



The Connection

at St Martin-in-the-Fields

DATA RIGHTS AND PEOPLE EXPERIENCING HOMELESSNESS IMPROVING TRUST AND EMPOWERMENT

The Connection at St Martin's report funded by the Information Commissioner's Office



EWA KAPICA
DAVID SHALLCROSS
TIM KEMP
DENNIS GOFFE
PAUL TAYLOR

AUTHORS

Ewa Kapica, David Shallcross, Tim Kemp, Dennis Goffe, Paul Taylor

ACKNOWLEDGEMENTS

We thank everyone who agreed to share their experiences through interviews, surveys and focus groups, and have their images used for this project.

This project was funded by the Information Commissioner's Office (ICO).
We thank the ICO for their support.

OCTOBER 2020

DISCLAIMER

The following is intended to provide general understanding and recommendations for practice around data protection in services that support people who face multiple disadvantage. It should not be considered legal advice, nor used as a substitute for seeking qualified legal advice.

The Connection at St Martin's is a registered charity that provide practical support and advice to people facing homelessness.

Company No.3852519

Registered Charity No. 1078201

Registered Office: 12 Adelaide Street, London WC2N 4HW

Contents

Summary.....	1
Overview of findings.....	3
Recommendations for future practice	4
Introduction.....	5
Methods.....	5
Initial research plan	5
Research team	6
Participants and setting	6
Study design, data collection and analysis	6
Stage 1: Formative research	6
Stage 2: In-depth qualitative research.....	7
Stage 3: Development and testing of new, client-centred materials.....	8
Ethics.....	9
Results.....	10
Thematic framework	10
Purposes of processing	10
Lawful basis.....	10
Data sharing.....	10
Data retention, storage and security.....	11
Data subject rights	12
Communication – Key Messages	14
Discussion and recommendations for practice	16
Transparency	16
Easy read documents and use of graphics.....	17
Retention and the Right of deletion	17
Data sharing and consent	18
Information about housing status as ‘sensitive data’	18
Control and empowerment	18
Data subject rights for people without ID	19
Limitations	19
Recommendations for future practice	19
References	21
Appendix 1 – Stage 1 survey and detailed results.....	22
Appendix 2: Tools for surveys, interviews and focus groups	29
Appendix 3 – Data extracted from thematic analysis.....	31
Appendix 4 - Key Messages with supporting images – full results.....	33
Appendix 5 – Key Messages with supporting icons – full results	35

Summary

Organisations which support people experiencing homelessness handle highly sensitive, personal information. The importance of transparency in this respect stems not only from the necessary legal compliance. It is also a way of gaining and maintaining trust with service users (hereafter referred to as clients) and empowering them to exercise their rights. To be effective, communication about data protection needs to be tailored to the recipient. We hypothesised that not all information contained in a privacy notice is equally interesting to clients, but that there are areas that, when emphasised, will improve the quality of relationships by addressing key concerns and clarifying expectations. We aimed to develop tools for delivering privacy information that would convey the information that clients are most likely to be interested in, concerned about or have the most misconceptions about. To achieve this, we conducted research into clients' chief concerns relating to personal data and any misunderstandings that threaten trust, and what communication methods are most effective with this group. We then tested the resulting tools.

As there has been no research on this topic in the past, we adopted an exploratory approach using mainly qualitative research methods. We conducted it as a piece of peer research - the research team included people with lived experience of homelessness. Client study participants were recruited amongst clients of The Connection and were either currently experiencing homelessness or had a recent experience of it. We also drew participants from The Connection's frontline practitioners. The research was conducted in three stages, using a mixture of focus groups, interviews and surveys. Firstly, we tested our initial assumption that not all elements of data protection are equally important or interesting to clients and got a rough understanding of their existing knowledge, attitudes and practices in this area. In the second stage we conducted in-depth research into the most significant sources of mistrust, confusion, concern or interest with respect to the processing of client data. To analyse the data, we used a thematic framework (Purposes of processing, Lawful basis of processing, Data sharing, Data retention, storage and security, Data subject rights and Other). The data fit in this framework well. Lastly, based on the findings from the previous stages, we produced a series of short messages (Key Messages) that focussed on the areas that were likely to be the most useful and interesting to clients. We then prepared and tested visual aides to the delivery of these messages.

Overview of findings

We found that the area that caused the most anxiety and confusion for clients was sharing of information, both internally and externally. Participants were predominantly worried about reputational damage should the information be shared inappropriately. The sharing of risk information, on the other hand, was seen as uncontroversial. Clients were unsure about the extent of internal sharing with some thinking that the information was restricted to the person they spoke to. Individual control over who information is shared with was of great importance; the clients that we spoke to want to be asked before the sharing takes place. Finally, the written consent process was a cause of confusion.

The second most debated topic was the data retention period and, by extension, the right to deletion. Clients largely conformed to the view that all information about them should be deleted when they leave the service, or at least upon request. Frontline practitioners told us that in practice such requests were usually made in conflict situations, when clients were displeased with the service and intended to leave.

The right of access to data was cited as the most important right by clients, because it acts an entry point to exercising other rights. Not all of them knew how to exercise it, with some citing barriers to access such as lack of ID or the necessity of filling out forms.

Clients also stressed the importance of the right to be informed as a way of earning trust, showing respect and redressing power imbalance. They said that if they wanted to find out more information about how their personal data is being used, they would most likely speak to their case worker. Frontline practitioners identified language and communication needs, outreach setting and conflicting client priorities during first contact as barriers to delivering the privacy information.

We constructed a series of eight Key Messages addressing the concerns around where and how data is shared, the use of consent, right of access, right of deletion and data retention period, written in plain English. To further improve

the ease of understanding we created graphic representations of these messages. Testing revealed that using literal representations, in this case photographs, worked better than abstract symbols. The Key Messages supported by graphics can be used to form a tool that should improve the uptake of full privacy notices by clients.

Recommendations for future practice

The Connection can build on this research to further improve its data protection practice. It would be of particular interest to trial and evaluate the Key Messages tool against the practicability of its delivery, the rate of take-up, and feedback from recipients, comparing to the standard privacy notice alone. The wording should be kept under review; e.g. if clients frequently ask for clarification or have follow up questions, this would indicate that the wording of messages should be changed or additional messages added. The charity may also consider implementing other measures for improving communication such as face-to-face information sessions with Q+A and promotion of the Privacy Notice on screens. As frontline practitioners act as a first port of call for data protection related queries, we recommend that The Connection ensure adequate staff competency in this area through role-based training. Providing printed copies of privacy notices in areas easily accessible to clients will ensure access to detailed information for those who do not wish to discuss this with staff members.

Other organisations that work with people who experience homelessness may find conducting a similar exercise useful. This is particularly true if they are not sure if their privacy information materials for clients are easily accessible or if their processes are working for the frontline practitioners tasked with delivering them. Such organisations may consider adding additional tools aimed at improving communication. As our Key Messages are so pared down, we think they may improve uptake of full notices or, at the least, provide the information clients are most interested in, during the initial contact. Other charities may choose to extend the Key Messages to cover the entire privacy notice or could extend the use of graphics to support the consent process. We believe that the process we designed in order to arrive at the Key Messages tool will transfer well to other settings and facilitate client-led improvements to practice. In particular, we recommend testing of any visual aids that organisations consider deploying – as our research demonstrates, the extent to which these are helpful can vary dramatically.

Our finding that housing status data is sensitive suggests that organisations take this into consideration when reviewing data security measures as it implies that any breach involving identifiable client data is likely to cause distress. It is also important that client data recording is reviewed regularly to ensure that only relevant information is recorded, and that it is used as intended. The detailed review of categories of data being recorded against its purpose may also reveal additional information that should be deleted upon request.

Finally, the procedures for clients wishing to exercise their data related rights should be as straightforward as possible and take into consideration the circumstances of individuals making such requests, such as potential lack of ID and other documents. As some clients may be apprehensive to exercise their rights for fear of repercussions, it is also the organisation's responsibility to provide reassurances in this area.

Introduction

According to the most recent estimates, there were over 280,000 people experiencing homelessness in England alone in December 2019 (Shelter, 2019). Snapshot data from autumn of the same year showed that 4,266 people were found sleeping rough on the night of the count, although the number of people sleeping on the streets per annum is likely to be much higher (MHLG, 2019; Booth, 2020). Losing one's home can be an intensely alienating and traumatic experience, frequently causing feelings of powerlessness and a lack of trust in mainstream society and social institutions. Although people who experience homelessness are not a homogeneous group, evidence shows a much higher prevalence of needs around health, mental health and substance misuse, in comparison with the general population, and people facing homelessness are also more likely to have experienced significant trauma. Hence, any organisation that works closely with this group of people is likely to face a double data protection responsibility of dealing with highly sensitive, personal information from a population that is marginalised and justifiably wary.

The Connection supports over 2500 people experiencing homelessness every year with matters ranging from access to basic facilities to specialist support around housing, health, income, immigration and other legal matters. Throughout this paper we will refer to people supported by the organisation as 'clients'. Like the vast majority of organisations who offer similar services, we strongly believe that our clients should be empowered to exercise their rights. This includes their rights as data subjects. We believe this will not only improve the quality of our services, but also contribute to greater trust and accountability between ourselves and our clients. However, when we informally consulted our clients, it became clear that they knew very little about their rights, and often did not believe that organisations such as ours would protect them as data subjects.

To improve our communication with clients around personal data, we identified a need for the following:

- further research to understand the main concerns of clients relating to personal data and/or any significant misunderstandings that threatened trust;
- further research to understand what communication methods are most effective and acceptable to clients;
- development, testing and eventual deployment of suitable materials.

There is very little published information on the topic of data protection awareness and communication needs among people who face homelessness, although the recent research by Andrews and Botting (2020) shows that Speech and Language Communication Needs are more prevalent amongst people who sleep rough compared to the general population. To meet our goals we chose to adopt an open, exploratory, predominantly qualitative approach. Moreover, we needed to include an 'action research' component to meet our final goal around developing and testing new materials. Finally, we decided that we wanted to do the whole project as a piece of 'peer research'. Peer research is an approach to research design in which researchers are drawn from among the 'researched' - in this case, people with experience of using our services (i.e. clients) were involved in researching materials or activities to empower their peers. We opted for this approach not only because it is consistent with our values and our belief in co-production, but also because we think that the reason our data protection materials failed to connect with clients before was precisely because of a lack of client involvement in their development and design. For a detailed analysis of benefits and challenges of the peer-research approach see e.g. Kelly et al (2017), Lowes and Hulatt (2005).

Although we conceived and implemented this project primarily to serve our internal needs around communicating with clients about personal data, we believe that it has much wider relevance. The lack of published studies on data protection and privacy in the context of homelessness points to a gap in understanding about how best to involve, inform and empower this marginalised group. We hope that our study can contribute to other organisations that work with people who experience homelessness and are interested in understanding their data protection needs, their preferences around communication methods, or even the process of conducting peer research.

Methods

Initial research plan

The project was conceived as open-ended and exploratory, hence the study design evolved over the course of the project. An important concept in the initial research plan was that of the "average client". In our view, the average client did not need or want to become an expert in every aspect of personal data legislation. Moreover, we thought

that expecting the average client to attain a high level of expertise was also unreasonable – most clients have other needs that take precedence e.g. obtaining healthcare, obtaining accommodation or paid work. This led us to propose an initial research plan that was focussed on identifying where there was the greatest distress, surprise or mistrust relating to personal data for the greatest number of people. Our rationale was that an effective information and empowerment campaign around personal data would focus valuable resources on these areas, while offering additional advice and support to the much smaller number of clients whose concerns fell outside the “average”.

This led to an initial research plan in three stages:

Stage 1: formative research to test our initial assumptions and to get a general sense of knowledge, attitudes and practices relating to personal data among clients;

Stage 2: in-depth qualitative research to identify which data protection issues were of greatest concern or interest to clients, or had the greatest potential to lead to misunderstandings between frontline practitioners and clients; to arrive at key messages that address these issues.

Stage 3: piloting of materials and tools that would address the gaps identified, thus informing and empowering clients with respect to their personal data.

Research team

The research team comprised volunteers (also referred to as ‘peer researchers’ in this report), some of whom had lived experience of homelessness, as well as two staff members, who had previously developed and implemented The Connection’s data protection policy and had experience in conducting peer research. The number of peer researchers fluctuated, with the maximum number being nine and the minimum two. Team members received training from both internal and external sources during the project – this is described in more detail in Figure 1.

Figure 1 – overview of training delivered to team members during project

Training topic	No. participants	No. hours	Training provider	Training content	Training period
Qualitative research methods	9	15	CSTM staff members	Study design, qualitative methods, research ethics	July 2019
Data protection	4	6	CSTM staff members	Data protection legislation – general knowledge; data protection legislation as applied at The Connection	October 2019
Communication methods	4	4	External provider	Communication difficulties prevalent in homeless population; examples of methods to overcome them	December 2019

Participants and setting

All participants in this study were recruited from amongst attendees of The Connection at St Martin’s Day Centre and its frontline practitioners. All client participants were over 18 years of age and were either currently homeless or still requiring support due to historic homelessness. They were a mix of males and females, UK nationals and those from abroad. Participants had a level of English sufficient for meaningful engagement in the research activity. All data was collected on the premises of The Connection at St Martin’s between March 2019 and February 2020.

Study design, data collection and analysis

Stage 1: Formative research

The two staff members who conceived the initial study design also designed the data collection activities in Stage 1. Our aim at this stage was twofold: first, to test our assumptions about the “average” client i.e. that such a construct was useful and that the “average” client did not care equally about all aspects of their personal data; second, to gain a sense of client knowledge, attitudes and practices to inform the next stage of research. We used two data collection

methods: a survey and a focus group discussion. We conducted the survey to have access to individual data from a larger sample, whereas the focus group helped us to start identifying group-level norms and values.

The survey comprised six questions on knowledge, attitudes and practices, with a particular focus on data rights and clients’ experiences of exercising them. We administered the survey to 30 clients accessing The Connection’s day centre over the course of two mornings in March 2019. Responses were collected anonymously via a tablet device onto Survey Monkey. Data was analysed using Survey Monkey and Excel. The full questionnaire can be found in Appendix 1.

We recruited eight focus group participants from among survey respondents as well as from clients who responded to promotional leaflets distributed in The Connection. The discussion was facilitated by a peer researcher and a staff member in April 2019. It lasted approximately two hours, and focused on group attitudes and practices. The staff member took notes by hand, because the team had previously agreed that electronic recording could negatively impact the freedom of the discussion. The notes were later pseudonymised and typed up for analysis.

The results informed the content of Stage 2 of the project as they indicated topics that were worth exploring in more detail, as well as who should be included from among the respondents. Reflecting on the process itself helped us tighten the procedure for future groups; e.g. we realised that we needed to manage the questions arising from participants, and that relying on hand written notes threatened the granularity of data collected. Note that the results of this stage are not analysed separately in the Results section of this report. We have added this data to the thematic framework arising from Stage 2 of the research.

Stage 2: In-depth qualitative research

The purpose of this stage was to identify our clients’ most significant sources of concern, interest or mistrust relating to personal data processing. The research team agreed on the study design for this stage as well as the data collection tools as part of the training on qualitative research methods. The details are presented below in Figure 2.

Figure 2 – study design for Stage 2

Data collection method	No. sessions	Content	Intended participant group	No. participants
Focus group discussion	2	Data rights and experiences in exercising them; personal concerns and interests about data processing	Clients – UK nationals	3
	2	As above	Clients – non-UK nationals	6
Individual, semi-structured interview	1	As above	Clients – not attending building	1
	4	Experiences in communicating privacy information; common client misconceptions; levels of trust clients have towards The Connection’s processing of their data	Frontline practitioners	4
Survey	1	Experiences in making subject access requests	Clients - general	25 (24 complete)

We considered it important to gather data from both clients and staff. Through focus group discussions with clients, we believed that we could gather information on prevalent attitudes and beliefs relating to personal data, as well as anecdotes of personal experiences in exercising data rights. However, given the large number of clients that each frontline practitioner comes into contact with, we thought they would be valuable informants on episodes relating

to personal data that had caused considerable distress. Moreover, since frontline practitioners (unlike clients) had received training in data protection, we thought that they might have a more accurate understanding of where clients misunderstood current legislation and practice. Finally, on the issue of trust, we thought it important to hear both client and practitioner perspectives.

During the training, we hypothesised about factors that could influence client attitudes relating to personal data. Our list included: age (we hypothesised that older clients might have a different attitude owing to their lower familiarity with social media and computers more generally); nationality (we hypothesised that non-UK citizens might feel themselves at greater risk from the state owing to the Home Office Hostile Environment Policy); criminal history; mental health history; experience of being excluded/marginalised from homelessness services etc. Practical and ethical constraints meant that it was not possible to investigate the influence of all these different factors, so we chose to focus on just two: nationality and experience of being marginalised from homelessness services. Hence, we attempted to run separate focus groups with UK/non-UK clients, and we also tried to interview clients who did not access the day centre. Unfortunately, it was not possible to conduct these activities exactly as wished: the focus groups with non-UK nationals had two UK nationals mixed in; moreover, we could only convince one client who didn't attend the day centre to be interviewed.

At the request of the ICO, we gathered more data relating to subject access requests via a survey. The survey comprised six closed and two open questions – please refer to the Appendix 2 for the full survey. Peer researchers conducted the survey in the centre's drop-in areas over two mornings. A 'convenience' (i.e. non-random) sample of 25 people agreed to participate and 24 completed the survey. Data was collated and analysed using MS Excel.

We audio recorded all the focus group discussions and interviews, but there was no transcription. Prior to data analysis, peer researchers received training from the principal investigator on data protection legislation and The Connection's data protection policy so that they could better distinguish any misconceptions on the part of the informants. To aid analysis of the qualitative data from interviews and focus group discussions, the principal investigator developed a thematic framework based on data protection legislation. The framework comprised the following six major themes:

- Purposes of processing
- Lawful basis of processing
- Data sharing
- Data retention, storage and security
- Data subject rights
- Other (comments that did not fit the previous categories but were important to the broader understanding of how participants felt about the treatment of their information by The Connection)

We listened to the audio recordings together and made notes of quotations that expressed concern, interest or mistrust relating to processing of client personal data, as well as any other quotations that we thought relevant to our research questions more generally. We categorised ("coded") each quotation under one of the major thematic headings in the framework. After each recording, we reviewed how we had categorised the quotations to resolve any differences. Overall, the above framework fit the data very well.

In the next stage of analysis, we reviewed how we had coded each recording to see if similar quotations could be grouped together into sub-themes under the major thematic headings. We did this for each recording, producing a list of conceptually distinct sub-themes – see Appendix 3 for full details. In the final stage of analysis, we reviewed the list of sub-themes and, taking into account the distribution of the data (i.e. which themes/sub-themes came up most often), as well as our impressions from the data collection, we agreed on a list of the seven most important queries to address in order to reduce client distress and mistrust.

Stage 3: Development and testing of new, client-centred materials

The purpose of this stage was to translate the key queries we had identified in Stage 2 into acceptable, effective messaging for clients. At the start of this phase, the team received training from a Speech and Language Therapist

specialising in communication needs amongst people who face homelessness, which informed the design of our materials. The points that the specialist emphasised were:

- effectiveness of visual and verbal messaging over textual messaging;
- need for visual messaging to be easy to comprehend and memorable, for example, by making use of emojis or other symbols that are in common use;
- need for any textual messages to be in simple language and very short.

Taking these points into account, we translated the key queries into statements in plain English – please refer to the Results section for the key messages. In order to check the level of readability we used the Flesch Reading Ease test via free WebFX Readability Test Tool.

We then identified a variety of different icons/symbols/images that could be used to reinforce the textual messages. We chose visual material that would satisfy two criteria: easy to photocopy in black-and-white (and therefore easy and cheap to reproduce in our setting), and consistent with the textual messages, as agreed by the research team. We tested two different types of visual material with clients in the day centre. In the first round, we tested icons sourced from Flaticon’s free collection, manipulated by one of the researchers to fit the message. Where we thought more than one icon may be a good candidate, we included multiple icons illustrating the same message. In the second round, we tested images based on real-life photographs of frontline practitioners performing data processing actions that illustrated the key queries. An example of both is included in Figure 3 below – for the full materials, please refer to the Appendix 4 and Appendix 5.

For each set of materials, we spoke to 12 clients and gathered their feedback using a researcher-administered survey. We asked each participant to tell us whether they thought the image was helpful or confusing in conjunction with the corresponding message. The researcher would then point at the image, read the message, and repeat the question of whether the image was helpful or confusing. The responses were then collated and compared using Excel to gauge which set of materials was most effective.

Ethics

Ethical considerations have been explicit at every stage of this project. At its inception, this project arose from a recognition that our existing privacy materials were not effective in informing and empowering our clients about their data rights, and that there was a corresponding lack of relevant resources in the sector as a whole. We considered that this was a serious problem that tended to exacerbate inequalities among an already marginalised social group. We adopted a peer research approach for this project because this method addresses – to some extent – the power imbalance present in services as a result of clients not being involved in their original design. We believed that this would result in better quality data and analysis, and finally improve the experience of the service. We were also aware of benefits that peer research can bring to the researchers themselves, such as development of new knowledge and skills, building social networks and having influence on the matter at hand.

We ensured that peer researchers were supported to fully participate in the project by addressing practical barriers, such as expenses, and providing training relevant to the research process and subject matter. We also held weekly lunches where we had a chance to informally debrief about our experiences and offer/receive support from each other. During the training on qualitative research methods, we drew on peer researcher feedback to refine the research plan and develop and test the data collection tools to ensure that they were appropriate. We explored ethical case studies with the team so that they would be better prepared for scenarios that can arise during data collection e.g. participants having strong emotional reactions to the topic or focus group discussions becoming confrontational. The research team analysed and coded all the qualitative data from Stage 2 together, and collectively agreed on the key queries. Two staff members drafted this final report, but it has been reviewed and authorised by the rest of the research team, to ensure that peer researcher perspectives were faithfully reflected.

An important consideration was the wellbeing and individual circumstances of both researchers and participants. We were aware that individuals might need to de-prioritise this work in order to address more urgent matters. For example, whilst recruiting focus group participants, we would encourage them to prioritise any housing or health related appointments.

Prior to data collection, all participants were assured that their participation was voluntary, that they could withdraw from the project at any time, and that their contributions would be pseudonymised. We explained the purpose and process of the project as well as the mechanism for withdrawing one's contribution. All recordings from focus group discussions or interviews were transferred to a secure, password-protected computer immediately after data collection. Clients who agreed to participate in focus group discussions or semi-structured interviews were offered a nominal reward for their time in the form of a lunch voucher.

Results

These results comprise data collected in all three stages of the project. First we present our findings using the thematic framework as the data we collected fitted well within it. For full results of the first, exploratory stage of this research please see Appendix 1. We also highlight themes that were outside of this framework but that we found relevant and potentially useful. Finally, we present the Key Messages we arrived at as a result of the data analysis, and the results of the testing of visual materials.

Thematic framework

Purposes of processing

The processing of personal information for the purpose of providing support was uncontroversial. Most people accepted that frontline practitioners needed to know certain things about individuals in order to offer a service that would be helpful. A few, however, disagreed and expressed a preference for services they could access anonymously. The respondents said that when practitioners explain about how their information will be used, it generates trust, and that this is important. They were worried, however, that after they move on from the service, this information may be used in an unexpected way that may cause them harm. The intersection between purposes and trust that we identified through the data analysis meant that purpose of processing was an important element in our Key Messages.

Lawful basis

Whilst some study participants acknowledged that different controllers may rely on different laws for processing personal data, they sometimes exaggerated the powers that statutory agencies have in relation to data processed by charities. For example, some participants claimed that homelessness charities had a legal obligation to share data with the police or the local authority upon request.

"I get this impression that clients don't know why they have to sign the paper but either they trust you or they feel they have no choice". (Frontline practitioner)

The majority of conversation about lawful basis concerned consent. Though clients were clear that they wanted to be asked prior to any external data sharing taking place, it appears that the process for evidencing consent (i.e. signing a form) causes anxiety to both clients and practitioners. One frontline practitioner said "I get this impression that clients don't know why they have to sign the paper but either they trust you or they feel they have no choice". This was echoed by a focus

group participant "You're quite vulnerable and don't always know what you're saying yes or no to". Gathering verbal consent for sharing information does not seem to create this kind of anxiety. Furthermore, respondents were not clear on whether or not they could withdraw consent, despite the information about the right to withdrawal being included in consent forms. Our final analysis indicated that the issue of consent should be addressed in the Key Messages, focussing specifically on the right to withdraw consent at any time.

Data sharing

Data sharing was by far the most worrisome issue for study participants. For example, the practitioners that we spoke to indicated that though their clients generally trust The Connection with their data, if there is any mistrust, it is usually in connection with sharing of information. People they support may be dealing with a number of issues, where the lack of control in how their information is shared may have immediate negative consequences or even be a risk to their safety. One practitioner remarked:

"When people are on the streets and they are involved in drugs or sex work... the barrier is there, that they don't want us to talk to anyone else about their activities. [They think] if anyone contacts you, are you going to tell them what I'm

doing, what the situation is? People who have left certain areas, different towns and came to London, escaping violence, drug dealers... is my information safe with you? Will people track me down?"

One practitioner also suggested that "I think a lot of the time people are worried that the information that's going to be shared is going to label them and then follow them on throughout their life". This fear was confirmed by focus group participants:

"The fear that goes through my mind (...) once you've given them information is that you don't want it to be held against you (...) when you are applying for different jobs or services (...) Things may become more difficult to achieve, you know?"

Statutory authorities, such as police, immigration and local government were often mentioned. Some clients stated that statutory bodies have almost unlimited power to access personal data, while others claimed that The Connection would not share information under any circumstances. There was also significant confusion about how information is shared between different organisations that directly support people who are homeless. Most clients were not clear whether information was shared at all and if so, what was shared. Where participants attended multiple services, they were often aware that at least some information about them was shared via a pan-London database (CHAIN). When we explained why such sharing may take place, the participants indicated that they thought it was fair and appeared largely unconcerned, which points to the importance of explaining the purposes of this processing activity.

Sharing of information aimed at reducing risk of harm to clients was uncontroversial and widely accepted. At the same time, participants worried about tertiary sharing, as this makes it more difficult to keep track of who has the information, what they will use it for and how long they will keep it. In contrast, practitioners observed that since the introduction of GDPR it has become more difficult to get relevant information from other agencies. This may indicate that organisations are now more cautious about sharing data but is understandably frustrating when requested for legitimate reasons and when delays can endanger people in precarious positions.

The internal sharing of information attracted some controversy, with some respondents expressing the expectation that information given to one practitioner would not be accessible to others. Other respondents said such sharing should take place on a need-to-know basis, and expected technical measures to restrict access accordingly. The principal benefit of internal sharing was understood to be that it prevented clients from needing to repeat themselves when dealing with different practitioners.

As this aspect of processing data attracted the most attention from our respondents, we decided it needed to be covered in as much detail as possible in the Key Messages. We identified that these messages should address the fact that information is shared internally, how it is shared externally and how it relates to consent.

Data retention, storage and security

We found that respondents generally understood that retention periods vary amongst controllers; i.e. that the police, banks and homeless charities would hold on to information for different reasons and therefore different time periods. None of the respondents knew how long The Connection keeps their information for and expectations varied wildly. While some people said it was good to keep information in case they needed to come back, others expressed views such as "I'm not happy with it [data] being held at all after I've left". This sentiment was most prevalent amongst UK-born participants. Although not mentioned directly by any of the participants, from our experience we know that having such a record can sometimes be the only way that people can evidence their presence in the UK for immigration purposes.

Clients expressed an expectation that individual practitioners should familiarise themselves with their stored personal data prior to case work meetings, and found it frustrating to have to repeat themselves when dealing with different practitioners. The participants said that systems storing information should be secure and should compartmentalise information in terms of access. They expected the organisation to treat their information with due respect with serious consequences for misuse of their data: "If I find out that my data has been leaked then it's punishable and I can, you know, [assert] my rights". At the same time, some participants expressed doubt that any electronic data could ever be truly secure from malevolent actors.

The discussion about data retention periods revealed stark differences between expectations and practice and as such was important to communicate to data subjects early. Upon further analysis we decided to include it in Key Messages, addressing the storage period and purposes.

Data subject rights

Most survey respondents had previously exercised their rights as data subjects. 58% said they had asked for their data to be transferred, although this number may include individuals who had asked to be referred to a different service, as opposed to the strict meaning of the right to portability in the Data Protection Act. 42% of people had asked for their data to be corrected and a third had asked for a copy of their data. Worryingly, some participants were concerned that attempting to exercise their data rights may have an adverse effect on their relationship with the organisations, which shows the importance of providing reassurance around this topic.

Right to be informed

The focus group participants emphasised transparency as a tool for earning trust, as the following quotations indicate: *“Information is power. If I don’t know my rights, I’m less likely to trust you. I need the information so I can open up for you”*.

“NHS has detailed information about what each cookie does. Makes people trust them more and tell them more”.

Participants also indicated that accurate information early on could prevent later misunderstandings. Lack of adequate information was described by one participant as disrespectful and deepening the sense of power imbalance between the organisation and those it is meant to support: *“They don’t have to show you this overt respect because*

(...) they are covered; you are the homeless one reaching out for help”.

When asked where they would look for information about how The Connection processes their data, four out of five survey respondents said they would talk to their case worker or the receptionist and almost all of the rest said they would look at the website. This is a particularly valuable insight as it highlights the importance of frontline practitioner competency in this area – as well as the importance of accurate information online.

Practitioners appreciated the significance of transparency when dealing with client information, echoing the points made by clients. Practitioners also noted that transparency can open opportunities to talk about other matters related to the person’s immediate situation. On the other hand, they admitted that open conversations about data could sometimes be challenging.

Right of access

Clients were generally aware that they have the right to access their data. Some identified

Main barriers to delivering privacy information identified by frontline practitioners:

- **Languages and other communication needs** – since a significant proportion of people who access the Connection do not speak English, communicating complex information contained in Privacy Notices can be very time-consuming. Moreover, some English-speaking clients cannot read, so providing them with written materials is not sufficient. A frontline practitioner commented *“I do wish things could be simplified. It’s very easy for someone in [the] abstract (...) but it’s quite another matter trying to explain to people who just get by in English”*
- **Clients’ priorities** – some people who attend the service are initially eager to access basic facilities such as food, showers and laundry, and care little for data protection. However, their attention to data protection may increase later on.
- **Outreach setting** – the office setting lends itself to talking about ‘official matters’ such as data protection, however, outreach work demands a more informal tone. Outreach workers expressed the view that starting a conversation on the street with a complete stranger on the topic of data protection would be off-putting, ultimately impacting on their ability to deliver successful interventions.

it as the most important right as it can serve as an entry point for exercising other rights, for example, one cannot correct data that one has not seen: *“Access is paramount. It’s the starting point to everything else”*. At the same time, some seemed to think that certain kinds of practitioner correspondence or notes were ‘top secret’ and therefore inaccessible to them. They also perceived barriers to accessing this information, such as being able to show ID, or even that they would need a solicitor to help them exercise this right. In our survey, 60% of respondents thought it was necessary to fill out a special form to request a copy of personal data. In the same survey most respondents said they could request a copy of their data from their GP and The Connection (80% and 76% respectively),

“Access is paramount. It’s the starting point to everything else”

Data rights and people experiencing homelessness

whereas few said they could make such request of a landlord or Facebook, suggesting that some of them perceive the right applies only in certain contexts. Some respondents queried the length of time it takes for such a request to be processed, suggesting that this time may be used to 'cover up'.

In a follow-up survey we asked about difficulties people experienced whilst asking for access to their data. 8 out of 25 respondents said they had tried to get copies of their data and only one of them reported that they couldn't access it due to lack of ID. Previously, requesting ID was standard practice among the majority of agencies working in this sector. As this right was so important to our respondents we decided to address it as part of the Key Messages, along with the process for making such requests and the length of time it may take to process.

Right to rectification

This right was rather uncontroversial; all focus group participants expressed the view that they had the right to have inaccurate information about them corrected (versus 83% of survey respondents) and that this process should be straightforward. Barriers to having data corrected could result not only in frustration but also in real life difficulties. For example, two participants spoke about being adversely affected due to systems being over-reliant on technology and offering limited routes to speak with a person to correct inaccurate data. One of them described a situation whereby their attempt to update the Department for Work and Pensions with their new address failed and they were left without money for a period of time while they struggled to resolve the matter.

Right to deletion

Client participants in focus groups expressed strong views about the right to deletion, and practitioners said this was the most frequently invoked right. Although the clients we spoke to weren't sure if they could ask for deletion, they said they should have an unconditional right to have all of their information deleted upon request: "If you ask for [it] to be deleted, you came back and they didn't, that would be a problem". The right of deletion generated some interesting discussion, with one participant advocating "If information is spreading everywhere, if I delete it, it can't spread" with another countering: "sometimes you shouldn't do it, when the safety of the masses depends on it. (...) if it's not deleted it creates a mentality of accountability".

Practitioners noted that this request most often comes up when a client is not happy with the service and wishes to break off contact. Our analysis indicated that the right to deletion should be addressed as part of key messages, and that it was important to inform the data subjects what they can expect in practice.

Other

Importance of data protection

The survey indicated that clients consider data protection to be an important topic. Half of the survey respondents gave it maximum points when asked to rate the importance on a scale from 1 to 10, with the average score being 8. The focus group participants said the rights that are the most significant for them are the right to be informed, right of access and the right of deletion, although some participants thought all were equally important.

Data protection knowledge and self-perception

The survey indicated that clients of The Connection feel reasonably well informed about data protection: when asked if they thought their knowledge was sufficient, the average response was 6 on a 1-10 scale. In the same survey, the average proportion of correct answers to the knowledge questions was 62% - an almost identical result.

Trust

The focus group showed unease around giving personal information to agencies, especially when it is going to be processed electronically. The concerns ranged from lack of trust in data security ("If it's on the computer, it's public") to lack of trust in the agencies themselves ("If someone wanted to buy the data for 50 mil I think they'd sell it"; "Everyone's got a price").

Participants appeared to be wary of 'big data', mass surveillance and the perceived lack of control over how their information is used and who accesses it. They said: "When you walk around London there is data being collected about you"; "If you are gambling in this country, your data is shared between other casinos. You don't have privacy. The government must do something to change this." Some had a more nuanced opinion, however: "I don't mind if

my data is held, it's about how you use it. If you use it to build a psychometric model of me then I do mind, that's scary, but if it's being used to improve treatment then it's ok."

Non-UK nationals we spoke to were less concerned about how their data is handled at The Connection than those born in the UK. One EU national said: "I've seen what people [get away with] in my country (...) I feel more confident in the system in the UK and how this country works". In contrast, it was the UK nationals who were the most concerned about selling of data and expressed the most mistrust: "They don't tell you lots of things because they know it's not mandatory, they don't have to tell you (...) you don't know what their thoughts are." Interestingly, this contrasted with the practitioners' view – and our own initial hypothesis – which supposed that non-UK nationals, in particular those from Eastern Europe, would be more mistrustful: "I think people who are British-born (...) are exposed to news and information in a different way and can capture all of it, because, obviously, it's in English, which they understand, and there has been a lot of publicity about data protection, so they are quite informed (...) people who come from different realities, where there are stricter regimes (...) and had different experiences, may be a bit more suspicious".

Communication – Key Messages

We used the feedback gathered in the process of this research to produce Key Messages (see info box below) that cover data processing that respondents were most interested in, worried about, or where they had the most misconceptions. We achieved the Flesch Reading Ease score of 80.4 which Flesch categorises as Easy. For comparison, such a score indicates that the text is about as difficult to read as a consumer advertisement (Flesch, 1979).

KEY MESSAGES

- We share what you tell us with other staff at The Connection to better support you. Other key workers will be able to see this information when they meet you.
- We do not share what you tell us with anyone outside of The Connection without your permission, except when:
 - If you go to The Passage, Seymour Place or meet Outreach (SOS)*, they will be able to see that you come here. This is so we do not duplicate work
 - We are worried about your safety or safety of others, or
 - We have a legal obligation (this is very rare).
- If we asked for your permission to share information with another organisation, then you can ask us to stop sharing the information at any time
- You can have a copy of the information we have about you. Just ask your key worker** or reception. We will give it to you as soon as we can but it may take up to a month
- You can ask us to delete information we should not have.
- It is unlikely that we will be able to delete the whole record of our work with you.
- As a rule, we will delete your information 7 years after you leave the service. We keep it this long in case you come back or we have to defend our work in court. We also use the information to improve our service.

*The Passage refers to the Passage Resource Centre, another day time service for people experiencing homelessness in Westminster, and Outreach (SOS) refers to the commissioned service delivering interventions on the streets. We used the vernacular most clients would be familiar with.

**The term 'key worker' refers to frontline practitioners who conduct case work. This is the term clients would be most familiar with.

Almost half of the messages (1-3) relate to the sharing of information, internal and external, as this was the area that respondents were most worried about and where they seemed to have the most misconceptions. Messages 4-6 relate to data subject rights of access and deletion, and message 7 deals with the retention period.

In order to aid understanding and retention of the information we chose simple icons that we considered would best illustrate the messages that we wanted to convey. The testing of these icons produced mixed results – whilst some icons worked well, some were described as confusing and too abstract by survey participants.

The second version of the information sheet used photographs taken at The Connection depicting the Key Messages in a more literal manner, some including The Connection’s frontline practitioners and the NHS Homeless Health Team based at The Connection. This version produced much better results; respondents showed interest in the messages, indicated that they understood their meaning and found the images (Lesley Lowes, 2005) helpful. Below are examples of the images that participants found the most helpful (Fig. 2) and the most confusing (least helpful) (Fig. 3). Full results of testing of images are in Appendices 4 and 5

Fig.2: Images assessed as most helpful






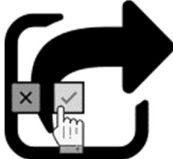
Image	Key message	% found helpful
	<p>If we asked for your permission to share information with another organisation, then you can ask us to stop sharing the information at any time.</p>	<p>100</p>
	<p>You can have a copy of the information we have about you. Just ask your key worker or reception. We will give it to you as soon as we can, but it may take up to a month.</p>	<p>100</p>
	<p>As a rule, we will delete the information we have about you 7 years after you leave the service. We keep it this long in case you come back or we have to defend our work in court. We also use the information to improve our service.</p>	<p>100</p>

Fig.3: Images assessed as least helpful

Image	Key message	% found helpful
	We share what you tell us with other staff at The Connection to better support you. Other key workers will be able to see this information when they meet you.	33
	We do not share what you tell us with anyone outside of The Connection without your permission, except when: <ul style="list-style-type: none"> • If you go to The Passage, Seymour Place or meet Outreach (SOS), they will be able to see that you come here. This is so we do not duplicate work, or • We are worried about your safety or safety of others, or • c) We have a legal obligation (this is very rare). 	33
	If we asked for your permission to share information with another organisation, then you can ask us to stop sharing the information at any time.	33

Discussion and recommendations for practice

Our research provided insights into the difficulties that people who face homelessness may experience when exercising their data rights and provide a basis for practical recommendations for other agencies offering support to this group. Here, we explore the tensions we found between clients' expectations and data protection practices at The Connection, along with possible, practical ways of addressing them. Other organisations may recognise similar dynamics in their services and may find the recommendations useful for their own practice.

Transparency

The client respondents were clear that they want to be informed about what happens to the information they give to the organisation that supports them. The complexity and amount of privacy information we have been providing, however, was cited as a hindrance by frontline practitioners. Although it was not directly mentioned by study participants who use The Connection's services, one may infer from the data that some of them find it confusing.

It is well understood that overloading the recipient with information does not amount to transparency, however the law is clear on what information must be provided prior to data collection. The information to be given in Privacy Notices as per GDPR requirements¹ is extensive and not always interesting or even possible to absorb when the

¹ Regulation (EU) 2016/679 of the European Parliament and of the council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection Regulation) (Arts 12-14, Rec 58, 60-62)

person receiving it is experiencing health problems, intoxicated or simply tired and hungry. Whilst data protection legislation is clear that the information must be provided to the individual prior to processing taking place, the individual is under no obligation to take it at that time. A pragmatic “middle way” would be to provide information that people are most interested in, such as Key Messages, during first contact. As this will, by necessity, omit some information clients have the right to have, they should always be offered alongside the full Privacy Notice which some clients may prefer to read straight away, some may choose to read at a later date. Providing this choice will likely result in better engagement with the process, help alleviate some concerns clients may have and should fit well within the initial trust-building.

Offering choice in the amount of information the person would like to receive, and the format in which they would like to receive it, appears to be the ideal solution. The Connection already offers short versions of privacy notices for assessment and casework which are being offered along with the full versions. Adding the easy-read information sheet to the tools they can use would be beneficial, especially considering the encouraging response we received when testing it. It is important to note that not everyone will be able to make use of written materials but may not disclose this unless prompted, so verbal delivery should always be offered.

Frontline Practitioners at The Connection already exercise some practice aimed at increasing transparency, such as allowing clients to look at the screen while they type, and recognise that it helps build trust and lessen anxiety. This could be enhanced, for example by routinely offering a copy of the assessment to the client at the end of the assessment session. Doing so would also improve the accuracy of the data as it would give the person an opportunity to clarify any misunderstandings. It is worth bearing in mind that this approach would mostly benefit those who can read English and may not be appropriate in all circumstances. As people using the service are far more likely to direct data-related queries to frontline practitioners than check the website, it's essential that practitioners are equipped with the knowledge needed to respond to these queries. Organisations should ensure that the practitioners are familiar with specifics about data processing relating to clients, such as retention times, sharing of data and procedures for rights-related requests. Frontline practitioners play an important role in instilling confidence in how the organisation processes its clients' data. They are also in the perfect position to provide reassurance to clients that exercising their rights as data subjects will not have a negative impact on their relationship as individuals, or with the organisation as a whole.

Easy read documents and use of graphics

The use of graphic representations to support the delivery of privacy information is not new and is mentioned in GDPR². As easy-read versions of documents become more and more popular in social care settings, our research demonstrates the importance of testing such documents on the intended recipients before rolling out, at least until standard icons are introduced. In our experience, identifying abstract symbols to visualise the textual content is not straightforward and better results can be achieved by more literal representation. Our use of black-and-white photographs was motivated by its cost-effectiveness and they were not compared to colour photographs or graphic representations of the same messages. Other organisations may find the latter to be more effective.

Retention and the Right of deletion

The discussion about the right to have one's data deleted revealed one of the starkest discrepancies between what our clients think should happen and what happens in reality. The Connection set its retention period for the majority of client data to a minimum of seven years, so as to guard against civil claims (which have a six-year limitation period). The Connection clients, however, see the information about them as purely their own and expect to have full control over whether or not the organisation gets to keep it. They see the information as an asset with possible underlying assumptions that it may be sold for profit. More importantly, it contains a record of the person's interaction with a homeless charity and as such may have real life consequences should it be released or intercepted. It is therefore

1. ² Regulation (EU) 2016/679 of the European Parliament and of the council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection Regulation) (Arts 12-14, Rec 58, 60-62)

important that organisations supporting people who face homelessness understand whether they store information that can be deleted upon request – this may apply to information stored purely for the benefit of the data subject such as National Insurance Numbers or documents stored for safekeeping. The headline-grabbing ‘right to be forgotten’ is often understood as unconditional and has the potential to cause conflict, deepen mistrust, and feelings of exclusion and powerlessness when it is denied. It is therefore important to manage the clients’ expectations when it comes to requests for deletion. This can be achieved by clear and transparent communication that includes not only the existence of the right but also how it is applied in the particular setting along with the rationale behind the retention period.

Data sharing and consent

The appropriate sharing of information between different agencies supporting people who are experiencing homelessness is vital to their ability to deliver services. At the same time, the regulatory environment for this type of processing is complex for charities that do not deliver services on behalf of the Local Authority (non-commissioned providers) as the information that is being shared almost invariably contains special category or criminal justice data. Whilst relying on explicit consent dovetails with the clients’ expectation to be asked before information is shared, the necessity of gathering the proof of consent may cause delays in the delivery of urgently needed support. It was cited by both clients and practitioners as confusing and anxiety-provoking.

Where The Connection relies on consent for sharing information, ensuring that consent is specific requires forms to be signed each time the practitioner liaises with a new organisation on behalf of a client. Most focus group respondents were clear that they want to be asked each time such sharing takes place. At the same time, and in some circumstances the same people, do not want to put their signature down each time they are asked.

The ICO’s Guide to Data Protection says that for verbal consent, an appropriate record should include time and date of the conversation and the name and date/version of the script used (ICO, 2018). Organisations considering this method will need to ensure that practitioners are appropriately trained in gathering and recording verbal consent and that where consent is gathered the data subject is given the information necessary for the consent to be valid³. Another solution that may work well is expanding the explanatory section of consent forms, including the use of graphics, to aid the understanding of the process and lessen anxiety.

Information about housing status as ‘sensitive data’

Although a person’s housing status, i.e. the fact that they are experiencing homelessness, is not special category data, it should be treated with equal care. The respondents to this study spoke about the stigma attached to homelessness and how it can hinder efforts to fully recover and move on. This stigma seems to be the common denominator for the concerns about data sharing, about agencies holding on to information after someone has left the service and about the security of their data. It is important that services that support people experiencing homelessness keep this in mind when risk-assessing their processing activities as any data breach that discloses someone’s ‘homeless status’ is likely to cause distress. Although in some circumstances such disclosure may be necessary, for example when accessing services open only to persons experiencing homelessness, in other situations it may not, e.g. when accessing training or employment. It is important that frontline practitioners help clients weigh up the pros and cons of disclosing housing status where such doubts exist.

Control and empowerment

Our research showed tension between the amount of control clients would like to have over their information, what control they think they have in practice, and the charity’s actual policy. The desire for control was usually expressed in terms of wanting to be asked before any data sharing, being informed about data-related rights, and the ability to have one’s data removed upon request. Although it was by no means universal, some clients expressed mistrust and despondence as to the actual state of affairs, doubting whether their rights would be respected. Organisations which

³ Regulation (EU) 2016/679 of the European Parliament and of the council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection Regulation) (Art 6(1)(a), Art 7, Rec 38)

cite empowerment of marginalised groups or individuals as one of the goals in their work will recognise that maximising individual control as well as enabling their clients to advocate for themselves are important elements of this process. Although there may be little room for manoeuvre in terms of data protection policies, we hope that our research shows that by improving how we communicate and explain privacy information to our clients we will arm them with the knowledge and confidence necessary for us to work together effectively.

Data subject rights for people without ID

Lack of ID is very common amongst people who are sleeping rough. This can present a barrier when attempting to exercise their rights as a data subject. Although the survey respondents who had attempted to make an access request all had the necessary identification, the survey results do not tell us whether others who did not try to exercise their rights felt that the lack of ID would prevent them from doing so. In fact, the focus groups' responses show that some clients see such access as very difficult to gain which supports this interpretation. As the ability to access one's data is adjacent to the issue of transparency and how it affects trust, it is important that any unnecessary barriers to such access are removed. This includes the necessity of filling out forms. The issue of access needs to be balanced against the issue of security, however – where ID is not requested, other ways of ensuring the data is disclosed to the correct recipients should be employed. In some circumstances, where the request comes from a known client in person, no additional security checks may be necessary. In other circumstances, using security questions that relate to the data may be the way forward.

Limitations

This project offers a unique insight into the experiences, worries and expectations clients of The Connection have in relation to how the charity handles their information. Although our findings can be generalised to some extent, it is important that we mention some potential limitations to this study. Firstly, we have not found any other studies we could compare our findings with – there is a lack of literature on the practical aspects of data protection in a homelessness charity setting, and very little has been written about the communication needs of people who come in contact with such agencies (Andrews and Botting, 2020). It is also important to note that the research was conducted in a central London day centre setting and as such the findings may not transfer adequately to settings that are less transient. For example, a residential setting may lend itself better to the provision of detailed privacy information due to a less time-pressured environment.

Due to the time limitations we were unable to trial the final version of the Key Messages in practice. This means we were unable to test our assumptions that this tool will improve engagement with privacy related information, beyond researchers' anecdotal feedback of them being well received by clients in the graphic-testing phase. It is important to note that the testing phase was focussed on establishing what graphics are helpful for understanding of messages, rather than the wording itself. The exact wording of the Key Messages may therefore change in the final version.

It should also be noted that the Key Messages we arrived at are specific to The Connection. Although the framework of what type of information clients will find interesting (i.e. data sharing, consent, retention, right of access and right to delete) is likely to be transferrable to other organisations that support people who face homelessness, the exact content of the Key Messages will likely differ.

We were unable to include the non-English speaking clients in the feedback due to financial constraints: employing a professional translator for this purpose would have exceeded the budget for the project. Because of this, the findings of this research cannot be generalised to the non-English speaking population.

Recommendations for future practice

The Connection can build on this research to further improve its data protection practice. It would be of particular interest to trial and evaluate the Key Messages tool against the practicability of its delivery, the rate of take-up, and feedback from recipients, comparing to the standard privacy notice alone. The wording should be kept under review; e.g. if clients frequently ask for clarification or have follow up questions, this would indicate that the wording of messages should be changed or additional messages added. The charity may also consider implementing other measures for improving the communication such as face-to-face information sessions with Q+A and promoting the Privacy Notice on screens. As frontline practitioners act as a first port of call for data protection related queries, we recommend that The Connection ensure adequate staff competency in this area through role-based training.

Providing printed copies of privacy notices in areas easily accessible to clients will ensure access to detailed information for those who do not wish to discuss this with staff members.

Other organisations that work with people who experience homelessness may find conducting a similar exercise useful. This is true in particular if they are not sure if their privacy information materials for clients are easily understood and accessible or if their processes are working for the frontline practitioners tasked with delivering them. Such organisations may consider adding additional tools aimed at improving communication. Our Key Messages represent an extremely pared down version of the full privacy notice, which we think may improve the uptake of full notices or, at the least, provide the information clients are most interested in, during the initial contact. Other charities may choose to extend these tools to cover the entire privacy notice, as well as extending the use of graphics to support the consent process. We believe that the process we designed in order to arrive at the Key Messages tool will transfer well to other settings and facilitate client-led improvements to practice. In particular, we recommend testing of any visual aids organisations consider deploying – as our research demonstrates, the extent to which these are helpful can vary dramatically.

Our finding that housing status data is sensitive suggests that organisations take this into consideration when reviewing data security measures as it implies that any breach involving identifiable client data is likely to cause distress. It is also important that client data recording is reviewed regularly to ensure that only relevant information is recorded, and that it is used as intended. The detailed review of categories of data being recorded against its purpose may also reveal additional information that should be deleted upon request.

Finally, the procedures for clients wishing to exercise their data related rights, should be as straightforward as possible and take into consideration the circumstances of individuals making such requests, such as potential lack of ID and other documents. As some clients may be apprehensive to exercise their rights for fear of repercussions, it is also the organisation's responsibility to provide reassurances in this area.

References

- Andrews, L. and Botting, N. (2020) The speech, language and communication needs of rough sleepers in London. *International Journal of Language and Communication Disorders*, XXXX 2020, VOL. 00, NO. 0, 1–19. Available from: <https://onlinelibrary.wiley.com/doi/epdf/10.1111/1460-6984.12572> DOI: 10.1111/1460-6984.12572
- Booth, R. (26 February 2020): UK's official rough sleeping numbers 'far lower than reality'. *The Guardian*. Available from: <https://www.theguardian.com/uk-news/2020/feb/26/uks-official-rough-sleeping-numbers-far-lower-than-reality#:~:text=But%20over%20the%20whole%20of,the%20council's%20total%20was%20679>. [Accessed 29 October 2020].
- Flesch, R. (1979). How to write in plain English. HarperCollins Publishers. Available from: https://web.archive.org/web/20160712094308/http://www.mang.canterbury.ac.nz/writing_guide/writing/flesch_h.shtml [Accessed 29 October 2020]
- Information Commissioners Office. (2018). *Guide to the General Data Protection Regulation (GDPR)*. Version 1.0.248
- Kelly, B., Gilligan, E., Friel, S., Smith, D., Pinkerton, J., & McShane, T. (2017). "More than we expected": A Guide to Peer Research with Young People. Queens University Belfast. Available from: <http://www.research.hscni.net/sites/default/files/More%20than%20we%20expected%21%20A%20guide%20to%20peer%20research%20with%20young%20people.pdf> [Accessed 29 October 2020]
- MHCLG (2019): Rough Sleeping Snapshot in England: Autumn 2019. Available from: <https://www.gov.uk/government/statistical-data-sets/live-tables-on-homelessness#rough-sleeping-tables> [Accessed 29 October 2020]
- Shelter (2019). 280,000 people in England are homeless, with thousands more at risk. Available from: https://england.shelter.org.uk/media/press_releases/articles/280,000_people_in_england_are_homeless,_with_thousands_more_at_risk [Accessed 29 October 2020]
- WebFX (n.d.) *Readability Test Tool*. Available from: <https://www.webfx.com/tools/read-able/> [Accessed 29 October 2020]

Appendix 1 – Stage 1 survey and detailed results

This survey was used for the first, exploratory stage of the project. It was administered in person, via Survey Monkey on a tablet. The survey materials include prompts for researchers collecting the data.

The survey

Introduction:

Thank you for agreeing to take part in our survey about data protection.

We would like to ask you a few questions to check how much you know about your rights and what you do with them (if anything!)

This survey is a part of a bigger research project about Data Rights in homelessness. It has 10 questions and shouldn't take longer than 5 minutes.

I will ask for your name and surname. We will only use it to avoid duplicating surveys and will destroy it as soon as we have checked for duplicates. This means that your answers will be anonymised and nobody will be able to check how you, personally, responded.

Are you happy to continue?

If yes –

1. If I find out that an organisation has wrong information about me, I can ask for this to be corrected.
 - True
 - False

2. I have the right to get a copy of my personal information held by (select all that apply):
 - My GP
 - Job Centre
 - Police
 - Connection at St Martin's
 - Facebook
 - My landlord
 - Outreach teams
 - None of the above

2. If I ask for my data to be erased from an organisation's recording system, they always have to do it.
 - True
 - False

4. I have to fill out a special form to request a copy of my personal data
 - True
 - False

5. An organisation has to tell me what they do with my personal information
 - True
 - False

6. Which sentence is true?
 - I can ask for an organisation to stop using my data and they have to stop using it no matter what
 - I can ask for an organisation to stop using my data and they have to stop doing it under certain circumstances
 - I can ask for an organisation to stop using my data but it's entirely up to them if they actually stop using it

7. Have you ever (select all that apply):
 - Asked to be given a copy of my personal data held by an agency
 - Asked for my data to be erased
 - Asked for an agency to stop using my data

- Asked for an agency to correct the information they have about me
- Asked for an organisation to transfer the information they have about me to another organisation

8. If I needed to find out more about how CSTM is using my information, I would (select most likely option):

- Check the website
- Talk to my key worker
- Talk to the receptionist
- Contact CSTM on Facebook / Twitter
- Ask someone else who is using the service
- Other (please specify)

9. How true is this sentence in relation to you?

I think I know as much as I need to know about my rights in relation to my personal information (1-10, 1 meaning I think I should know a lot more, 10 meaning I feel I know everything I need to know)

10. On a scale of 1 – 10, how important is data privacy for you? (1-10, 1 meaning 'I couldn't care less' 10 meaning 'I think about it a lot')

After survey is completed:

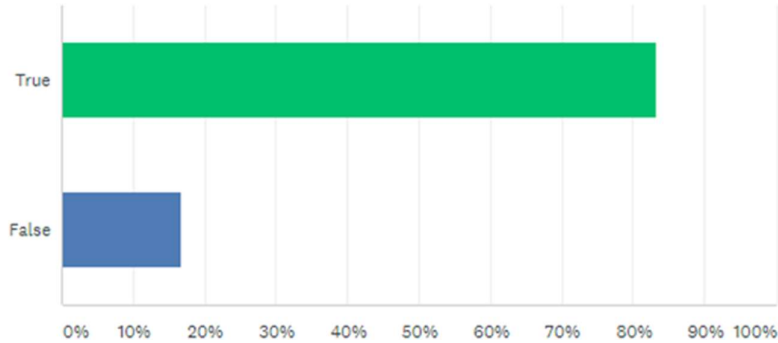
We have a Focus Group on Friday at 1pm in the Small IT Room – please let us know if you are interested! (give leaflet)

If you would like to volunteer as a Peer Researcher, or would like more information about the project, please give me your contact details and I will pass them on to Ewa who is the coordinator of the project.

Survey results

If I find out that an organisation has wrong information about me, I can ask for this to be corrected

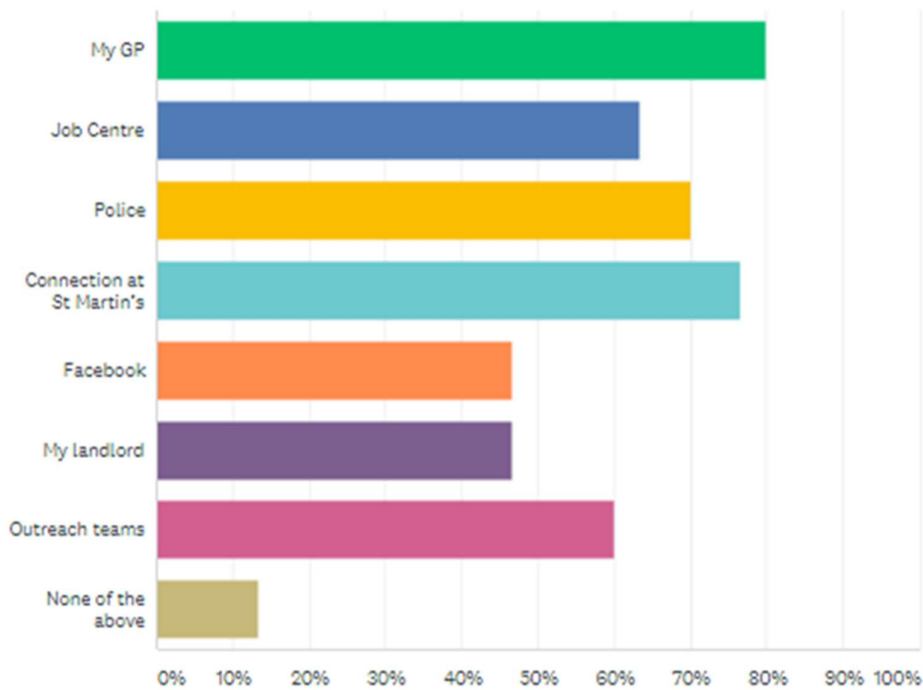
Answered: 30 Skipped: 0



ANSWER CHOICES	RESPONSES
True	83.33% 25
False	16.67% 5
TOTAL	30

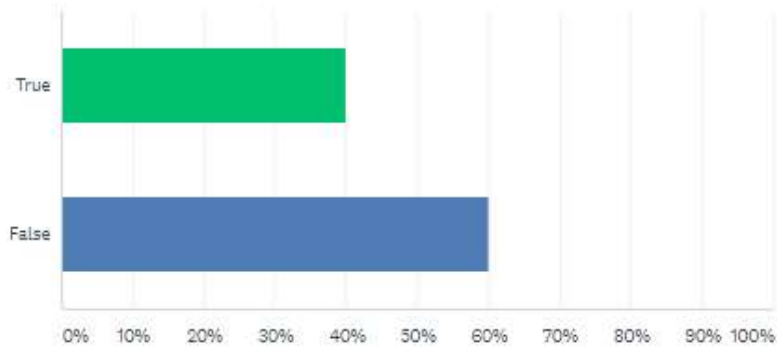
I have the right to get a copy of my personal information held by me by (select all that apply)

Answered: 30 Skipped: 0



If I ask for my data to be erased from an organisation's recording system, they always have to do it

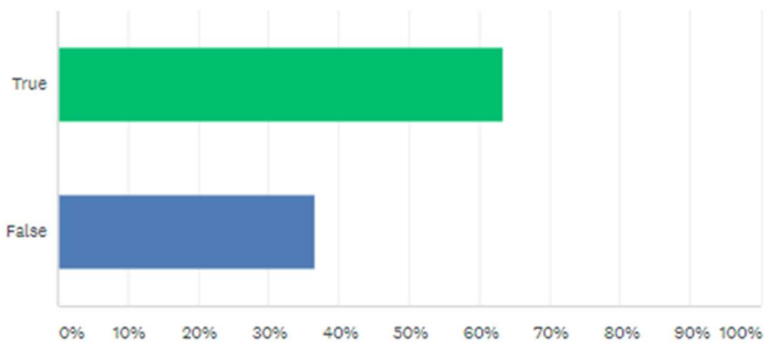
Answered: 30 Skipped: 0



ANSWER CHOICES	RESPONSES
True	40.00% 12
False	60.00% 18
TOTAL	30

I have to fill out a special form to request a copy of my personal data

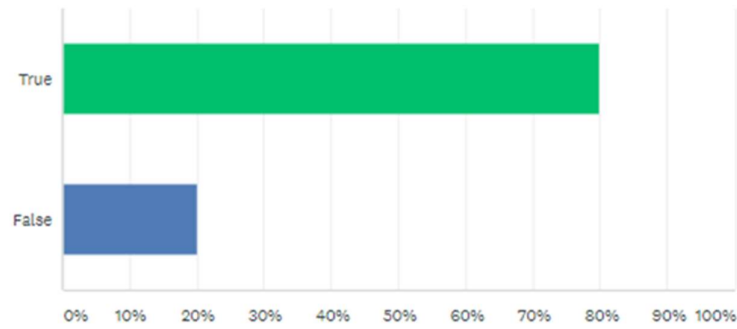
Answered: 30 Skipped: 0



ANSWER CHOICES	RESPONSES
True	63.33% 19
False	36.67% 11
TOTAL	30

An organisation has to tell me what they do with my personal information

Answered: 30 Skipped: 0

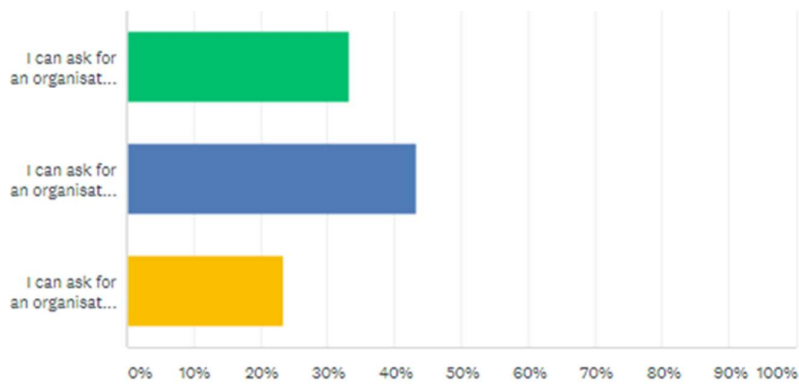


ANSWER CHOICES	RESPONSES	
True	80.00%	24
False	20.00%	6
TOTAL		30

Q6

Which sentence is true?

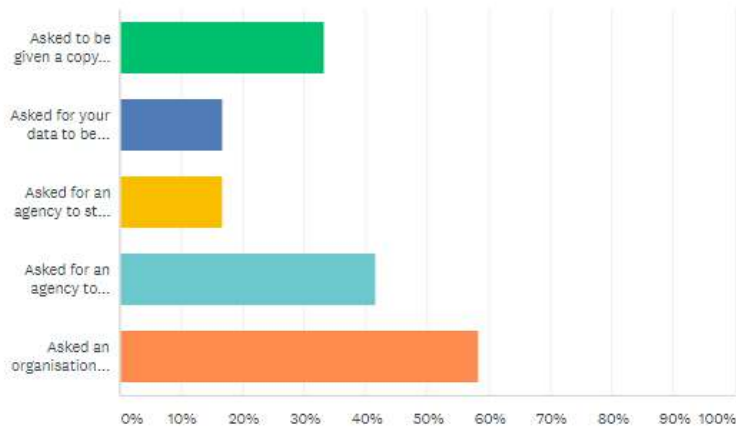
Answered: 30 Skipped: 0



ANSWER CHOICES	RESPONSES	
I can ask for an organisation to stop using my data and they have to stop using it no matter what	33.33%	10
I can ask for an organisation to stop using my data and they have to stop doing it under certain circumstances	43.33%	13
I can ask for an organisation to stop using my data but it's entirely up to them if they actually stop using it	23.33%	7
TOTAL		30

Have you ever (select all that apply)

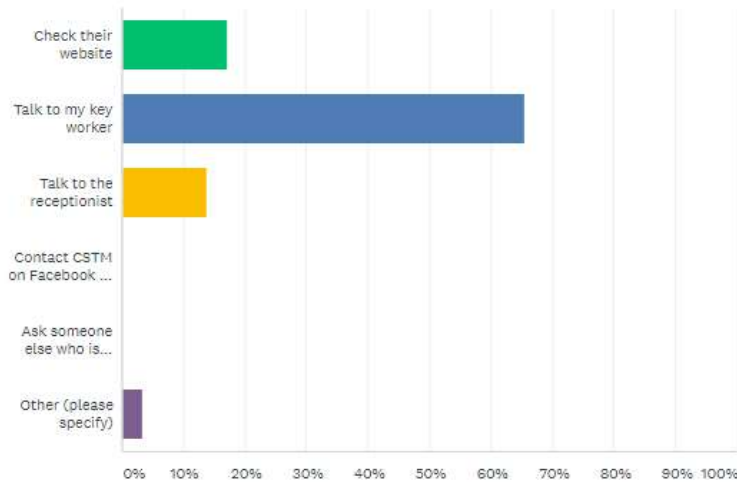
Answered: 24 Skipped: 6



ANSWER CHOICES	RESPONSES
▼ Asked to be given a copy of your personal data held by an organisation or company	33.33% 8
▼ Asked for your data to be erased	16.67% 4
▼ Asked for an agency to stop using your data	16.67% 4
▼ Asked for an agency to correct the information they have about you	41.67% 10
▼ Asked an organisation or company to transfer the information they have about you to another organisation or company	58.33% 14
Total Respondents: 24	

If I needed to find out more about how The Connection is using my information, I would (select most likely option)

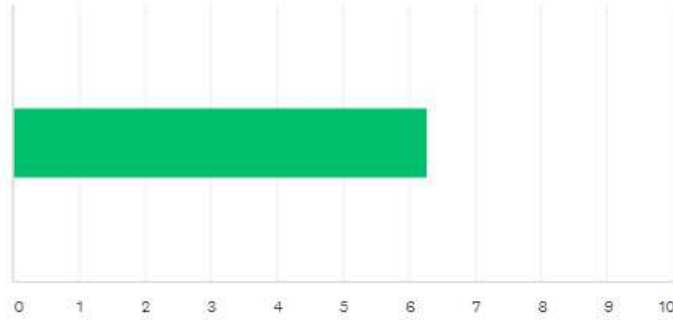
Answered: 29 Skipped: 1



ANSWER CHOICES	RESPONSES
▼ Check their website	17.24% 5
▼ Talk to my key worker	65.52% 19
▼ Talk to the receptionist	13.79% 4
▼ Contact CSTM on Facebook / Twitter	0.00% 0
▼ Ask someone else who is using the service	0.00% 0
▼ Other (please specify)	Responses 3.45% 1

How true is this sentence in relation to you: I think I know as much as I need to know about my rights in relation to my personal information (1-10, 1 meaning I think I should know a lot more, 10 meaning I feel I know everything I need to know)

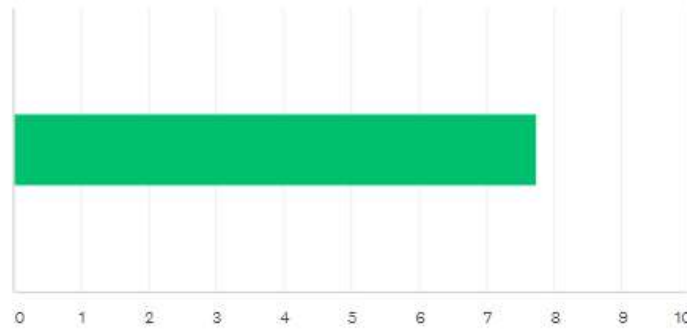
Answered: 29 Skipped: 1



ANSWER CHOICES	AVERAGE NUMBER	TOTAL NUMBER	RESPONSES
Responses	6	182	29
Total Respondents: 29			

On a scale of 1 – 10, how important is data privacy for you? (1-10, 1 meaning 'I couldn't care less' 10 meaning 'I think about it a lot')

Answered: 30 Skipped: 0



ANSWER CHOICES	AVERAGE NUMBER	TOTAL NUMBER	RESPONSES
Responses	8	232	30
Total Respondents: 30			

Appendix 2: Tools for surveys, interviews and focus groups

We are sharing the tools we used to elicit the feedback from clients and frontline practitioners that informed the development of Key Messages and recommendations for better practice around data protection in homelessness services. We hope these will be helpful for other organisations going through such process.

Focus group – session guide for facilitators

In this group we want to find out what rights people have in relation to their data and any experiences when they tried to exercise them, especially anything that was blocking them from exercising their rights.

Set ground rules:

Please be respectful to one another, try not to have more than one conversation at a time. We will try to make sure that everyone has space to speak. Also, please don't discuss what people said outside of the group. Anything else you would like to add?

Topic 1 – What rights do you have in relation to your information?

- At CSTM or other homeless charities
- Are they different elsewhere? (e.g. GP, bank, shop, police)?
- Are there situations when this right wouldn't apply?

KEEP A LIST OF RIGHTS PEOPLE HAVE MENTIONED SO YOU CAN EXPLORE THEM

- IF PEOPLE HAVEN'T MENTIONED, prompt for right of deletion, correction, objection to a specific use of information, withdrawing consent (e.g. do you think you have a right to have your information deleted? Always or only in some situations?)

Topic 2 – Have you ever felt like your data rights have been breached?

- At CSTM or elsewhere
- What was it
- What did you do? What happened next?

Interview questions – clients who do not access building-based services

- You give a lot of personal information to workers at the [name of your organisation]. What do you think happens with it?
- How it's used
- Is it shared with anyone?
- What happens with it when you stop working with them?
- Do you think you have any rights when it comes to this information? What are they?
- [Name of your organisation] has the obligation to tell you about how they use the information you give them. What do you think is the most important thing they should be telling people about?

Interview questions – frontline practitioners

- In your experience, what are the most frequent data related questions or requests coming from clients?
- How do you find the process of giving privacy notice to clients? (Any difficulties? Examples?)
- In your experience, what are the most common misconceptions amongst clients as to how CSTM uses their data? Where do you think they come from?
- Do you think our clients trust us in the way we handle their information? (If not - where do you think the mistrust comes from?)

Survey on experiences of exercising the right of access.

Thank you for agreeing to take part in our survey about data protection.

We would like to ask you a few questions about your experiences with using your data protection rights.

This survey is a part of a bigger research project about Data Rights inclusion for people who experience homelessness. It shouldn't take longer than 5 minutes.

I will ask for your name and surname. We will only use it to avoid duplicating surveys and will destroy it as soon as we have checked for duplicates. This means that your answers will be anonymised and nobody will be able to check how you, personally, responded.

Are you happy to continue?

1. Have you ever tried to get a copy of your information from anywhere? (can be another homeless charity, GP, Facebook, council, HMRC, Home Office etc...)

IF NO – terminate the survey

IF YES

2. Where from?
3. When was it?
4. Did they ask for your ID?
 - Yes
 - No
 - Can't remember
5. Did you have ID?
 - Yes
 - No
 - Can't remember
6. Did you have any problems getting the information you wanted?
 - Yes
 - No
 - Can't remember
7. Please describe what happened
8. How was it resolved in the end?

Appendix 3 – Data extracted from thematic analysis



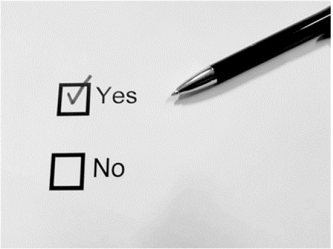
Theme	Proposed Key Message
1. Suspicion about what we need the data for when the person doesn't use the service	After you leave the service we will keep this information secure for 7 years in case you come back or we have to defend our work in court
2. Selling of data for commercial purpose	We will never sell your information
3. Sharing with statutory / authority is a worry <ul style="list-style-type: none"> a. Police (people think they have more powers than they do to get information) b. Immigration c. Local Authority 	We will not share the information outside of The Connection, e.g. with police, immigration, council, unless...(safety, in rare circumstances legal obligation)
4. Other homeless organisations <ul style="list-style-type: none"> a. Clients not clear if and what gets shared b. Not very concerned when explained 	If you come into contact with Passage or outreach, they will be able to see that you come here – this is so we don't duplicate work.
5. Internal sharing <ul style="list-style-type: none"> a. Should be on a need-to-know basis b. Expectation that confidentiality means only one person has the info (key worker) but no confidence that worker wouldn't 'blab' c. Function – the person doesn't have to repeat the information 	Information will be shared internally on a need-to-know basis – other key workers will be able to see it if they meet with you.
d. Expectation it will be shared, and should, to safeguard	We may share information about you without telling you if we are seriously worried about your safety or safety of someone else
1. Security <ul style="list-style-type: none"> a. Expectation it will be secured b. Some people think they should be able to use service anonymously c. Staff think clients usually not concerned d. British clients appear resigned to data not being secure anywhere e. "no faith in law that says my information is safe" 	We keep your information secure so it can only be accessed by people who have the permission to access it.
2. System complexity <ul style="list-style-type: none"> a. Difficult to explain b. Clients want full control, think we process too much to handle c. ~complexity increases anxiety? 	This is complicated so please ask me to explain again if you're not sure about something – added to the introduction
3. Clients think we store less data about them than we do	We will take notes from our meetings
4. Expect that consent will be sought before sharing (some people think they should always be asked)	We may share information about you without telling you if we are seriously worried about your safety or safety of someone else

Data rights and people experiencing homelessness

<p>5. Lack of understanding of consent</p> <ul style="list-style-type: none"> a. Not sure if can be withdrawn b. Process confusing (why do I have to sign multiple times) c. Languages / literacy d. Mistrust/cynicism 	<p>When we ask for your permission to share information about you, you can always tell us to stop and we will stop.</p>
<p>6. Some would be reluctant to exercise for fear of reprisals</p>	<p>Reassurance that exercising rights will not have any negative consequences</p>
<p>7. Right to be informed</p> <ul style="list-style-type: none"> a. Not sure if would be given all the information (mistrust) b. Clients want to be informed about sharing c. Some client have little awareness where to find the information, some are not that interested / motivated 	<p>If at some point you want to find out more about what we do with your info, talk to staff or check website</p>
<p>8. Right of access</p> <ul style="list-style-type: none"> a. Most people think they should be able to access (“of course I do, it’s me!”), although don’t know if they could access notes of staff, conversations between practitioners b. May need a lawyer, fill out a form or show ID c. 4 weeks to access – possible cover-up (mistrust) 	<p>You can ask us for a copy of what information we have about you – all you need to do is talk to a member of staff. We’ll do our best to give you what you need as soon as possible but it may take up to a month.</p>
<p>9. Correction</p> <ul style="list-style-type: none"> a. Generally people think right applies and should be straightforward 	<p>If you think we’ve written something about you that isn’t true, you can ask us to correct it.</p>
<p>10. Remedies</p> <ul style="list-style-type: none"> a. Should be compensated if data is misused b. Would go to Police / courts 	<p>If you have any questions or complaints about how we treat your information, please let us know. You can also complain to the regulator, the Information Commissioner’s Office.</p>
<p>11. Amount of data / what’s recorded</p> <ul style="list-style-type: none"> a. Clients think we store too much or are not aware how much we store 	<p>We only record information that we need in order to support you.</p>

Appendix 4 - Key Messages with supporting images – full results

As part of the research we have created and tested photographs representing actions performed on client data, to support the delivery of key facts about data protection at The Connection. The photographs were judged by clients as helpful, rather than confusing, and overall worked better than abstract icons (see Appendix 5).

	<p>We share what you tell us with other staff at The Connection to better support you. Other key workers will be able to see this information when they meet you.</p>	<p>85</p>
	<p>We do not share what you tell us with anyone outside of The Connection without your permission, except when:</p> <ul style="list-style-type: none"> a) If you go to The Passage, Seymour Place or meet Outreach (SOS), they will be able to see that you come here. This is so we do not duplicate work, or b) We are worried about your safety or safety of others, or c) We have a legal obligation (this is very rare). 	<p>80</p>
	<p>If we asked for your permission to share information with another organisation, then you can ask us to stop sharing the information at any time</p>	<p>100</p>



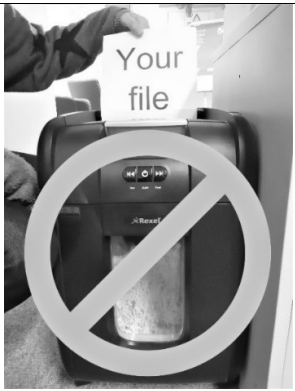
You can have a copy of the information we have about you. Just ask your key worker or reception. We will give it to you as soon as we can, but it may take up to a month.

100



You can ask us to delete information about you that you think we should not have.

92



If you ask us to delete all your information, it is unlikely that we will be able to do so.

62








As a rule, we will delete your information 7 years after you leave the service. We keep it this long in case you come back or we have to defend our work in court. We also use the information to improve our service.

100

Appendix 5 – Key Messages with supporting icons – full results

As part of the research we have created and tested a number of icons to support the delivery of key facts about data protection at The Connection. The icons were judged by clients as less helpful and more confusing than the photographic images in Appendix 4. We are sharing these as an example of what hasn't worked well.

		% found helpful
	We share what you tell us with other staff at The Connection to better support you. Other key workers will be able to see this information when they meet you.	33
	We share what you tell us with other staff at The Connection to better support you. Other key workers will be able to see this information when they meet you.	42
	We share what you tell us with other staff at The Connection to better support you. Other key workers will be able to see this information when they meet you.	67
	We do not share what you tell us with anyone outside of The Connection without your permission, except when: a) If you go to The Passage, Seymour Place or meet Outreach (SOS) , they will be able to see that you come here. This is so we do not duplicate work, or b) We are worried about your safety or safety of others, or c) We have a legal obligation (this is very rare).	50
	We do not share what you tell us with anyone outside of The Connection without your permission, except when: a) If you go to The Passage, Seymour Place or meet Outreach (SOS) , they will be able to see that you come here. This is so we do not duplicate work, or b) We are worried about your safety or safety of others, or c) We have a legal obligation (this is very rare).	33

	<p>If we asked for your permission to share information with another organisation, then you can ask us to stop sharing the information at any time.</p>	<p>33</p>
	<p>If we asked for your permission to share information with another organisation, then you can ask us to stop sharing the information at any time.</p>	<p>42</p>
	<p>You can have a copy of the information we have about you. Just ask your key worker or reception. We will give it to you as soon as we can, but it may take up to a month.</p>	<p>50</p>
	<p>You can have a copy of the information we have about you. Just ask your key worker or reception. We will give it to you as soon as we can, but it may take up to a month.</p>	<p>75</p>
	<p>You can ask us to delete information about you that you think we should not have.</p>	<p>58</p>
	<p>If you ask us to delete all your information, it is unlikely that we will be able to do so.</p>	<p>58</p>
	<p>As a rule, we will delete the information we have about you 7 years after you leave the service. We keep it this long in case you come back or we have to defend our work in court. We also use the information to improve our service.</p>	<p>42</p>
	<p>As a rule, we will delete the information we have about you 7 years after you leave the service. We keep it this long in case you come back or we have to defend our work in court. We also use the information to improve our service.</p>	<p>50</p>
	<p>As a rule, we will delete the information we have about you 7 years after you leave the service. We keep it this long in case you come back or we have to defend our work in court. We also use the information to improve our service.</p>	<p>50</p>