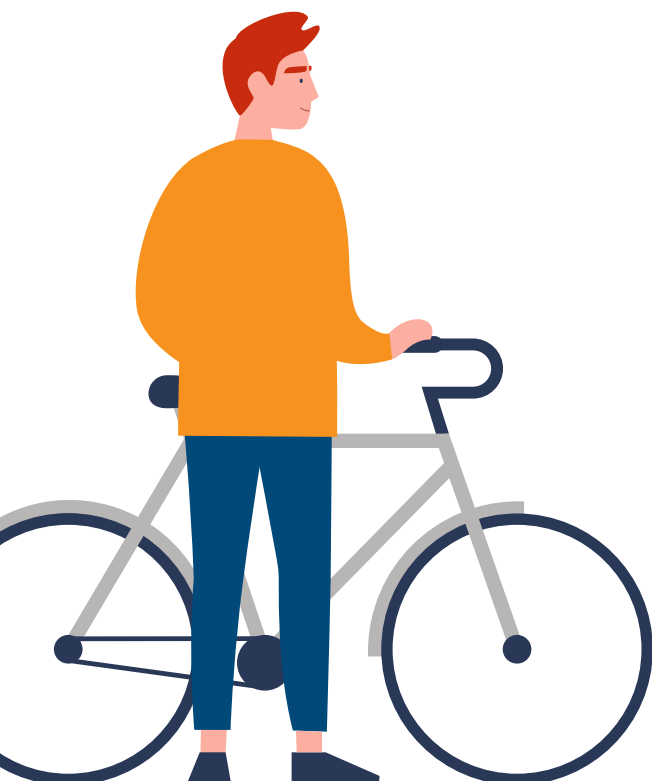
" I don't mind public services having my data, but private companies that make money like Facebook, I don't trust them. Especially with the data hacking stories in the news. "

Ben, 15

Key Finding 5

} People feared not having a choice of how their data is used, and what the interventions might be

- Citizens often reacted negatively initially to the idea of sharing data. They presume that we will need to know everything about them and that there will be no limits on who in the organisation will see any data. This initially defensive response confirms the prevalence of the narrative that data disclosure or sharing of any kind is tantamount to a lack of privacy or control over your information

- They fear that if even a small amount of data sharing happened, this could escalate into something much larger. Many pointed to fears of a "nanny state" where everything is known about them. As a result, their initial reaction was one of resistance

- Most citizens are unclear on the benefits of disclosing data in the first place. Even when they start to understand more about the help that is on offer, they find it hard to see how any help could be translated across organisations through data sharing. Some relationships make more sense, for example, data sharing between adult social care and GPs

- Citizens are unclear on the safeguards that are in place. They are unaware of organisations such as the Information Commissioner's Office and feel that organisations are not held accountable when handling and using sensitive information. Many citizens do not know where the information sharing stops.

** I don't want data gathering to be a tick in a box. Make sure action happens. **

Sharon (former Police Officer)

Key Finding 6

} Being labelled a 'bad area' can have real and enduring consequences

- Essex has a few locations where the general public have entrenched, negative perceptions. People worry that there is no sign that these perceptions are changing and that the public sector and ecda have a role to play in:

  » Avoiding further stigmatisation of these and different areas through publishing insight

  » Changing the narrative

- People could clearly understand that a negatively labelled area could have wide-ranging implications – for getting work, for their children and schools, for insurance and housing. Some were aware that negative labelling could become a 'self-fulfilling prophecy'.
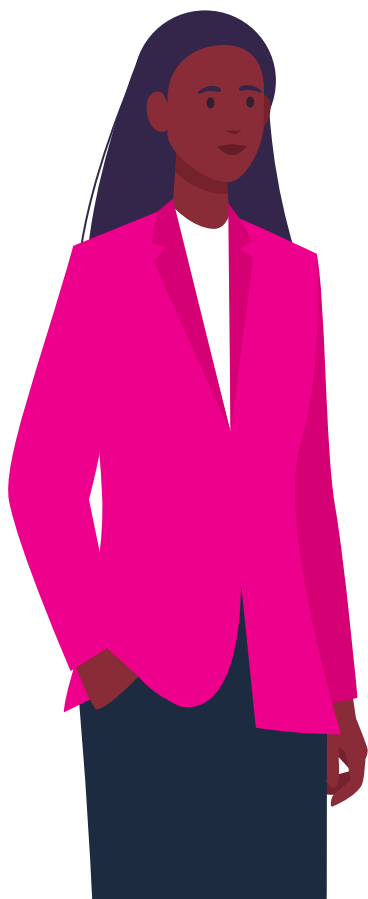
" Make sure you know the people behind the data and how the insight might impact their lives. **"**

Jackie (Deputy Head)

Key Finding 7

} People feared being profiled or labelled negatively by their data

- People worried that their data could be used to profile or label them negatively

- Some struggled with the idea that their own data would be separated from personally identifiable information when collated into a larger data set, and so worried it would be traced back to them

- Even those who understood the data would be anonymised, worried that they would be stereotyped negatively if they fed into a data set considered 'at risk'

- Several raised concerns that this data could be used against them – for example, if a potential employer felt that they were at risk of poor mental health and so decided not to hire them.

** Predictive analytics looks like profiling to me. **

Adam (retired)
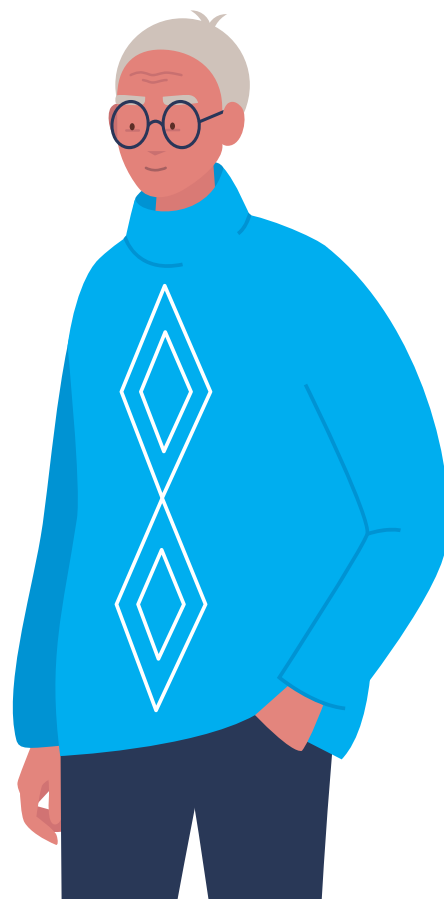
Key Finding 8

} Third party anonymisation of data is a tricky concept to understand

- People lacked reference points or conceptual frameworks for 'third party handling of data and anonymisation'

- Most people defaulted to the concept of sharing between providers directly, even when the idea of the third party was explained several times

- Lack of understanding or any reference points, reduced confidence in the overall idea

- People were concerned with how the providers may share data, who they might be, and what they might be seeking to gain from the process. People regularly raised the issue of contracts and long-term data protection, for example, incentives to keep the data safe.

** What concerns me is how do you know that you can trust the companies it will be outsourced to? **

Melissa (scientist)

Key Finding 9

} It is difficult to engage citizens beyond the most civically minded

- There are some challenges in engaging different people on the issue of data analytics

- Those coming forward for phase 1 of this research were the most interested, engaged and civically minded, for example, they put themselves forward to participate. This was addressed in targeted recruitment for phase 2 of the research, however, this reflects the challenges of engaging more widely with citizens, and the need to ensure there are no gaps around understanding those who are less interested in local issues and the workings of their local institutions.

" You need to be attentive to the level of understanding and interest that people will have. "

Nina (university student)

Key Finding 10

} People say they want to be informed 'on an ongoing basis' - but in reality they do not…

- People typically said they were interested in the idea and wanted to be 'better informed' – but generally not unless it affects them directly

- While people reported they wanted to know more, it is unlikely they would be proactive in looking for information about data analytics in their daily lives – instead suggesting the data should all be available online for them to be signposted to

- Some felt that it would be overkill to be repeatedly asked for consent to share data and would rather continue to give this as a one-off and are satisfied with public sector legal obligations to protect personal information under privacy and data protection laws.

❝ I don't need to know what's going on all of the time. If it involves us, ask us. **❞**

Olivia, 15

Quantitative Findings

Summary of the findings from the Essex County Council residents' survey

Summary of quantitative findings

The Essex Residents' Survey was conducted from 4 March to 27 April 2020, with a total of 3,021 responses received.

It included questions to better understand residents' attitudes towards the use of their personal data for a range of purposes.

Respondents were, on average, more likely to agree to the data sharing statements than to disagree. Around seven in 10 agreed that with their consent and knowledge, their data could be used to 'improve health and wellbeing services', and to 'reduce risk, harm and keep people and places safe'. This indicates that public support for data sharing is increased when it concerns services that can bring direct benefits to them and their families.

Residents' data sharing attitudes have been found to be influenced by two types of factors:

- Demographic factors (age, area, health issues)

- Their opinions and experiences.

Data sharing attitudes related to health and wellbeing services are more likely to be positive among those aged 65-years-old and above, or among those with a long-standing health concern. There is a significant relationship between those living in a deprived area and attitudes to data sharing. Those living in non-deprived areas are far more likely to support data sharing.

Positive attitudes towards data sharing correlated with:

- Positive views on Essex County Council

- Strong sense of community in local area

- Feeling involved in local democracy.

People who find Essex County Council trustworthy are significantly more likely to hold a positive attitude towards data sharing.

Respondents who feel there is a strong sense of community in their area are significantly more likely to agree with all data statements than those who do not.

Respondents who believe they can influence decisions in their local area are five times more likely to agree with data sharing statements than those who do not.

Detailed quantitative findings are available in appendix 2, page 35.

Recommendations

Moving beyond
trust, knowledge
and engagement
deficits
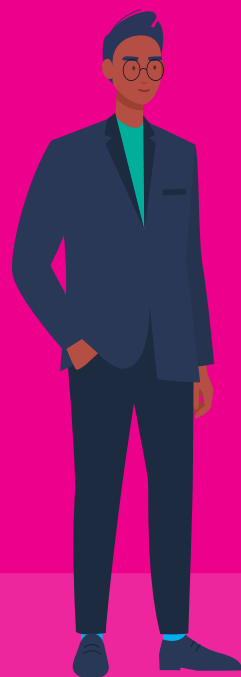
Tell me

Until now, ecda's citizen engagement has been focused on gaining insights and co-commissioning services based on these insights.

Building on this citizen engagement, we will:

- Develop a public engagement strategy and toolkit that aims to empower citizens to engage in a conversation with public sector/policy makers about emerging data technologies; recognising the differences in the ability and opportunity of individuals to engage; and providing critical and ongoing deliberation opportunities that enable citizens to influence the creation of a data ecosystem for Essex public services.

Citizens should know what happens to their information beyond giving consent at the point of collection, particularly when data science technologies have the potential for evidencing service provision.

We will:

- Implement a consistent approach to transparency across ecda's three core partners, to include publishing:

  » Business cases that communicate project scope, outcomes and analytics methodologies

  » Transparency notices that communicate what data is being joined, for what purposes and legal consent

  » Real time project progress reports

  » Evaluation and impact reports

- Collaborate with information governance leads across our organisations to review the language used for data consent and ensure that data joining for analytics is explicit.

Tess has a learning disability and has accessed mental health services.

She could see the benefit of sharing data between services if it meant vulnerable people who might have communication difficulties **"wouldn't need to keep explaining their condition over and over"**.

Respect me

Safety, security and robust governance of third-party relationships were a greater priority to citizens than the commercial re-sale of data.

We will:

- Publish a statement that explicitly communicates that there are no circumstances in which ecda would share personally identifiable data with a commercial partner

- Prioritise commercial relationships that seek to achieve better outcomes for, and empower, our citizens, and build public and expert industry collaborations that drive innovation and best practice

- Communicate details of all commercial relationships, and associated policies, procedures and governance, through publication of individual collaboration agreements.

Protect me

We understand citizens' concerns about individuals and organisations accessing and processing their data for joining and analytical purposes. We recognise the importance of good data practice to ensure that the use of data science technologies, and the publication of insight, serve the public good.

We will:

- Implement and communicate a 'fitness to practice' standard for all ecda data analysts accessing data, which will include organisational and legal requirements covering data security, governance, and management

- Implement peer review of methodologies and data analysis as standard practice on all ecda projects

- Update the organisation maturity assessment carried out as part of ecda's project feasibility assessment criteria, to include an appraisal of any data breach history and mitigation as part of the standard judgement criteria

- Utilise the independent Data Ethics Committee to consult on implications of communicating insight.

Involve me

The people of Essex have a fundamental stake in the results and development of data science techniques, including application, improvement and regulation of its use.

We recognise that ethical and transparent data use takes into account the views of the people we serve and that citizens can provide a unique perspective on the purposes and design of data technologies. Their involvement will build social and technological robustness.

We will:

- Create new opportunities, using a variety of engagement methods, to enable critical and ongoing citizen participation in ecda's work, including but not restricted to:

  » Recruiting citizens to the independent Data Ethics Committee

  » Involving citizens in selecting the types of projects that ecda prioritises

  » Collaborating with citizens to develop ecda's research questions and checking all insight with citizen research

- Advance digital methods and tools to scale up engagement with the public and develop participatory design methods to enable citizens to participate in work with data

- Develop a data charter in collaboration with citizens and other key stakeholders that communicates ecda's commitment to the public, including our values, priorities, and standards of practice.

Emily is her mother's power of attorney and un-paid carer. She had concerns about making decisions around data sharing on behalf of her mother, and maintaining and respecting personal choice.

"You can't really have all the positives of data sharing without the risk of the negatives. I know that ECC and ecda want to try and help vulnerable people, but I want to know that you're doing the right things, people just want to feel safe and secure."

} Appendix 1

Literature review

The application of data science technology within the public sector is still relatively new. Research scopes have been narrow and focused on determining the public view on privacy issues around data science, and particularly on data sharing relating to personal data (Cameron et al., 2014; Davidson et al., 2013; Ipsos MORI Social Research Institute, 2016b; MRC, 2007; Sciencewise, 2014, 2012).

These government public consultations have found publics hesitantly supportive of the use of personal data that is informed by a clear public benefit. These studies concluded that public concerns are often embedded in commercial access to personal data, and the complexity of algorithmic mechanisms such as machine learning, that is, digital and automated processes of decision making (Davidson et al., 2013; Cameron et al., 2014; Ipsos MORI Social Research Institute, 2016b; Sciencewise, 2014).

There is not a large literature on public engagement with data science yet, however during 2015-18, Emily Rempel, Julie Barnett and Hannah Durrant from the Department of Psychology and Institute for Policy Research at the University of Bath conducted research on public engagement and policymaking in the era of big data. This included six research programmes to examine the creation and use of data in aiding policy deliberation, decision making and engagement in democratic societies.

Four qualitative exploratory streams of research were contextualised through the history of public engagement, the environment of public engagement around data, methods used by government data teams, and pilots of new public engagement initiatives. It included a comprehensive literature review of public engagement for new technologies.

Rempel, Barnett and Durrant conducted qualitative focus groups enrolling participants from three different publics: local government officials, technical specialists, and non-technical publics, in their study ***Contrasting views of public engagement on local government data use in the UK*** to compare and contrast differing public views on public engagement with local government data usage.

Table: Thematic analysis results by workshop group

	Workshop Group		
	Non-Technical	**Technical**	**Government**
Themes related to government data use	Participants discuss data in terms of its potential to do harm but also believe in the potential for it to benefit local communities.	Participants describe complex behaviours and a critical trust involved in deciding what was and was not a presonal risk in relation to data.	Participants express personal fears related to data that results in a critical trust in organisations and safeguarding behaviours.
	Participants are critical of government data use based upon a perceived lack of change in their local area.	Participants question whether government uses data, while also being open and supportive of the use of data in government.	Government data use fits within a complex administrative culture where capacity is limited but data analysis is prized.
	Data technologies have changed the way the participants perceive the risks of their behaviours, particularly with commercial organisations.	It is impossible to separate out commercial involvement and the discussion of government data use in the context of data risks.	Data use in government exists within an inseparable ecosystem of both commercial and government data.
Themes related to public engagement on government data use	Good data engagement empowers publics, recognises differences in the ability for individuals to engage, and offers multiple venues for engagement.	Good data engagement is flexible, problem-focused, and guided by intermediaries between publics and government.	Good data engagement is timely thus influential, is purpose-focused, and of benefit for the organisation in question.
	Challenges for the success of data engagement include whether trust exists between publics and government and perceived public disinterest in civic activism.	Public engagement should be about empowerment, but empowerment may be a challenging and dangerous precedent to set.	Governments face risk in engaging publics as publics are imagined as combative and unknowledgeable about data use.

This study concluded that all three groups expressed a wariness towards data collection around their day-to-day activities, as well as a critique of how well local government uses data in policy decision-making. The groups diverged in their discussion around public engagement. The technical and government groups focused on their concerns around the 'public' as being data illiterate, while all groups expressed concerns around the 'public' as being disinterested in data use and policymaking. However, all groups described good public engagement as focusing both on the means and ends of policymaking with data, being influential on local government process, and offering multiple mechanisms of participation.

Overall, the groups discussed several lessons that would be useful both for practitioners and future academic study. Participants preferred public engagement that:

1. Empowers publics

2. Starts early in the policy process

3. Influences political decision-making

4. Is flexible both in topic and form

5. Focuses on the means and ends of data use

6. Builds capacity and knowledge of data processes in non-technical publics.

In their study *Exploring public preferences for engagement with UK government data use: a quantitative analysis*, Rempel, Barnett and Durrant concluded that participants held a high expectation of government to be more transparent in how they use data but also to be more open to public influence in debating the future of data use in government. They found that types of data, particularly health, social media, employment and GPS data, and feelings of data ownership, were important for predicting the engagement that publics preferred.

In their paper; *Public engagement with UK government data science: Propositions from a literature review of public engagement on new technologies* (published 2018) Rempel, Barnett and Durrant present a deficits model and three key deficits that need to be addressed by public sector organisations:

- **Trust deficit:** While trust is a component of public and government interactions, it should not be the aim of public engagement. Similar to communication, trust is necessary but not sufficient. Demonstrating trustworthiness through the implementation of sturdy information governance protocols and procedures is more effective to building trust than seeking trust via engagement and communication

- **Knowledge deficit:** Publics are wary because they do not understand work on data analytics. There is a need for highly visible communications regarding data use and sharing, security protocols, procedures, and breeches. However, communication is not enough, and dissemination of information alone does not lead to greater acceptance. The public must be involved in work programmes in a more significant way to create understanding

- **Engagement deficit:** The lack of impact from public sector engagement around data often occurs because it is limited to one-off small group discussions. In addition, there is an absence of tangible public engagement with the way in which new forms of data and analytics are explained, collected, and used by government.

Their key recommendation for moving beyond these deficits is collaboration with diverse publics and operationalising openness:

- Involve the public in imagining what is possible in the application of data analytics to foster trustworthiness

- Leverage open data as a mechanism and opportunity for enhancing transparency and accountability of governments and empowering engagement with public policies.

They set out five propositions for government-driven public engagement with data science:

1. Think critically about the potential publics that can be involved in data science

2. Do not assume that informing the public about data science initiatives will lead to acceptance

3. Determine the contingencies of trust for government data science and engagement through trustworthy practices

4. Design public engagement that incorporates robust, critical and ongoing deliberation of data science

5. Ensure that public participation moves beyond the topics of privacy and consent.

} Appendix 2

Results of the Essex County Council residents' survey 2020

The Essex County Council residents' survey was conducted between from 4 March to 27 April 2020, with a total of 3,021 responses. It included questions to better understand residents' attitudes towards the use of their personal data for a range of purposes.

As the sample for this survey is both small and self-selecting - they have chosen to complete the survey – the data is weighted by age, gender, and district to ensure that findings are representative of the Essex population.

Residents were asked how far they agreed with the following statements using a scale of 'strongly agree, slightly agree, neither agree nor disagree, slightly disagree, or strongly disagree".

I feel that with my consent and knowledge my data could be used to...

A. Support and protect vulnerable people from harm, e.g. provide early support to young people at risk of violence and vulnerability

B. Improve health and wellbeing services available to you, e.g. provide services to help residents improve their health

C. Reduce risk, harm and keep people and places safe, e.g. establish links on emerging threats

D. Shape local places and understand communities better, e.g. help families with under-fives to be ready to start school
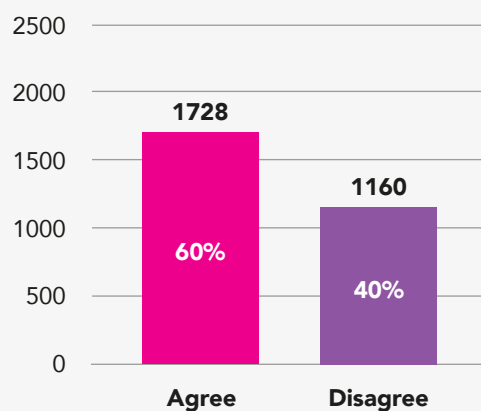
Respondents were, on average, more likely to agree to the data sharing statements than to disagree. This was particularly the case for statements B and C, indicating that public support for data sharing increases when it concerns services which can bring direct benefits to individuals and families.

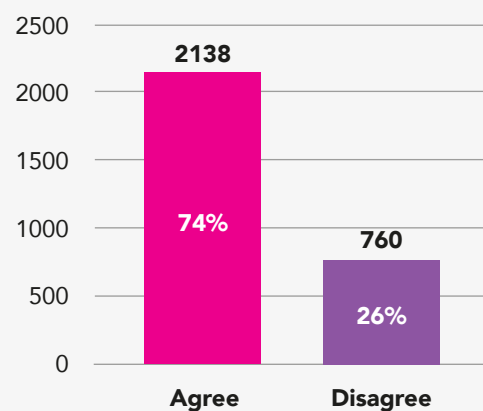## Residents' attitudes towards the use of their personal data for different purposes

Respondents were on average **more likely to agree to the data sharing** statements than to disagree. This was particularly the case for statements B and C, indicating that public support for data sharing is **increased** when it concerns **services which can bring direct benefits to them and their families**.

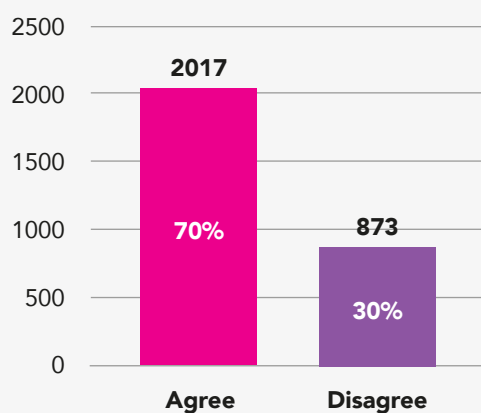} **I feel that with my consent and knowledge my data could be used to…**
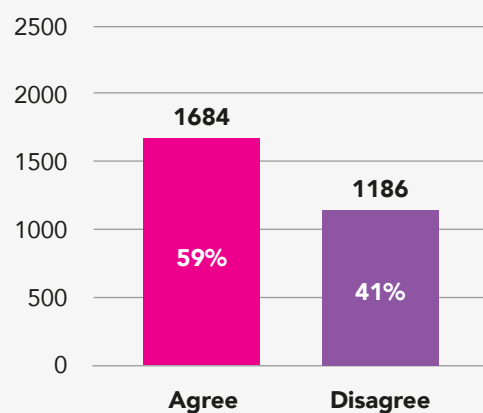
A. Support and protect vulnerable people from harm

	Agree	Disagree
Value	1728	1160
Percentage	60%	40%

B. Improve health and wellbeing services available to you

	Agree	Disagree
Value	2138	760
Percentage	74%	26%

C. Reduce risk, harm and keep people and places safe

	Agree	Disagree
Value	2017	873
Percentage	70%	30%

D. Shape local places and understand communities better

	Agree	Disagree
Value	1684	1186
Percentage	59%	41%

Residents' answers to the data sharing statements have been combined in the category **Agree** for those who responded 'Agree strongly' or 'Agree slightly' and in the category **Disagree** for those who responded 'Disagree strongly', 'Disagree slightly' or 'Neither agree nor disagree'.

Residents' data sharing attitudes have been found to be influenced by two types of factors:
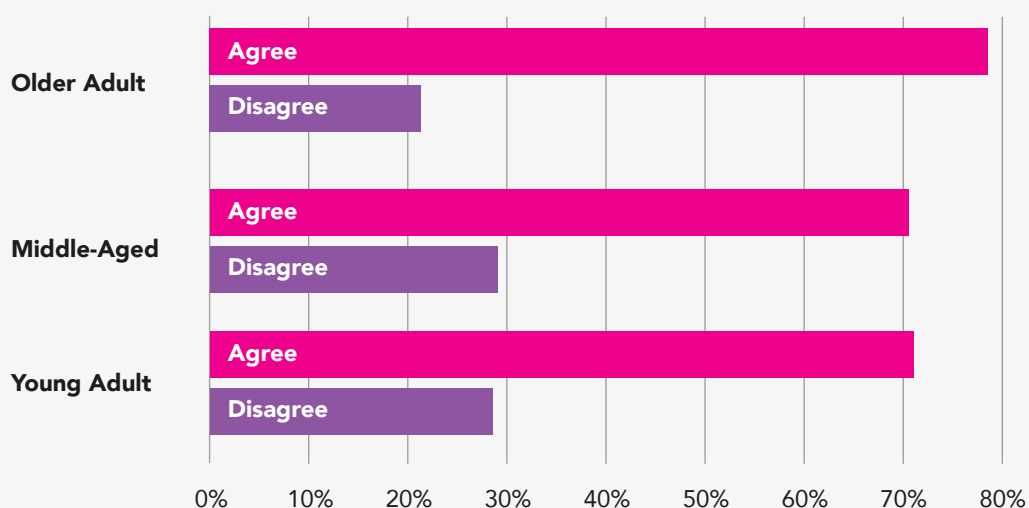
- Demographic factors (age, area, health issues)

- Their opinions and experiences

Understanding residents' attitudes towards the use of personal data: respondents' demographics

Age may play a role in people's views on data sharing

Responses to statement B broken down by age

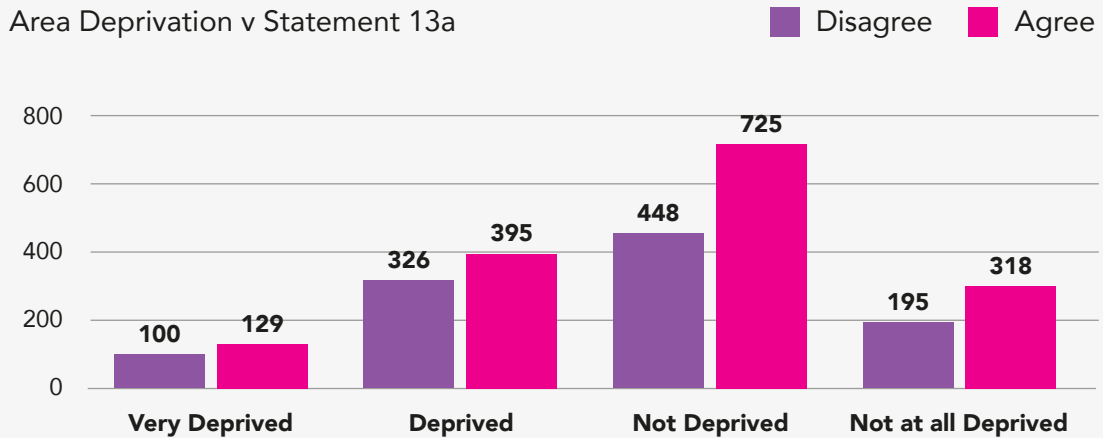**"Improve health and wellbeing services available to you"**

The category 'Young Adult' includes respondents aged between 18 and 34 years old. The category 'Middle-Aged' includes ages 35 to 64. The category 'Older Adult' includes ages 65 and above.

- Age has been identified as significant **only** in relation to the statement "my data could be used to improve health and wellbeing services available to you".

- **Older residents are as such significantly more likely to support data sharing for health services.**

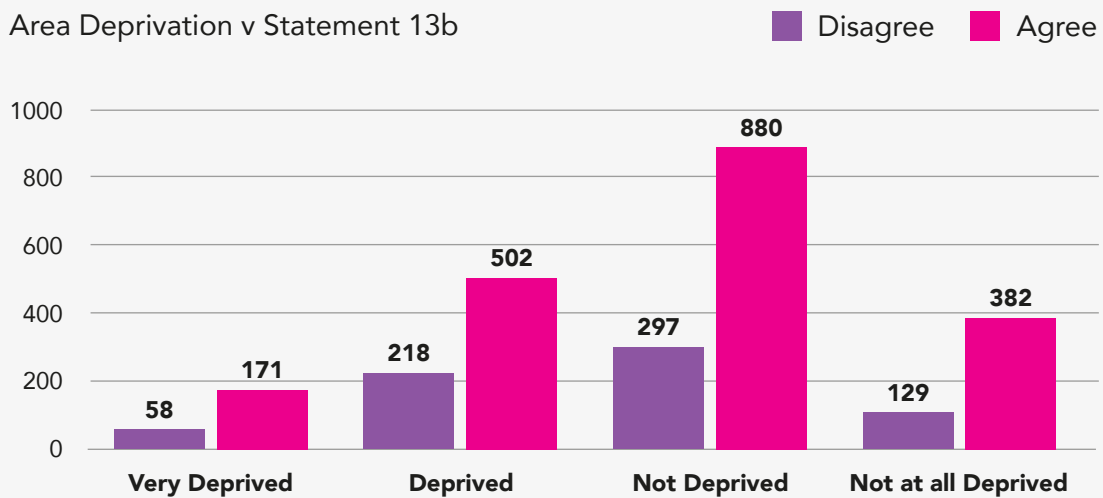- This finding supports the theory that personal experience influences data sharing attitudes.

Data sharing attitudes related to health and wellbeing services are more likely to be positive among those aged 65-years-old and above, or among those with a long-standing health concern.

} **Living in a deprived area diminishes support for data sharing**

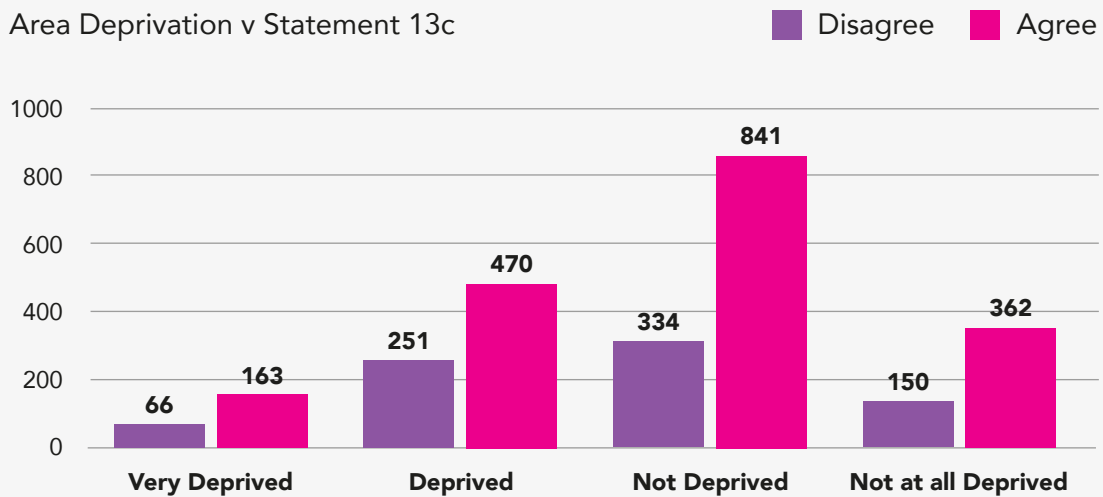**A. Support and protect vulnerable people from harm**

Area Deprivation v Statement 13a   ■ Disagree   ■ Agree

B. Improve health and wellbeing services available to you

Area Deprivation v Statement 13b   ■ Disagree   ■ Agree

C. Reduce risk, harm and keep people and places safe

Area Deprivation v Statement 13c

Disagree **Agree**

	Very Deprived	Deprived	Not Deprived	Not at all Deprived
Disagree	66	251	334	150
Agree	163	470	841	362

D. Shape local places and understand communities better

Area Deprivation v Statement 13d

Disagree **Agree**

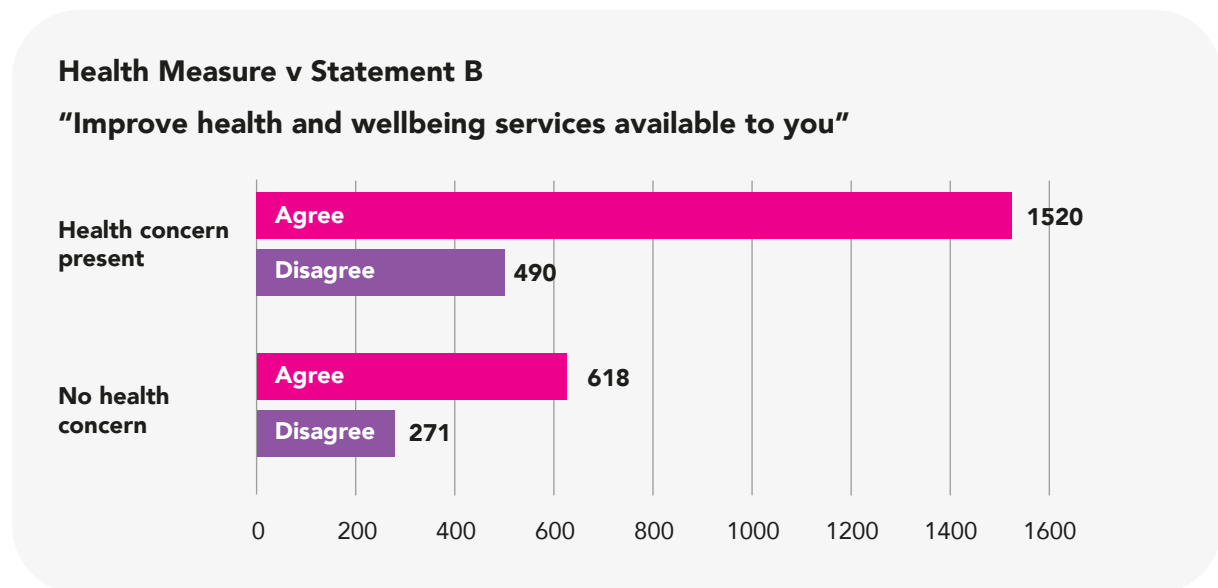|	Very Deprived	Deprived	Not Deprived	Not at all Deprived
Disagree	99	342	458	194
Agree	129	376	715	318
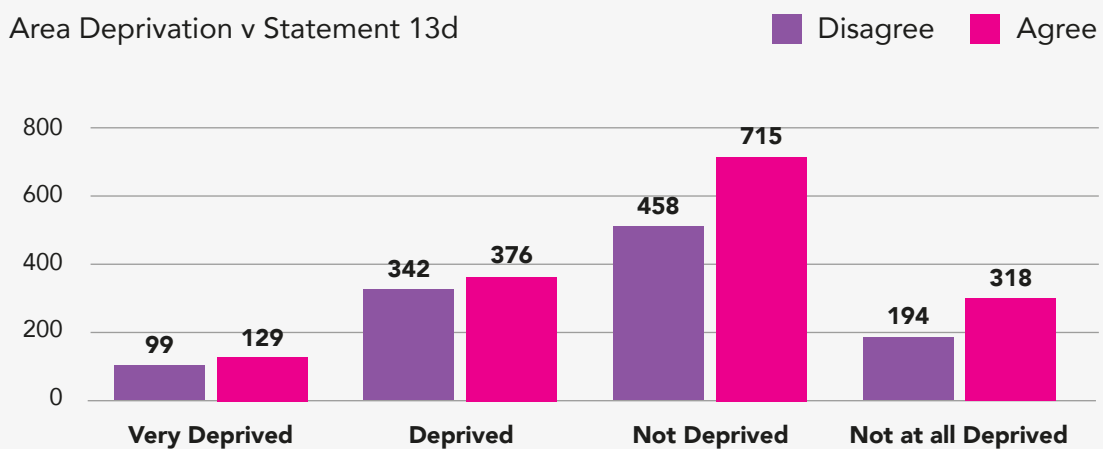
Area deprivation score was here calculated based on deprivation quintile (IMD report scale), and the perceptions of residents of opportunities and safety in their local area.

- There is a significant relationship between those **living in deprivation** and their **attitudes on sharing data**.

- Those living in **non-deprived areas** are far **more likely** to support the sharing of their data.

- This indicates that the state of services in people's local area influences their willingness to share data.

} **Support for data sharing is higher among those with a long-term health concern**

Health Measure v Statement B

"Improve health and wellbeing services available to you"

Health concern present	Agree — 1520
	Disagree — 490
No health concern	Agree — 618
	Disagree — 271

Scale: 0, 200, 400, 600, 800, 1000, 1200, 1400, 1600

- The respondents seem **very happy** to share their data to improve health and wellbeing services; especially among those that have a physical impairment.

- There is a significant relationship between having a health concern and views on data sharing focused on improving health and wellbeing services.

- This was as expected with the respondent's **personal experiences** and **close attachments** to this issue being important factors for promoting data sharing. These respondents will have more emotion and a better understanding to health and wellbeing services, and if they are improved there is a good chance they will personally benefit from this.
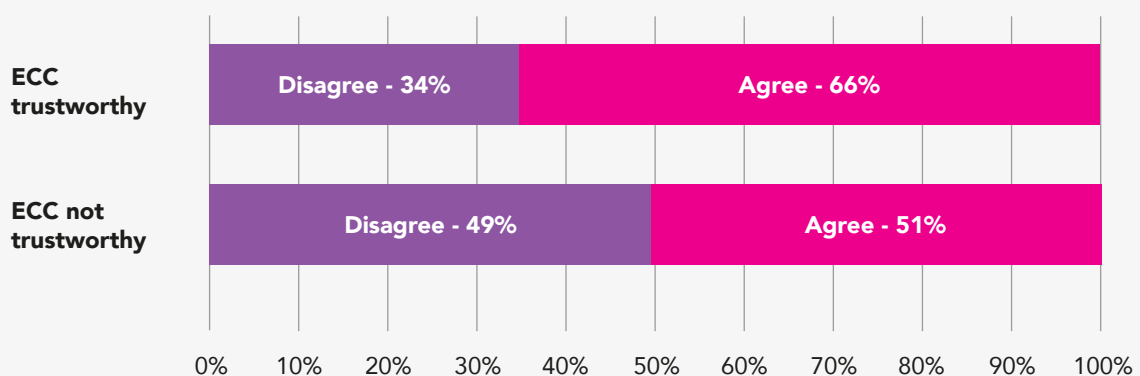
Understanding residents' attitudes towards the use of personal data: respondents' experiences

Positive attitudes towards data sharing correlated with:

- Positive views on Essex County Council

- Strong sense of community in local area

- Feeling involved in local democracy

} **Respondents with positive views on the ECC show more support towards data sharing**

Attitudes towards statement D v data sharing attitudes

"Shape local places and understand communities better"

ECC trustworthy	Disagree - 34% / Agree - 66%
ECC not trustworthy	Disagree - 49% / Agree - 51%

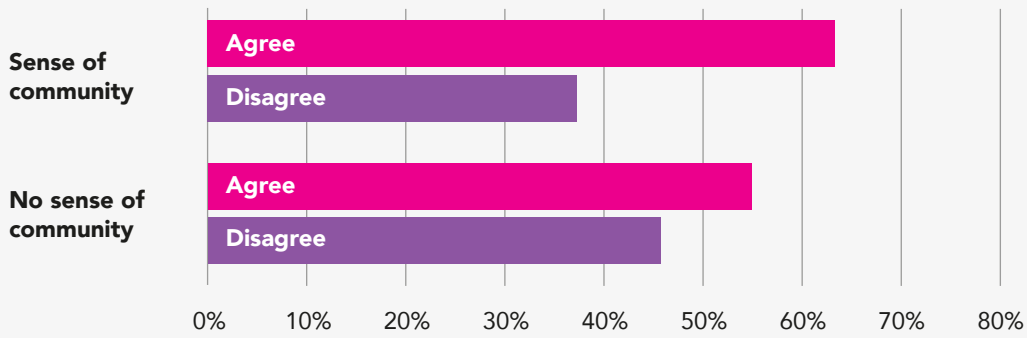0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Respondents' answers to the question "To what extent do you believe the statement 'The Essex County Council is trustworthy' does apply?" have been divided as follows: the answers 'A great deal' and 'To some extent' have been categorized 'ECC considered trustworthy', while 'Not very much' and 'Not at all' have been categorized as 'ECC not trustworthy, leaving out the 'Don't know' answers.

- People who find the ECC trustworthy are **significantly more likely** to hold a positive attitude towards data sharing.

- This finding was consistent across all statements regarding data sharing.

} **A stronger sense of community correlates with more positive data sharing attitudes**

Attitudes towards statement A v Sense of community
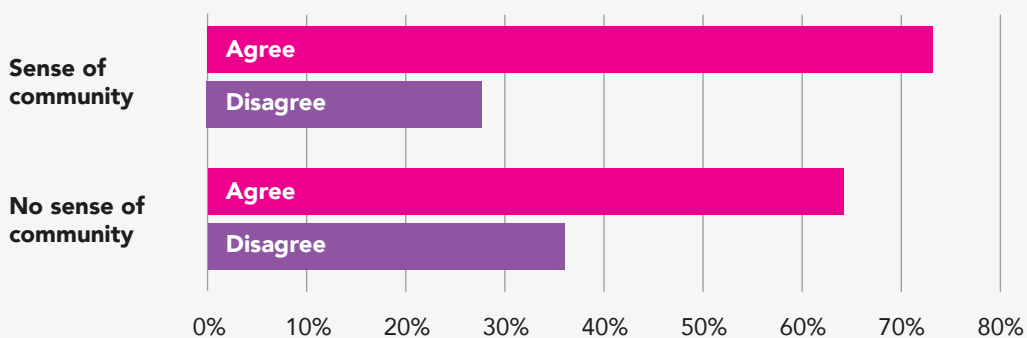
"Support and protect vulnerable people from harm"

	Agree	Disagree
Sense of community	Agree	Disagree
No sense of community	Agree	Disagree

0% 10% 20% 30% 40% 50% 60% 70% 80%

Attitudes towards statement B v Sense of community

"Improve health and wellbeing services available to you"

	Agree	Disagree
Sense of community	Agree	Disagree
No sense of community	Agree	Disagree

0% 10% 20% 30% 40% 50% 60% 70% 80%
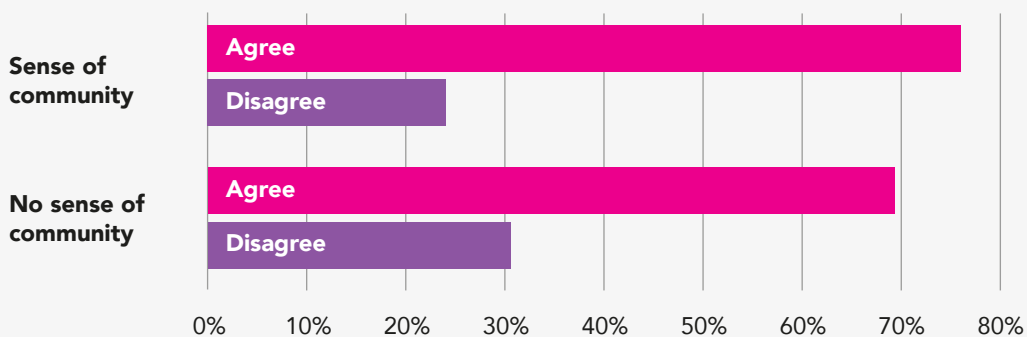
Attitudes towards statement C v Sense of community

"Reduce risk, harm, and keep people and places safe"

	Agree	Disagree
Sense of community	Agree	Disagree
No sense of community	Agree	Disagree

0% 10% 20% 30% 40% 50% 60% 70% 80%

Attitudes towards statement D v Sense of community

**"Shape local places and understand communities better"**
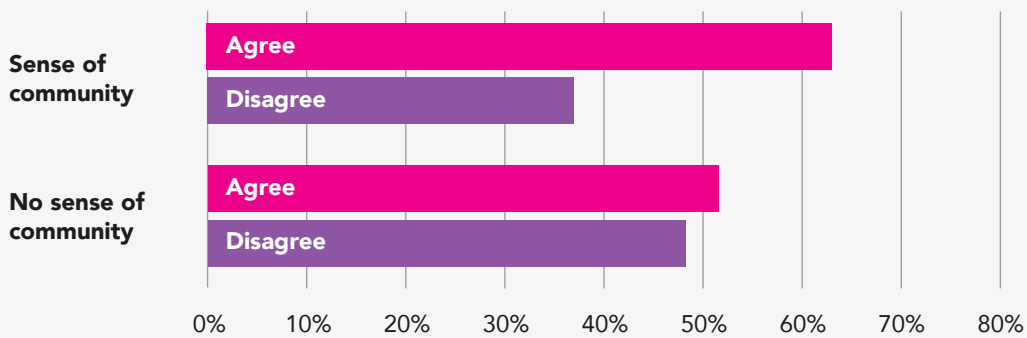
The answers 'Agree strongly' and 'Agree slightly' to the question "To what extent do you agree or disagree that there is a sense of community in your local area?" have been combined into the category 'Sense of community', while the answers 'Disagree strongly', 'Disagree slightly' and 'Neither agree nor disagree' were categorized as 'No sense of community'.

- Respondents who feel there is a strong sense of community in their area are significantly more likely to agree to all data sharing statements than those who don't.

} Positive perceptions of local democracy coincide with increased support for data sharing
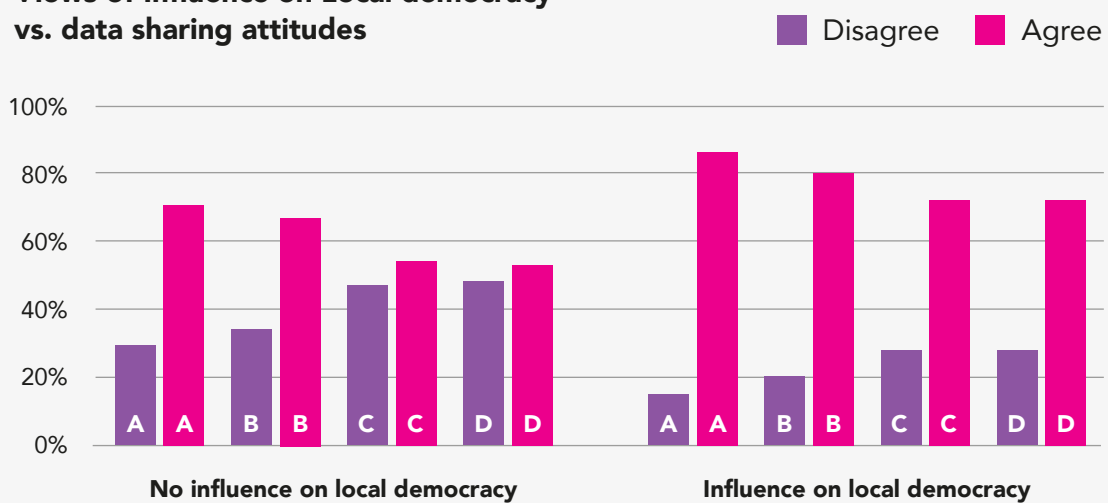
- Respondents who believe that they can influence decisions in their local area are **up to 5 times more likely** to agree to the data sharing statements than those who do not.

carry on the conversation

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