Working together to support vulnerable consumers

REVEALING REALITY

uk
rn

CONTENTS

FOREWORD

At some point in our lives, most of us will be in a situation that makes us vulnerable. This could be anything from having a loved one dying, to having our eyesight worsen as we grow old. When this happens, we'll need the support from the companies that provide us with life's essentials. This can take many forms: someone coming to help check your meter, being offered assistance when travelling, or even lowering the price of bills.

Currently, the prospect of financial vulnerability looms large for many people. Since COVID-19 struck, the number of people finding it difficult to make ends meet has increased by nearly 40%.[1] Now more than ever it is crucial that companies such as banks and utility providers understand their customers' individual needs so that they can work out how best to support them. Sadly, essential service providers often struggle to obtain and share important data on customers' circumstances, meaning many of the most vulnerable miss out on much needed support.

More must be done to address people's anxiety about sharing personal information and to improve the confidence companies have in doing it in a safe and responsible manner. Addressing these matters will unlock vital support for vulnerable customers.

This report provides an important window into customer attitudes on data sharing. It highlights the fantastic opportunity, currently being missed, to provide invaluable support to those who need it most. It sets out some practical steps that need to be taken in order to reach this goal.

Rachel Fletcher

Chief Executive of Ofwat
and UKRN

---

[1] https://www.citizensadvice.org.uk/about-us/policy/policy-research-topics/debt-and-money-policy-research/life-on-less-than-zero/

Executive Summary

WORKING TOGETHER TO SUPPORT VULNERABLE CONSUMERS

The UKRN and Revealing Reality have worked together to understand consumer attitudes towards the collection and sharing of vulnerability data. Our research combined industry interviews with firms and regulators alongside in-depth interviews and focus groups with members of the public. As part of the interviews and focus groups, researchers engaged with a range of individuals, experiencing a variety of vulnerabilities, conditions and life circumstances.

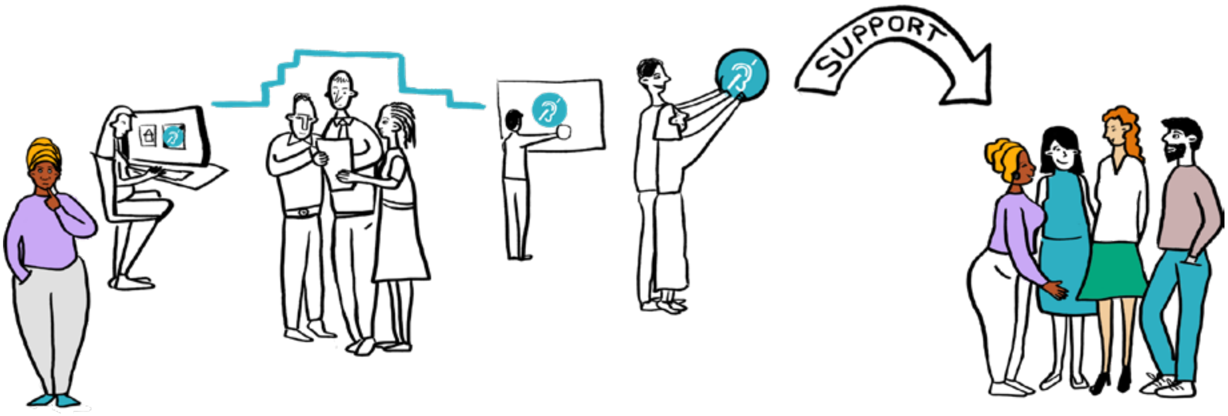
THE NEEDS OF THOSE WHO WOULD BENEFIT MOST FROM SHARING DATA ARE BEING OVERLOOKED

Those who have not experienced the impact of firms knowing about a condition or vulnerability find it hard to imagine the benefits this can have. As a result, those who are less vulnerable or in a period of transient vulnerability don't see the need for the sharing of vulnerability data between firms. They also find it hard to empathise at a societal level - struggling to envisage the massive benefits available from firms to those in less fortunate positions than themselves; their worries and concerns are therefore often the most vociferous. **Opinions seem to be clouded by a culture of fear and distrust when it comes to discussing data.**

Our research found that there was a **clear relationship between severity of vulnerability, and openness to disclosing and sharing data.**

In fact, some of the most **vulnerable people suggested it was a firm's duty** to help their vulnerable customers. They felt that firms can provide real benefits, such as help with everyday necessities like checking a water meter or even reading a bill, to make their lives better.

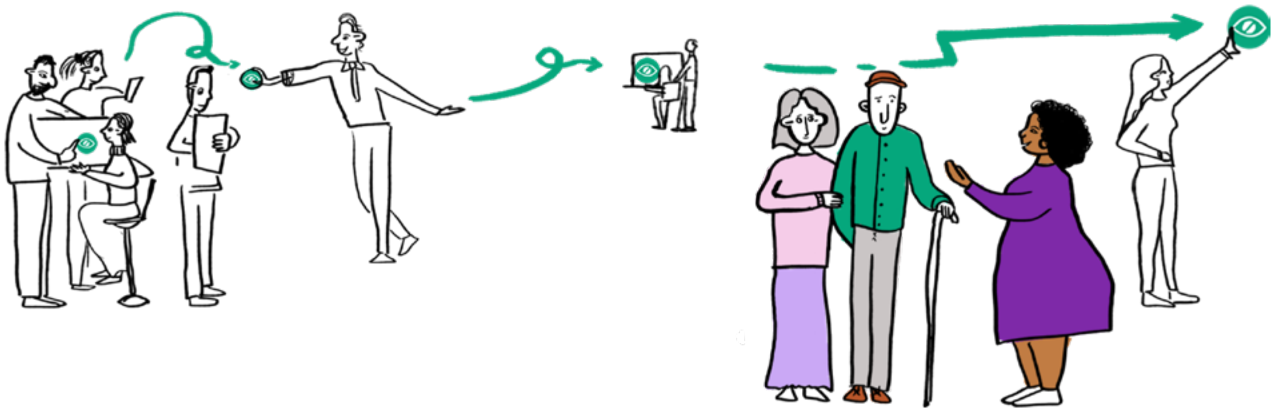
Many factors influence more vulnerable consumers' openness to data sharing. These include eliminating the need for consumers to repeat themselves to firms and instilling the feeling of having a safety net to support them should a condition or life circumstance worsen. **Positive progress in this area has been made,** for example, between the energy and water sectors - but more can be done.



FIRMS *AND* CONSUMERS OVERESTIMATE THE RISKS, AND UNDERESTIMATE THE BENEFITS OF DATA SHARING

Fear on the part of consumers and firms is standing in the way of progress. Whilst many concerns are valid, fear is often based on misconceptions that have stemmed from a lack of clarity when it comes to discussing data in general.

- **Consumers often react negatively initially to the idea of sharing vulnerability data.** They presume that firms will need to know everything about them and that there will be no limits on who in the organisation will see any vulnerability data.
- **Consumers are unclear on the benefits of disclosing vulnerability 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 sectors through data sharing. Some sectors make more sense, for example utilities, but others, such as finance, seem harder to imagine.
- **Consumers are unclear on the safeguards that are in place.** They are unaware of organisations such as the ICO and feel that firms are not held accountable when handling and using sensitive information. Many consumers don't know where the information sharing stops.
- **Firms are underconfident in their ability to combat consumer reluctance to sharing vulnerability data.** Whilst some sectors/firms have made progress on the data sharing process, many are naturally concerned that consumers do not want data sharing to happen.
- **Firms and consumers are nervous navigating the legal parameters of data sharing, and working through the practicalities.** There is a reliance on consent and confusion around when other legal bases can and should be used.



MOVING FORWARD

There is genuine consumer concern about the disclosing and sharing of vulnerability data – firms are right to recognise and appreciate this concern due to the sensitivity of the information. People *are* reluctant to disclose data about their vulnerability, and they *are* sceptical about firms sharing this information between each other. It is therefore conceivable that this issue spirals to the point where the data sharing process is impossible to fully achieve – and that the barriers seem too difficult to overcome.

However, there is a significant group of people who know about the help that's on offer, value it, and want to see it further improved and utilised.

The most vulnerable people are not only the most in need of help, but they are also the most open to the disclosing and sharing of data as a means to get that help.

There is an opportunity right now to make a difference in this space. The barriers articulated earlier by both firms and consumers can be addressed and overcome.

Potential next steps:

- **Reframe the language around 'data sharing'** to combat negative associations with the term. This will boost confidence for both consumers and firms in discussing and being able to recognise the benefits of data sharing.
- **Use a needs-based approach.** To consumers, this feels like the right balance of storing and using information in a non-intrusive, but useful, way.
- **Build empathy with those who would benefit from data sharing.** Help consumers to understand and value the support that is in place for vulnerable people. This will enable them to better conceive of the benefits that would come with firms being able to share information between them.
- **Better communicate the safeguards in place.** Make consumers aware of who firms are accountable to, provide guarantees on how data will be used and who it will be shared with, and offer clarity about what type of data is being shared.
- **Use a data sharing model that gives consumers control.** Consumers would like to know exactly what information is held about them, and have the ability to update this.
- **Build confidence using legal bases.** Consumers and firms need to understand and feel confident using legal bases other than consent. Consumers default to wanting to be asked for their consent before firms do anything with their information. However, when the other legal bases are explained, they can see the value.

Introduction and methodology

Introduction

Too often vulnerable people in the UK do not receive the help they need. This is something that both firms and regulators are aware of but changing things is difficult. The UKRN has made the improvement of outcomes for this cohort central to its work. The use of vulnerability data presents a significant opportunity to help those living in the most difficult circumstances. Work has been done to understand just how feasible this is, based on consumer attitudes and firms' willingness to make it happen. However, up until now, there hasn't been enough done to fully explore the potential of data sharing to make positive change. This is something that must and can be progressed.

This work was commissioned by the UKRN to explore vulnerable consumers' attitudes towards the identification, collection and sharing of data relating to their vulnerability. Our research has included interviews with professionals, in-depth interviews with vulnerable consumers and focus group sessions.

RESEARCH OBJECTIVES

The key aim of this research is to provide a clear understanding of what vulnerable consumers currently think about sharing vulnerability data. There were also several more specific research objectives:

- To explore consumer attitudes towards the collection, use and sharing of data relating to vulnerability – within and between sectors
- To explore barriers and enablers to disclosing vulnerability data to different firms
- To understand what influences these attitudes and to examine any "red lines" around the use and sharing of vulnerability data between firms
- To explore attitudes towards possible solutions designed to improve outcomes for vulnerable consumers, such as PSR (Priority Services Register) data and Tell Us Once
- To identify underlying principles that vulnerable consumers believe should inform the approach of government, regulators and firms in this area

During the research, the whole 'journey of data sharing' was explored with consumers. The data journey starts with how a vulnerability is disclosed, how it is recorded and stored, and how this could be used by a firm, including the possibility for it to be shared within and between sectors. The research is most interested in understanding the attitudes towards data sharing between firms, both within and across sectors.

This report details our research findings, and subsequent analysis, based on the fieldwork. It's split into a number of sections and sub-sections, but the three key ones are based around:

- Reasons why sharing vulnerability data matters
- Barriers to making this a reality
- Starting points for how this can be achieved

Methodology

There were several important elements:

- 13 industry interviews with representatives of a range of firms and regulators to help understand more about the current industry attitudes to vulnerability and data sharing
- 20 in-depth video call interviews with members of the public experiencing a range of vulnerabilities
- 12 remote focus groups (4 consumers in each group, 2 sessions per group) and online activities with members of the public experiencing a range of vulnerabilities (including those who are currently non-vulnerable)

The topic of sharing vulnerability data is a complex one. In order to gain meaningful insight, it was important to disentangle the different elements that sit behind people's perceptions. We adopted a deliberative approach during the in-depth interviews and focus group sessions where respondents learnt about, and reflected on, new information to provide an informed view.

The consumer voice was at the heart of our research. It was essential to not just ask consumers what they thought, but to suggest different solutions and to challenge opinions. This enabled a deeper level of analysis to help move towards developing the underlying principles vulnerable consumers thought should inform the future of data sharing.

The 68 consumers spread across the UK who participated in the research (20 across the in-depth interviews, 48 as part of the focus groups), live with a range of conditions/ circumstances, including: physical health conditions, mental health conditions, developmental disorders/learning disabilities and challenging life circumstances (for example being a carer or having recently divorced). These vulnerabilities were all either permanent or fluctuating.

It is important to recognise that anyone can become vulnerable at any time in their lives, therefore consumers who are not currently experiencing any form of vulnerability were also included in the research.

CHAPTER 1

The opportunity to improve vulnerable consumers' lives

Lots of vulnerable consumers are struggling. Everyday practices such as reading meters or thinking about bills are harder than they should be. They need and could benefit enormously from the support that is already available from firms. Simple things such as being on a Priority Services Register (PSR) or getting help when travelling can make vulnerable consumers' lives better.

Mary 54,

lives in Cardiff and teaches English to oversees students. Mary previously ran a small business that created bespoke English language courses for individual and small groups of students. Four years ago, Mary was diagnosed with rheumatoid arthritis:

"For a year I was extremely poorly because I couldn't walk very much..."

Things are now better for her as she has been able to learn how to manage her condition.

Mary is on the PSR with her water and energy company. This helps her to feel better supported and looked after:

"...you feel a bit more confident that people understand how important the service is to you..."

Being on the PSR has helped to improve Mary's life since her diagnosis.

Susie 35,

is based in Manchester and lives alone. Susie lives with chronic pain in her back due to a fall in 2002. Susie has also struggled with anxiety, depression and panic attacks:

"I've had injections and tried everything that there is to try... nothing really helps, it's just something I've got used to..."

Telling different companies about her physical conditions has enabled her to be better supported. For example, letting an airport know about mobility needs has allowed her to travel:

"...an airport is a really big place to walk around...I've needed help to sit in a wheelchair".

Susie is also on the PSR with her energy provider:

"...they can get people to come and take my readings for me because I struggle trying to do that myself..."

Sharing vulnerability data between firms, both within and across sectors, is an under-utilised tool that could make a huge difference to some of the most vulnerable consumers' lives. If more firms knew about conditions and circumstances, which could be facilitated by data sharing, vulnerable consumers could get the help and support they need.

However, most consumers, unless they are very vulnerable, are either unaware of, or have misgivings about the support that is on offer. They are also not informed about the positive impacts that data sharing could have on the lives of vulnerable people. Talking with consumers in more vulnerable circumstances, it became apparent that when firms know about their needs, they are able to impact their lives in a positive way. Though some had questions about the safety of information and the practicalities of how sharing would happen, anything that takes some of the burden off their shoulders makes life better and more manageable.

James 48,

lives with two of his sons in Portsmouth. James has sural nerve damage, spinal damage and a brain injury. He also has a diagnosis of depression and anxiety. James used to work as a bricklayer and a roofer but has not worked for a number of years. Although regularly taking medication, using a wheelchair and being supported by his sons helps:

"Pain is in me all the time…the medication masks it a lot but it's always, always there…".

James' sons play an important part in helping him organise his bills and relationships with providers. James was open to the idea of sharing vulnerability data, as if his vulnerability information was more readily available to companies, it would save him a lot of hassle:

"It's not nice having to keep repeating yourself and say the same thing over and over to different people, it's horrible…it's hard to make people understand how bad the situation is…"

James felt that data sharing between firms,

"…would make life a lot easier but that's not the way it [currently] works…"

If companies James was aware of could share data about him, and he could maintain a relationship with his providers (for example over the phone), he could make sure his condition was known about.

As a result of his complex conditions, James never wants to switch providers as he doesn't want to go through the process of repeating himself again. Although this feels like the safe option for James, he could be missing out on better deals or support from other providers. If there were robust data sharing practices in place, this could empower James to think about his providers and if they are offering the best support available

Rita 43,

lives with her husband and their dog in South Wales. Rita describes the area as "lovely and quiet" and she gets on well with her neighbours. She had a car accident in 2015 and has been a wheelchair user ever since. Rita has also been diagnosed with bipolar disorder.

Letting companies know about her situation has made life easier. For example, Rita is on the PSR with her energy provider (EDF) and can't be without electricity as she has a stairlift installed in her home.

Rita was open to the idea of data sharing as any help from companies could make her life easier. Not missing out on support that she was entitled to was also very important to her.

"As long as I'm not getting scammed, it's good if they can get me a discount and it saves me time from repeating myself…"

THE NEEDS OF THOSE WHO WOULD BENEFIT MOST FROM SHARING DATA ARE BEING OVERLOOKED

For an individual who does not regularly rely on extra support from firms, it's much harder to see the benefits of telling a firm about a condition in the first instance, let alone being open to the sharing of this information. **It's much easier for consumers to align themselves with a negative narrative about data sharing**. This narrative - which places vast emphasis on privacy risks and lack of personal control of one's data - currently dominates consumer opinions. On top of this is the issue that many believe big commercial companies are not capable of putting the needs of their customers first.

Chris 26,

lives in a city in Scotland and is currently not experiencing vulnerability. Chris did not trust that commercial organisations could devote time to thinking about the needs of vulnerable consumers:

"… I don't think that good ethics and large business have ever shared a room together…"

Fiona 73,

is based in Cumbria and, like Chris, does not see herself as vulnerable. Fiona felt that there were too many possibilities for something to go wrong when it came to sharing vulnerability data:

"It feels like another hike up into the unknown for me, with too many people [firms] trying to do one thing…I don't feel comfortable with it and I wouldn't if it were me who's information was being passed around…"

Holly 51,

is self-employed and lives in Edinburgh. She found it hard to see how different sectors could be aligned when it came to sharing vulnerability data:

"I think that it can become a bit too complicated and it opens things up for the information to be misused…is there going to be integrity?"

Some also 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.

Adeep 41,

is married, living in London and has a young daughter. At the time of taking part in the research, he was recovering from a recent operation and had recently lost his mother. This had a big impact on day to day life.

When Adeep was discussing the idea of data sharing, he was very concerned that any information shared could result in a society where everything is known about individuals**:**

"I think it ends up being a big nanny state if they [firms] provide all of that help..."

Adeep struggled to see how vulnerability data would purely be used for the purpose it was initially intended for.

Adeep's position is not uncommon; those less vulnerable or with short term issues find it hard to see past their own experience and empathise with those in much more need of help. This is present with a wide range of consumers who are either non-vulnerable, or in a temporary, manageable state of vulnerability.

At present, concerns about the data sharing process are stopping essential progress being made to help those most in need. This was echoed during engagement with firms and regulators. The industry is struggling to move forward due to the idea that consumers are resistant. **The result is a spiral effect where the end goal of effective data sharing seems too complicated to achieve**.

THE MOST VULNERABLE PEOPLE ARE THE MOST OPEN TO DATA SHARING

However, there is a clear relationship between severity of someone's vulnerability, and their openness to disclosing and sharing data. In fact, some of the most vulnerable people feel that that it is a firm's *responsibility* to look out for the most vulnerable and actively try to make a difference to their lives. There *is* resistance to data sharing – but the voices expressing this sentiment are often the ones that don't require as much help. The voices that need to be listened to are the voices of the most vulnerable, who are willing the firms and providers to use and share their vulnerability data in order to ensure they can get as much help as possible.

"Who wants to share their data?"

"No one?"

That's not true.

Those who had experienced firms and providers accessing this information about them had felt the tangible benefits. For example, they valued not having to constantly repeat themselves to different firms when discussing their condition. This becomes tiring; even distressing in certain cases.

Some more vulnerable consumers also feel positive about the idea of **having a “safety net”** if more firms know about their condition. If something was to happen to them or their situation was to worsen, knowing that firms would be able to recognise this and share the information with each other provided another layer of protection.

Ellen 44,

lives with her family in North Yorkshire. She is diagnosed with hypothyroidism, type 2 diabetes and ADHD. Ellen’s youngest son and husband both have autism as well as other conditions. As a result, planning is an important part of Ellen’s life, especially in order to keep her son reassured and calm:

“I have told some of our providers about our conditions…they have been able to support us a little.”

Ellen understood how it could be distressing to repeat yourself to multiple firms when informing them about a condition:

“…it would be difficult to have to repeat your information over and over…”

Natalie 48,

is based in Preston and lives with epilepsy, deep vein thrombosis and endometritis. Natalie works part time as a senior care assistant and finds her role fulfilling. However, Natalie struggles to work full time due to her epilepsy:

"If I work full time it would be too much stress..."

Natalie explained how for a long time her providers did not know about her conditions. However, she now feels reassured that if her condition was to worsen, her providers will help:

"...they [Eon] won't charge me a late payment fee as they understand why it might be late..."

When discussing sharing vulnerability data, Natalie said,

"I can only see the plus side of helping other people" as long as safeguards are in place.

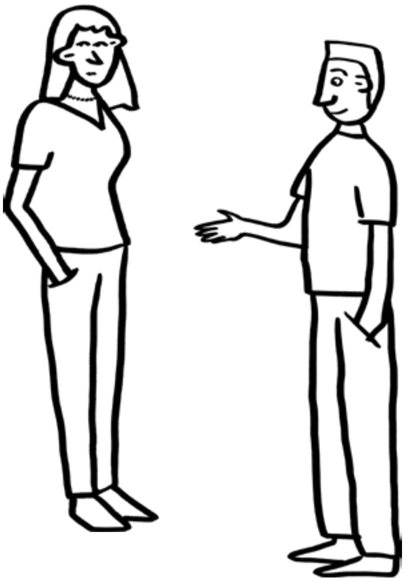
Rej 36,

has ulcerative colitis, anxiety, depression and is financially vulnerable:

"I've had to take time off as well which is an issue, but there are times when I have been bedbound..."

He felt that companies having access to information about his conditions could help him if anything was to happen to him in the future:

"...in the long run it will help me, it's not going to make my life harder, just easier if other companies or organisations know about my medical condition. They are there to help I don't think they are there to discriminate against my medical condition..."



Rej and Natalie exemplify that those who are more vulnerable are actually less concerned about who has access to information about their condition or circumstance. **Those in the most vulnerable situations feel that if more firms know about their situation, they'll have a greater chance of being supported**.

VULNERABLE CONSUMERS ARE SIDE-LINED, MISSING OUT ON SUPPORT

The culture of resistance to data sharing, created by those who are not in need of extra help, is causing those who need support the most to miss out. Some did not receive support until much later or did not receive any at all.

Paul 60,

lives in West Yorkshire and relies on his wife to manage details such as bills and navigating online forms, as he finds online systems confusing. He lives with MS, OCD and anxiety. Paul is not on a PSR with his energy provider, as he didn't know this was an option. This could be something that could help him.

"There was a power cut and I had to contact the National Grid. If they had had my phone number, they could've contacted me to make it easier".

On another occasion, he called his energy provider to request help for reading his meter and he told them about his health condition, MS. However, the staff didn't ask much about his needs or explore if any other type of support would benefit him. They only sent a person to read his meter, as requested.

If Paul had been aware of the support earlier on, their lives could have been made easier. Vulnerable consumers who have missed out on the help that they need, do not want or need to go through this experience again. A starting point could be if staff are trained in a way that ensures they are asking more questions to understand *why* people need the help they do, and if there is anything more they can do – instead of just *whether* they need help or doing what is asked.

The opportunity in short: a culture of data sharing is something to strive for

Whilst there is genuine consumer concern about the disclosing and sharing of vulnerability data, which firms are right to recognise, there is a significant group of people who know about the help that's on offer, value it, and want to see it further improved and utilised.

The most vulnerable people are not only the most in need of help, they are also the most open to the disclosing and sharing of data as a means to get that help.

There is an opportunity right now to make a difference in this space. More consumers in vulnerable circumstances can be helped through data sharing, even if the risks are currently at the forefront of most people's minds. **Regulators and firms can and must work together** to reassure each other and consumers that identifying vulnerabilities and working towards a culture of sharing this information is something to strive for.

CHAPTER 2

The barriers to data sharing

FEAR MEANS THAT FIRMS AND CONSUMERS OVERESTIMATE THE RISKS AND UNDERESTIMATE THE BENEFITS

There is a degree of fear detectable when talking to anyone about data sharing. This is true for consumers, firms and some regulators. 'Data', as will be explored further in this section, is a loaded word that has myriad menacing associations, some of which are reasonable; others which are not. These fears can be allayed when there is more clarity around the data sharing process and what it can do to help. So, it's important to address this head on.

The first step is to break down the fear into individual barriers. It is these barriers, often based on misconceptions, that can and need to be addressed in order to move the data sharing conversation forward – and they exist at each level of the data sharing process, from initial disclosure to wider sharing.

A clear understanding of these obstacles is essential if we are to break the misconceptions down and ensure people are getting the help and support they need.

Consumers' barriers

CONSUMERS HAVE NEGATIVE REACTIONS TO THE TERM 'DATA'

‘Data’ is a contentious word, and people don’t trust it. When it is brought up in relation to sensitive information about a person, it can be a trigger during conversation – reactions can be seen forming on faces before sentences are complete. Once consumers hear the word ‘data’, there is a risk that they double down on more resistant positions.

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.

Kimberley 41,

lives in rural Scotland and at the time of the research had recently been made redundant. Kimberley reflected that

“People are also worried because there are so many scandals about information being stolen and sold…people are generally not trusting…”

Oscar 32,

lives in Huddersfield and currently works part time for a local charity. He suffers from ongoing anxiety and depression:

“There’s too many occasions of millions of people’s information being stolen because someone has skimped on security somewhere…”

Bob 64,

is based in a town in Northern Ireland. He is diagnosed with accurate anxiety and has also taken voluntary redundancy. Bob was nervous about how large companies handle consumer information:

“I’ve heard on the news times where these large companies are selling on details to other companies and I’m very frightened about that…”

Dominic 68,

is not experiencing a vulnerability and lives in a city in Scotland. Dominic felt that

“…lots of trust has disappeared in the last 20 years with the advent of call centres…”

CONSUMERS ASSUME THIS ‘DATA’ BEING REFERRED TO MEANS EVERYTHING ABOUT THEM

Many referred to stories they’d heard or read about concerning big tech companies having access to terrifying amounts of personal information. They find it hard to discern how the issue of sharing vulnerability data is any different. To many, the word ‘data’ is innately menacing, and results in the consumer losing control and losing privacy.

It is, however, important to note that when people think about this more, and when the nuances of data sharing are laid out for people, they tend to engage more with the benefits, and understand why it is important. **These attitudes, as will be further explored later, can be changed.**

Nick 52,

lives in Cardiff and cares for his father. He works as a property developer which was difficult during the Coronavirus pandemic. Nick was reluctant to pass on what he considers “personal information.” He referred to information that was handed over to firms as just being

“more and more... everything about you...”

Nick was very suspicious when it came to talking about data.

Dan 46,

lives in Sheffield with multiple sclerosis. Dan was worried that large firms already know everything about consumers:

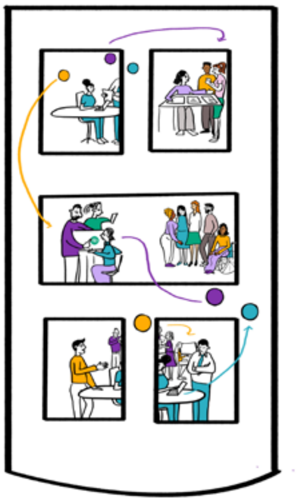
“Facebook has access to a million data points...they know everything already...”

WHO HAS ACCESS TO THE DATA?

One widely held misconception is that once the vulnerability data is disclosed, everyone at the company/provider has access to it. Consumers were asked directly who they thought would have access to data within an organisation:

Information is accessible by **one team**

Information is accessible by **several teams**



Information is accessible by **the whole company**

Most said they thought that anyone could access it. They felt that vulnerability data should only be kept within the appropriate department. However, they worried that it might be shared around a firm with few checks in place (finding its way, for example, to marketing teams).

Val 42,
lives in Northern Ireland with her children and cares for her elderly mother. Val has lived with a number of mental health conditions since she was a teenager. Day to day things are difficult for Val:

"I just have to get up and get on with it and do my best."

Val was concerned that any information disclosed would be readily available to the whole company, with few checks in place:

"I can't see them [firms] having different computer systems for different teams…"

This made Val fearful of revealing too much to firms.

Charlie 59,
lives in rural Wales and at the time of the research had a temporary physical health condition. Charlie thought:

"Possibly everyone in the organisation would have access to our data. I've had access to things I shouldn't know in some places I worked…"

Harriet 56,
is from Cardiff and cares for her mother. Harriet was concerned that there were few limits in place when it came to disclosing any information to a firm:

"All the customer services in the world have got it [vulnerability information] …"

Some of those with mental health conditions are more concerned that firms might use their conditions against them. They're often worried that firms may not have adequate training in place for staff members. This could result in staff not knowing how to talk to them about, or help them with their condition. In addition, some had concerns about being treated differently as a result of staff's potential pre-conceptions about their condition.

Keir 62,

is living in Yorkshire and has a PTSD diagnosis, sleep apnoea, depression and hearing loss. Keir felt:

"If you have a mental illness, it might affect your everyday life, do you take the big risk [of disclosing] given the stigma that there is around mental illness?"

Overall Keir felt that "...it's none of their [firms] business..." as firms can't do anything to help.

Val 42,

is diagnosed with a number of mental health conditions. During group discussion Val said,

"I wouldn't disclose it [MH condition] as you don't want to have a label and I don't know how other people see things like depression..."

Val was concerned that disclosing a mental health condition to a firm would result in being labelled.

Harley 55,

is diagnosed with Bipolar Disorder and lives in a town in Northern Ireland. Harley said

"I wouldn't reveal unless it was necessary...part of a mental health condition is that you feel apart from everyone so you don't want to go into too much detail..."

Harley was not comfortable telling commercial organisations about his mental health.

So, the first major barrier is that consumers are reactionary about the word 'data' and immediately associate it with misuse and abuse of privacy. This reaction is understandable given the narrative often peddled around data leaks and abuse of privacy. However, this story lacks nuance and is too broad– it needs breaking down and clarifying. Once there is more clarification, and the misconceptions about what this data *is* and *who* has access to it are explained, progress can be made. Consumers need to be reassured, and more detail on how to do this will be explored in the opportunities section of this report.

CONSUMERS ARE UNCLEAR ON THE BENEFITS OF DATA SHARING

Many people believed that firms could do little for them beyond providing whatever service they paid for, and thus had not actively tried to seek out support. **Most didn't expect firms to go out of their way to help.**

They also don't usually know about PSR's and other forms of extra help available. This is even true for those who had been vulnerable for some time. If these people had been known to providers already, they could have accessed the available support.

Amy 32,

lives with three young children and her husband in Northern Ireland. She has been diagnosed with rheumatoid arthritis for 2 years and is currently not working. The family are based in a very rural area and live off out of work benefits and savings.

When Amy was first diagnosed, things were very difficult. and she was in lots of pain. Taking medication has helped to manage pain and Amy is now more mobile. During an in-depth interview Amy learnt about the PSR for the first time and was keen to sign up:

"I didn't know it [the PSR] existed, but I'll check if my provider has it so I can sign up. They should 'advertise' it more, so people know that it is a thing..."

Val 42,

is diagnosed with a number of mental health conditions.

"I never ever thought to tell people about my illness, I never felt like I had to, or it would benefit me..."

Val felt that firms could do more to make consumers feel comfortable and aware of the support that was on offer.

Consumers who are either non-vulnerable, or who are able to support themselves, often feel that it is up to an individual to be proactive if they want a company to know about their condition. These consumers don't think companies are obliged to identify the most vulnerable members of our society. Therefore, the notion of sharing an individual's vulnerability data seems redundant.

Clearly there's both a lack of awareness of the support and a lack of understanding around the societal benefits. In order to change this, there needs to be more clarity around the kind of help on offer, and the less vulnerable consumers need to be aware of the massive societal benefits that come with companies actively identifying their vulnerable consumers.

Diana 39,

lives in Glasgow with her husband and two children and works part time. At the weekends she enjoys being out and about with family. Diana is not currently experiencing a vulnerability. Diana felt that:

"It's nobody's business, it's up to the individual to tell who they want to tell…it's up to the person to apply for it [support]…"

Sammi 34,

lives in Stockport with her fiancé.

When Sammi took part in the research she was recovering from a recent operation. As with Diana, Sammi explained that

"…they [firms] would have to really rely on a customer contacting them 80% of the time. People should tell them if they feel like they need to - unless they have a severe mental health issue and can't do it themselves."

THE BENEFITS OF SHARING DATA *BETWEEN* SECTORS IS NOT CLEAR

Consumers are quick to anticipate complications - even for firms within the same sector - with sharing vulnerability data. This includes concerns about different companies using different systems or having different policies in place about access to data.

Once again, consumers tend to focus on the perception that this is too practically difficult to achieve. For example, many are quick to jump to the conclusion that not all data is relevant for multiple firms – as Annabel suggests below. There is also a concern about the relevant information being passed on once someone leaves a firm.

Adeep 41,

was recovering from a recent operation and had recently lost his mother when he took part in the research:

"They're [firms] all going to have different policies internally...one company could be strict, one company could be relaxed..."

Annabel 44,

is living in rural Scotland and has osteoarthritis. Annabel also cares for her partner who has prostate cancer:

"I might not want the airline to know the same information as the energy provider. You might want different people to know different things, some you might not want to know anything. If you change provider would it be passed on?"

David 31,

is a teacher at a hospital school in Oxfordshire and does not see himself as vulnerable. David was concerned that

"Different companies might have different approaches..."

He felt that one firm might choose to help a vulnerable person, but another might not have the same processes or support in place

Sammi 34,

was recovering from a recent operation at the time of the research. Sammi would not be comfortable with other providers sharing information with banks:

"With banks you have to be really careful because it's all about your money..."

When presented with a tangible example, almost all consumers could see the benefits of data sharing happening.

For example, consumers were shown the death notification service as an instance of data sharing that is currently in place. In this situation, the vulnerable person is the bereaved person. The service allows the bereaved person to notify a number of banks and building societies of a person's death at the same time. Its aim is to make the process quick and easy for the user in a time of grief and stress.

Sian 29,

lives in a small rural area outside of Glasgow. Sian currently lives alone although she has a very strong network of friends and family. During 2020, Sian went through a relationship breakdown. Sian could see the benefits of the death notification service:

"...it would definitely be a benefit to a family member, making a horrible time better."

Jake, 59,

has atrial fibrillation, type 2 diabetes and is based in rural Northern Ireland. Like Sian, Jake could see the benefits of the death notification service:

"I think it will be very useful, not only for banks...it would make life a lot easier..."

Despite most consumers being open to the idea of the death notification service, they struggled to be as open with the idea of sharing vulnerability data more broadly. The lack of tangible evidence for sharing vulnerability data across a range of firms and sectors made consumers hesitant to open up to the potential benefits.

CONSUMERS ARE SCEPTICAL THAT FIRMS ARE HELD TO ACCOUNT

Some assume that holding vulnerability data and sharing it is always in the firms' best interests and not helpful for consumers. Many feel that firms are purely commercial entities that would always put their own needs ahead of consumers. Others fear that information could be shared with whoever a company chooses, and that there were no rules in place to monitor this. Most are also concerned that vulnerability data can potentially be sold on to shape advertising.

Larry 45,
lives in a town in Essex and is diagnosed with dyslexia and dyspraxia. Larry struggled to see how firms would ever share data with the sole purpose of helping a consumer:

"The only benefit would be to the company not the consumer..."

Douglas 31,
has a diagnosis of Keratoconus and lives in Surrey. Douglas was concerned about the potential for advertisers using vulnerability information:

"In the right hands, this type of responsibility is fine. But there are too many people, like advertisers, that want to use this information for the wrong reasons."

When discussing the recent example of water companies not being allowed access to the Coronavirus shielding list, many felt this denial of access was a good thing. For them, there is always a risk that companies are acting as commercial entities first and are keen to make the most of a situation where they can gain access to data, rather than helping vulnerable people. And then there's the persistent fear that the data could be at risk of being stolen or manipulated.

Chris 26,

was not trusting that firms were acting to only help vulnerable people during the pandemic:

"...companies will try at every chance to get the information... you just don't trust the companies at all to use the information correctly..."

Adeep 41,

was recovering from a recent operation and had recently lost his mother when he took part in the research. Adeep felt that

"If you set a precedent like that [sharing the shielding list] where does it stop..."

When asked about accountability and who oversees the data sharing processes, most consumers were unaware that there are safeguards and limits in place. **So, on top of their assumption about the widespread risks associated with data sharing, many feel that firms are not penalised if data is mishandled**. Few knew about the ICO, although were reassured when they learnt about it. It may not come as a surprise that many consumers didn't know about the ICO, but their general lack of awareness of any kind of accountability in place is striking. More needs to be done to ensure people are aware of these safeguards in order to help change consumers' initial resistance.

This general distrust of firms in part stems from a concern that those who work for firms are not experts when it comes to dealing with vulnerabilities. Many consumers who had not experienced disclosing vulnerability data to firms automatically assumed that "firms are not Doctors" - so should not be trusted with this information.

Fiona 73,

is based in Cumbria and does not see herself as vulnerable:

"Even though they have their terms and conditions and small letters, no one reads that. And also, I'm not sure if anything would happen if they don't comply to that..."

Shauna 54,

lives in London with her children and at the time of the research was recovering from a recent operation. Shauna felt that

"Customer services are so generic, not medical people, they don't understand."

Tammy 50,

cares for her husband in Cardiff. Tammy did not know about the safeguards that were in place to protect her personal data:

"...it [data sharing] should be policed more."

CONSUMERS ALMOST ALWAYS DEFAULT TO CONSENT

Consumers think that they “always have to be asked first” before anything is done with any information that they provide. If any part of the data is to be used or shared, consumers think that they need to “say yes”. This is true from the more vulnerable to the non-vulnerable, but is especially the case for those who do not currently rely on support.

Whilst it is a valid concern to be anxious about having control of your personal data (especially relating to vulnerability), being bound to consent makes it hard for consumers to understand how data sharing could ever work if they are not always consulted. When presented with the other legal bases for processing data, they initially struggled to see how these could ever be used whilst also keeping their best interests safe.

Giselle 64,
lives in North London and has worked in social care for 18 years. Giselle's husband passed away 12 years ago, and she now lives with one of her two daughters. Giselle is diagnosed with type 2 diabetes.

As a result of working in social care, Giselle felt that she a good understanding of how medical information is used. When discussing data sharing, Giselle felt that firms would need permission in order to do anything with consumer information:

"If it's without my consent, I would get angry!"

Sian 29,
had recently been through a relationship breakdown at the time of the research:

"I would want to choose who I share the information with...I wouldn't want them [companies] to share it with others unless they specifically ask me..."

Sammi 34,
was recovering from a recent operation at the time of the research. Sammi felt that it was important for firms to always have consent:

"No, I think they always need to consent of that person...if the person isn't' getting back in touch then that's their doing..."

Due to the fear and lack of understanding around how data is stored and managed within a firm, most default to thinking: 'keep me constantly up to date about how my data is being used'. Without prompting, it was hard for them to think through the consequences of firms relying on individual consent, and how this could result in missing out on benefits or support they may be entitled to.

In some cases, people could see how "emergency situations" may necessitate information sharing without consent. But even then, some had reservations and concerns that companies should not be trusted to act in a consumer's best interest.

Vivian 34,
lives in Leicester and has a range of conditions including fibromyalgia and central sensitisation. Vivian was concerned about circumstance where consent was not used:

"When there are things like 'your life is at stake' there needs to be a loophole, but who decides what's an emergency?"

Barriers for firms and regulators

The possibility of data sharing amongst firms and regulators is currently very sector specific, with utilities being further ahead in terms of the culture around sharing vulnerability data. There are several barriers facing firms and regulators preventing the data sharing conversation from moving forward. These challenges are linked to some of the barriers expressed by consumers.

It should not go unmentioned that some firms and regulators have been making progress with regard to sharing vulnerability data. Furthermore, the COVID-19 pandemic has acted as a trigger to demonstrate how important data sharing can be. This willingness from firms and regulators to use and share vulnerability data should be captured and **momentum should not be lost.**

FIRMS ARE NERVOUS NAVIGATING THE LEGISLATION

The legislation around data sharing exists for a reason as personal data must be kept safe and secure. However, certain firms and sectors are unclear of the boundaries and guidelines, and thus are more reluctant to prioritise data sharing.

One regulator highlighted how some firms can use legislation as a reason to *not* progress data sharing, due to fear of breaking the rules. For example, GDPR can cause firms to take the utmost caution and not take proactive steps. However, the representative of the regulator explained that *"…if they [firms] looked at the detail, they would find that it doesn't have to be a barrier…"*

As with consumers, firms lack confidence when considering the use of other legal bases. As a result, they still rely on consent. Some firms have misconceptions about when it is appropriate to use the different legal bases, assuming that certain bases are for certain sectors. However, the ICO clearly states that the lawful bases are written for certain types of processing, rather than types of organisation. Firms would benefit from having some more clarity in this area so that they can more readily and effectively use the different legal bases to share vulnerability data.

When examples of the other bases for consent were clarified, consumers were able to see their utility. One respondent who cares for his father was able to see how, for example, public task was an important legal basis for the sharing of data in the event of a deadly disease. Clarity from about the legal bases at both the consumer and the firms' level would help to enable their use going forward.

THE NARRATIVE OF CONSUMERS' RESISTANCE TO DATA SHARING MAKES IT DIFFICULT FOR FIRMS TO MAKE CHANGE

A number of firms identified the challenges of "chasing consumer disclosure" in the first place, and there is a consensus amongst some that consumers may not be interested in data sharing becoming a reality. If firms feel that consumers are reluctant, then why try to make change happen?

The narrative of consumer reluctance can stem from media narratives and some of the previous research on this subject, which points to consumer scepticism and distrust of firms when discussing data. For example, a recent BritainThinks report found that the majority (81%) of participants are concerned about organisations selling data to third parties.[2]

In particular, firms and regulators in the financial and telecommunications sectors generally hold the view that consumers are less confident sharing personal information with more "commercially orientated" organisations. There is a feeling that consumers may be nervous about financial institutions using personal information in a way that could impact the price of a product.

If change is to happen, different sectors must begin to share models of best practice and foster an environment where positively sharing vulnerability data is encouraged and does not provoke nervousness. **Firms and regulators also need help to see that there are consumers who would value progress being made.**

FIRMS AND REGULATORS WORRY ABOUT THE PRACTICALITIES OF WORKING TOGETHER

There *are* some examples of firms working together to achieving data sharing. For example, this has been piloted and carried out further by United Utilities and Electricity Northwest.[3] In this case, the firms are able to use needs codes to transfer PSR data in a succinct way.

However, a number of regulators and firms noted that as the definitions of vulnerability and the way the information is recorded are not standardised, firms and regulators across and within sectors find it hard to see how progress can be made.

---

[2] 'Control, Alt or Delete? Consumer research on attitudes to data collection and use', 2018, https://britainthinks.com/pdfs/Consumer-Data-Research-report.pdf

[3] UKRN, 'Making better use of data to identify customers in vulnerable situations', 2018, https://www.ukrn.org.uk/wp-content/uploads/2018/11/UKRN-Making-better-use-of-data-to-identify-customers-in-vulnerable-situations-follow-up-report.pdf

Different regulators have varying levels of control when it comes to monitoring vulnerability. For example:

OFCOM

Ofcom do require companies to have policies in place for vulnerable consumers, and providers must include details for how they record the needs of vulnerable consumers. However, the way these needs are recorded is up to the individual providers.[4]

OFGEM

In contrast, **Ofgem** require distribution network operators, through license obligation requirements, to establish and maintain a Priority Services Register to support vulnerable consumers.[5] The energy sector also operates within the parameters of industry developed needs codes for both gas and electricity.[6]

OFWAT

In the water sector, **OFWAT** have overseen many companies expanding their PSR, ensuring more vulnerable customers can be identified and helped. Plenty is being done is this space, but the variance of detail around this can make some regulators outside of utilities unsure of their ability to make sharing happen within their sector.[7]

FCA

However, regulators like the **FCA** have been doing something similar, and have provided consultation and advice to financial firms on how to best identify and help vulnerable consumers, which, as they say, will have become even more pressing since the outbreak of COVID-19.[8]

---

[4] 'Treating vulnerable customers fairly: a guide for phone, broadband and pay TV providers', 2020, https://www.ofcom.org.uk/__data/assets/pdf_file/0034/198763/treating-vulnerable-customer-fairly-guide.pdf

[5] 'Standard conditions of the Electricity Distribution License', 2020, https://epr.ofgem.gov.uk/Content/Documents/Electricity%20Distribution%20Consolidated%20Standard%20Licence%20Conditions%20%20-%20Current%20Version.pdf

[6] 'Vulnerable consumers in the energy market: 2018', 2018, https://www.ofgem.gov.uk/system/files/docs/2018/11/vulnerability_report_2018.pdf

[7] "Customers in vulnerable circumstances" - https://www.ofwat.gov.uk/out-in-the-cold-next-steps/customers-in-vulnerable-circumstances/

[8] "Guidance Consultation and feedback statement: Guidance for firms on the fair treatment of vulnerable customers", 2020 - https://www.fca.org.uk/publication/guidance-consultation/gc20-03.pdf

When considering cross sector sharing, there are also different *types* of detail that firms need to know to support vulnerable people. For example, an airline may only need to know about a consumer's mobility needs to provide support. Whereas a bank may need to have a much more holistic understanding of a consumer in order to provide support. This sticking point can make it hard to consider how data sharing would practically work across different sectors. There are also questions around how long data will "stay on file" if information is shared, and who is responsible for managing any sort of shared database between firms.

Different sectors also offer different types of support to vulnerable people. Utilities can be seen to provide "lifesaving" services (for example an electricity supplier needs to know if an individual is on a dialysis machine). The emphasis on this kind of support makes some other types seem less relevant, and can detract from the determination on the part of some firms to make this positive change, as they don't get the same recognition or sense of importance from consumers.

There is currently a dearth of positive data sharing examples for firms and regulators *across sectors* to draw on. As a result, it is easier for some firms to avoid the issue of data sharing and be wary of moving the conversation forward.

CHAPTER 3

How to move forward

There is genuine consumer concern about the disclosing and sharing of vulnerability data. Most consumers are initially resistant to disclosing vulnerability data, and sceptical about firms sharing this information between each other.

Firms are right to recognise this concern, as the nature of the information can be sensitive and personal. This is why, despite there being recognition amongst firms and regulators of the efficacy of data sharing, the barriers have proved hard to overcome.

Data sharing is not a new concept and has been on the agenda for some time, however, the issue has reached a point where it seems impossible to fully achieve. It's true that data sharing will be difficult to implement due to the dynamic and flexible nature of vulnerability data, and the range of different firms and sectors that are involved. Progress has somewhat stagnated and this is partially the result of firms running into technical difficulty.

However, most firms and regulators want change to happen, there just needs to be a united drive to move the conversation forward. For example, when thinking about the legal bases in place, regulators mentioned how it could be helpful to have some sort of "Q and A" to lay out what firms can and can't do in more basic terms. The desire to make change happen is present but needs to be acted on. The forthcoming ICO guidance should be a big help here.

It's not only firms and regulators that are ready for positive change. There is also a group of consumers who know about the help that's on offer, value it, and want to see progress. As mentioned earlier, some of the most vulnerable consumers – consumers who need the most help – have suggested that it is a firm's duty to try to help them, and their openness to data sharing is evidence of this desire to help to move things forward.

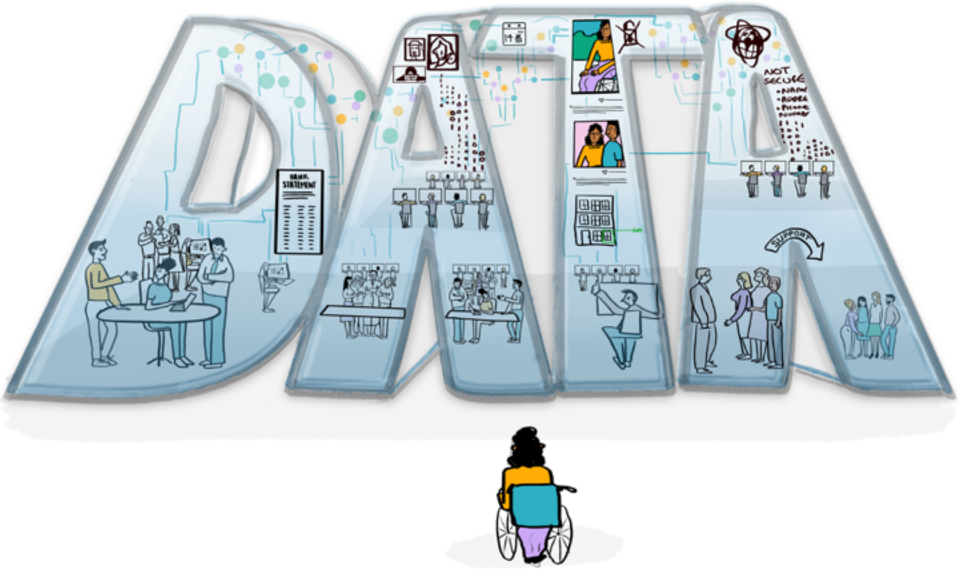
The barriers articulated within this report can be addressed and overcome. What's more, **consumers within the research who were initially averse to firms sharing vulnerability data were much more open to change once they understood the potential benefits, and there was more clarity about the nuances of the data sharing process.**

With consumers on side, and firms wanting to be able to help make a difference, there's nothing stopping significant change, where previously progress has been slow.

The findings from this research have produced starting points for how the key barriers can be tackled. The final part of this report will outline these recommendations.

Don’t call it ‘data sharing’

The word ‘data’ can be intimidating…



…and can hide the fact that people are trying to help.

Both consumers and firms feel concerned and pressured when it comes to discussing "data". This fear arises, in part, from the use of the term in different contexts (e.g. websites, social media, financial services) which not everyone understands. Fear also stems from misinformation, fuelled by the media and a lack of confidence more generally about how personal data will be used.

Across our sample, it was only those who has either experienced disclosing vulnerability data or worked in a relevant field (e.g. education or the police) who felt confident discussing the topic.

Therefore, a few changes to the technical language used when engaging consumers and discussing internally will start to boost confidence and trust amongst a wider audience. As a starting point, it could help to move away from the term "data" when discussing vulnerabilities, as this throws up negative associations for both consumers and firms.

A reframing of data sharing should be:

- **Outcome focused** – highlight the support/benefits that it will enable
- **De-stigmatising** – feel relevant and relatable to everyone
- **Give the consumer agency** – helps the consumer to feel in control
- **Human** – humanise the language
- **Clear on the firms' responsibility** – communicate the firms' responsibility to protect consumers

For example, instead of referring to 'sharing your data' using language such as 'sharing what works for you' may lead to more support from consumers, as well as reducing fear within firms.

USE A NEEDS-BASED APPROACH

Individuals are much more comfortable when vulnerability data is stored and shared as *needs* rather than in relation to specific conditions or circumstances.

At first, some feel that firms should hold the least amount of information possible on a consumer – whether someone is "vulnerable" or "non-vulnerable".

Some are also worried that more detailed descriptions of a consumer's vulnerability are more susceptible to hacking if information is shared.

Oscar 32,

lives with ongoing anxiety and depression. Oscar felt that when it came to disclosing information to a firm, minimal information was important:

"...the less specific the better for me, privacy protection is my thinking on that..."

However, most understand that only knowing someone is "vulnerable" or "non vulnerable" is not enough detail to provide adequate support.

David 31,

is a teacher at a hospital school in Oxfordshire and does not see himself as vulnerable. David expressed the opinion that it would be "useless" for firms to only know if someone was vulnerable:

"What does it mean? What do you have to do for that person?"

Deb 56,

lost her job as a result of the Coronavirus pandemic and suffers from migraines:

"Vulnerable can mean various different things...I suffer from migraines and I'm completely incapacitated for a few days and then I'm fine again..."

Recording data relating to needs made consumers feel much more confident that the information would be relevant across firms and would also be safe. This aligns with progress that has already been made in this space - for example, the energy sector's needs codes (which details the specific needs people with certain conditions may have, making it a more needs-specific experience for consumers, rather than condition-specific). Holding information relating to needs felt like the right balance of storing information in a non-intrusive, but useful way.

Sam 54,

has a serious back injury and is diagnosed with depression. Sam felt strongly that firms only need to know the needs of a vulnerable person:

"I don't see why they [a firm] need to know that they [the consumer] have depression and cancer, purely that they need time and possibly physical assistance..."

Ellen 44,

is diagnosed with hypothyroidism, type 2 diabetes and ADHD. Ellen felt that

"The information behind it [a condition or vulnerability] is not what's important or necessary... it's how it impacts you and what support you need..."

BUILD EMPATHY FOR THOSE WHO WOULD BENEFIT FROM DATA SHARING

From talking to people with diverse vulnerabilities, only those who rely on support are fully aware of what is on offer. It often came as a surprise that firms offer a range of support for different vulnerabilities. This made it difficult for some people to appreciate how impactful data sharing could be for those in need.

Firms must be better at communicating the kinds of support they can offer people, and the impact this can have on their lives. Once consumers know of the help that is on offer, and its value to vulnerable people, it can change their perceptions of how firms treat those in need and make a difference to their lives.

With greater awareness of how firms can support those who need it, consumers will be able to better conceive of the benefits that would come with firms being able to share information between them.

Charlie 59,

lives in rural Wales and at the time of the research had a temporary physical health condition.
Charlie had not thought about how the sharing of information enables vulnerable people to receive the support they need:

“...at the train station, if somebody with a wheelchair’s going to turn up, I had no idea that they [a train company] were informed beforehand...”

Maeve 50,

lives in Manchester and has permanent nerve damage. At the end of the focus group sessions Maeve said

“I’ve learnt a lot to be honest, I’ve never really thought about how providers can help if they know your situation...[energy or water] providers actually coming into your home, thinking about that now I think it’s ideal for them to know...”

COMMUNICATE MORE CLEARLY THE SAFEGUARDS IN PLACE

Consumers are largely unaware of the safeguards in place to keep their data safe. Once consumers are made aware that firms are accountable and monitored by organisations such as the ICO, they become much more confident and feel reassured that firms don't just do as they please. The protections in place must be communicated to consumers.

Some of the other safeguards consumers say would be necessary for them to feel reassured are:

- Clarity about what type of vulnerability data is being collected, stored and shared
- Guarantees about how any vulnerability data would be used
- Clarity about which organisations data would be shared with
- The ability to see who has your information at any given time
- Confidence you'd be able to remove the information if needed

Shauna 54,

was recovering from a recent operation at the time of the research. Shauna was not aware of the safeguards that are in place:

"I haven't heard of the ICO, it's good to have an organisation that oversees and has an overview of what's going on."

Maeve 50,

lives in Manchester and has permanent nerve damage. Maeve did feel more confident once she was more aware of the protections in place:

"It's definitely reassuring to know; I've not heard of any of this [the safeguards] before..."

Annie 42,

is based in rural Northern Ireland and lives with chronic bronchiectasis and scoliosis. Knowing about the ICO did make Annie feel more confident:

"It's good that they [the ICO] are there, at least there is something there to hold companies to account..."

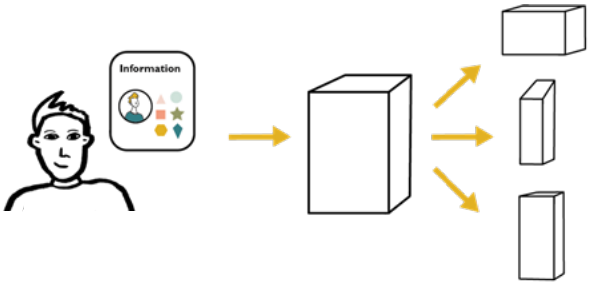
Harriet 56,

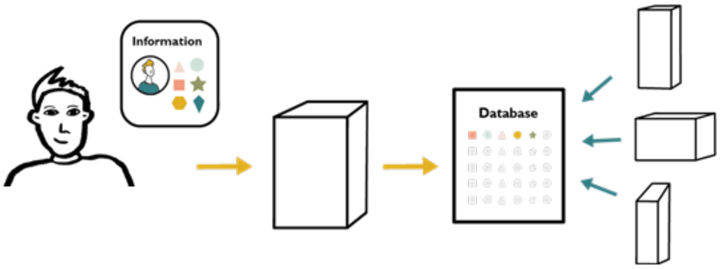
is from Cardiff and cares for her mother. Harriet felt that

"they [firms] would need to be able to guarantee it would not be used in a negative way, and only be shared with people I am happy for it to go to."

USE A DATA SHARING MODEL THAT GIVES CONSUMERS CONTROL

During the research a number of data sharing models were tested with consumers. These models are based on ideas from the "Sharing is caring? Could data-sharing improve the support provided to customers in vulnerable situations?" report published in April 2018.[9] The models tested were company to company sharing, a customer facing vulnerability register/database, and a third-party inter-company database.





Consumers preferred a data sharing model where they could input, have access to and edit their information. They also wanted the ability to oversee which firms have access to their data. A customer facing vulnerability register/database made the majority of consumers feel most comfortable. Some consumers could point to potential flaws. For example, a reliance on the individual to make sure that the information is recorded correctly and kept up to date, which may be challenging for some individuals, and the potential safety risk of having all the information in one place.

---

[9] http://www.bristol.ac.uk/media-library/sites/geography/pfrc/pfrc1804_sharing-is-caring-exec-summ.pdf

However, this idea presented consumers with an opportunity to know exactly where their information was and who had access to it. The idea of a database being overseen by one 'independent' organisation, with clear policies for storing and using the data, was also reassuring.

Annie 42,

lives with chronic bronchiectasis and scoliosis. When discussing data sharing models, Annie commented that

"I prefer the database...you know exactly what information you're inputting."

Annie wanted to have control of any information that might be inputted to a potential register/database.

Annabel 44,

is living in rural Scotland and has osteoarthritis. Annabel also cares for her partner who has prostate cancer.

Annabel felt that a consumer facing register/database would allow her to feel confident in the knowledge that her data was safe:

"...you tick which group of providers you're consenting to having access to your information..."

Ellen 44,

is diagnosed with hypothyroidism, type 2 diabetes and ADHD. Ellen felt that

"If there were very clear parameters about how that [a customer facing register/ database] would be used, I think the database would be a good option..."

Having a clear outline of how a customer facing database/register would be used and who would have access to the information was important to Ellen.

BUILD CONFIDENCE USING LEGAL BASES

Alongside promoting consumer trust, it is important to help firms and regulators feel confident when using the data protection legislation that is in place. Firms need to be given guidance when it comes to the role of the different legal bases and when they can and can't be used. The ICO has already made progress in this space, for example with the Data Sharing Code of Practice. **Firms need to be reassured that data protection should not stop the sharing of vulnerability data.**

Consumers similarly need help to see the relevance and use of legal bases other than consent. Once consumers start to gain a basic understanding of how the other legal bases could be used, they tend to move beyond their fixation with consent. This is an important step in enabling consumers to envisage a world where sharing vulnerability data is common practice.

Vivian 34,

has a range of conditions including fibromyalgia and central sensitisation. During a focus group session, Vivian could understand the reasoning behind the legal bases other than consent:

"They [different legal bases] do take away some of our 'civil liberties' but sometimes it's needed; there's reason why it needs to happen..."

Annie 42,

lives with chronic bronchiectasis and scoliosis. As with Vivian, Annie was able to move beyond only thinking about consent:

"I know it's [different legal bases] there trying to protect me and protect the whole country as a common good...I kind of trust that these systems are transparent enough..."

Consumers understand the negative implications of firms always relying on consent if anything happens to the vulnerability data. For example, many appreciate that firms having to go back to consumers each time something changes uses up significant resource. Furthermore, consumers understand the risk of a vulnerable individual missing out on support if consent is standing in the way.

Gil, 68,

lives in rural Northern Ireland with Parkinson's. Gil could see some of the problems with firms relying on consent:

"They're [firms] going to find it time consuming, and they're going to find it difficult to get on with tasks they're trying to do..."

Felicia 43,

lives in Exeter and is not experiencing a vulnerability:

"From a customer's perspective, if you think about how many firms your signed up to, would you get phone calls from them every week?"

Felicia could see how it would be frustrating to be contacted by a firm each time something was to change or be shared.

Kimberley 41,

lives in rural Scotland and at the time of the research had recently been made redundant. Kimberly could understand the problem with relying on consent in relation to the Coronavirus shielding list and helping vulnerable people during the pandemic:

...with the shielding people, lots of GPs have information but lots of them [the people] might be living alone...if they were relying on consent in that scenario that would not be very helpful, so the public task is probably in order..."

MAKING THE MOST OF THE OPPORTUNITY

There is an opportunity right now to make a difference in this space. Those who are reliant on support agree that firms have a responsibility to offer these services and continue to work to make the lives of vulnerable people easier. Data sharing is an essential part of making this a reality.

The starting points presented above, for how the key barriers to sharing vulnerability data can be tackled, aim to provide stimulus to the data sharing conversation. Firms and regulators should work together, taking into account the voice of consumers, to ensure that progress is made, and data sharing can be utilised to its full capability in the future.

Specifically, firms and regulators should work together to:

- **Reframe the language around data sharing**
- **Use a needs-based approach that is consistent across sectors**
- **Help consumers to understand and empathise with the benefits of data sharing**
- **Better communicate the safeguards in place**
- **Use a data sharing model that helps consumers feel in control**
- **Ensure firms and consumers feel confident using the different legal bases**


SUPPORT