

Accessing care records and information rights – analysis of survey

Economic analysis – impact and evaluation

June 2024



The survey 'Accessing care records and information rights' ran for a little over six weeks from February to April 2024. It collected 208 responses, of which 172 were from respondents over the age of 18 who were care experienced or third parties trying to access the care records of someone close to them.

Respondents belonged to a mix of age groups, and covered all UK regions. This provides us with a reasonably good sample, which makes our findings reasonably representative of the experience of people who have been in care and are trying to access their records.

The findings from this survey analysis are part of the evidence base we collected in 2024. The evidence base underpins the ICO's next steps in this space, including the comms campaign being launched in December 2025.

Main findings

The prevailing **reasons for wanting to access the records** were to fill gaps in their identity and memory, and understand choices made about them. Other common reasons were to gain a better understanding of their own health and medical history, and to gather evidence to support legal claims (eg Redress Scheme in Scotland, or other child abuse inquiries).

Common **barriers** faced by respondents when trying to access care records included:

- long waiting times;
- challenging communication with organisations; and
- lack of support.

These barriers had a negative impact on respondents, including a negative emotional impact.

Three in four respondents who had asked for care records had received at least some of them. However, they often found that the information they received was not enough for what they needed. Many of them were also left with questions and concerns after receiving the records.

Another common challenge faced by respondents who accessed their records was the **redaction of records**:

- 80% of respondents had their records redacted;
- only half of them knew it would happen; and
- respondents often thought the records are over-redacted.

The content and language of the records had a negative impact on many respondents. They however overwhelmingly agreed that they have the right to access information recorded about them, despite the discomfort that reading this information may cause.

In support of this point, we also found that not being able to access care records had (or would have had) a strong negative impact.

In conclusion, analysis of survey responses confirmed much of what we had already heard from other sources. It also shed more light on care experienced people's journey and how it affects them.

Interaction with the ICO

Respondents gave the following feedback on ICO resources and services:

- They found the templates useful, and valued the accessibility of the information on our website.
- They had mixed opinions on ICO processing complaints: some found that complaining to the ICO would help progress the process, others felt they weren't taken seriously, the ICO didn't follow through, or the ICO didn't hold organisations accountable.

A respondent suggested that the ICO should consider implementing a trauma-informed approach to complaints and data breaches relating to care records.

1. Introduction

The ICO has received anecdotal evidence that people with care experience face significant challenges in exercising their information rights and accessing support from the ICO. Our initial work (engagement with advocacy groups and with care experienced people) suggested people with care experience are at risk of suffering harm in relation to their information rights.

Motivated by this, the ICO started a project to gain an enhanced understanding of what the barriers are, and how we can better support this cohort to exercise their rights. This exploratory project involves direct engagement with care experienced people, representative groups, local authorities and other relevant statutory bodies.

As part of this project, we have developed a survey to collect first-hand evidence of the barriers faced by care experienced people when trying to access records about their time in care, and their impact. This survey was aimed at:

- people who wanted to, were trying to, or had accessed their records from their time in care;
- people wanting to access someone else's records; and
- charities and advocacy organisations supporting care experienced people.

The survey ran from 28 February to 15 April 2024. This document presents the analysis of responses, contributing to the evidence base in this topic area.

The main body of the report is structured as follows:

- **Section 2** gives an overview of respondents, and in particular care experienced people and third-party respondents.
- **Section 3** reports respondents' experience of reaching out about care records, including their reasons for seeking access, the organisations they contacted, and the barriers they faced.
- **Section 4** covers the experience of accessing the records, including views on the information received, and more detail on delays and obstacles.
- **Section 5** explores the impact of being able to access records from the time in care.
- Finally, **Section 6** summarises the findings.

Annex A presents views from other respondents, including charity or advocacy organisations, adoptees, and local council officers and social workers.

⚠ CONTENT WARNING

This document contains mentions of topics that can be challenging or distressing for readers, including abuse and child abuse, death, mental illness, and suicide.

2. Respondents

The survey received a total of 214 responses. Excluding one duplicate answer,¹ one suspected spam response and five empty responses, the survey had 208 responses. As Table 1 shows, the majority of these were from care experienced people, the main target of this survey.

Table 1: Respondents

Respondents	Number	Share
Care experienced people	162	78%
Third party	11	5%
Charity or advocacy organisations	6	3%
Other	29	14%
Total	208	100%

Source: EA analysis of survey.

Section 2.1 gives more detail on the first two groups of respondents. We have grouped third-party respondents along with care experienced people, as they are facing many of the same barriers and challenges when trying to access the data. The small sample size for third-party participants also means we cannot analyse this cohort separately.

Sections 3 to 5 discuss the views shared by care experienced people and third-party respondents. The views of charity or advocacy organisations and other respondents are summarised in Annex A.

2.1. Care experienced people and third-party respondents

Of the 162 care experienced people, 158 responded themselves and four had someone help them respond. Of these four, two respondents were helped by a family member, one respondent was helped by a friend, and one respondent was helped by a charity or advocacy group. The 11 third-party participants were seven family members, two friends, and one adoptive parent of people who are care experienced. Their answers are reported together with care experienced people, as mentioned above.

Collating the responses from these two cohorts, we can account for the experience of 173 people trying to access records relating to time in care.

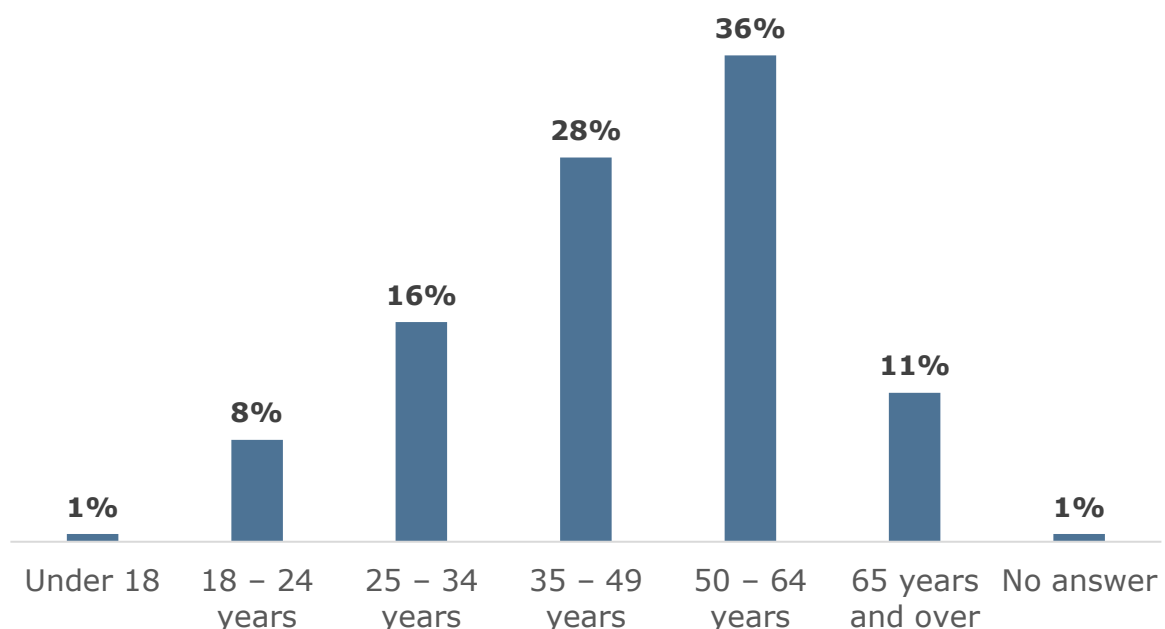
¹ The respondent emailed the ICO to warn about having submitted a duplicate partial response because of technical issues.

One respondent indicated they were under 18, and they were excluded from the rest of the survey. The views shared by the remaining **172 people** make up the main evidence for this analysis.

For the cohorts aged 18 to 64, engagement with the survey increased with age, as seen in Figure 1. The higher participation from older cohorts could be due to an increased desire to access records as people get older, or people facing more challenges when trying to access older records.

Engagement was lower for the cohort of care experienced people aged 65 or over, likely due to a combination of factors including accessibility and digital exclusion,² and records being less likely to still exist for this generation.³

Figure 1: Age of care experienced people



Source: EA analysis of survey, N=173.

We asked respondents where they or the person close to them had been in care. Collating the responses, our sample covers all administrative regions of the UK.⁴ This gives us confidence that our findings are UK-wide, and not only pertinent to some parts of the UK.

² See for example ONS discussion of the [digital divide by age](#).

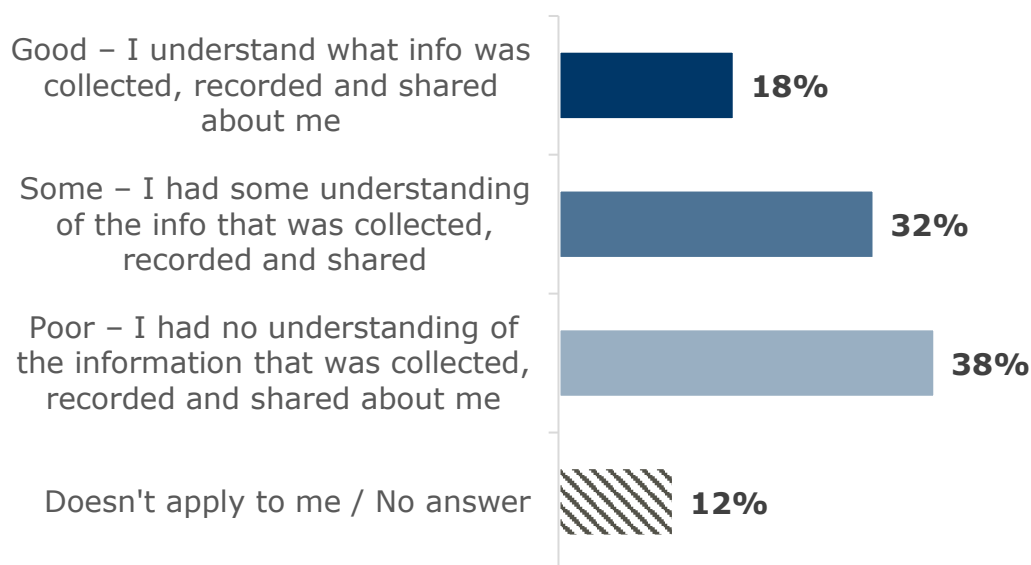
³ SAR rights were introduced in 1998 by the [Data Protection Act 1998](#). By then people in this cohort were at least in their 40s, and the records created in their childhood had probably already been destroyed.

⁴ These were: North East, North West, Yorkshire and the Humber, East Midlands, West Midlands, East, London, South East, South West, Wales, Scotland, and Northern Ireland.

Nine in 10 respondents had been in care in one region only, with a minority of respondents indicating they had been in care in two or more regions. One respondent said they had been in care outside of the UK, as well as in Scotland.

Less than one in five care experienced respondents said that they had a good understanding of information recorded about them about their time in care. As Figure 2 shows, care experienced respondents who engaged with the survey were more likely to have a poor or partial understanding rather than a good one.

Figure 2: Respondents' understanding of information recorded about them about their time in care

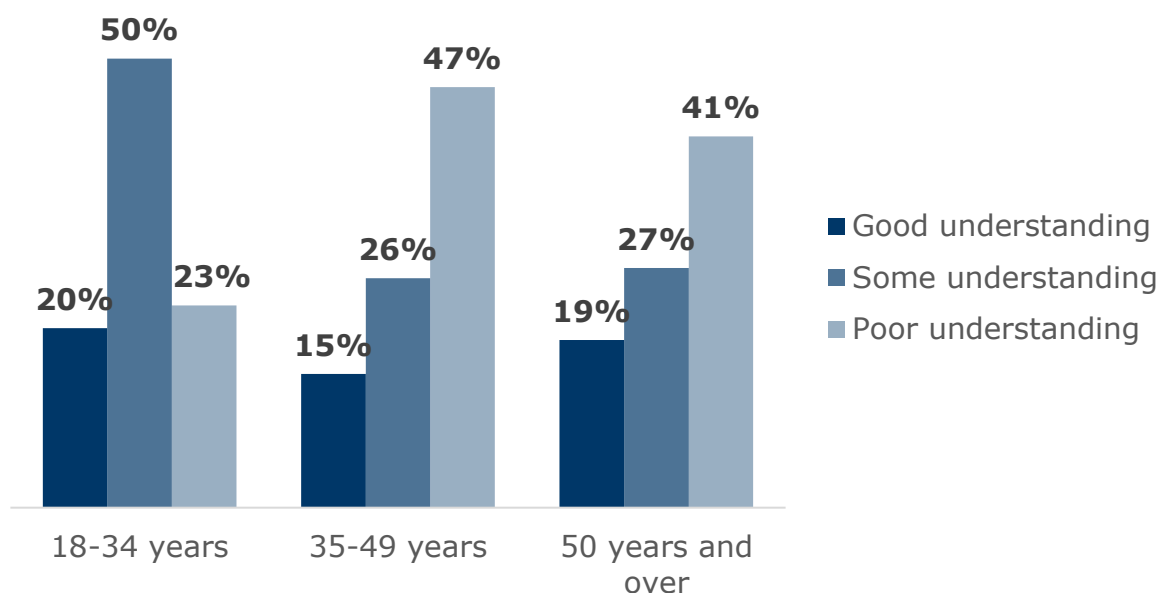


Source: EA analysis of survey, N=162.⁵

Figure 3 shows that respondents aged 35 to 49 and respondents aged 50 and older had similar understanding of the information recorded about them. Compared to them, respondents aged 18 to 34 tended to have better understanding, being more likely to have some rather than poor understanding of the information recorded about them. This could be due to the events being more recent, or due to better data protection practices being in place in more recent years.

⁵ This question was only asked to care experienced people, not to third-party respondents.

Figure 3: Respondents' understanding by their age group



Source: EA analysis of survey, N=162.⁶

Our survey indicates that respondents who seek access to their records are unlikely to have a good understanding of what information was collected, recorded and shared about them while in care. At this stage, it is not possible to tell whether care experienced people were overall more likely to have poor or partial understanding of the information recorded, or if care experienced people who have poor or partial understanding were more likely to seek access to their records and face challenges in the process.

2.2. Data quality

Surveys where people are asked to voluntarily disclose their experience and opinions, as the one analysed here, are subject to self-selection bias: people with stronger opinions are more likely to participate.⁷ Since we don't have information on the overall population of care leavers, it's not possible to validate our findings by comparing the sample to the overall population.

The survey collected responses from 172 care experienced people from a mix of age groups and who had been in care all around the UK, providing

⁶ This question was only asked to care experienced people, not to third-party respondents.

⁷ [What is Self-Selection Bias & How to Avoid it?](#)

us with a reasonably good sample. In the absence of any obvious issues, we consider our findings to be **reasonably representative** of the experience of people who have been in care and are trying to access their records.

Finally, it is worth noting that the evidence presented here collates respondents' experiences when trying to access care records. Some of these experiences were recent, while others occurred years ago. The [Data Protection Act \(DPA\) 1998](#) introduced SAR rights in 1998, and since then attitudes towards care experienced people have seen significant change. In the words of a respondent,

"Institutional attitudes have changed over the decades[,] from us 'care leavers' being looked down on as inferior and not having any right to their records, to now being much more open and accessible".

3. Reaching out about care records

Close to nine out of 10 respondents have already asked to see care records, or were in the process of asking at the time we conducted this survey. A further 8% of respondents wanted to ask but didn't know how or hadn't started. This means that a total of 167 respondents, or 97% of all care experienced or third-party respondents, wanted to see their records.

Figure 4: Have respondents asked organisations to provide them with a copy of the records, or are they planning to?



Source: EA analysis of survey, N=172.

The vast majority (92%) of respondents who wanted to see the records were trying to access records created prior to GDPR being introduced, and close to half (48%) were trying to access records created more than 30 years ago. Older records are often harder to locate, as they will likely have moved places over the years. They are also more likely to have been lost or destroyed.

A handful of respondents indicated that they did not want to see the records. Some reasons they cited referred to the inability of care experienced people to deal with more information for the time being, and the risk of being re-traumatised.

3.1. Reasons for seeking access

Care experienced respondents mentioned the following reasons to want access:

- to (re)build their identity;
- to understand their life story, including why they went into care and why they were moved around as children;

- to find their parents, and how to get in touch with family members;
- to better understand their own health and to know their family medical history, for example in relation to genetic diseases or heart conditions;
- to gather evidence supporting their child abuse inquiries, applications for the Redress Scheme in Scotland,⁸ or civil legal claims against their local authority, social services, and the care system; and
- to understand “if social services were aware of some of the things that were happening”, including abuse in the household.

Some respondents approached the records with specific questions, while others wanted to fill a gap in their life story, or understand the social workers’ perspective of what they went through. Many care experienced respondents talked about seeking the truth and wanting to find closure from their records.

“I wanted to find out where I came from. Without this information I felt untethered”.

Some respondents also expressed a sense of ownership towards the records: when talking about their records, for example a respondent said that “they are rightfully mine”. The desire to own their records – their story – appears to stem from the fact that the early parts of the story were decided by others, who often made life-altering decisions about the care experienced people without them being able to participate in those decisions. While many were not involved in the choices made for them, they now feel they should at least own access to their story, in its entirety.

3.2. Organisations and people contacted

More than two thirds of respondents who wanted to see their records had contacted a local council to get access, as seen in Table 2. About one in five had contacted a health provider, and the same proportion had contacted a voluntary charity organisation.

The majority (57%) of respondents wanting to access their records had contacted only one type of organisation. Most often, this was a local council. It should be noted that respondents indicated what type of

⁸ [Scotland's Redress Scheme](#) offers redress payments to people abused in care as children in the past, and some next of kin.

organisation they had contacted, not how many organisations of that type they had reached out to.

Some of the other organisations contacted by respondents, beyond those mentioned in Table 2, included: religious orders (2%); courts (2%); social services (2%); counselling or psychological services (1%); media (1%); and police (1%).

Table 2: Who have respondents contacted to see the records?

Organisation contacted about records	Share
Local council	72%
Health provider (NHS, Health and Social Care Board)	23%
Voluntary charity organisation	23%
Other government department	13%
Private care provider	8%
Other	14%
Doesn't apply to me – I haven't started the process yet	6%

Source: EA analysis of survey, N=167.

Three in four people who wanted access to their records had sought advice or support with accessing records. The most common options for advice and support were the council itself, and a social worker. One in four people had looked to an advocacy group for support throughout the process.

For those who said other, a common response was paid-for services. Ten respondents (6%) looked for advice or support from adoption and DNA services, solicitors, or private detectives.

Table 3: Where have respondents looked for advice or support with accessing records?

Organisations or people contacted for support	Share
Social worker	29%
Council	29%
Advocacy group	24%
People who have already accessed their records	22%
Friends and/ or family	19%
ICO	10%

Other	10%
None of these – I didn't need any advice	15%
None of these – I haven't started yet and/ or was unsure	6%

Source: EA analysis of survey, N=167.

The experience of reaching out to organisations and people about their records or about support was frequently a negative one. There were three recurring issues encountered by respondents:

- **Lack of clarity on the process, and lack of support navigating it.** This leaves respondents feeling demoralised and neglected.

"No one is explaining to me why, what happens and there is no support. It seems there is no clear pathway of how to access records".

- Organisations **not releasing records, or providing redacted records without explaining why.** The lack of explanations worsened care experienced people's distrust for these organisations and people they'd reached out to. This intense distrust led some respondents to believe they were being lied to by organisations trying to protect their reputation.

"[The organisations contacted] refuse outright to provide primary sources of information or reason why they are withheld in their entirety".

- Organisations communicate **contradicting information**, which contributes to care experienced people's distrust.

"They said they had no records[,] that they where [sic] all burned in a fire when I inquired 16 years ago. And when a charity inquired [...] two years later they where [sic] told they had been destroyed in floods. When I took out a civil case against [them] at the start of last year my lawyer wrote to my local council and low [sic] and behold they sent all my records to the lawyer".

Sections 3.2.1 to 3.2.6 go into more detail on respondents' experience reaching out to social workers, councils, advocacy groups, people who have already accessed their records, friends and family, and the ICO. As mentioned above, these experiences span the course of many years, potentially decades.

3.2.1. Social workers

Respondents reported having mixed experiences with social workers. Social workers often offered advice on the process and in some cases additional support going through the records, warning they'd be distressing. However, as one respondent explained, this was nice but not enough: care experienced people accessing their records needed a follow-up, or to be pointed towards organisations or groups that can support them.

Other respondents shared that the social workers had not been supportive with them, including:

- questioning whether the respondent “really wanted to read my file because there might be disturbing things in there”;
- gatekeeping the records and only giving their interpretation of what they thought was relevant; and
- seemingly contradicting themselves on what information was available.

Some respondents believed social workers were lying to them, especially in cases where the social workers had contradicted themselves. The lack of trust that care experienced people had for social workers was worsened by information becoming distorted when passing through multiple hands and by records previously deemed lost suddenly reappearing. This all happened in a context of generally poor support. Whether or not social workers were indeed lying, these interactions tainted by mistrust ended up hurting people trying to access care records.

“The impact this has on you is indescribable, you are asking people for help, they can see how it affects you and still they lie”.

3.2.2. Councils

About half of the respondents who contacted councils said they received advice on the process to follow from the organisation. Many respondents found councils to be unsupportive or even unresponsive, and only a handful of respondents were offered support.

Respondents looking to find further records from third parties have expressed their frustration at the council not being able to tell them who they should contact. One respondent suggested that the solution would

be to have “a central voluntary specialist agency to [...] act [as] the conduit between the record holder and the subject”.

3.2.3. Advocacy groups

Respondents unanimously found advocacy groups supportive: they said that these groups aided them filling in the forms, gave advice on how to proceed and potential pitfalls, intervened when there were difficulties accessing files, encouraged people to be reflective before accessing the records, and helped them understand what to expect. In the words of a respondent,

“It was my journey but they chaperoned me”.

3.2.4. People who have already accessed their records

Survey responses highlighted the importance of having other people with lived experience to rely upon. They can give advice and useful tips, warn about the difficulties in the process and the loss of records, and provide a “space to talk about the feelings of being a care experienced person”.

“The biggest support has been other [care experienced people], because they get it”.

In some instances, other care experienced people were the key to respondents figuring out how to access records, or even that they could in the first place. In these cases, the care experienced peers were stepping in to support where other organisations had failed to do so.

“My friend who was also care experienced told [me] to ask the local authority as they were actually my corporate parent. Without my friend I would still be the none the wiser as none of the social workers had ever bothered to explain it to me”.⁹

3.2.5. Friends and family

Family and friends can offer emotional support and a safe space, with some respondents sharing that their family and friends had taken time to

⁹ A corporate parent is an organisation or person who has special responsibilities to care experienced children and young people.

educate themselves on the challenges and mental health issues care experienced people can face.

Other respondents expressed that, despite their effort, friends and family sometimes could not really understand what the care experienced person was going through. This reinforced the importance of having other people with lived experience who can give support and make people feel seen.

3.2.6. ICO

Respondents shared their experience interacting with the ICO at different stages of the process, as outlined below.

- Practical and accessible information: respondents found the templates useful, and valued the accessibility of the information on our website.

“Having dyslexia, I normally find searching information hard but the icowebsite was written [sic] in laymen’s terms so I was able to understand the process and without the information listed in the ICO website, I wouldn’t have got passed [sic] the application of a SAR”.

- Processing complaints:
 - Some respondents found that complaining to the ICO would get the process moving, and would push organisations to provide records.
 - Other respondents thought that ICO did not take their complaints seriously, didn’t follow through, or didn’t hold organisations accountable.

Respondents looked to the ICO to rebalance the power asymmetry between themselves and the organisations who held their records, and to help give them the clarity lacking from the responses they received from organisations that held their records. One respondent suggested that the ICO should have a trauma-informed approach to complaints and data breaches relating to care records.

3.3. Barriers

The most common barrier faced by respondents trying to access records was that the communication with the organisation was challenging. Some examples included frustration at organisations that “don’t return my calls, my emails or call backs”, or respondents saying that they were accused of

lying. Respondents who found communication with organisations to be challenging were more likely to have sought support from advocacy groups.

Challenging communication with the organisations often went hand in hand with the second most common barrier, the process taking longer than expected. Close to two thirds (62%) of respondents faced both of these barriers, which suggests the two barriers mentioned were widespread and often intertwined.

As Table 4 shows, the least common barrier faced by respondents was not knowing they had the right to ask. It should be kept in mind that this survey's main target was care experienced people who have requested access to their records. In the wider care experienced population this could be a bigger barrier, as those who don't know they have the right to ask may have never got around to requesting access.

Half of respondents faced five or more of the barriers in Table 4, indicating that care experienced people and those close to them have to go through many hurdles in their efforts to access records. Only five respondents (3%) said that they did not face any of these barriers.

Table 4: Barriers faced when trying to access records

Barrier	Share
Communication with the organisation is/ was challenging	71%
The process taking longer than expected	69%
Not knowing where the records are held	65%
Not being kept up to date on how my request is/ was progressing	61%
Not having support	57%
Not knowing how to make the request	57%
Not knowing I had the right to ask	35%

Source: EA analysis of survey, N=167.

A legal barrier faced by many respondents was the inability to [access records about someone who had died](#), unless they had power of attorney or had been given consent before the person in question passed. Respondents found this extremely confusing and frustrating. They felt these records were an important piece of their personal puzzle, and the

knowledge that they had lost access to these records often hurt them deeply:

"I will now never see this information which likely could have helped me process my trauma and experiences".

Other challenges faced by respondents included:

- accessibility of files;
- council mixing up records;
- having to access paid services to find siblings;
- lack of empathy or concern from social workers;
- local authority boundaries changed over the years, making historical records hard to locate;
- not being given autonomy;
- receiving incomplete records;
- records being unreliable;
- records could not be located or no longer existed; and
- records delivered or handed to respondents without warning they would be arriving.

These barriers and challenges often had a negative impact on respondents. As seen in Table 5, for more than half of respondents the barriers faced made the process longer.

Table 5: Impact of barriers

Impact	Share
Made the process longer	55%
Made it impossible to access the records	38%
Discouraged me from asking about the records	35%
I received the information I needed too late	16%
Doesn't apply to me	13%

Source: EA analysis of survey, N=167.

As respondents faced multiple barriers, it is not straightforward to identify to what extent single barriers contributed to specific impacts. Our analysis suggests that not having support was linked to respondents being discouraged from asking about the records. Similarly, communication being challenging was connected to a longer process.

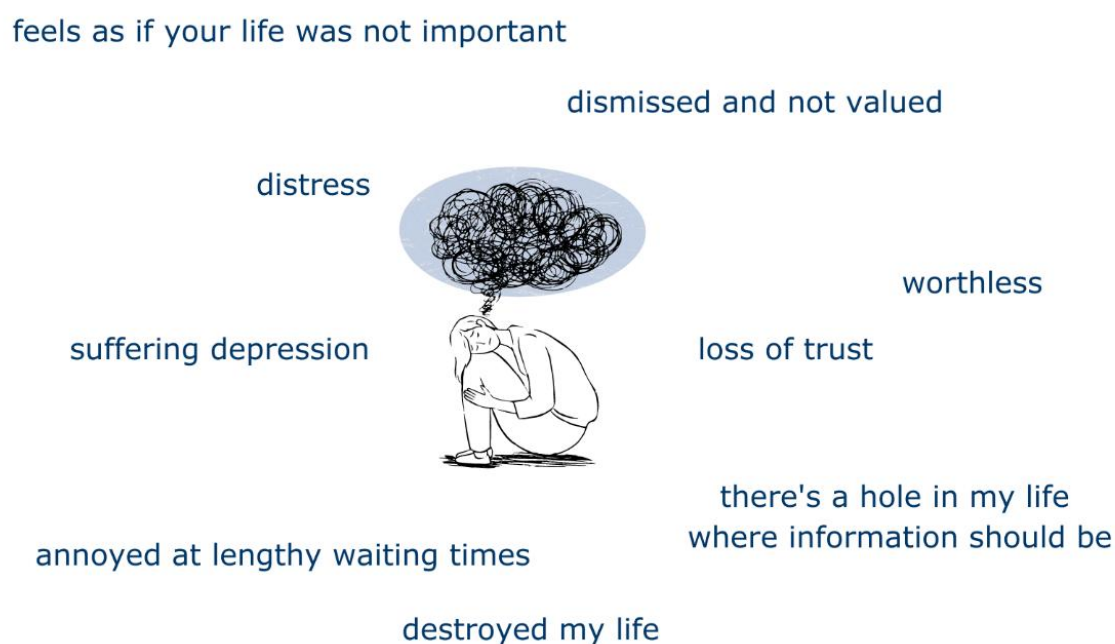
The impact of the legal barrier mentioned above is easier to identify. Not being able to access records about their deceased parents deprived some respondents from the chance to connect with other members of their biological family:

"I may never have the opportunity to make contact with my older brother".

Not receiving the records, receiving them too late, and key information being redacted or missing from the records meant that some respondents were unable to access justice or appropriately support their redress application.

Finally, many respondents (about 10%) spoke about the emotional impact that the barriers had on them. We've collated some of these responses in Figure 5.

Figure 5: Emotional impact of barriers

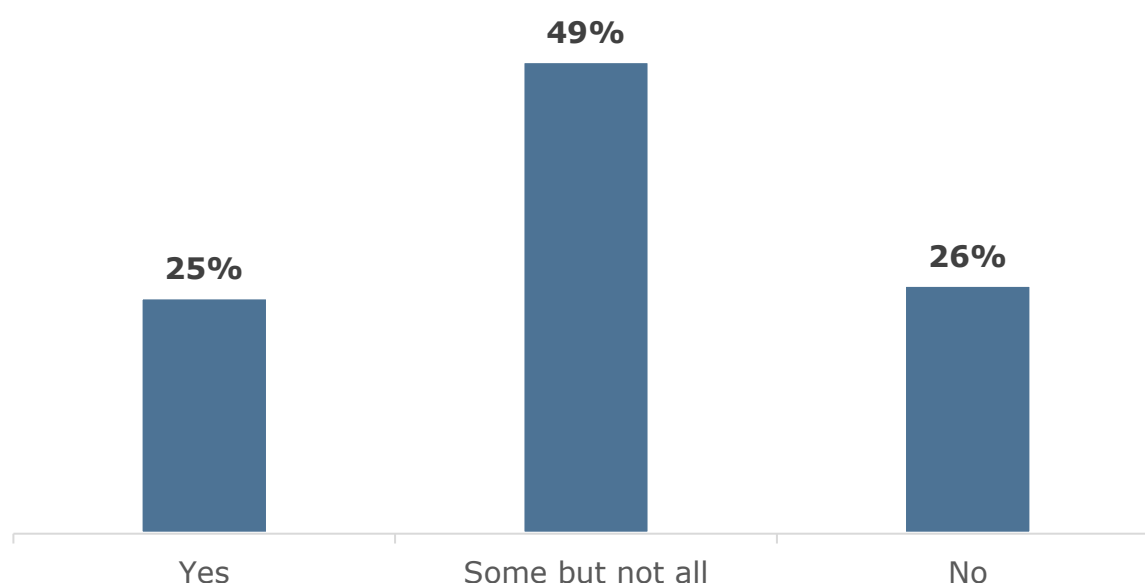


Source: EA analysis of survey, N=167.

4. Accessing the records

Respondents who had already asked for the records, or were in the process of asking, indicated whether they had received these records, as shown in Figure 6. Three in four respondents who had asked for records related to time in care had received at least some of them.

Figure 6: Have respondents received the records they asked for?



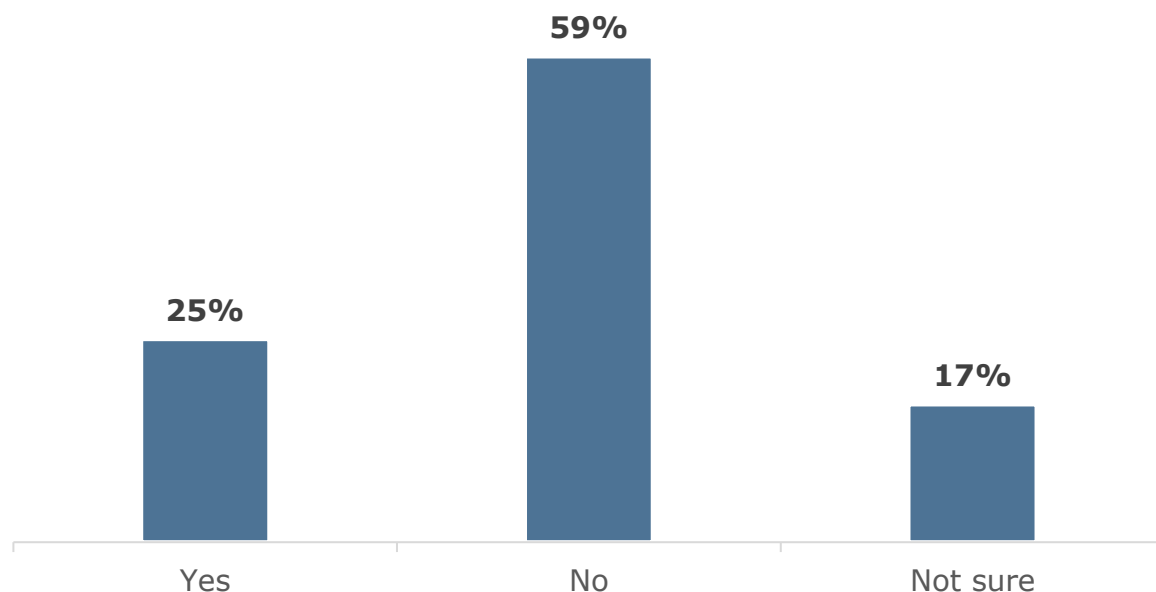
Source: EA analysis of survey, N=154.

Respondents were more successful in accessing more recent records. Eighty-six percent of respondents trying to access records relating to care experienced people aged 18 to 34 had received at least some of the records they asked for. For records relating to people aged 50 or older, only 69% of respondents had received at some of the records.

4.1. What information is received

Only one in four respondents who received at least some of the records said that these had enough information for what they needed. As shown in Figure 7, the majority (59%) of respondents who were asked this question replied that the information they received was not enough.

Figure 7: Was the information in the records enough for what the respondents needed?



Source: EA analysis of survey, N=114.

For the respondents who thought the information they received was not enough or were not sure, there were broadly three reasons why:

- For over a third of these respondents, the records they were hoping to access were missing. This was either because the records were not found or were lost, or because the information had never been recorded in the first place.
- For one in five respondents who didn't receive enough information or were unsure about it, the information they were looking for was redacted.
- Among respondents who said the information wasn't enough or were unsure, about one in 10 said the records did not have the detail they were hoping to find.

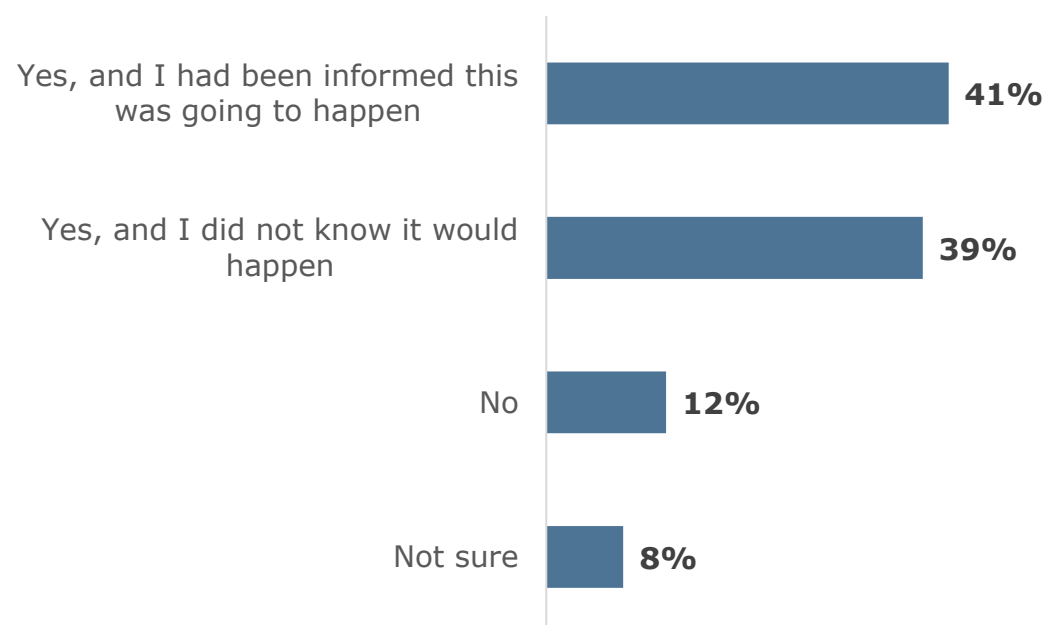
A handful of respondents cited issues with being sent records about another child by mistake, receiving duplicates, the files not being sorted in chronological order, and terms used in the records being unknown to them.

Overall, the fact that records did not have enough information was distressing for respondents. This was especially true for those who had spent considerable time and energy, and in some cases even financial resources, seeking the information. Other ways that the information not being enough impacted respondents included:

- couldn't provide as much information to inquiries (eg Child Abuse Inquiry, Redress Scheme in Scotland, or Truth Recovery Process in Northern Ireland), or any at all;
- having to pay a parent's debt until the respondent can prove that they were estranged from the parent;
- needed proof from police records to be able to gain support;
- information accessed didn't give answers the respondents were after;
- names of relatives were redacted, so respondents couldn't find them; and
- no access to family medical history.

As discussed above, redactions were one of the reasons why respondents couldn't access the information they needed. Eight in 10 respondents who accessed their records found them to be redacted, as shown in Figure 8. Only half of them had been informed that this was going to happen.

Figure 8: Were the records redacted?



Source: EA analysis of survey, N=114.

4.2. Concerns

Close to nine out of 10 respondents who received their records were left with questions or concerns about them. Only about half of them followed up on these questions or concerns, most often with the organisation that had their information, as seen in Figure 9.

Figure 9: Did respondents have questions or concerns after receiving the records?

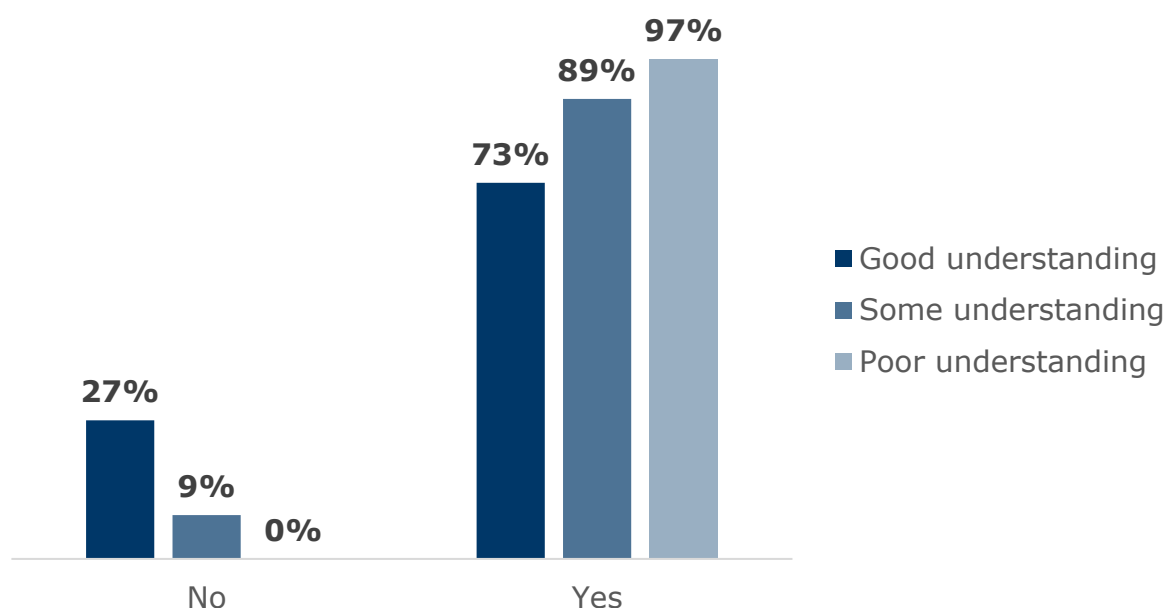


Note: all percentages shown in the figure are calculated as a share of the total number of people who received their records.

Source: EA analysis of survey, N=114.

Our analysis showed that care experienced respondents were more likely to have questions or concerns if they had lower understanding of what information was collected, recorded and shared about them during their time in care.

Figure 10: Share of care experienced people with questions or concerns after accessing their records, by level of understanding of the information recorded about them about their time in care



Source: EA analysis of survey, N=107.

Common concerns cited by respondents were:

- Records heavily **redacted**, with entire pages of blacked out text.
 - In their records, care experienced people's data is intertwined with the personal data of others: family members, friends, neighbours, professionals. This is often the case when the records discuss decisions made about them, and especially decisions on why they were put in care: "the information wasn't 'their personal data', would often have been given in confidence and seeking consent wasn't an option". As a result, this data was redacted. This creates a significant barrier for care experienced people, leaving them unable to understand decisions made about them.
 - One respondent provided an example about a council unnecessarily redacting information about the person's behaviour who, they argue, would have reflected poorly on the council. The redaction was unnecessary and only done to "remov[e] anything from the files that might make the councils look bad". This sentiment was shared by many respondents, who had come to distrust the reason for the heavy redactions. They suspected that the organisations were overly-redacting records to protect their reputation.

- In one case the respondent's own name was redacted, which suggests that the organisation had not put enough thought into the redaction process and further exacerbated the respondent's mistrust for the organisation.
- Respondents found it extremely frustrating to have information about deceased parents or relatives redacted. In some cases this information was key to finding other relatives or fully understanding themselves, as already mentioned. One respondent expressed how distressing it was to see their younger brother's name redacted: "[t]his is especially disturbing as he recently died and to see his name blacked out like this hurts even more now".
- Respondents also mentioned that the amount of redacted information would change if people applied again after some time, or complained about the amount of redacting. This suggests an inconsistent approach to redacting from organisations.
- **Missing information**, especially when the information missing was related to abuse in the household, or about events that they felt would have constituted a liability for the social worker.
- **Inaccurate information** reported in the records. In the words of a respondent, "[t]he recordings had assumptions and not facts recorded".
- **Missing records**, which could leave people with gaps of years.
- The **language** used in the records was in cases **inappropriate and upsetting**, as was the focus on the child's behaviour rather than on the abuse in the household that some respondents found in the records.
- Not being allowed **access to the full file**.
- As previously mentioned, the **lack of support and sensitivity** for people accessing the records.

Respondents also mentioned that the records were not always in chronological order, the response had not been timely, and there had been no accountability for the failings.

4.3. Complaints

About three in 10 (28%) respondents who received their records said that they had raised a complaint. Most often these complaints did not lead to any improvement, with respondents often indicating that they were still waiting for a response to their complaint. A handful of respondents said

that they had received an apology in response to their complaint. One respondent faced barriers even when trying to raise a complaint:

“I tried to ask to raise a complaint but they kept passing the complaint to the Team manager that I wasn't [sic] happy with so it didn't [sic] allow me to make an official complaint”.

Among those who had raised complaints, around one in five (22%) shared that they had brought the complaint to the ICO. Echoing the findings discussed in Section 3.2.6, respondents had mixed experiences from complaining to the ICO about accessing the care records.

- Some respondents shared that complaining to the ICO, sometimes numerous times, had helped them move their cases along and get responses from the organisations they had been contacting.
- Others shared that the ICO had explained that redactions were due to privacy laws, or confirmed that the records were lost. In one case, the respondent felt the ICO didn't care to hold the organisation accountable to the required timelines.

Respondents were left with unaddressed questions, which stood in the way of finally getting closure:

“I feel that nothing has been addressed and never will be”.

4.4. Delays and obstacles accessing records

For the 26% of respondents who tried to access the records but didn't receive them, Table 6 shows what had happened up to that point.¹⁰ About half of these respondents were still waiting for the records, with some having waited up to 16 years at the time of the survey.

Respondents who were told by the organisation that they didn't have the records had had to wait between two-three weeks and four and a half years to get this information. Some respondents had to wait an even longer time to be told that the organisation had the records but couldn't give them to them. Being made to wait years to then receive a negative response contributed to the distrust that many respondents had for

¹⁰ This was a multiple-choice question, as it's possible that respondents have not received records from more than one source, and multiple options can apply at the same time.

organisations, as well as their perception of being treated like an afterthought.

Table 6: Outcome for respondents who have not received any of their records

Outcome	Share	Waiting times
Still waiting	48%	Up to 16 years
Told that the organisation doesn't have the records	40%	2-3 weeks to 4.5 years
Told that the organisation has the records but can't give them to them	25%	8 months to 9 years
Never found who had the records	10%	-

Source: EA analysis of survey, N=40.

5. Impact of being able to access records from the time in care

We asked the 114 respondents who had received at least some of the records what the impact of accessing the information had been.



For **one in three** respondents, accessing the records was on the whole or totally **negative**.



They found it frustrating, and didn't feel they had gained anything in the process. Many people were triggered and re-traumatised by the process and the records, and wished for mental health support.



For **one in five** respondents, it was **mixed**.

They were also triggered by the process and the records, but were able to find some closure from the information. Some people were able to use this experience as motivation in their career, educating social workers or becoming social workers themselves.



For **one in five** respondents, it was on the whole or totally **positive**.

They gained insights on decisions made about them, and were able to reconnect with family members. The records were often difficult to read, but these respondents found comfort in knowing the truth. Accessing the records allowed them to understand their life story better and fill at least some gaps in their identity.



The remainder of respondents did not answer, or didn't qualify the impact in positive, negative or mixed terms.

A clear theme that emerged from the responses is how distressing, triggering and potentially re-traumatising the experience can be. This is due both to the content of the records and to the process itself, which respondents often found cold, demoralising and infantilising. These feelings mirror how people felt about being in care, left in the dark about decisions made about them and not in control. In the words of a respondent,

"[i]n broad terms the process of accessing records as it is set out in the

legislation and in practice compounds the trauma of [being in care and] adoption, removing the sense of agency and forcing dependence upon social workers”.

Compounded with the content of the records, the experience of accessing the records often made respondents feel lost, depressed, and in some cases even self-destructive or suicidal.

In some cases, respondents seemed to have had very different reactions to getting access to similar information. Some people were made to feel worthless by the language used to describe them in the records, while others found the motivation to educate social workers and social work leaders on the importance of language and other best practices. How people reacted to their records from their time in care was influenced by their own personal circumstances, the support networks they have available in their daily life, and their mental health resilience.

For the above reasons, it's extremely complicated to foresee how people will react during the process and after being sent their records. Some respondents highlighted the importance of continued mental health support throughout the process and after access. This was a theme that emerged throughout the survey. Respondents also stressed the value of having access to other people with lived experience who could guide them and they felt understood by.

The content and language of records can have a negative impact on many respondents. These cannot be changed, though the impact could be mitigated by offering various support options. Respondents overwhelmingly agreed that the content of the records being painful didn't mean people shouldn't have access to them: **care experienced people have the right to access information recorded about them, despite the possible hurt that reading this information may cause.**

This is supported by the answers reported in Table 7: respondents largely agreed that not being able to access information was linked to a variety of negative impacts. Over two in three respondents said that not being able to access the information meant not understanding who they were, and what had happened to them.

This question was asked to those who had already accessed their records,¹¹ and to those who had not yet been able to. Their answers were

¹¹ This cohort was asked the hypothetical question 'If you had not been able to access the information, how would that have impacted you?'.

largely similar, though people who had not yet accessed their records were more likely to suffer from negative impacts. In particular, people who had not accessed the records were more likely to be suffering from emotional distress, compared to how people who accessed the records thought they would have felt if they had been unsuccessful.

Table 7: Impact of not being able to access the information

Impact	Share
Less able to understand my life story	72%
Emotional distress	71%
Not able to understand decisions that were made about me	69%
Less understanding of time in care or experience of care	66%
Unable to challenge the accuracy of my personal information or decisions made about me	50%
Missed out on an opportunity because I didn't have proof	34%
I was unable to apply for Redress/ take further action	29%
No impact	2%

Source: EA analysis of survey, N=167.

The ability to access records gave many respondents a better understanding of their own life and story, the ability to process memories, the opportunity to (re)connect with family members, and the chance to heal psychologically and emotionally. On the other hand, it left a number of respondents feeling anxious, frustrated, and re-traumatised. Respondents were angry at the injustice as well as at the information not being kept safe.

Other changes that stemmed from the ability to access the records included:

- taking action (eg redress, court cases) thanks to stronger evidence;
- supporting others through their journey;
- accessing medical info and receiving diagnoses; and
- raising awareness.

For a minority of respondents, nothing changed. These tended to be respondents who received heavily redacted records, or whose records were missing, meaning they have received very little to no information.

6. Conclusions

Table 8 summarises the key ICO-related findings from the analysis of the survey.

Table 8: Key findings

Evidence of data protection harms.

We found evidence of harms during the process of accessing care records, including data protection harms: loss of control of personal data, psychological harms, bodily harm, chilling effects, adverse effects on rights and freedoms.

Need for increasing regulatory understanding for care

Care experienced people tend to have poor understanding of what information was recorded about them about their time in care. As commonly observed by the ICO's teams when handling complaints, poor understanding often links to unclear expectations on the outcome, which leave people feeling let down by the process.

Need for increasing regulatory certainty for care experienced people.

Care experienced people accessing their records lack clarity on the process, and lack support navigating it.

Need for encouraging organisations to follow best practice

We heard from respondents that:

- communication with organisations is often challenging;
- organisations don't explain enough what to expect, eg timelines and redactions; and
- organisations don't explain enough why they're not releasing records, or why they're redacting them.

Need for encouraging regulatory certainty and proportional approaches for organisations.

Organisations don't have a consistent approach on releasing records, and on redacting them. They may be over-redacting to be on the safer side, suggesting they don't have enough clarity on legal requirements.

Opportunity to continue strengthening our empathetic customer

Many care experienced people come to us after being triggered and let down by the process. In line with our ambition to provide great customer service,¹² we will continue to reflect on and enhance our approaches.

¹² See strategic enduring objective four in our [ICO25 strategy](#).

Annex A: Other views

A.1 Charity or advocacy organisations

Six charity or advocacy organisations also responded to our survey. Collectively, these six charities operated across all UK nations.

We had previously engaged with this group through our in-person workshops with representative groups, which took place between September and December 2023. As part of this survey we further collected their views on what examples of good practice are, and how the ICO could better support care experienced people trying to exercise their information rights.

In this survey, organisations shared their views on the following:

- Need for clear guidance for local authorities on the process, including:
 - how records should be provided;
 - keeping applicants informed on progress, and clarity around timescales;
 - notifying applicants when the records can be collected and how (collected in person or sent via signed-for post);
 - what must be redacted – and what doesn't need to;
 - an expectation on authorities that they deal with this sensitively and thoroughly as there may be a need to review family files; and
 - potential fines or other consequences for LAs when there have been delays or wrong doing to encourage compliance.
- Organisations could better advise young people leaving care that their files are on record for a lengthy period of time, so they know they can access them in years to come.
- Care experienced people could be supported in streamlining their request enough, where appropriate, so that they get the answers they need rather than an overwhelming amount of paperwork.
- Care Leaver teams duties end at 25 so often people are accessing their records without a social worker to support them through this process. The emotional impact of files needs to be fully considered, to give the person adequate support.
- Need to consider who is best placed to support the care experienced person:

“It is arguable that a Local Authority representative is not best placed to be this support person as they may be constrained by a need to protect the organisation or the care experienced person may be rejecting of any help offered by them because of their negative experiences whilst in care”.

Advocacy groups who engaged with our survey shared that they can provide the care experienced people they support with a short chronology of the contents of the records “so we can prepare them for what they are about to read and also help them focus on the key period of time they wish to look at”. Another advocacy group mentioned that their services to support care experienced people accessing their records can be commissioned by local authorities.

A.2 Adoptees

Many care experienced people were also adopted – some people only referred to themselves as adoptees, for example in cases where they spent only a few months in care when they were babies. Adoptees have similar challenges to care experienced people when trying to access information about their birth family and the circumstances of their adoption.

Some findings pertinent to adoptees:

- Adoptees were sceptical to engage with adoption agencies or other organisations run by adopters, who they often do not feel understood by and may even see as biased.
- Difficulty accessing records, as adoption records are exempt from data privacy legislation and are governed by different legislation.

A.3 Local council officers and social workers

A small number of local council officers and social workers engaged with our survey. Their views cannot be considered representative of all organisations, but we report them here to give insight, perspective, and context to the analysis of this report.

- SARs only give a fraction of the information compared to what organisations hold – multiple SARs to all organisations involved in care are needed to get the full picture.

- Need for clear guidance and good practice examples on SARs for care experienced people, especially in relation to third-party information.
- Importance of setting expectations about the information care experienced people think the organisation holds – if social worker wasn't aware of it, it wasn't recorded.
- Timescales are hard to meet – especially when needing to digitalise records, which is very time consuming, before the council can even start collating, reviewing and redacting.

The reality of handling one care leaver request is that it takes several months from start to finish to ensure appropriate records are provided in a controlled and supported way. It is emotionally demanding on the case officer to review what is sometimes extremely distressing information, particularly if there has been childhood abuse.

- A respondent told us that the court social work statements are a useful and concise summary of events about why a person goes into care, but they can't be released to the care experienced person. They suggested that, if there's no better alternative, "then links with CAFCASS¹³/Court should be formulated to work together with local authorities to provide a joint approach".
- Care experienced people end up having to read through hundreds or thousands of documents, often with many gaps. Perhaps they could be offered – as alternative or add-on – a balanced summary outlining the story of their care experience, put together by a social work professional.

¹³ Children and Family Court Advisory and Support Service