

DSPT
Better security.
Better care.



It's my information: keep it safe!

People who use care and support services and their families talk about how information about them is used.



EasyRead version

Published March 2023

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International

<https://www.lscpinfo.co.uk/>

www.digitalsocialcare.co.uk



We are the Liverpool Social Care Partnership

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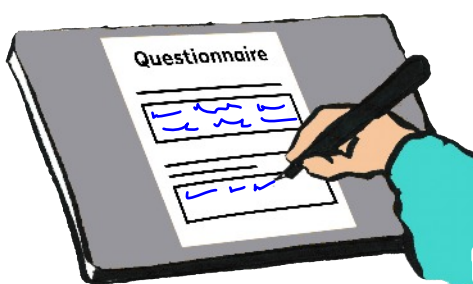
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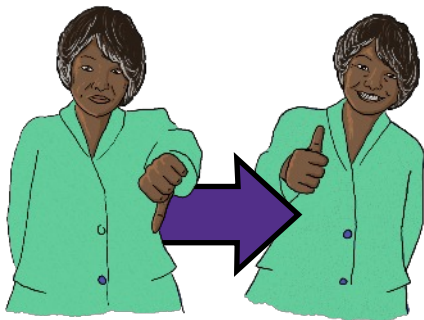
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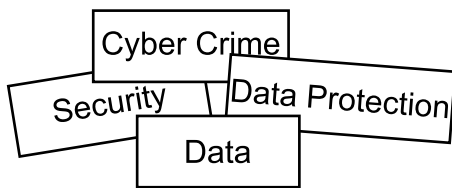
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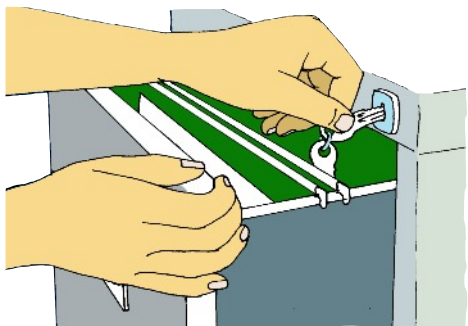
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We are the Liverpool Social Care Partnership

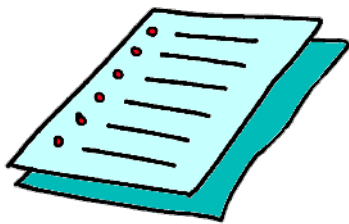
2022			
Jan	Feb	Mar	Apr
May	Jun	Jul	Aug
Sep	Oct	Nov	Dec

In 2022 we did some work which was part of **Better Security, Better Care**.

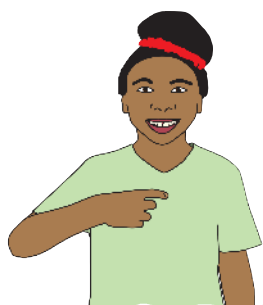


Better Security, Better Care helps social care services keep your information safe.

1. Introduction



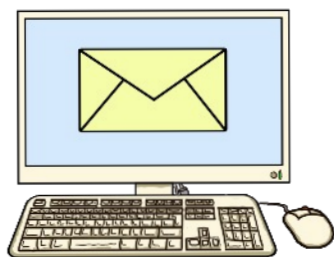
Care services need to keep a lot of information about the people they support. This includes personal information such as:



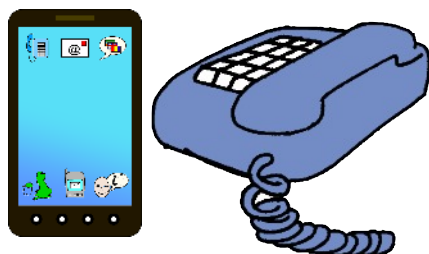
- your name



- address



- email



- telephone number



- health and care needs.



It might also include information about your family, and about your finances if you are paying for your care.

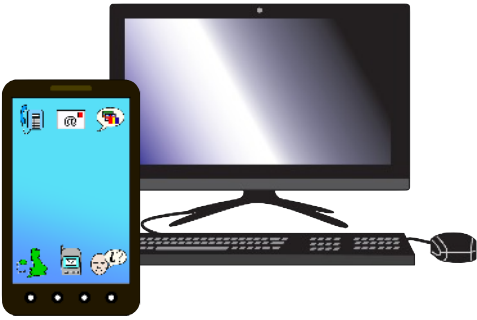
Personal information is sometimes called **personal data**.



Your personal information helps the service understand what care and support you need and want. Sometimes they need to share information with other organisations, such as doctors or the council, so that they can get the support you need and want.



It is important for care services to keep your information safe and only use it and share it in the right ways.



More care services are using computers and other digital technology like mobile phones to keep and share information.



Some care services also keep information on paper. Sometimes they call that information **data**.

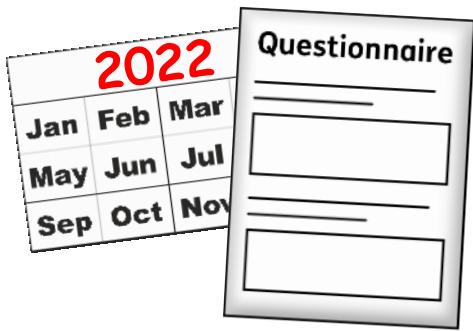


They have to keep information safe – whether its written down on paper or kept as a digital or electronic record. This is called **data protection**.



If services keep your information on a digital system they need to protect that information from **cyber crime**.

Cyber crime is where criminals try to steal personal or financial digital information. For example if someone tried to access your bank account electronically to steal money from it.



In 2022 we wrote a **questionnaire**.

A **questionnaire** is a list of questions.

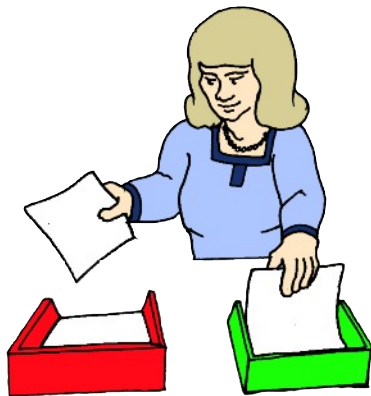


In our questionnaire we asked a lot of people who use social care and support about:

- the data or information their care services keep about them



- how services use and look after that data or information

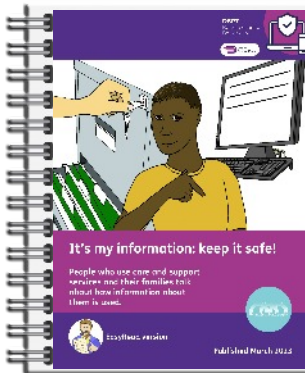


- how important they think it is to manage people's information.



We wanted to know what people think about data protection and **cyber security**.

Cyber security is about keeping that data safe.



We wrote down what people told us in this report.



The report tells you:

- what they thought about the way care services look after their data



- how care services could keep information safe in the future.

2. How we contacted people

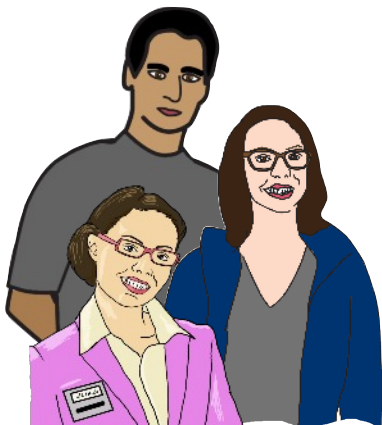


Liverpool Social Care Partnership contacted:

- people who use support services



- family carers



- care and support providers



- organisations who are in touch with people who use care and support services.



The organisations included:

- care and support organisations



- advocacy organisations



- Age Concern



- Citizens Advice

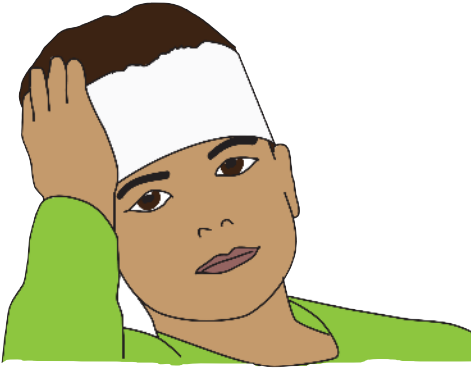


- local Healthwatch organisations.



Around 60 organisations shared our questionnaire with people they knew.

Three organisations gave us extra help:



1. A charity supporting people with brain injury helped us to meet people who use their services and family members to complete the questionnaire with them.



2. A charity running local keep fit classes for older people invited us to attend and complete the questionnaire.



3. Journey Enterprises is a charity which supports people with learning disabilities in the North East. They organised 4 meetings and asked people to complete an easy read version of the questionnaire.

3. How we found out what people knew about data security



We used 2 ways to ask people what they knew.

1. Questionnaires



2. Focus groups and workshops.



1. Questionnaire

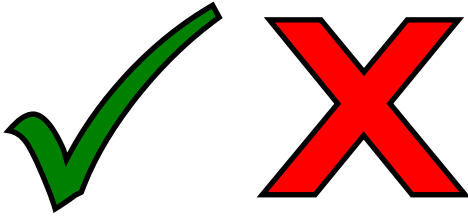
112 people filled out our questionnaire.



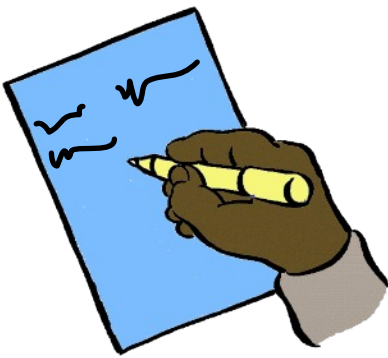
52 questionnaires were in standard English.



60 questionnaires were in easy read.



People could say yes or no to the questions.



Some people wrote more information and we worked out if they were saying yes or no.



We looked at the 52 standard English questionnaires and found:

- half were people who use care services



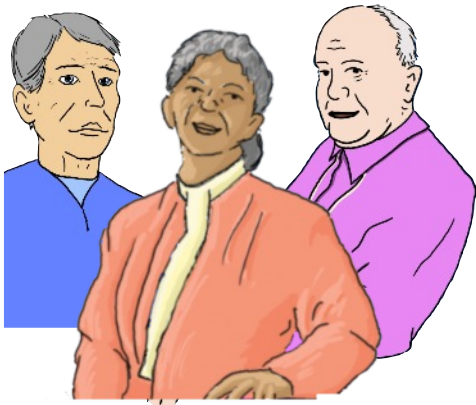
- half were family carers



- the people were about half women and half men.



29 people told us they use care services.



18 people were older than 65.



11 people were between 18 and 64.



2. Focus groups and workshops

We wanted to talk to groups of people.



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



We held three focus groups.

There were some older people and some younger adults at the focus groups.



The focus groups gave people the chance to talk about things in more detail.



We invited some people to a training session about data protection and cyber security.



The session helped us talk with some older people and people with sensory impairment.

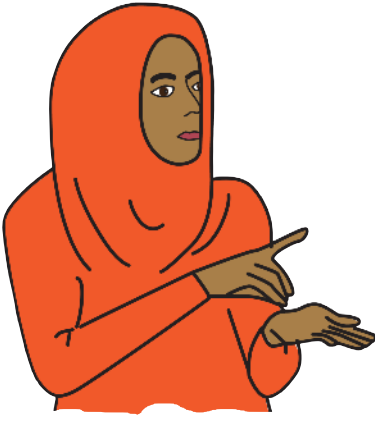


We held four meetings with groups of the people supported by Journey Enterprises.

This included people with learning disabilities.



Some of our focus groups and workshops were online using video conferencing and some were face-to-face.



We had provided interpreters where needed. This included:

- BSL interpreters



- foreign language interpreters



- Makaton, which can help communication with some people with learning disabilities.

4. What we found out: Questionnaire answers



Here is a short summary of what people said in their questionnaires.



Question: What information is kept and used by care services?

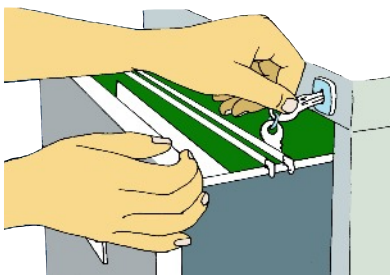
Many people said they did not know much about:



- what information services keep about them



- how the information used



- how it is looked after.



Older people (over 65) were unsure.



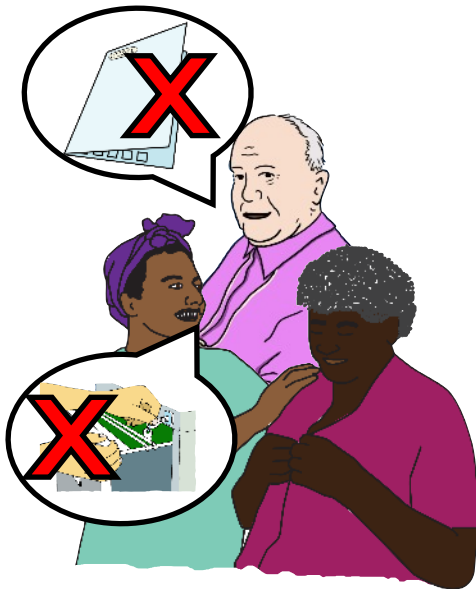
Younger adults and carers knew a bit more.



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



Question: Did services tell people how they use and look after their information?

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.”

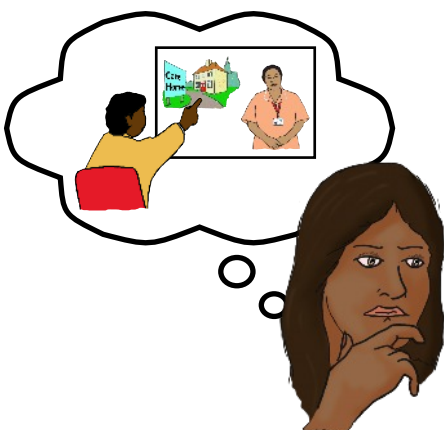


Question: How did people feel about the way services use their information?

We asked people if they worried about the information their care service keeps about them.



Most people said no. These were mainly older people and carers.



But after thinking about our questions they said it is something that will help them choose a care service in the future.



Most people said they want to learn how to check if their information is safe. Older people were less interested.



Only people supported by Journey Enterprises said they felt in control of their information.

“If information is lost, it makes you feel insecure.”

“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.”

“I don’t feel in control of my information once it’s left me, I really don’t.”

Question: Ways to know if a care service will protect your data



We asked 30 people if they would like to see a **quality mark** that tells you how well a care service protects your data.



A **quality mark** is a symbol or logo that will tell you how well a service is looking after everyone's information.

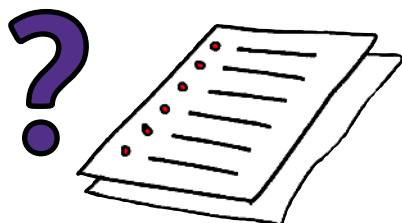


26 people said a strong yes.

“That would be really useful.”

“Could be a great assistance in choosing care organisation.”

5. What we found out: what people said at discussion groups and in one-to-one conversations



Topic: What information care services keep

People knew that care and support records can include some very personal details about their lives.



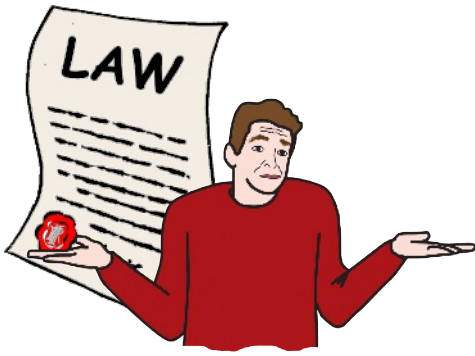
For example, information about physical, emotional and mental health needs, and sometimes information about social behaviours, personal and family relationships.



People worry about scams.



These discussions made people more aware of the need to protect their sensitive personal information, such as health and care needs.



Topic: Laws about protecting data

Many people said they did not know about data protection laws.



They took part in a training session.



Then they said that they felt the current laws should provide a reasonable level of protection for their personal information and for their privacy.



Topic: How people felt care services were doing

People know that data protection and cyber security are difficult issues for care services.



This was made more difficult during the Covid-19 pandemic.



They understood that care services need to have:

- training for staff



- procedures that services regularly try and test

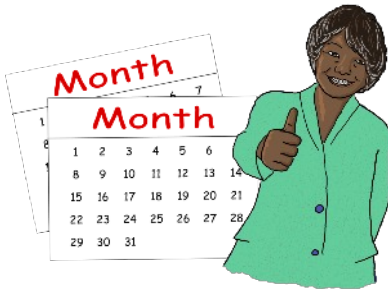


- digital protection such as firewalls; regular software updates; secure Wi-Fi; and strong passwords.



People want care services:

- to protect their information

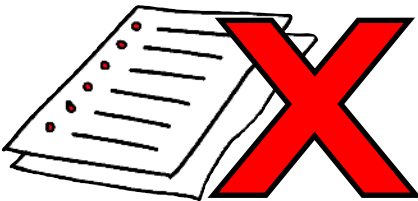


- keep up to date with best practice



- make sure that care services train all staff in data protection and cyber security.

People felt care services:



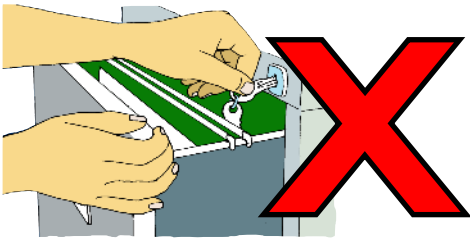
- sometimes did not protect their information



- had not explained to them about the data they keep and how they share it



- had weak cyber security which meant their personal data could be leaked or stolen



- did not store paper records safely



- did not help staff understand how to keep personal information safe.



Topic: Cyber crime

Many people said they sometimes did not think about keeping their information safe.



An example is if you give information over the phone without asking what it was for.

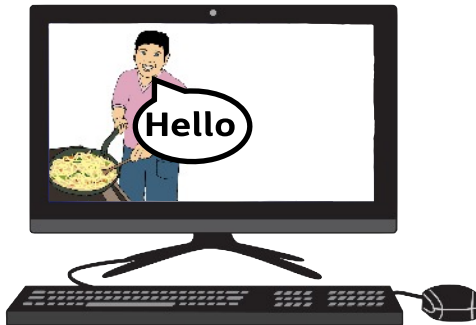


This could put your information and privacy at risk.

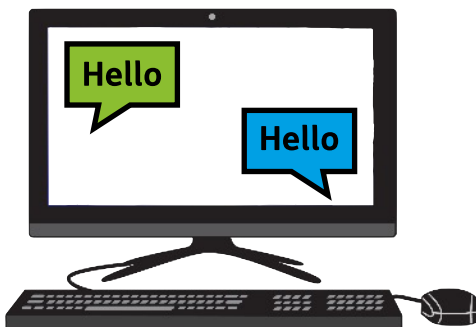


Here is an example

A woman with learning disabilities is a keen cook and follows several celebrity chefs on social media.



Someone contacted her pretending to be a famous chef.



They started an online “friendship” with her.



The person asked her for a loan and sent some emails which she described as “not very nice.”

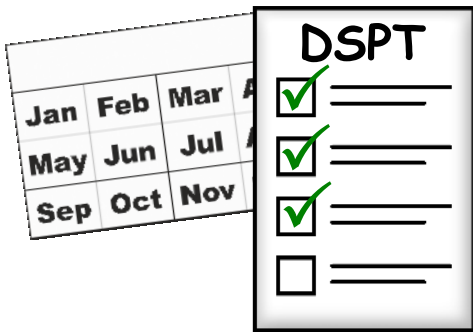


Luckily she told her father and he stopped any more contact.



Topic: The Data Security and Protection Toolkit (DSPT)

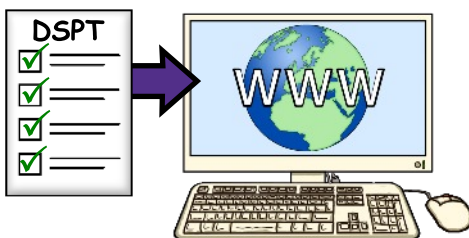
The Data Security and Protection Toolkit is often called the **DSPT**.



The DSPT is a tool all health and care organisations can use each year to check their data protection and cyber security arrangements.



People thought it was a good idea for care services to use the DSPT.



When a care service has completed the DSPT it shows up on a website.



But at the time that the survey took part, the service does not get a badge or logo to show that they have used it.

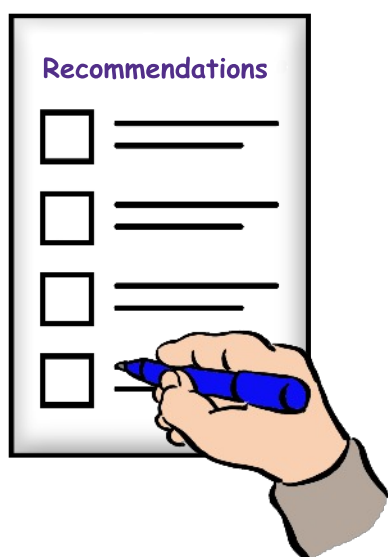
6. What we think care services can do better



We read what people said in the questionnaire.



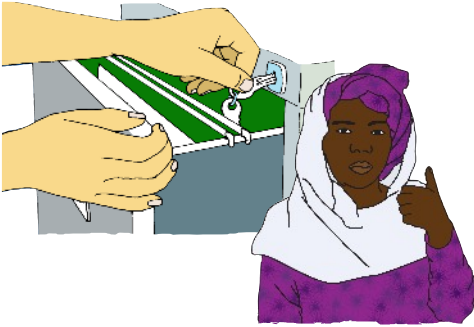
We listened to people at face-to-face meetings.



Then we wrote a list of things that could be done (**recommendations**).

Recommendations means ideas for how care services and other organisations can protect your data better.

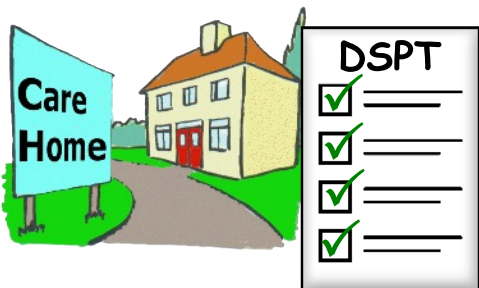
1. How to tell if a care service will look after your information



Most people said that the way a care service looks after their information is important when they choose a care service.



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



When they heard about the Data Security and Protection Toolkit, people said they would like to know if a care service had reached a good standard on the DSPT.

Things that could be done (recommendations)



- Change the DSPT website so it has a page to help members of the public find out if a care service has the DSPT in place.



- Make a badge or logo to show a care service has completed the DSPT.



- Advertise the new DSPT website page and the badge or logo.



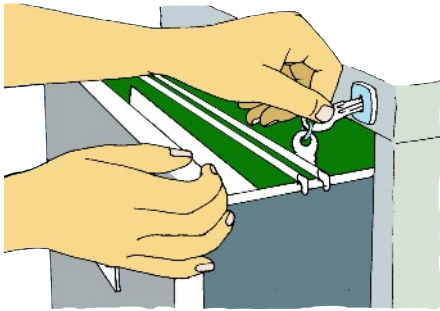
- Ask local councils, health services, charities and advice services to tell people about how to see if a care service has completed the DSPT.

2. What care services must tell you about the personal information they keep



The law says organisations must tell people:

- what personal information they keep about them



- what they do with it



- who they might share it with.



They write a privacy notice which explains what they do with information.



Some privacy notices are often long and hard to understand.

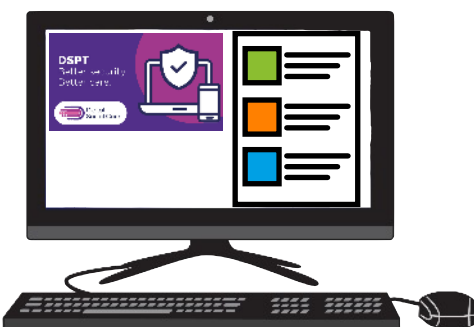


Some care services write the privacy notice in easy read.

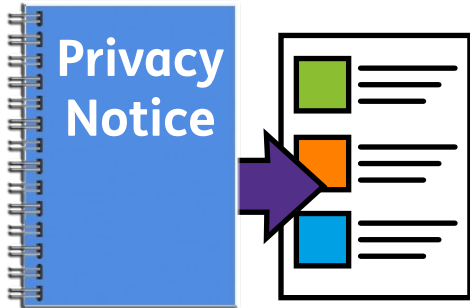


We think more services should make their privacy notice easy to understand.

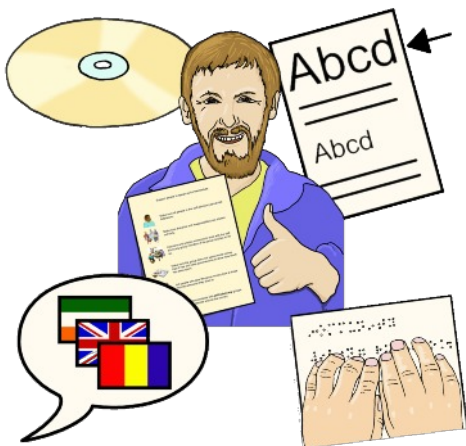
Things that could be done (recommendations)



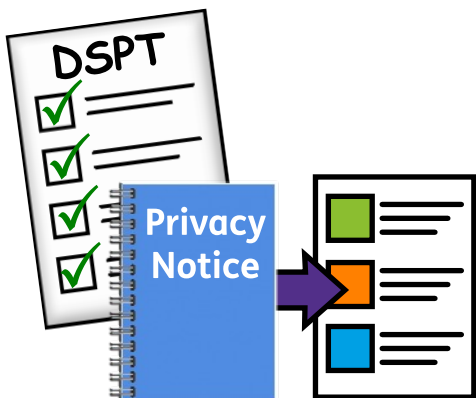
- Put an example of clear privacy notice on the Digital Social Care website.



- Suggest care services use the simple example when they make their own privacy notice.



- Remind care services to make their privacy notice accessible for the people and family members they support.



- Check the Data Security and Protection Toolkit (DSPT) reminds services about making their privacy notice clear.

7. What the words mean

Cyber crime is where criminals try to steal personal or financial digital information.

Cyber security is about keeping information that is stored on computers or other digital systems safe.

Data protection is about keeping information about a person safe. It includes information that is kept on paper, as well as information that is kept on a computer or other digital systems.

Data means information. It includes personal information such as someone's name, contact details, financial information, and health or care needs. The information could be about the person who uses care and support services, their friends and family, and the staff who work in the service.

Digital means keeping information in a computer.

DSPT is the short name for the Data Security and Protection Toolkit. The DSPT is a tool all health and care organisations can use each year to check their data protection and cyber security arrangements.

A **quality mark** is a symbol or logo that will tell you how well a service is looking after everyone's information.

A **questionnaire** is a list of questions.

Recommendations means ideas for how care services and other organisations can protect your data better.

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Ref ISL362 22. March 2023.

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