

# DSPT

Better security.  
Better care.



# It's my information: keep it safe!

What people who use care services and their families say about data protection and cyber security

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[www.digitalsocialcare.co.uk/bettersecuritybettercare](http://www.digitalsocialcare.co.uk/bettersecuritybettercare)

# 1. Introduction

Care services need to keep a lot of personal information about the people they support. It helps them to understand what care and support people need and want. But it's also very important that they have the right measures in place to keep that information safe, and that they only use it and share it in the right ways.

In addition, instead of just using paper records, care services are doing more and more digitally. It is therefore getting more and more important for care services to protect their electronic records from cyber crime. This is where criminals try to steal personal or financial information.

This report tells you about a project which spoke to a lot of people who use social care and to family carers about the information their care services keep about them, and about how their care

services use and look after that information. It is about data protection and cyber security.

The project was run by **Liverpool Social Care Partnership (LSCP)** in 2022. It was commissioned as part of a wider programme to improve data protection and cyber security amongst care services – called **Better Security, Better Care**.

The project asked people if they knew what information their care services keep about them, and if they knew how that information is used and looked after. It also asked people how important they think managing people's information is.

This report tells you what the project did, and what it found out. It suggests some things that could be done in the future as a result of what people said to the project.



## About the Better Security, Better Care programme

This project was funded by the **Better Security, Better Care** programme. This is a national programme to help care services for adults in England to check and improve their data protection and cyber security. The programme provides national guidance, resources and webinars. It also gives funding to local care sector organisations so that they can help care services in their local area.

Better Security, Better Care is funded by the **NHS Transformation Directorate**. The **Local Government Association**, which represents local councils is also part of the programme. The third main partner is **Digital Social Care**.

Digital Social Care is a project run by care organisations for care organisations, covering everything to do with data protection and digital technology in care services. It is led by several of the **national trade associations** working together.

*“Never thought about information safety influencing my choice of care providers before now, but it is concerning because of cyber crimes, cloning of IDs, wars etc. It is something that I would now 100% take into account.”*

## 2. How the project reached out to people



**Liverpool Social Care Partnership contacted people who use support services, family carers, care and support providers and organisations who are in touch with people who draw on services.**

This included care organisations, advocacy organisations, Age Concern, Citizens Advice and local Healthwatch organisations.

Around 60 organisations shared a questionnaire with their contacts. (See the Appendix at the end of this report for more information.)

Three organisations gave extra help:

- A charity supporting people with brain injury allowed researchers to meet people who use their services and family members and complete the questionnaire with them.
- A charity running local keep fit classes for older people invited researchers to attend and complete the questionnaire.
- Journey Enterprises, a charity which supports people with learning disabilities organised four meetings between the researchers and people supported by the charity. It also encouraged people to complete an easy read version of the questionnaire.

### The questionnaire

Altogether, 52 standard questionnaires were completed. In addition, over 60 easy read versions of the questionnaire were also completed.

All of the questions had YES/NO answers. However, some people answered with a sentence, rather than just a YES or a NO. Where that happened, the project looked at what had been written and worked out, as far as possible, whether the answer should be counted as a YES or a NO.

Of the 52 people who completed the standard questionnaire:

- 29 (56%) were people who use care services
- 23 (44%) were family carers
- 28 identified as female
- 23 identified as male
- 1 preferred not to select a gender.

Of the 29 people who draw on care services:

- 18 were aged over 65
- 11 were between 18 and 64.

### Discussion groups and workshops

The project also wanted to talk in more detail to some groups of people. It therefore:

- held three focus groups, giving people the chance to talk about things in more detail (this included older people and some younger adults).
- arranged for some people to come to a training session on data protection and cyber security, and it used the training session as a chance for some more discussion (this included older people, people with sensory impairment).
- held four meetings with groups of the people supported by Journey Enterprises, (this included people with learning disabilities).

Some of these discussion groups and workshops were online using video conferencing, and some were face-to-face.

Interpreters were arranged where needed. This included BSL interpreters and several foreign language interpreters. Some of the meetings used Makaton, which can help communication with some people with learning disabilities.

Altogether, around 100 people came to these discussion groups and workshops.



### 3. What people said in their questionnaires

Here is a short summary of what people said in their questionnaires. You can see more detail at the end of this report.

#### What information is kept and used by care services

Many people's responses to the questionnaire suggested that they did not know much about what information is kept about them, how it is used and how it is looked after.

Older people (over 65) generally said they did not know what information their care services keep about them, or how it is used and looked after.

Younger adults and carers knew a bit more.

The people who said they knew most were those supported by Journey Enterprises.

*"I believe they keep health information, care plans, medication details... Emergency contacts and records of any medications... Name, address, date of birth, contact number, email address, condition... Marital status."*

*"I would be able to guess some things."*

*"I know they keep some information, but I don't know what that information is."*



*Older people (over 65) generally said they did not know what information their care services keep about them, or how it is used or looked after.*



#### Whether people had been told what service use their information for and how it is looked after

Older people and carers mainly said that they had not been told what their care service uses their information for, or what they do to keep it safe.

Some younger adults said they had been told this.

More than half of the people supported by Journey Enterprises, said they had been told this.

*"Yes...to develop a personalised care plan... to provide support to service user... only certain people who need the info can access it... to inform staff and medical professionals..."*

*"Some, in letters, they quote the law, but I don't always understand what it means."*

*"Never explained to me but possibly to my mum."*

*"They haven't mentioned it."*

## People's feelings and opinions about the use of their information

Most people, particularly older people and carers, said that they had not previously thought about or worried about the information their care service keeps about them. However, after thinking about the questions asked by the project, most people said that it was something that would influence their choice of care service in future.

Apart from older people, most people said that they would like guidance about how to check that their information is safe.

Apart from people supported by Journey Enterprises, most people said that they did not currently feel in control of their information.

*"If information is lost, it makes you feel insecure."*

*"I don't feel in control of my information once it's left me, I really don't."*

*"If you are in (desperate) need then cyber security may be the least of your concerns. Which provider provides the best care might be the critical factor."*

*"Yes - was not aware until you have made me aware of it. I suppose we should be made aware and reassured by relevant service providers, especially as so many scamming techniques exist."*

*"Never thought about information safety influencing my choice of care providers before now, but it is concerning because of cyber crimes, cloning of IDs, wars etc. It is something that I would now 100% take into account."*

## Views on a quality mark for care services' data protection and cyber security

A question was added about the value of having a quality mark for care services' data protection and cyber security. This question was added to the survey halfway through. 30 of the 52 people who completed a questionnaire were asked this question and there was strong support for the idea from them. 26 out of 30 people who were asked said they would like there to be a quality marker, while four said no.

*"That would be really useful."*

*"I think that would help me make a decision."*

*"Could be a great assistance in choosing care organisation."*

26 out of 30 people said a quality mark for data protection and cyber security would be valuable.



*"If you are in (desperate) need then cyber security may be the least of your concerns. Which provider provides the best care might be the critical factor."*

## 4. What people said at discussion groups and in one-to-one conversations

This section of the report gives a summary of some of the things people said to the project during discussion groups, training sessions and in one-to-one conversations.

### What information is kept

People recognised that care and support records can include some of the most intimate details about their lives. For example, information about physical, emotional and mental health needs, and sometimes information about social behaviours, personal and family relationships.

Before these discussions, people had often been most worried about being scammed, or about losing information that could allow criminals to steal money from them. These discussions made people more aware of the need to also protect their sensitive personal information, such as health and care needs.

### Data protection legislation

Many people said they were unfamiliar with data protection laws. After some people attended a training session with the project, they said that they felt that data protection laws should provide a reasonable level of protection for their personal information and for their privacy.

### How well care services were felt to be doing

People recognised that data protection and cyber security are challenging issues for care services. This was made more difficult during the Covid-19 pandemic.

They understood that care services need to have a lot of different arrangements in place to ensure that information is kept safe. Examples mentioned included training for staff, procedures that are regularly tried and tested, and also technical defences such as: firewalls; regular software updates; strengthen security on Wi-Fi; and use of strong passwords.

There was a strong feeling that people who use care services, and their family carers, should be able to trust care services to protect their information. It was also felt that care services should be expected to keep up to date with best

practice, and to ensure that all staff are appropriately trained in data protection and cyber security.

However, people also felt that, in practice, care services may not always protect people's information as well as they could. Some people also felt that care services had not informed them well enough about the data they keep and how they share it.

There was also concern about the use of electronic records. Some people were concerned that sensitive personal information might be leaked, stolen or hacked because of weak cyber security.

However, people felt that it is not just about digital records and technology. There was also worry about how paper records are stored, and about how well staff understand their responsibilities.

### Cyber crime

There was often a low level of awareness of how a cyber crime could be committed. (An example of a cyber crime would be if someone tried to access your bank account electronically and to steal money from it.)

Many people said that they had done things such as: giving information over the phone or giving information they had been asked for by professionals without questioning what it was for.

Doing these things could put people's information and privacy at risk. For example, one woman with learning disabilities is a keen cook and follows several celebrity chefs on social media. She was contacted by someone claiming to be one of her idols and who started an online "friendship" with her. The person asked her for a loan and sent some emails which she described as "not very nice." Fortunately, at this point she made her father aware, and he prevented further contact.





## The Data Security and Protection Toolkit (DSPT)

The project talked to some people about the **Data Security and Protection Toolkit**, often called the DSPT. The DSPT is a self-assessment that all health and care organisations should complete each year to check their data protection and cyber security arrangements.

People thought that the DSPT sounded like a good thing to show that their care services are protecting their information and using it correctly.

There is a public website where it is possible for anyone to check whether a care service has completed the DSPT. However, it is not designed or promoted for use by members of the public.

At the time that the research was carried out, care services who have completed the DSPT did not receive any sort of badge or logo to show that they have done so.

The DSPT is a self-assessment that all health and care organisations should complete each year to check their data protection and cyber security arrangements.



## 5. Summary

**Most people knew very little about the information that care services keep about them, how it is used or how it is looked after.**

Most people also said that their care service had not told them how their data is used or kept.

There were some variations. The responses of younger people and carers suggested that they were more aware than older people. In addition, the responses of the people supported by Journey Enterprises suggested they were the most knowledgeable.

This may reflect the fact that Journey Enterprises is understood to have been talking with the people it supports about these things for some time.

Most people (almost 75%) said that, before taking part in this project, they had not thought or worried about what information their care service holds about them.

They also had not thought or worried about how that information is used, shared and looked after.

However, after thinking about the project's questions, people often said that this would be more important for them in the future. And, as people spent more time talking to the project, and thought more about this, they expressed more concerns.

This suggests that:

- Care services should proactively tell people what information they use, and how they store and share it safely
- The wider care sector should encourage people to think about how their information is used, stored and shared, and to ask their own care services what they are doing to keep their information safe.



## 6. Recommendations:

### What could be done as a result of what people said to this project.

#### How to find out how well care services look after information

Most people said that how a care service looks after their information would influence their choice of service in future.

26 out of 30 people said they would like care services to display a quality mark for their data protection and cyber security.

When told about the Data Security and Protection Toolkit, people felt it would be good to know if a care service had reached a good standard on the DSPT.

#### Things that could be done

1. The DSPT website could be redesigned to include a page designed specifically to help members of the public find out which care services has the DSPT in place
2. A badge or logo could be introduced which care services who have completed the DSPT could display on their website, in their buildings, in email signatures or letters.
3. The new DSPT website page and the badge/logo could be publicised to members of the public.
4. When local councils, health services, charities and advice services are talking to people about how to choose a care service, they could highlight the DSPT and how to find out about it.



#### What care services tell the people they support and family members about the personal information they keep

There is a legal requirement for organisations to tell people what personal information they keep about them, what they do with it and who they might share it with.

This is usually done by writing a Privacy Notice. This is a well-known legal requirement, and most care services probably have one.

However, often Privacy Notices are long and detailed and written in legal language. Most people do not read them, and if they do, they struggle to understand the technical language that they often use.

Some care organisations also produce a short summary of their Privacy Notice, written in language that is easier to understand. Some organisations also produce a summary using Easy Read. (Easy Read means having pictures alongside the words to help explain what is being said.)

This project suggests that it would be a good idea for more organisations to do this.

#### Things that could be done

1. An example of a short, easy to understand Privacy Notice could be produced and published on the Digital Social Care website.
2. Care organisations could be encouraged to use the example to produce a summary Privacy Notice for their own organisation, in the best format for the people they support.
3. Guidance for care services about how they look after personal information could say that they should find ways to make the contents of their Privacy Notice accessible for the people they support and for family members.
4. The requirement in the Data Security and Protection Toolkit (DSPT) for care services to have a Privacy Notice could be extended to say that they should find ways to make the contents of their Privacy Notice accessible for the people they support and family members.



## Appendix 1: Questionnaire responses

The questionnaire included 10 questions, all of which had YES/NO answers. However, some people answered with a sentence, rather than just a YES or a NO. Where that happened, the project looked at what had been written and worked out, as far as possible, whether the answer should be counted as a YES or a NO.

Mainly yes	More than 75% of answers were YES.
More yes than no	Between 60% and 75% of answers were YES.

Mainly no	More than 75% of answers were NO.
More no than yes	Between 60% and 75% of answers were NO.

For each question, we have counted up how many answers were YES, and how many answers were NO. We have used the colour coding to give an overall picture of the results.

Some yes and some no	There were about the same number of YES and NO answers.
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How much people said they knew about their information and how it is used and looked after.	Adults of working age	Older people	Carers	Journey Enterprises
1. Do you know what types of personal information are held by your care provider about you/your relative?	Mainly yes	More no than yes	More yes than no	Mainly yes
2. Do you know how to find out what types of information the care provider holds about you/your relative?	More no than yes	More no than yes	More yes than no	Mainly yes
4. Do you know who your information may be shared with?	Mainly yes	Mainly no	Some yes and some no	More yes than no
7. Do you know how to check that the information they have is safe?	More no than yes	Mainly no	Mainly no	Some yes and some no
10. Do you know to whom you should report any concerns you may have about cyber security? (*)	Some yes and some no	Mainly no	More no than yes	More yes than no
<b>Summary:</b> Older people generally said they did not know about their information or how it is used and looked after by their care service. Younger adults and carers knew a bit more. The people who said they know most were those supported by Journey Enterprises.				

\*The full text of question 10 was “Do you know to whom you should report any concerns you may have about cyber security (i.e. the safety of your personal information held by your care provider)?”

Whether people had been told about what their information is used for and how it is looked after.	Adults of working age	Older people	Carers	Journey Enterprises
3. Have they told you what they use that information for?	More no than yes	Mainly no	Mainly no	More yes than no
5. Have they told you what they do to keep your information safe?	Some yes and some no	Mainly no	Mainly no	More yes than no
<b>Summary:</b> Older people and carers mainly said that they had not been told what their care service uses their information for, or how they look after it. Some younger adults said they had been told this. The people who most often said they had been told this were those supported by Journey Enterprises.				

People's feelings and opinions	Adults of working age	Older people	Carers	Journey Enterprises
6. Is this something you have ever thought, or worried, about before reading this questionnaire?	More no than yes	Mainly no	Mainly no	Some yes and some no
6a. Would information safety influence your choice of care provider in the future?	Mainly yes	More yes than no	More yes than no	Did not include this item
9. Do you feel in control of your information?	More no than yes	Mainly no	Mainly no	More yes than no
8. Would you like help or guidance about to how to check that the information they have is safe?	Mainly yes	Mainly no	More yes than no	Mainly yes

**Summary:** Most people, particularly older people and carers, said that this was not something that they had ever thought about or worried about before. However, most people said that it was now something that would influence their choice of care provider in future and, apart from older people, most people said that they would like guidance about how to check that their information is safe. Apart from people supported by Journey Enterprises, most people said that they did not currently feel in control of their information.



## Better Security, Better Care support programme

Get free, expert advice on the DSPT and other data and cyber security issues from your local support organisation.

Visit: [www.digitalsocialcare.co.uk/bettersecuritybettercare](http://www.digitalsocialcare.co.uk/bettersecuritybettercare)

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**Data Security and Protection Toolkit**  
All adult social care providers



At least once a year