

Short Report

Accessing Records in Scotland: What care experienced people tell us about the Right of Access

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Introduction

This report talks about something that is very important to people with care experience: accessing their records from the time they were in care in Scotland.

Access to records has long been an important issue to people with care experience because these records are unique and can provide information about their past unavailable from any other source.

All of us need to know our history and how it has shaped who we are. More people with care experience are accessing their records for many reasons explained further in this summary. How these requests are managed can vary, from speed of response to what support is given, across the country.

The voices of people with lived experience of care and accessing records are at the heart of this project.



“...it’s our life on paper...”

“I have a right to know about my childhood and I have a right to read the full story to help me try and make sense of things for my own sanity, and so does every other care experienced person.”

“...to understand what I was like as a child... the only thing I would have would have been my records.”

“It’s not just data that you are handing over, it’s someone’s life...”

Care experienced people

By 'people with care experience', we mean anyone who as a child lived somewhere other than with their parents. Specifically living in short term or long term residential care (including residential school) or foster care, or placed by the local authority in kinship care.

Aim

The fundamental aim of this report is to provide the foundation for developing a consistent, trauma-informed rights-based framework for everyone responding to Right of Access requests, prompting a paradigm shift to make sure that when people access their records they are safe and supported.

We heard people's stories and experiences of accessing their records, drawing together conclusions and recommendations for improvement.

If you would like to see a much longer and more detailed version of the research report, you will find it on Social Work Scotland's website at Social Work Scotland - Leading the Profession.

The story behind this report

In 2018, the Social Work Scotland Historic Abuse Practice Network established a Right of Access project group. It included people from Aberdeen City Council, CELCIS (Centre for Excellence for Children's Care and Protection), the Champions Board of West Dunbartonshire Council, The City of Edinburgh Council, Future Pathways, Social Work Scotland and Who Cares? Scotland.

This report is a short summary of the project group's findings.

The Right of Access

The right of access gives individuals the right to obtain a copy of their personal information from any organisation who has supported them, they have engaged with or been involved with. The organisation must by law provide a copy of their personal information.

This report reflects what people with care experience have told us about the meaning of their records; their purposes for accessing their records; their experiences of engaging with record holders; and the impact of the content and presentation of their records. They also told us what it feels like to deal with record holders and to receive their records.

The group engaged with enough people with care experience to be confident in what they learned and that their recommendations are based on a solid understanding of those people's experiences.

You can read those recommendations on page xx.

A brief summary of what care experienced people said

Care experienced people talked about the **deep personal significance** of their records. Many people said that they did a lot of thinking before deciding to make a Right of Access request, and that this was a very emotional time for them.

For some people, accessing their records reminded them vividly about past traumas. For others, it affected their relationships with other people. Some gained closure, but many were left with more questions than answers. Some people felt anger, mistrust or powerlessness, especially where records had parts missing or redacted* (removed by blanking out) because of data protection. Redaction – to comply with data protection regulations, other people's personal information must be removed from the record as set out in law. This was not always done in similar ways and people with care experience wanted to see more consistency. They also wanted record holders to talk clearly about why some information was redacted. Some people felt that the laws should be changed so that they could see all of their records and there is no redaction.

Most people we spoke to had several **reasons for accessing their records, including:**

- Wanting to know more about their childhood
- Seeking information about family members
- Wanting to read someone else's version of their life experiences
- For legal purposes.

Most people felt strongly that people with care experience had the right to read their care records.

People talked about their experiences of **engaging with record holders**. These varied. Some people said that record holders communicated with them clearly and helpfully; others felt unimportant, anxious or powerless. A lot of people told us they felt record holders did not recognise the importance of records to people with care experience, and that being informed, listened to, and supported by record holders was important to them.

People said that **what was in the records, and the records' appearance**, was important.

We took account of all of this in our recommendations.

What we did

We considered the work of several other projects:

- A member-led Who Cares? Scotland care records campaign
- The Memory, Identity, Rights in Records, Access (MIRRA) Project
- The Write Right About Me project facilitated by Aberdeen City Council
- A CELCIS-hosted care records local authority roundtable
- A survey of local Champions Board members conducted by West Dunbartonshire Council
- Future Pathways' support to people who sought records after experiencing childhood abuse in care in Scotland
- Monash University Setting the Record Straight for the Rights of the Child Summit 2017
- Social Work Scotland's Global Records Access Information Exchange

We also established an Expert Reference Group. This consisted of people who had accessed their records, and people who had supported people to access their records. The Expert Reference Group influenced the surveys, focus group questions and analysis.

Our research included four areas: two online surveys, one for people with care experience and one for record holders; a series of focus groups and semi-structured interviews; and a review of documents about the Right of Access. We now explain a bit more about each of these.

1. Care experienced people: online survey

We invited people from the community with care experience to complete a survey. This was aimed at people with care experience who had requested to see their records successfully or unsuccessfully. Some people who were thinking about accessing their records (although had not done so already) also responded to the survey.

The survey asked about areas such as why they wished to access their records, what the experience felt like, the presentation of the records and the impact of the process. This was balanced by information from people who had not accessed their records.

Information about the survey respondents

Age of the people we spoke to

- 56% were aged 50 or over
- 31% were aged 25-49
- 13% were 24 or under

Previous access to records

- 45% of people in the survey had accessed their records from their time in care.
- 55% had not accessed their care records. Some of these had tried unsuccessfully.

2. Care experienced people: focus groups and interviews

Everyone who completed the survey was also invited to participate in focus groups and interviews.

Focus Groups

We held two focus group sessions, each with eight people. We asked about people's experiences of accessing their records, and their suggestions for improving this process.

Interviews

We carried out semi-structured interviews with eight people, people had also participated in focus groups.

From these we identified key points and themes.

3. Record holders: survey

We circulated a survey to all 32 Scottish local authorities. It asked about how they responded to Right of Access requests for records including any training and support provided and whether they had dedicated staff. We received responses from 13 local authorities.

4. Record holders: document review

Some information about the Right of Access process is published by local authorities and is available for anyone to look at. This covers areas such as rights, identity requirements, tailored information for children, and care experienced individuals, redaction, information on processes and help available. We examined it carefully.

Some of the things we learned: care experienced people

We learned a lot about what accessing records felt like for people with care experience, and what a significant decision it is. This included how important their records are to them, and how much the process of accessing their records impacted on their lives and relationships. Having the right support through that process is one of the most important lessons. Without that support, seeing their records can re-traumatise some people.

People shared their experiences in their own words

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“I didn't know what to do or who to talk to, so it was really good support, she talked me through everything. It was really helpful.”

Interview participant about the support of a trusted person

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“I don't think I realised the impact it had on me. I thought I knew everything because I remembered everything, but it actually turned out I didn't. It just affected me – I went forward six steps and then I would go back again. Every time I started to feel better, I would read a bit more and I'd just end up feeling rubbish again.”

Focus Group participant

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“I was looking for information that I didn't get, but then got other information I didn't know about that set me off. I read things that never even entered my head. Now I have read things that were a massive blow to me, things that my mum had done that I didn't know about... me and my mum don't have a relationship and I can't stand her, and it's made me just totally hate her now. ”

Focus Group participant

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“There was hardly any information or case recording and I was very upset to see how little social work appeared to be involved despite various significant changes going on for me and my siblings in our lives.”

Survey respondent

The decision to access records



“We want you to understand that there is a process people go through before they even make the decision to access their records. This is a massive decision to make, and a lot of self-care and acceptance work goes in before you even put in a request. We’ve got to accept that there could be things we find out about ourselves and our lives that’ve been locked away because of trauma. The decision to access records could be one of the biggest decisions someone makes in their life.”

Chris Marshall – Expert Reference Group member

The effects of accessing records

- 59% of the survey participants who had read their care records told us that this had a negative effect on them (either ‘very negative’ or ‘quite negative’)
- 14% reported a positive impact from accessing their records (either ‘quite’ or ‘very positive’)
- 27% of participants told us that reading their records had neither a positive nor negative impact on them.

Accessing records enables some to experience closure from their past experiences. For others, accessing records left more questions than it answered. Almost all people with care experience told us that records are really important to them, and that the whole experience of accessing those records can affect them hugely, in different ways.

Trauma and distress

People said that reading records could be very distressing. This was particularly true for those who had experienced trauma in the past. Some participants learned new information from their records about why they went into care, including emotional information about themselves or family members. A few discovered that abuse had happened to them within their families, which was often very distressing.

For many, this negatively affected their mental health. A few people described going into a 'spiral' or 'not coping' after discovering new information.

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“It was an entire sea of emotions – I found out who my abuser was as a child. No one in the family could ever tell me who it was based on my memories so finding this out messed me up a bit. It was difficult reading about my childhood and who I was.”

Interviewee

Some said that it was helpful to get support from a professional – whether an advocate, a lawyer, or another trusted person – with reading their records.

Relationships

Some participants talked about how the experience affected their relationships with family members or carers, or how it altered the way they thought about previous relationships with social workers, carers and other professionals. Some people found that reading their records helped them to understand the circumstances of their family members before or during their care. Others found that this negatively affected their relationships, both past and present. In most cases this invoked feelings of being uncared for.

Closure

Some people described gaining a better understanding of themselves, their families, and their care journey through reading their records. Some said that learning about their childhood experiences helped them to understand themselves better, enabling them to gain closure from their past.

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“It filled in gaping holes in my knowledge about myself and the circumstances that brought about my existence. I learned how decisions were made about me when I was a baby and that bolstered my sense of identity. It gave me more confidence and fulfilment.”

Survey respondent

However, others described having more questions about themselves, their families and their care journeys after reading their records than they had before, and how difficult it was to realise that they may never get the answers.

Anger, mistrust and feeling powerless

For some people, the experience of trying to access their records – and reading their contents – created feelings of mistrust, powerlessness and disappointment or anger.

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“The first few times I went through them I didn't feel much, but further times I felt angry and sometimes unable to read them. My records really showed the failings of social work.”

Survey respondent

This was often the case when people had been unable to obtain access to their full records. While some people managed to gain access to their full records, many of them had worked with specialist record searching organisations to do so. Indeed a few people said that they only obtained their records after seeking additional support: they could not do it on their own. Others got only partial records, or were unable to obtain any records at all.

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“I have tried various routes to access my education, welfare and medical records without success. It makes me feel frustrated, anxious and adds to the feeling that I never mattered.”

Survey respondent

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“[The local authority] cannot find any information about us being taken into care. We are not talking prehistoric here, and they have mislaid or lost or ‘I can’t be bothered to find’ our documents. I started to believe that there were people out there that were deliberately preventing people getting documents but more and more I’m believing that there was a cavalier attitude to storing and keeping the documents.”

Interviewee

While a few people were given explanations for why their full records could not be found, most were not. Some had been told that their records may have been destroyed or were untraceable due to their age and retention periods. Data protection laws have changed over time, so this may have been completely legal at the time. Nonetheless, people often expressed frustration and confusion about why their records had been destroyed.

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“I tried to access [my care records] at 16 to be told that they were lost in transit when they moved from an area into another office building. I was told that there were no records.”

Interviewee

For a minority of people, being unable to access their records was a positive experience. One person – who had tried to access records at 16, but been told they were ‘lost in transit’ when an office move occurred – said that they felt it was positive that they had not been able to access their records when they first requested them.

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“Probably at 16 I wouldn't have been able to process what I've processed upon reading them as an adult and gone through what I've gone through, but I think it should have been readily available, maybe at 18 rather than being so young.”

Interviewee

Generally, people who had been unable to access records felt disappointment, anger, frustration and/or mistrust of the record holder. In some cases, this mistrust was deeply rooted in past experiences of neglect or abuse in care settings. A few felt determined to continue searching for their records as they felt these had been intentionally hidden or destroyed to cover up bad practice.

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“I really think that my personal Care Records were deliberately destroyed because they highlighted the confusing and punitive care which I'd had inflicted upon me.”

Survey respondent

Reasons for accessing records

Most people had several reasons for wanting to access their records, including understanding their childhood both before and during their time in care, or for legal purposes. People felt strongly that every person with care experience has the Right of Access to their records to allow them to understand their history and story. People generally felt that anything written about a person should be easily accessible by that individual.

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“These records account for the reasons behind hugely impactful life-altering decisions made about Care Experienced people. We have a right to know why certain actions were taken or not taken and a right to look at the full body of evidence so that we can judge those decisions for ourselves.”

Survey respondent

The most common reason for accessing records was learning about experiences, events or decisions made when they were in care which were unknown or which people had forgotten. People hoped this would help them to understand their life story, heal from trauma and gain closure. Most people wanted a clear timeline of the events that led to them entering care, about family and of significant moments throughout their time in care.

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“It can help reconcile events and experiences that we may have difficulty remembering. Often, the emotional turmoil we experience as children in the care system, we unconsciously put up psychological barriers to protect ourselves. This can lead to incorrect or no recollection of events. Access to records is imperative in gaining understanding of events that have shaped our lives.”

Survey respondent

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“I had a younger brother who was put into the care system but was put into the fostering system first and then was put on to adoption. So, I was trying to find out a little bit more about him.”

Interviewee

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“My mum and my gran are always playing against each other, so my gran will tell me one thing then my mum will tell me another, and that is just how it is, they blame each other. None of them want to take responsibility for it, so I thought getting my records would help me find out about a lot of stuff.”

Focus Group participant

A few people wanted to understand the perspective of those involved with their care. These people often felt they already understood what had happened to them, and how this had affected them; they were motivated more by curiosity.

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“It would be really interesting to see what people had written based on what I think and thought about me, it would be really nice to see what they'd written. So that's why I did it.”

Interviewee

Understanding 'who I am'

Some people wanted to understand how their childhood experiences contributed to who they are now. They often used phrases such as 'knowing who I am'.

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“I think as you get older, you start to question things to do with your childhood, you want to learn more about your background, your experiences, and just try to make sense of things. It's like trying to learn about your identity, a lot of care experienced people get their identity taken away from them.”

Survey respondent

Many people had no photographs of themselves as children, and no sense of what they were like as children. They were hopeful that their records would give them an insight into this.

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“...to understand what I was like as a child, I don't have any pictures of me as a kid, and also wanted to know about maybe the behaviours I had as a child. I've recently been diagnosed with a mental health condition, and I think a lot of that stems from when I was younger, so I wanted to see if maybe there was any behaviours that when I was younger that maybe led to that. Like, my family never really told me anything, cause I wasn't with them so they didn't know either, so the only thing I would have would have been my records.”

Focus Group Participant

Legal purposes

Just under a quarter of survey respondents accessed their records for legal purposes, such as pursuing a criminal or civil case.

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“Because it's our life on paper. It is our story, it is our only way to finding out the truth of how we may have been failed. It's our information so I think we are clearly well within our rights and law to request them. It can be our last hope.”

Survey respondent

Engaging and Communication with record holders

- 36% of the survey respondents who had accessed their records felt 'quite', 'somewhat' or 'extremely' happy with communication with record holders.
- 64% were 'not happy at all' or 'not very happy'.

Many of those who had accessed their records felt that record holders did not recognise the importance of records for people with care experience. They described varying experiences, some receiving clear, consistent communication and offers of support while others expressed feelings of unimportance, anxiety and powerlessness.

Many people said that record holders' approach to communication was not ideal. For example, many people received a standard email or letter informing them that the record holder had thirty days to respond to their request. Few people had any further communication with record holders until they received their records, or until their records were ready to be delivered. This lack of communication left them feeling unimportant, uncared for and, in some cases, burdensome.

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“There was no guidance about next steps, no enthusiasm from them when I had gone to them to see if it could be requested which at the very start was a bit off-putting... I got the impression that maybe the people that I had spoken to perhaps didn't have the knowledge on the subject or how they could help me.”

Focus Group participant

In contrast, support through the process made their experience better.

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“The offer of extra support was constant – every time they phoned, they always asked where I had support from and if I had someone to go to, and if at any point I didn't, there would have been something they could offer me.”

Interviewee

Those who responded offered suggestions for how engagement could be improved, stressing the importance of feeling informed, heard and supported by record holders when accessing their records, as well as having some say about the circumstances in which they read their records.

Suggestions for improvement included record holders taking the time to understand their purpose for accessing records, letting people know about support and understanding the importance of compassion, empathy and awareness.

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“It's not just data that you are handing over, its someone's life, so put that relationship before that bit of paper. 'What do you need from me? I will meet you where you are.', 'What is it you actually need for you to actually read these papers and get from it what you are looking for?', 'What is it that you are looking for and what help do you need to do that?' It's putting that relationship before the data.”

Focus Group participant

Starting the access process

Many people felt uncertain about how to access their records. Some started by sending an email to local authorities where they had been looked after. A few attended their local authority building in person to make this request.

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“I had to go through my workers to even find out how to get my records I didn't have a clue how to even do it, my worker helped me find out who it is you email. [...] if I didn't have a worker or if I was a bit older, I would have had no clue how to do it.”

Focus Group participant

Many people said that they felt anxious about the process as record holders did not explain what to expect. Some worried their request had not been properly received. Others wanted to know what to expect from their records.

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“I had to send an email, then I waited for someone to get back, then they said it would take a couple of weeks and they then messaged me saying, what part of your records do you want? I didn't know it gets sectioned, so I didn't know what to say. So, I just said when I was a child... It was confusing, I only really wanted to know why I was in care.”

Focus Group participant

Some were helped by a social worker, therapist and/or a specialist record search organisation such as Birthlink or Wellbeing Scotland. These organisations provide initial support to understand the person's needs, deal directly with record holders, carry out record searches and support people with receiving and reading their records. Some people talked about how important this support was.

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“I'm glad Birthlink was there. I would never have known where to start or how to get [records] from the government. I never knew about any of these organisations. I'm glad they were there. I wouldn't have changed anything. She was helpful and it was a case of 'we can get access to things you can't' – that was the impression I got, and I thought 'that's great cause I wouldn't know where to start'.”

Interview participant

People stressed the importance of making it easier to access records by providing clear, accessible and consistent guidance about the process. They also suggested that having one point of contact from the start of the process would help a lot. One person suggested putting the process online.

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“Perhaps if there was an online route to request records and track progress. It would be good if it was centralised rather than bitty and all over the place. At the moment it can be unclear who to contact at the record-holder organisation or how long you can expect to wait.”

Survey respondent

Speed of accessing records

The word most often chosen to describe communication with record holders was 'slow'. Records holders normally have to respond to the request within one month. If the person has made a number of requests or if the request is complex, an extra two months can be allowed, three months in total.

People generally understood the reasons for delays, especially during the Covid-19 pandemic, and appreciated that record searches were difficult and time-consuming. Where record holders kept applicants up to date this helped. Those who did not receive updates reported feelings of anxiety and mistrust towards record holders.

Delivery of Records

Receiving records was a significant area which needs attention. Quotes from participants illustrate this.

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“I was naively waiting on an email telling me they were on the way, but they just arrived. I kept nervously checking my emails but there was no correspondence or nothing. So, I kept thinking I would get an email. There was nothing.”

Focus Group participant

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“We had already made plans, me and my advocate, and we were going to sit down and read it together. It got taken out of our hands cause it actually just got shoved through my letterbox. I was in a bad place and we had told that to whoever was dealing with me [...] I needed someone to support me but that was taken out of everyone's hands. I didn't expect them to just arrive in my letterbox so it was a bit like woah ... obviously you are curious so I opened them but looking back I shouldn't have.”

Focus Group participant

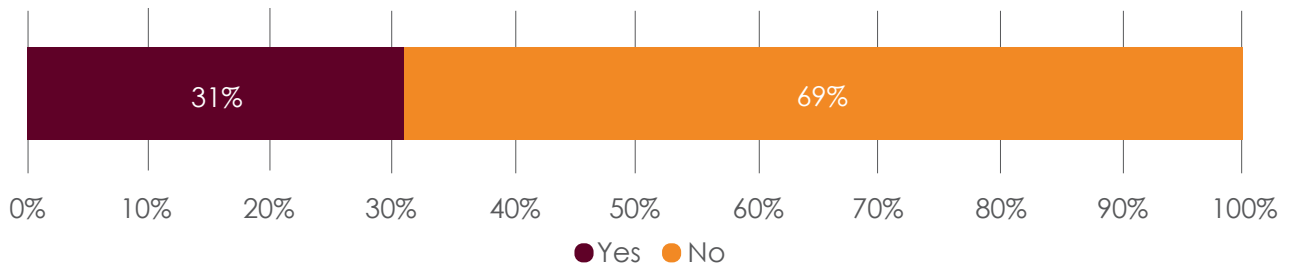
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“I was handed a folder full of written records. I was left alone in a room to read them. I read some then walked out. I thought about taking them as they were the originals. I thought why should these strangers keep such records about me? No-one came after me, called or wrote to me to find out if I was ok. It was quite traumatic, and I have been left with residual feelings that are not altogether pleasant.”

Survey respondent

6.3.1. Support

Did you receive support when you accessed your records?



Support to access records was important, and of those who were supported in accessing their records, most were either satisfied or extremely satisfied with this. Most people who did get support got it from people that they already knew – independent advocates, social workers or other professionals like solicitors. These people helped them to make requests, understand the process and understand their records.

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“The lawyer was very supportive of us getting them, and once we got them, we then got them home, read through them a bit and then I put them away.”

Interview participant, accessed within the last year

We asked people how helpful different types of support would have been when accessing records. Independent advocates, counsellors or therapists and trusted friends all scored highly.

Figure 7: Average helpfulness scores (n=141)



Content and presentation of records

People’s experiences of the content and presentation of their records varied greatly. Common challenges included receiving records in a confusing order; receiving incomplete or inaccurate records; difficulty reading records; challenging language within records; and/or some information being redacted.

We also heard some examples of care experienced people being informed about, and actively involved in, the content and presentation of their records. Understanding and being involved in the process was crucial to having a positive experience.

Some of the things we learned: record holders

Redaction

People had varied understandings of why some parts of their records had been redacted. They therefore reacted in different ways. Generally, people understood the need to protect other people's personal data, but they often expressed confusion about how record holders decide what to remove. For most people, this was only explained in a letter which accompanied their records.

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“They just said ‘obviously it might take a bit longer because we’ll have to redact things. And I thought maybe that makes sense because they’ve had to redact a lot of files. I also knew that redaction was about third-parties and their information.”

Interview participant

A few people had been helped to understand redaction before or during the process, so they knew what to expect.

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“I got a lot of calls about home environment, where I stayed, and this was to allow them to find out what can be left in the record. They tried to leave in as much as they can. And then even when I had the records, I was able to contact the team to ask about redactions and they spoke it over with me, obviously adhering to data protection laws, but at some points there was areas where I could ask is this referring to this and it would be discussed and/or removed the block so I could see when it was known I knew. The reason for redaction was clearly explained and consistent.”

Interview participant

However, 73% of survey participants who received their records described themselves as 'not satisfied' with the redaction of their records. The main reasons for this were inconsistent redaction or extensive redaction.

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“I had an array of emotions – anger at treatment and confusion as to why some things were redacted and other important information was not redacted.”

Survey respondent

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“I thought it was only supposed to be names that were redacted but I've got eight or nine full pages blacked out. I was like 'how is anyone meant to understand their life?'"

Focus Group participant

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“Most of my records were blackened out, which was really disappointing and upsetting. I was left still unclear as to why I was placed in care [...] I feel it was a waste of time trying as hard as I did to get my records.”

Survey respondent

Incomplete records

Many people reported receiving incomplete records. Some also described the impact of a lack of records about significant moments, like moving care institution, school or foster family. This made them feel unimportant and invisible.

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“It made me feel as if I wasn't important enough to have anything recorded about me. There were no records of achieving any milestones or having achieved anything at all. It would seem like I never even existed.”

Survey respondent

Historic Recording Practices

A key issue was how records were written in the past.

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“I think recording is so, so important. Again, it's a legal tool at times but actually it is someone's life. It should be written in such a way that they recognise it as being themselves. People need to be better at recognising the audience and the audience should be the person you're writing about, not anyone else.”

Interview participant

Organisation of records

Unless otherwise specified, a Right of Access request applies to all information held about an individual, involving many different types of records. Records may therefore be stored in an ordered way that is not chronological. For example, records may contain input from multiple services or professionals. This means that records may be arranged in a way that is confusing for people.

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“[The records] were very jumpy – there would be times were I was younger and older and then back to younger like nothing was in line. I feel like when you read your records it should start with your youngest year in care and be an easy timeline going up. It wasn't – it was all over the place.”

Focus Group participant

Legibility of records

Some people found it difficult to understand their records due to poor handwriting or faded type. This made reading their records time-consuming and frustrating. Most people who experienced poorly handwritten records were older, suggesting this may be a bigger problem with records that were written longer ago.

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“It would take two or three times to read it so you could actually understand what the words were. It was shorthand. So, I read them over the period of a week and a bit. It took me a while to understand. It was like scribbles.”

Interview participant

Opinions, judgement and bias

Nearly 80% of the people we surveyed were ‘not very satisfied’ or ‘not at all satisfied’ with how their records were written. Many people felt that their records reflected the opinions of those writing the record. People described reading impersonal or judgemental statements about themselves, their circumstances or family.

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“There was lots of inappropriate language, comments. Insensitivity, clear lack of support or contact. There were many inaccuracies, and it was quite shocking to see things that occurred actually written in black and white. It actually seemed so wrong that many people could document their views on my life without actually talking to me or asking me anything about this.”

Survey respondent

Language of records

Some people pointed out that it was important for writers of the records to use neutral or positive language, which focuses on achievements rather than failings or deficits.

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“For me, it has to be family sensitive – it has to be the whole family picture, not just the child and the parents etc, but the siblings and the whole family. For me it has to be individualistic as well, that individuals age and what they are able to contend with at that point. This sensitive information has to be about facts.”

Focus Group participant

Inaccurate information

Some people reported reading inaccurate information in their records, including addresses or dates of birth. A few said that events were described differently to how they remembered. Some felt that some things had been deliberately described wrongly to cover up events, such as abuse within institutions.

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“There was stuff in there that I knew wasn't true. It was contrary to what I actually went through. I was surprised and... it was like a lot of stuff was covered up. I would say to my wife while I was reading them, 'well that's a lie for starts, that's not what happened.' After I had read them, a lot of it was true, but there was other stuff that was in there that wasn't true.”

Interview participant

Right to Reply

Some participants called for people with care experience being able to contribute to their records.

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“I should have a voice as an adult, I should be allowed to write a statement on my records. This could be offered to everyone – the opportunity to add something to your records, because I feel my story is completely different to what my records tell me.”

Focus Group participant, accessed between one and two years ago

Digital passports

Some people talked about the idea of a ‘digital passport’. This means that records would be co-created with the person in care, and stored online. The person with care experience would be able to access them. This will ensure the person with care experience will have more ownership and control over their life stories.

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“My ideal is – everywhere we go as care experienced people, we take our records with us, and they carry on. Just like a health record book and whoever is looking after you is appointed to write in them.”

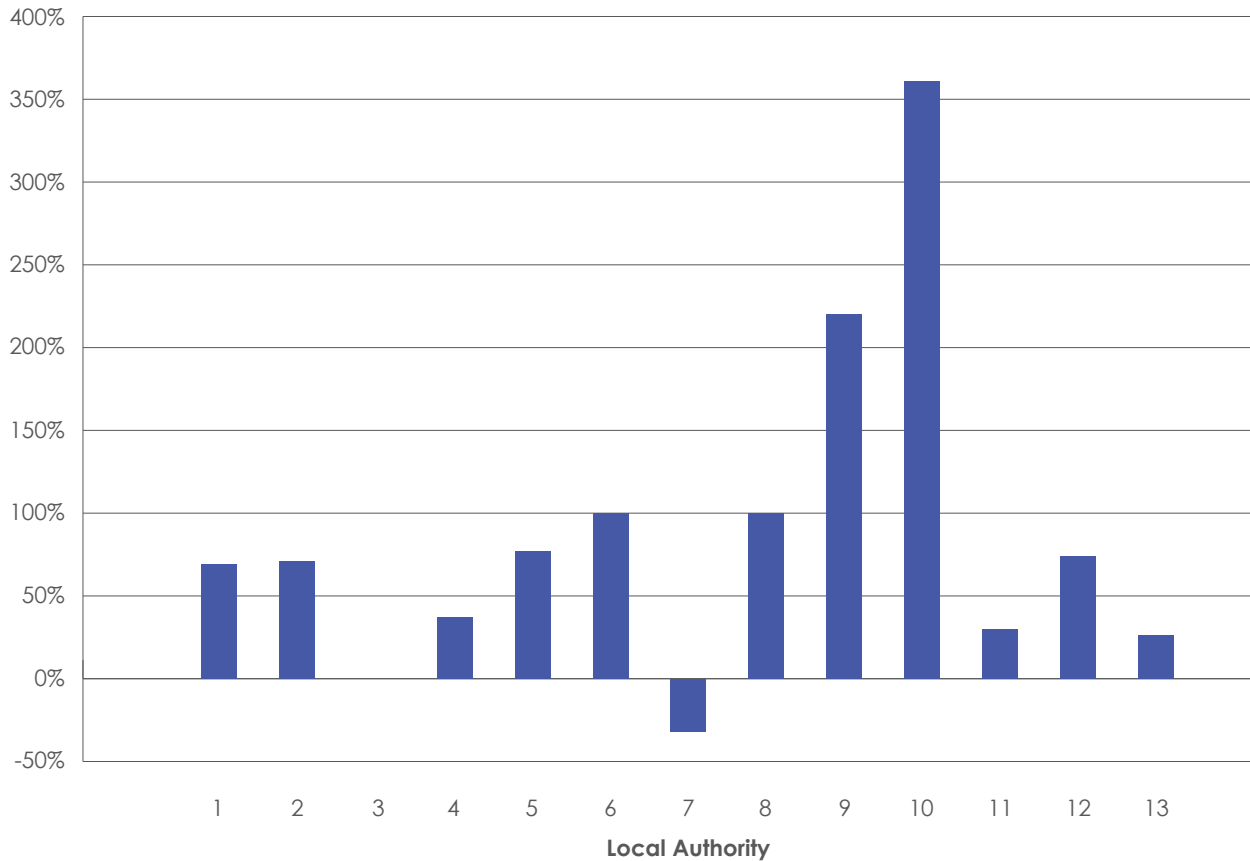
Focus group participant, accessed unknown number of years ago

Number of Right of Access requests

All but one of the local authorities who responded had seen an increase in the number of access to records requests and the average number of requests had roughly doubled. Five local authorities said that they had a backlog of requests awaiting responses and twelve authorities had written procedures for responding to Right of Access requests. However, only four had specific procedures for responding to requests from people with care experience.

The chart below shows the change in the number of requests received by all thirteen local authorities.

Figure 4. Volume of RoA Requests 2017/18 vs. 2019/20



We asked the local authorities if they thought that their current processes met the needs of care experienced people.

- Four said that they did
- Seven felt that they did not
- Two did not answer the question

Local authorities were also asked if they provided support. Eight did, four provided no support, and one provided support to both care experienced people and staff. In relation to training, all the local authorities who responded provided training to staff on access to records and related matters such as data protection.

Document analysis

When people access their records, if they don't completely understand the Right of Access process this can cause problems. And if record holders don't fully appreciate the reasons why people may want to access records, and how important this is to them, that can mean that the service they provide does not meet expectations.

We wanted to know more about all of these things. So we looked carefully at a wide range of publicly available resources. This included information provided on local authorities' websites and some internal documents, designed to help their staff to respond to Right of Access requests.

Public documents

We analysed 30 webpages that provided information about data protection and submitting Right of Access requests.

- Two provided specific information for care experienced people who want to access their records,
- Most local authorities provided a Right of Access request form on their website. However, these were often difficult to find. Some could be found on pages called 'Children and Families' and 'care experienced young people' which could be confusing.

Internal documents

We received internal documents from four local authorities. Three of them provided internal documents about the Right of Access process and how requests were dealt with. One provided the form and cover letter used to respond to Right of Access requests. While the forms contained similar material, the level of detail varied a lot, and though all covered guidance and data protection not all spoke about the needs of care experienced individuals.

The most detailed documents also provided links to public webpages that have advice for people with care experience about the Right of Access process. Many of the documents gave some guidance about good practice but did not provide full details of the Right of Access process.

Recommendations

Recommendation 1: Structural

Right of access to records recognised as an integral part of ongoing care and support irrespective of when they are accessed. Alongside recognition of the importance and significance of accessing records and the reasons for doing so. Underpinned by the human rights to protection and preservation of identity and family life and special support for recovery from trauma under Articles 8, 16 and 22 UNCRC and Article 8 ECHR.

Recommendation 2: Policy and Practice

To align with the changing structural landscape and to meet the needs of people with care experience. Given the specific circumstances, purposes and needs of people accessing records, it is appropriate to develop a specific Right of Access Request policy for care experienced individuals accessing their records.

Recommendation 3: Rights Based Right of Access Framework

Development of protocols to easily identify, share and integrate information across multiple locations and organisations to allow open and transparent access to policy, process and practice.

Providing clear, accessible information about the process of accessing records would enable care experienced people seeking their records to approach this process from an informed perspective. It would also ensure compliance with the DPA 2018 and the UK GDPR as it applies in the UK.

Include information about:

- How to access your records.
- Engagement and reasons for engagement; development of relationships to allow safe support and conversations on the journey and after the journey.
- Regular updates on the progress of the record holder's response, speaking to any emergent complexities or delays and giving the person an opportunity to discuss these matters.
- Rights-based redaction; clear explanations and reasons about the decision making process-to redact or not to redact; type of information redacted, how to ask questions about redacted areas and how to challenge redaction. Redaction practice should be guided fundamentally by the individual's vital interest – protected under Article 8 ECHR; Article 8 UNCRC – in receiving the information necessary to know and understand their childhood and early

development. Understanding that the autobiographical information which may be most important to care experienced people accessing records will often be relational information belonging in effect to more than one person.

- Record holders should include alongside records, supporting material which explains and justifies any redactions which have been made, outlining the type of information which has been redacted and the reasons for the redaction.
- Due time, care and attention should be afforded to the production and review of records prior to delivery, with the understanding that records access is an integral component of loving care. Where possible, records should be organised in a clear manner before delivery, or otherwise explain to the person how their records are structured. Ideally record holders should provide chronology and/or an organised summary of the records provided.
- Contextualising records; use of language which may cause offence, practice and policy of the era.
- Receiving records with preferences respected.
- Support after receiving the records to discuss areas of redaction or any questions that arise.

Recommendation 4: Wrap-around support

Wrap-around support should be provided by suitably qualified and experienced personnel, who understand the importance of records to people with care experience and the context of record keeping over decades. They should provide an explanation of what was recorded, the language used and the historic use of family files. This would help to recognise the importance of records in supporting identity (re-)formation and recovery from trauma.

Practitioners to have sufficient time and support to work with people in a person-centred way. With clear pathways for signposting and referral to a choice of support(s) where required.

Supporting access should embed person-centred principles and the principles of trauma-informed practice, identified in NHS Education for Scotland's Transforming Psychological Trauma: A Knowledge and Skills Framework for the Scottish Workforce - choice, collaboration, trust, empowerment and safety.

Effective delivery in this area is likely to involve management activity to map team capacity, to create appropriate team structures, to provide regular and effective organisational and clinical supervision. Useful additional mechanisms may involve the creation of communities of practice bringing together

practitioners across record holders and measures to avoid or mitigate the impact of isolated or lone working.

Recommendation 5: Right to Rectification

Record writers and holders should provide opportunities for care experienced people to contribute to the content of their records, both while in care and/or when they access their records, particularly where the individual feels that the records accessed miss information or contain inaccurate information. Not only does this reflect DPA legislation – part of which guarantees a right for individuals to have inaccurate personal data rectified (Article 16) – but allows for gaining a sense of empowerment and ownership through this experience.

Correspondingly, The Promise report urged Scotland to develop digital tools that would enable records to reflect not just the facts about a child's experience of care but also the stories of the person themselves. In practice, the Creating My Care Records Project is building on previous work done during the Independent Care Review (ICR) with the Digital Health & Care Innovation Centre and partners to explore co-produced records that give ownership to and reduce stigma for young people. Providing the opportunity to adjust records could make the experience of accessing records more empowering for people with care experience.

Recommendation 6: Destroyed, lost, or otherwise compromised records

Where records are partially or completely lost, destroyed or otherwise compromised, record holders should take a sensitive and empathetic approach to communicating this, while providing wrap-around support to process and mitigate the impact of these circumstances on the care experienced person concerned.

