

Accessing Records in Scotland:

What people with care experience tell us about the Right of Access

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1

Foreword

1 Foreword

“

“...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...”

All of us need to know our history - and how it's shaped who we are. More people are asking to see their care records across the country. How these requests are managed can vary, from speed of response to what support is given, across the country.

The Right of Access gives all of us the right to obtain a copy of our personal data from any organisation which holds information about us. 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 which is unavailable from any other source.

In May 2018 Social Work Scotland's Historic Abuse Practice Network hosted Associate Professor Joanne Evans from Monash University, Australia, Professor Andy Kendrick and Moyra Hawthorn from Strathclyde University as part of seminars held in Aberdeen and Edinburgh. The focus for their meeting was

historic child abuse, records, record keeping and access to records. Parallels are illustrated between people in Scotland and Australia when seeking records, with some systemic issues recognised.

People with care experience, supporting organisations, statutory bodies and record holders wanted to work together to enable positive change. The Social Work Scotland Historic Abuse Practice Network established a Right of Access subgroup, which was made up of Practice Network members, including representatives from the Information Commissioners Office (ICO) and Who Cares? Scotland.

Social Work Scotland's Historic Abuse Practice Network then also established a Right of Access project group, which had representatives from Social Work Scotland, CELCIS (Centre for Excellence for Children's Care and Protection), the Champions Board of West Dunbartonshire Council, City of Edinburgh Council, Aberdeen City Council, the In Care Survivors Alliance (Future Pathways, Redress Support Service) and Who Cares? Scotland.

The project group was particularly concerned with the Right of Access to records that professionals such as social workers, teachers, health workers and residential and/or foster carers may have contributed to. Members of the group also have wide-ranging experience of supporting people with care experience to access their records (to read more about each organisation's projects see appendix 11.1).

The aim of this project is to make sure that when someone accesses their records, they are safe and supported. We will work alongside record holders to develop a Gold Standard Best Practice Guide. This guide will support record holders to develop Right of Access processes informed by people with care experience.

In particular, thanks go to the care experienced community and people with care experience in the Expert Reference Group (ERG) for their contribution, support and for sharing their experiences. The ERG membership included members from the Champions Board of West Dunbartonshire Council; those supported by BirthLink and Wellbeing Scotland and members of Who Cares? Scotland.

2

Executive Summary

2 Executive Summary

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.

This report lays the foundation for a Gold Standard Best Practice Guide.

In 2010, the Researcher Zachari Duncalf completed a UK-wide study of young people's experiences of care, which included a discussion on accessing records (Duncalf 2010: 38-41). This project intends to build on this by exploring people's experiences of accessing their records in Scotland, which has a distinct legislative context.

Inevitably, the project's scope was somewhat limited, and it does not provide a representative reflection of record holding or care experienced communities across Scotland. However, by bringing together people's lived experiences, the project has laid the foundations for developing a greater understanding of what it is like to access records in Scotland and how this can be improved. Every aspect of the experience – from deciding to make a request, to the process of acquiring the records, to reading them – can be highly emotional in many ways.

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

People talked about the deep personal significance of their records, and the reflection and turmoil that often preceded making a Right of Access request. Records represented a means of forming, understanding, and reclaiming their identities. Accessing records can thus form a vital part of a person's development – now and in future.

Most people had several reasons for accessing their records. Some wished to discover more about their childhoods, including information about family members. Some wanted to read a third-party perspective on their experiences, while some wished to access their records for legal purposes. Despite the differences in people's motivations, most shared a strongly held conviction that people with care experience had the right to read their records.

People's various reasons for accessing records have led us to make several recommendations about how these can be reflected in the Right of Access process. For example, the report recommends that record holders regularly review their practice and processes, to make sure that they are aligned with people's reasons for accessing their records. People with care experience also suggested providing more opportunities for people to contribute to their records, and they highlighted the importance of being helped to access support throughout the process.

This report suggests some ways to improve how people access records. People made many recommendations. These include enhancing training opportunities for record holders, so that they could learn about the significance of records, the impact of trauma and re-traumatisation. People also recommended taking a rights-based approach to providing access to records and considering the psychological harm that redaction can cause to people with care experience. All of this is covered in this report, which also recommends a shift towards considering access to records as an integral aspect of care in Scotland and Scotland's commitment to The Promise.

This matters because accessing records affected people in different and often detrimental ways. For some, accessing their records resurfaced past traumas, although effective support could mitigate the distress this caused. For others, accessing their records affected their relationships with other people. Some gained closure, but many were left with more questions than answers. The experience could prompt powerful feelings of anger, mistrust, and disenfranchisement, which were particularly acute when people were unable to obtain full records.

Acting on these recommendations would make sure that every person with care experience who accesses their records can do so safely and with support.

Throughout this project, people shared their experiences of engaging with record holders. These were also varied. Some people felt that record holders had communicated with them clearly and supportively. Others felt unimportant, anxious, and powerless in these interactions. People generally felt that record holders did not recognise the significance of records for people with care experience. People with care experience told us that being informed, listened to, and supported by record holders was important to them.

This report therefore recommends that record holders involve people with care experience throughout the process of accessing their records. We also recommend that record holders provide and honour choices about how people wish to receive their records, and we describe ways in which record holders could develop tailored processes for people with care experience making Right of Access requests. The report also stresses the detrimental impacts of being unable to access full or partial records, and the importance of communicating this situation with compassion.

People said that their responses to their records could be heavily influenced by those records' content and presentation. They called for a consistent, transparent, and tailored approach to the redaction of records. Some felt that data protection legislation should be changed to prevent redaction of records; others stressed the importance of record holders explaining, justifying, and involving applicants in the process of redaction with opportunities to explain and discuss decision making around redacted and or unredacted elements of the records.

This report recommends informing people about redaction processes and actively collaborating with applicants in this process. People also felt that the negative impacts of accessing records would be mitigated by more careful, chronological organisation; more context for their content; and better legibility. The report therefore recommends that record holders create open lines of communication from the very beginning of the Right of Access process, by providing clear information about how people can access their records. We recommend clear and, where possible, chronological organisation of records, and the implementation of protocols to make accessing records from agencies easier. And we highlight the importance of supporting people with care experience to understand the context and content of their records.

The report also looks at avenues for future discussions about the Right of Access. As we state in the Conclusion section, the fundamental aim of this report is to provide the foundation for developing a consistent, trauma-informed, rights-based framework for record holders responding to Right of Access requests. The first step towards that goal is to listen to the voices of people with care experience.

You will hear them clearly in this report.

3

Context

3 Context

3.1. LEGISLATIVE AND POLICY CONTEXT AND HISTORY

The legislative and policy background of the Right of Access puts into context many of the challenges faced by record holders and people seeking their records. As is demonstrated below, guidance about writing, storing, and accessing records has evolved over time in Scotland.

The 2007 Historical Abuse Systemic Review (The Shaw Report) identified that poor record-keeping created difficulties for former residents of residential schools and children's homes when they attempted to trace their records. Many factors affected the generation, preservation and accessibility of records at all levels of government and within organisations. While undoubtedly many poor records management practices existed, they did so within a context of inadequate statutory records regulation, standards and guidance. This prevailing legal context has seriously impacted the preservation of public records generated by central government, local governments and organisations (Shaw, 2007). The Shaw Report recommended that the government commission a review of public records legislation.

3.1.1. Record Keeping

- Various children's legislation in the 1930s also required reports every 6 months about statutory visits to children boarded out in state care.
- The 1933 law required managers for approved schools to ensure proper record keeping, which included 'punishment books', and to review the records, possibly to monitor children's safety and quality of service provision.
- Written records about children in care were first required in the late 1940s: for fostered children in 1947, through the Children (Boarding out etc) (Scotland) Rules and Regulations; and, for those in residential care, as per the Children Act 1948. While written records for foster care were required in the 1940s some records were required to be kept before then – details of carers and children placed and other factual information such as age, religion, and gender. There was no requirement of maintenance until later (see Retention of Records section).

- From 1950 to 1995, the law specified what records needed to be generated within approved schools, children's homes, residential placements for children with 'mental disorders' and remand homes, for example. The law outlined managers' and the Secretary of State's duties and powers relating to records, imposing an oversight responsibility for individual children's welfare and children's residential establishments facilitated through records.
- The 1952 and 1959 regulations for children's homes show the association between records and the duties of managers, inspectors and the Secretary of State, who was to receive 'punishment returns'.
- The 1961 rules included additional requirements such as keeping records of children's progress and absconding. Approved school managers, who had an obligation to manage '...the school in the interests of the welfare, development and rehabilitation of the pupils', were also required to read the log book, keep meeting minutes, report to the Secretary of State and make records available to inspectors.
- During the 1970s and 80s, there was a shift in focus from child welfare to child protection in social work recording practice (Paton 1996).
- In the 1980s, new regulations for secure accommodation also demanded records for children placed there and access to those records by inspectors. The Secretary of State could request individual records for children placed in secure accommodation.
- The 1987 regulations continued to place duties on managers for proper record generation and required managers to prepare a statement of functions and objectives for their establishment. In particular, managers had responsibility for ensuring children's records, including 'health particulars', were kept along with a log book registering important events, such as 'discipline' administered. The language in the 1987 regulations changed to 'discipline' from 'punishment' used in earlier legislation, which coincided with the banning of corporal punishment in schools.
- The Children's (Scotland) Act 1995 and other regulations, including those for secure accommodation, followed. The legal provisions for records associated with children's residential establishments changed once again and became more expansive, suggesting a growing reliance on records as a method for monitoring and improving services to children. Managers of children's residential establishments continued to have responsibility for records, including detailed statements of function and objectives. The law introduced statements on 'children's rights and responsibilities' to be given to children along with information about complaints procedures. The requirement to generate personal records for children in children's residential establishments continued although the requirements for what those records must contain developed further under the 1995 Act.

- The Scottish Social Services Council (SSSC) Codes of Practice for Social Service Workers and Employees 2003 (revised 2016) emphasised the importance of maintaining clear, accurate and up-to-date records.
- In 2007, The Shaw Report was published. This report revealed poor record-keeping policy and practice, and identified several challenges faced by people who experienced abuse while in care attempting to access their records. The report called for a review of public records legislation.
- Contemporary practice encourages practitioners to reflect the views of people with care experience in their records (Social Work Inspection Agency 2010: 1.1). Best practice recognises records as ‘a biography ... for a looked after child to read at a later date to provide them with their history’ (Social Work Inspection Agency, 2010: 1.2)
- In 2009 the Keeper of the Records of Scotland published a report (Report to Scottish Ministers, October 2009) in response to The Shaw Report, which concluded that existing public records legislation was not fit for purpose, it was out of date, too narrow and not relevant to contemporary conditions.
- Following the Keeper’s recommendations, the Public Records (Scotland) Act became law in 2011 and obliges named public authorities, including local authorities, NHS, police and courts as well as the Scottish Government and Scottish Parliament to prepare and implement records management plans which set out proper arrangements for the management of their records. These plans must be agreed by the Keeper of the Records and regularly reviewed.
- In 2017 The Care Inspectorate published a Practice Guide to Chronologies which set out up-to-date guidance on the importance, purpose and creation of Chronologies for the Care sector.
- In 2020, the Independent Care Review published The Promise, which calls for love to be at the centre of the care system and for children and their families to be listened to, respected, involved and heard. The Promise also highlights the importance of embedding trauma-informed practice into care provision – including into the writing of records, since ‘language creates realities’. To keep The Promise, people with care experience must have a sense of ownership over their records, so that these records reflect their stories, memories, emotions and needs (Independent Care Review, 2020; 69).
- In 2021, the Each and Every Child (EAEC) initiative developed a toolkit to empower professionals working with people with care experience to change narratives about care experience.

3.1.2. Retention of Records

- From 1930, adoption records had to be kept for 75 years from the birth of the child.
- The Public Records Act 1937 was the main legislation responsible for ensuring the preservation of public records, which included records for children's residential services. There was no adequate definition of 'public record' and no duty imposed on local authorities to transfer their public records to archives for preservation. There was also no legal specification about how records generated by private bodies receiving public funding should be preserved and made accessible. The public records legislation sat alongside other law.
- The Boarding out of Children (Scotland) Regulations, 1959 stipulated a retention period for fostered children's records for the first time. These records had to be kept until three years after the child turned 18.
- Major local government reorganisations 1950-1995 and changes to children's services legislation in 1968, Social Work (Scotland) Act 1968 impacted on the generation and preservation of records associated, directly or indirectly, with central government as well as local authorities and organisations. The reporting and policy relationship between organisations and central government changed throughout the years, with significant implications for records. The absence of appropriate records legislation also impacting on record preservation at all levels.
- The Local Government etc (Scotland) Act 1994, provided for the transfer of records between the old and new authorities. While the law said local authorities should make "proper arrangements" for the "preservation and management" of their records, it did not require them to do so. Furthermore, the 1994 Act allowed local authorities to dispose of any records it did not consider "worthy of preservation".
- In 1996, the Arrangements to Look After Children (Scotland) Regulations and the Residential Establishments – Child Care (Scotland) Regulations required records about children in foster and residential care to be kept until the person turned 75 or if the child dies before attaining the age of 18 years, for a period of 25 years beginning with the date of his death.
- The Looked After Children (Scotland) Regulations 2009 extended the retention period for records for children in foster and residential care to 100 years from the date of their birth, or if the child dies before attaining the age of 18 years, for a period of 25 years beginning with the date of death.
- Since 2009, adoption records must be kept for 100 years under the Adoption (Scotland) Regulations.

- Records about children looked after at home or in kinship care are not subject to the 100-year retention rule. The Looked After Children (Scotland) Regulations 2009 require that records for children looked after in kinship care are kept for 25 years from the placement date. Records for children looked after at home must be kept for as long as there are children in the home under 18 years.
- Since October 2015, for the duration of the Scottish Child Abuse Inquiry, there is a moratorium on the destruction of records of children who have been in care.

3.1.3. Accessing Records

- Since 1930, adopted people in Scotland have had the Right of Access to their birth certificates after turning 16. Since the Adoption and Children (Scotland) Act 2007, support, including counselling, is offered to adopted people accessing their records.
- The Data Protection Act 1984 gave people the Right of Access to computerised personal information held by public bodies.
- The Access to Personal Files (Social Work) (Scotland) Regulations 1989 stipulated that people with social work records could also access their records in hardcopy.
- The Data Protection Act 1998 gave everyone the Right of Access to computerised and hardcopy personal information.
- The Data Protection (Subject Access Modification) (Social Work) Order 2000, stipulated that where serious harm may be caused by providing access to social work records, record holders are not required to provide access.
- The Shaw Report 2007 highlighted that the Human Rights Act 1998 'has implications for what records are created, maintained and accessed' (Shaw, 2007: Appendix 3), since Article 8 of the European Convention on Human Rights guarantees the right to privacy and a family life. This article arguably speaks to people with care experience's right to information about their family.
- Currently, the General Data Protection Regulation 2018 and the Data Protection Act 2018 gives everyone the Right of Access to their personal data from any organisation. However, under the regulations, some records may be exempt from disclosure, for example, third party and health, education, and social work data where the serious harm test applies. The serious harm test for social work records stipulates you are exempt from complying with the request where it would be likely to prejudice carrying out social work, because it would be likely to cause serious harm to the physical or mental health of any individual.

- Since the Children and Young People (Scotland) Act 2014, corporate parents have been responsible for providing aftercare for people with care experience until they turn 26. This includes providing advice, guidance, and assistance including support with accessing records.
- The Promise reiterates that individuals accessing their records must be properly supported through that process, in the knowledge that records may contain distressing material (Independent Care Review, 2020; 69).

It should be noted from experiential learning across local authorities that there are likely no or minimal records for children in the following scenarios, making records access more complicated and complex:

- post war abandoned babies
- children left with and privately placed with relatives, friends, and other private arrangements
- children left with religious institutions by family members
- private arrangements for adoption and migration.

3.1.4 Lived Experience Context

- In 2016, Future Pathways was set up to support survivors of in-care abuse in Scotland. This includes supporting survivors to access their records through Delivery Partners.
- In response to people with care experience sharing the importance of accessing their records to their sense of identity, a group of Who Cares? Scotland members launched a Records Access Campaign in 2019 – Our Lives, Our Stories, Our Records. Central to their ask was that when redesigning systems to access records about care experienced people, the professionals involved should 'ensure that the lived experience of those people is central to shaping and influencing the design and implementation of any changes'.
- The CELCIS briefing on Developing practice for records in Scotland, 2022 surmises that – despite some recent improvements in practice in the creation, storage and support to access records in Scotland – further developments are required. As the 2019 briefing Access to Records concluded, 'ensuring a sensitive, responsive system for care experienced people to access their records is an important responsibility'.

As is clear above, people with care experience and organisations have continually campaigned to improve how their records are written, stored, and accessed. This report seeks to amplify care experienced voices to influence further improvements.

3.2. GEOGRAPHICAL CONTEXT

Below are three case studies of countries which have comparable legislative and policy backgrounds to Scotland. These case studies are intended to provide broader context for the experience of accessing records in Scotland, and to provide examples for how some common challenges have been or are being addressed elsewhere.

3.2.1. England

Care provision and record keeping in England has a similar legislative landscape and background as Scotland. Thus, the experience of accessing records in Scotland is comparable to England.

In 2015, an Independent Inquiry into Child Sexual Abuse began in England and Wales. Its 2018 interim report highlighted the difficulties faced by survivors when accessing their records and indicated that the Inquiry was likely to recommend changes to record keeping practices to mitigate these challenges.

The 2016 It's My Journey, It's My Life project undertaken by the Access to Care Record Campaign Group, and the Memory – Identity – Rights in Records – Access project (MIRRA), by University College London, takes a broader view of the difficulties faced when accessing records. The MIRRA project brings together people with care experience, social care practitioners, information professionals, and academics. The project aims to research the importance of records, barriers to accessing them, and the legislative background of writing, storing, and accessing records. In 2022, Elizabeth Shepherd, lead researcher with MIRRA, published *Good Practice in Recording and Access to Records*. This report acknowledges the importance of records to care experienced individuals; summarises the legislative background to social records; promotes good practice; and provides guidance on supporting access to records.

3.2.2. Ireland

In 2009, the Final Report of the Commission to Inquire into Child Abuse (the Ryan Report) was published. This report emphasised the importance of records for people with care experience – and for the Inquiry, since historical records provided vital evidence. Indeed, the Ryan Report considers failure to provide care leavers access to their medical records to be neglect (CICA Report Vol. III Confidential Committee: 172).

In line with the UN Convention on the Rights of the Child (8.2) and Clann's Submission to the Commission of Investigation into Mother and Baby Homes in Ireland (inquiry into the Magdalene Laundries), the Ryan Report recommends that '[t]he full personal records of children in care must be maintained', and refers to records as 'essential to validate the child's identity' and retain 'their social, family and educational history.' It also stipulates that records 'be kept secure and up to date. [...] The privacy of such records must be respected' (CICA Report Vol. IV: 464. Recommendation 20).

The report included an action plan incorporating four actions related to record keeping:

- Personal records will continue to be provided to individuals on request, under the terms of the Freedom of Information Act (action 19)
- All records of children in care and in detention will be kept to good standard and will include details of any child who goes missing in care (action 74)
- A professionally managed national archive was to be developed as a central repository for the records for all children in care (action 75)
- Records created in non-statutory agencies should be secured in the national archive (action 76)

The Fourth Progress Report on the 99 actions resulting from the Ryan Report, noted that of the 99 identified actions, only four had not been implemented. Of these, two refer to the creation of a national archive of records for all children in care (actions 75 and 76). Delays to creating the national record archive have been attributed to 'resource restrictions' (Ryan Report Implementation Plan: Fourth Progress Report, 2014: 45).

In November 2020, the Minister for Children, Equality, Disability, Integration and Youth provided an update on the ongoing development of the National Childcare Information System (NCIS), which was established in 2015. At that time, the NCIS was the central repository for all records for children currently in care and of historical records 'held in legacy ICT systems formerly managed by the HSE [Health Service Executive].' There are ongoing plans to extend the scope of the records held in the NCIS repository. This is a long-term initiative as historical files must be located, audited, recorded, and digitised.



“When witnesses left care, the failure to provide them with personal and family records contributed to disadvantage in later life. Many witnesses spent years searching for information to establish their identity.”

Ryan Report, Executive Summary: 26

3.2.3. Australia

A series of inquiries into care institutions have been conducted in Australia. The Royal Commission into Institutional Responses to Child Sexual Abuse ran from 2013-2017.

In December 2017 the Final Report Recommendations by the Royal Commission into Institutional Responses to Child Sexual Abuse was published. The Final Report and Case Studies contained many recommendations about recordkeeping relevant to organisations holding records relating to Care Leavers.

Volume 8, Recordkeeping and information sharing recommendations include:

- minimum retention periods
- record and record keeping principles
- records of non-government schools are required to comply, at a minimum, with standards applicable to government schools, the creation, maintenance and disposal of records relevant to child safety and wellbeing, including child sexual abuse
- improving information sharing across sectors
- improving information sharing in key sectors
- introduction of carers registers

The similar historical landscape of care in Australia and the UK has resulted in people with care experience facing similar challenges. Australia has implemented several initiatives to address these challenges.

Record keeping practices in Australia are historically modelled on UK procedures. Research indicates that difficulties with obtaining complete records and familial information from records are common. This experience can be distressing and traumatising for people with care experience in Scotland and

Australia alike (Goddard, Murray and Duncalf 2013). Early Australian data protection legislation did not stipulate what information should be stored and how it should be maintained, resulting in many historic records being difficult or impossible to obtain due to record destruction or loss (Humphreys & Kertesz 2012). Like in Scotland, records in Australia are often stored by both governmental and non-governmental bodies, which are subject to different access legislation. This means that the process of accessing records in Australia can be time-consuming (Goddard et al 2011: 767).

The Australian government provides extensive support to people with care experience who are attempting to access their records. In 2011, the Australian government launched (and continues to fund) Find and Connect, a centralised online hub which facilitates individuals accessing personalised support and counselling; obtaining records; and reconnecting with family members where possible. This service was developed by a team of historians, archivists and social workers from the University of Melbourne and the Australian Catholic University. Find and Connect brings together historical resources about institutional care in Australia and provides training resources for record holders about improving the experience of accessing records for people with care experience.

Additionally, the Australian Department of Social Services recommends that facilitating access to records be conducted by specialists with empathy, listening and counselling skills, and expertise in the specific challenges accompanying these requests (Australian Dept. of Social Services 2015; 56). However, research demonstrates that the skillsets of staff who facilitate access to records can vary in practice (Yu, 2019).

When people with care experience cannot access their records – because they were lost or destroyed or were never created at all – some Australian organisations have found alternative ways of helping care experienced individuals to understand their past. For example, some people are provided with contemporary information about the place(s) they stayed during their period of time in care (Goddard et al 2013: 770-1).

Other people report that information in their records conflicts with their own memories. In these cases, provisions within data protection law enable them to correct the information in their records or to write their own accounts of their experience (Golding and Wilson 2019: 318-9).

At the 2017 Setting the Record Straight for the Rights of the Child Summit, participants imagined a transformational shift away from organisation-centric records of control and surveillance towards child-centred and care

leaver-centred record keeping frameworks, policies and systems. They envisaged participatory record-keeping systems that would document their lives, support the development of their sense of identity and belonging, keep them connected with family and community, and address their questions about who they are, where they come from, and why they are in care. Aboriginal and Torres Strait Island participants emphasised the important role recordkeeping could play in truth-telling and connecting to their rich heritage and country.

3.3. RESEARCH ABOUT RECORDS

3.3.1. The Significance of Records

Research suggests that records can enable people with care experience to construct a coherent narrative about their lives, thereby contributing to their sense of identity. This process is particularly important for people with care experience who may not have contact with family members, and whose memory may be negatively impacted by past trauma(s) (MacNeil et al. 2018, Hoyle et al. 2019). Research affirms that developing a life-story and connecting past to present (Biehal and Wade, 1996) by learning about one's family contributes to mental and emotional wellbeing (Pugh 1999). For people with care experience this process is often disrupted (Hoyle et al. 2019) and records can replace 'the familial repository of personal histories' (MacNeil et al. 2018; 7). Conversely, people with care experience can also experience feelings of 'marginalisation and powerlessness' if they are unable to access their records (Hoyle et al. 2019;16).

The content of records also has a profound impact. Many care experienced people would prefer their records to reflect the love they experienced while in care (Who Cares? Scotland 2019). Records lacking documentation about positive moments and achievements can compound feelings of insignificance and being uncared for (Murray and Humphreys 2014; 220). Providing a list of birth family characteristics in adoption records – and including physical copies of letters, childhood belongings, and accounts of special events such as birthdays in records – can improve this experience (Gannon 2005).

Mills and Douglas assert that records 'were not designed to meet' the emotional needs of care leavers. Rather, records were 'compiled for bureaucratic reasons to preserve the forms and documents necessary to ensure the efficient operation of an organisation without making any attempt to tell the story of a life' (Swain and Musgrove 2012; 7 Mills and Douglas 2018). As such, record holders must 'reimagine the relationships between archivists, creators of documents, the records themselves and the people about whom the records contain information'. Increasing awareness about why people with care experience access their records is crucial to changing practice around the writing, storing, and providing access to records (Murray 2017; 2).

3.3.2. Common Challenges

People with care experience encounter challenges when accessing their records.

These include receiving incomplete and/or inaccurate records, or missing records. This can be deeply distressing and, in some cases, (re)traumatising for care experienced people (Jones and O'Neil 2014). Receiving disordered records without explanation or support (Who Cares? Scotland 2019; 4); receiving illegible records; and/or older records maintained on easily damaged microfiche material can be similarly distressing. Records may not provide a clear description of events including incidents of abuse. They may include inaccurate or highly subjective information and/or be written in stigmatising language (MacNeil, et al. 2018).

Receiving poor quality records or being unable to access records can negatively affect the person's sense of identity, and compound feelings of being uncared for. Where records fail to contextualise the person's childhood life experiences, people can feel disappointed, betrayed, and/or can find their records 'bland' since 'they didn't talk about anything that [they] had done or achieved' (Murray and Humphreys 2014; 220). The experience of attempting to access records from multiple agencies mirrors some care experienced people's experiences of living with multiple carers in multiple settings (Royal Commission into Institutional Responses to Child Sexual Abuse 2016).

Supporting practitioners reflected that they would, in practice, adopt techniques to mitigate the effects of negative or challenging content in records by summarising, interpreting, and contextualising the information (Gannon 2005). Existing literature includes several suggestions for improving the experience of accessing records. For example, carefully organising, summarising, and presenting autobiographical information can positively impact recipients of records. Moreover, being supported to understand and contextualise emotive information may mitigate the negative impacts of receiving records containing distressing language or content. Thus, record writing and holding practice has great potential to positively influence the experience of accessing records.

3.3.3. The Challenge of Redaction

Records include information about the care experienced person themselves, as well as information about important people in that person's life, such as family members, professionals, and other people with care experience. Records can also contain information about unrelated people and people not known to the person for example related to legal processes and systems.

Data protection legislation in the UK protects privacy by controlling the collection, processing, and sharing of 'personal data'. Personal data is 'any information relating to an identified or identifiable living individual' (UK GDPR Article 4[1] and Data Protection Act 2018, s.3[2]). Data protection law also gives individuals the Right of Access to data held about them by organisations (UK GDPR Article 15 [3]), as long as that right does not 'adversely affect the rights and freedoms of others' (UK GDPR Article 15 [4]). Therefore, accessing records containing the personal data of more than one person can involve 'balancing' rights. While an individual has the Right of Access to their own data, others (third parties), whose data can also be found within the same records, have the right to their data being protected.

Consequently, third party information is generally exempt from disclosure unless the third party has given consent, or it is otherwise reasonable to disclose the data without consent given the balance of competing interests. In practical terms, this means that the names of social workers, carers, or other professionals related to the person's care can be left in records as public, and not personal, data. However, names of private individuals such as family members or other people with care experience, and their personal information may be redacted where disclosure would breach these individuals' right to data protection. Records received by people may therefore not contain the information they were expecting, given that the most autobiographically significant data may typically be information about their family.



"The [Data Protection Act] was not designed with the needs of post-care adults in mind. The restrictions it imposes regarding disclosure of third-party information can result in post-care adults not being able to access significant family history information, including details of their parents, siblings and extended family."

Feast (2009; 2)

International human rights legislation speaks to the 'balancing of rights' that redaction often requires. Specifically, Article 8 of the European Convention on Human Rights protects the right to respect for private and family life, home and correspondence. In the landmark 1989 case *Gaskin v United Kingdom*, the

European Court of Human Rights concluded that in respect of records, Article 8 protected an individual's 'vital interest' in 'receiving the information necessary to know and understand their childhood and early development'.

Consequently, the Court decided that records access systems were only in conformity with Convention rights if access is secured to records in such cases where contributors to the record are either not available or improperly refuse consent.

Further, Article 8 of the United Nations Convention on the Rights of the Child (UNCRC) states parties 'respect the right of the child to preserve his or her identity, including nationality, name and family relations as recognised by law without unlawful interference'. In practice, this requires effective record keeping, the provision of access to such records by the individual concerned as well as the opportunity to inform decisions as to who else can access them (Article 16, UNCRC).

In 2020, the Scottish Children's Reporter Administration (SCRA) published guidance on records access. This guidance recognises that redaction in records can be distressing and outlines the processes in place to explain and justify decisions to redact information, as well as how these decisions can be challenged (2020; 7). This aligns with research which emphasises the importance of support to understand redaction where this cannot be avoided (Murray 2017; 180).

The Information Commissioners Office (ICO) also provides guidelines to record holders on the Right of Access social work data. In the case of third-party information, they suggest that record holders seek consent from these individuals to disclose their information. The ICO recognises that in some cases the record holder must weigh up the rights of the third-party individual against the rights of the person requesting their records.

While recognising the sensitive nature of information present within records (including safeguarding and family history, which may be subject to a duty of confidentiality), record holders can use an individual's right to identity and a family life (Article 8 ECHR; Article 8 UNCRC) as a deciding factor when making redaction decisions about records. Some third-party information will almost certainly be redacted, however, such as any medical or criminal justice information that is unique to those third parties.

Third-party information already known to the person requesting the records, such as the names of siblings they know, or first names of other people with care experience, can also be left in (often last names will be redacted in the latter

case). As such, the ICO advises the record holder to communicate with the individual seeking to access their records, to gain an understanding of the information already known to the person, and which can therefore be shared.

3.3.4. Support when Accessing Records

Accessing records can uncover difficult memories or reveal unknown trauma (MacNeil et al. 2018; 7). Many people have interacted with multiple agencies throughout their care journey. They may also have felt that decisions were taken without their views being considered. These experiences can be mirrored by the process of accessing records which may also involve interacting with multiple organisations and feeling excluded from decision-making (Jones and O'Neil 2014). Where records are incomplete or inaccurate, the risk of re-traumatisation may be particularly acute (MacNeil et al. 2018; 7). It is important that people with care experience access support to understand, contextualise, and process their records, in order to mitigate distress.

Some research advocates for a person-centred approach to supporting people with care experience, and the 'supported release' of information (Murray 2017). This approach involves being guided by the needs of each person, and providing supporting materials and evidence to explain how redaction decisions are made (ibid.). This approach involves record holders committing to believing people with care experience (ibid.) and undertaking training about the social context of the 'care system' (ibid.). Consistent with this person-centred approach is the need for records release to be guided by input from care-leavers themselves. (Murray 2017; 19-20)

Older records are more likely to have been destroyed, lost, fragmented, or to contain stigmatising language (Murray and Humphreys 2014). In these cases, people with care experience may need specific support when accessing their records.

3.4.5. Practice Development

Social work record-holding practice has developed rapidly and continues to evolve. Social work students undergo training about improving the accuracy and clarity of records (Savaya 2010). However, this training does not specifically consider the needs of people with care experience accessing their records. Nor does this training focus on the role of records in preserving the life story of care experienced people, or the importance of trauma-informed record keeping.

Moreover, those facilitating access to records vary and can be social workers (who typically have other responsibilities), administrative team members who are not trained in trauma-informed practice (Murray and Humphreys 2014) or experts in records access and data protection. Goddard, Feast, and Kirton's

research highlights that some practitioners facilitating access to records often lack specialist training. This may mean that some practitioners are not aware of the potential impacts of accessing records, or of the importance of trauma-informed practice (2005).

Furthermore, people with care experience may have varying levels of contact during this process. Some people receive face-to-face support when accessing their records, while other may access support over the phone. Others have minimal contact while waiting to access their records. However, people are usually warned (either in person or via telephone call) if the content of their records may be distressing or offensive (Murray 2015; 221).

Research suggests that specialised training, and opportunities to create communities of practice for ongoing professional development, would embed good record writing and keeping practice, and significantly benefit people accessing their records (Murray 2017; 177).

4

Influences and Support

4 Influences and Support

4.1. PROJECT INFLUENCES

This project was influenced by several related projects including:

- A member led Who Cares? Scotland records campaign
- The Memory, Identity, Rights in Records, Access (MIRRA) Project
- The Write Right About Me project
- A CELCIS-hosted 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 and Aberdeen City Council's Global Records Access Information Exchange

4.2. EXPERT REFERENCE GROUP

An Expert Reference Group for this project. This group comprised of practitioners experienced in supporting people to access records and care experienced people who had accessed or attempted to access their records. The group met six times and informed the design, implementation, and outcomes of this project. In particular, the Expert Reference Group contributed to:

- Project framing and question design: opportunity was created for the reference group to inform and develop the questions asked of care experienced participants via the online survey
- Focus group/interview design: the reference group supported the development of the focus group session plan and design of the interview guide
- Analysis: the reference group was supported to engage with the anonymised dataset produced by the project and contributed to the thematic analysis outlined in this report

We also established an Expert Reference Group for this project.

4.3. SOURCES

We gathered information about people's experiences of accessing their records by conducting an online survey, a series of focus groups and semi-structured interviews. We also assessed current record holding practice by conducting a survey with record holders and reviewing internal and external documents about the Right of Access.

4.4. PARTICIPANTS WITH CARE EXPERIENCE

4.4.1. Survey

We invited participants with experience of care to complete an online survey which explored:

- The significance of records
- Their purposes for accessing records
- Their experience of engaging with record holders
- The content and presentation of their records, including their experience of redaction
- Their degree of satisfaction with the process
- The impact of accessing their records

We also invited participants who had not or not yet accessed their records to complete an abbreviated survey. This focused on their understanding of the Right of Access process, their confidence in record holders, and what support needs they anticipated.

We collected information from these surveys between 27/11/20 and 31/01/21. We used a total of 141 survey responses in the analysis.¹

We exported and cleaned the results of the survey. We then anonymised respondents (See Appendix 11.1.2) and identified the key themes which emerged from the responses. These findings into the graphs which can be found throughout this report.

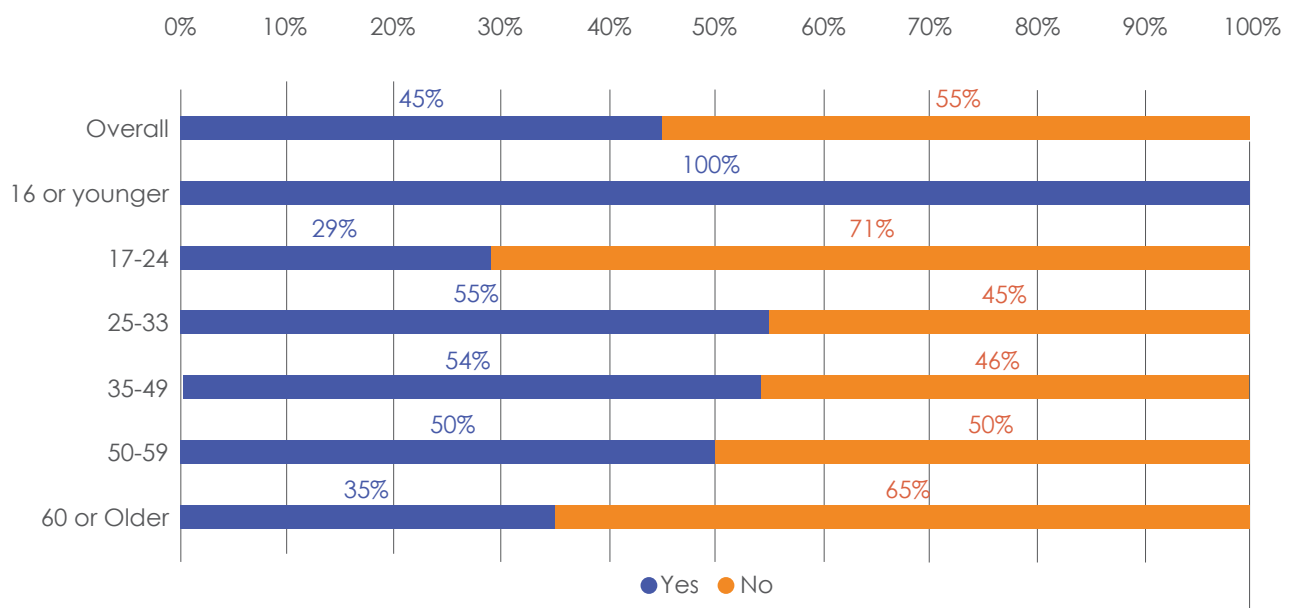
¹There were a total of 151 responses, ten were not valid as had not given consent or did not have experience of Care in Scotland.

Key Demographics of Survey Respondents

Figure 1 below shows the relationship between respondent age and whether they had accessed their care records..

- 45% (n=64) people with care experience had accessed their records from their time in care
- 55% (n=77) people with experience of care had not accessed their records. Some who had not accessed their records had attempted to, but had been unsuccessful
- 13% (n=18) of people who responded were 24 or under
- 31% (n=44) of people who responded were aged 25-49
- 17% (n=24) aged 25-49 had accessed their records
- 56% (n=79) of people who responded were aged 50 or over (with 11 of the 79 being over 60)
- 35% (n=11) of respondents over 60 had accessed their records

Figure 1. Records access – survey participants



4.4.2. Talking to People with Care Experience

We aimed to explore a range of perspectives and experiences through this project. For example, we aimed to explore the experiences of men and women of all ages, living in various parts of Scotland, and of participants who had accessed their records at different points in time.

We recruited 16 participants for interviews and focus groups through project group members' contact lists and social media channels. We invited people with care experience with whom we had existing relationships to engage with the project. Participants who completed the survey were also invited to participate in focus groups and interviews. All participants who expressed interest in focus groups were included in these. We also recruited participants for interviews and focus groups via project members, contact lists and social media channels and those with whom we had existing relationships.

We purposely selected interview participants for age, local authority area and date of accessing their records from those who registered interest to increase the likelihood the data gathered was as representative as possible. See Figures 2 and 3 below.

Figure 2. When records accessed – interview & focus group (n=16)

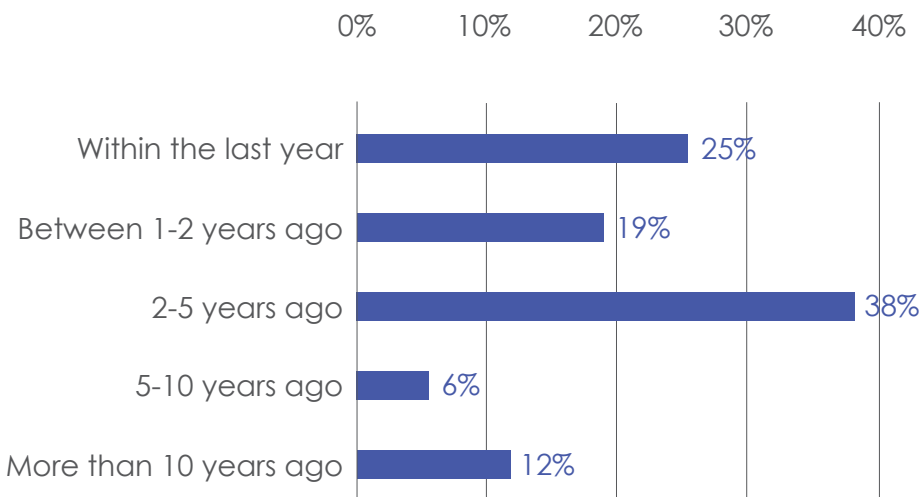
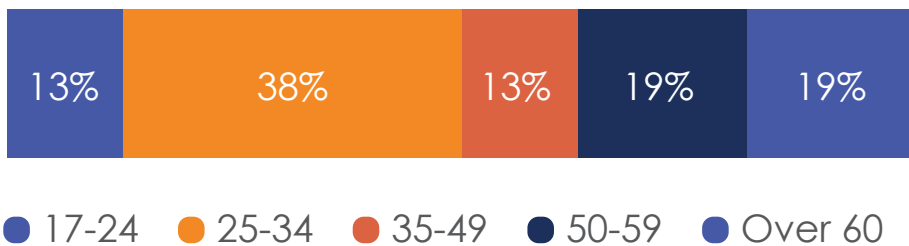


Figure 3. Age of interview & focus group participants (n=16)



Because participants were not originally selected to reflect the broader population of care experienced people, the findings of this report are not necessarily representative of care experienced people generally.

4.4.3 Focus Groups

We facilitated two focus group sessions with eight participants with care experience on 30/03/21 and 01/04/21. During these, we explored participants' experiences of accessing their records and their suggestions for improving this process. We based the session plans for focus groups on the key themes which emerged from the existing research (see Section 3.4) and the information gathered from surveys.

Focus groups included several activities designed to encourage different interactions with participants. We adjusted the structure and content of these focus groups – for example by using mixed medias – to encourage engagement from all participants regardless of learning style, ability, and experience. We also provided opportunities for focus group participants to suggest improvements to our questions and highlight any other key themes they felt were important.

4.4.4. Interviews

We carried out semi-structured interviews with eight participants with care experience between March and April 2021. We developed a simple interview guide to structure these conversations. It included some open introductory and structural questions, and some optional clarifying questions to develop discussions. Interviewers encouraged participants to respond with what the participant considered to be the most relevant and important aspects of their experience. Interviewers altered the order of questions and the time spent on each question accordingly.

4.4.5. Representing 'care experienced voice'

We transcribed all interviews and focus group discussions. The project team then reviewed the transcripts and results in detail and identified key observations and themes. We used Dedoose, a qualitative analysis platform, to further identify and group themes. We analysed 157 responses in total. The project team used these groupings to structure this report. We asked the Expert Reference Group for feedback about this structure before including findings. We have included quotations from survey responses, interviews, and focus group transcripts throughout the care experienced Voice section (Section 6). As far as possible, we have retained the original language of these direct quotes.

4.5. RECORD HOLDER PARTICIPANTS

We also involved local authority practitioners with experience of responding to or supporting Right of Access requests from people with care experience in this project to gain insight into the issues record holders face when facilitating access requests.

4.5.1. Record Holder Survey

We circulated a survey to all 32 Scottish local authorities to learn more about current processes for responding to Right of Access requests for records. The survey asked about:

- The volume of Right of Access requests received
- Average response timescales
- Staffing levels
- Training provided
- Support for those accessing records

We received responses from 13 of the local authorities we surveyed. Therefore, findings in this report may not represent all Scottish local authorities and are instead only intended to provide some context and highlight some of the possible challenges facing record holders. The findings of this survey are detailed in section 5.1.

4.5.2. Document Review

We reviewed the information which 30 Scottish local authorities provide publicly about the Right of Access process. This included information on webpages, uploaded resources, and other public-facing materials. We also asked local authorities to provide internal guidance about Right of Access policy and procedures. Three local authorities provided us with their internal guidance, which we analysed in light of the issues people with care experience report as barriers to accessing their records (Who Cares? Scotland 2019), and the issues practitioners report as barriers to best practice (Murray, 2017).

We compared internal and external sources to identify differences in the information provided. We searched local authority websites for descriptors including: 'health and social care', 'children and families', 'care leavers', and 'adoption and fostering'. We also searched terms including 'access request', 'care experienced access request', 'subject access request', and 'care record(s)' on internet search engines.

These documents generally provided information about:

- Relevant legislation
- Data rights and associated human rights frameworks
- The need for proof of identity when accessing records
- Tailored information for children making a Right of Access request
- Tailored information for people with care experience making a Right of Access request
- The potential support needs of people with care experience
- Support available for people with experience of care
- Procedures for delivering records
- Third-party information redaction
- Excluding information from records which could cause harm
- Records management and storage requirements and processes
- How to make a Right of Access request

5

Mapping Record Holder Practice

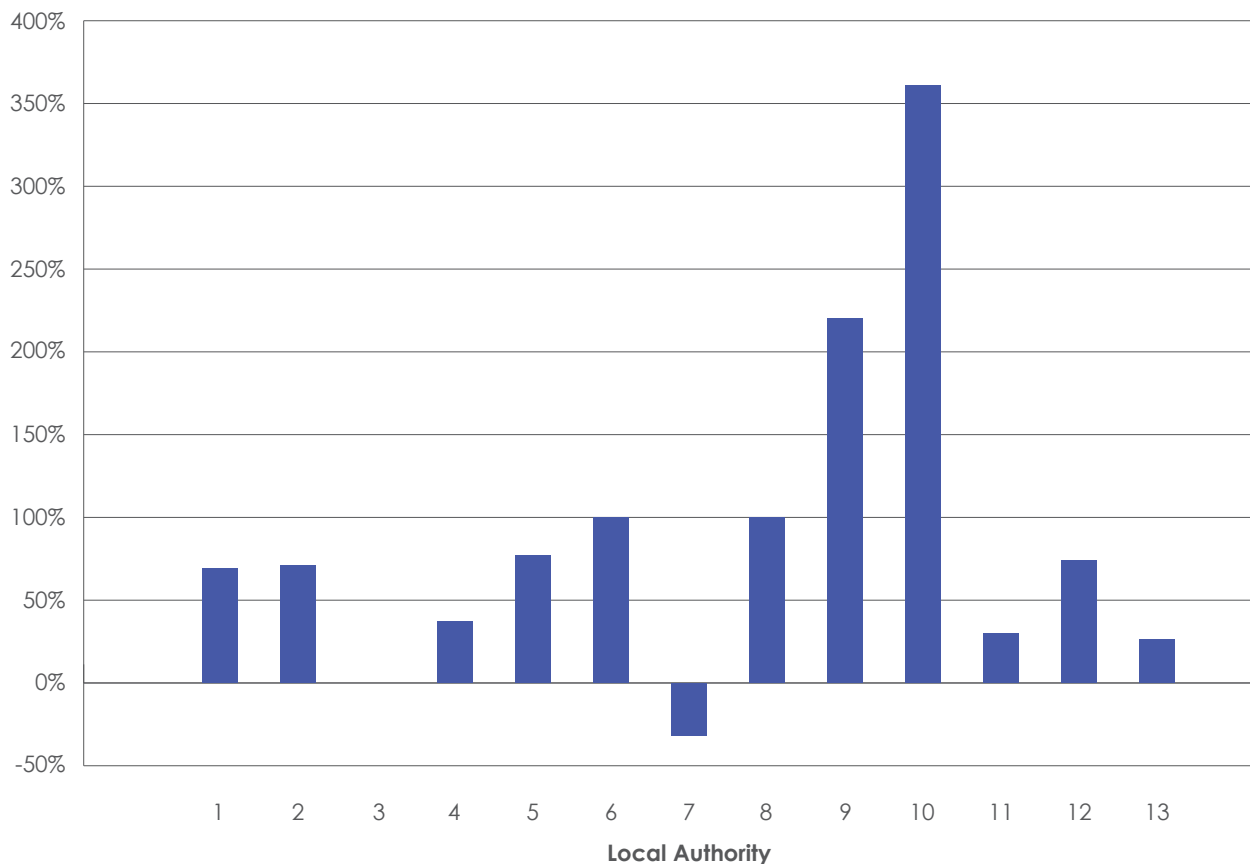
5 Mapping Record Holder Practice

5.1.1. Volume of Right of Access Requests

Eleven local authorities reported that the volume of Right of Access requests increased between 2017/18 and 2019/20. The volume of Right of Access requests increased by an average of 106% in this timeframe among these local authorities. Many local authorities reported struggling to respond to the volume of Right of Access requests within statutory timescales. Only 34% (n=690) of the 1,365 requests made that year were addressed within statutory timescales. Five local authorities reported that they had a backlog of Right of Access requests awaiting responses.

One local authority reported a decrease in requests. One had no data available.

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

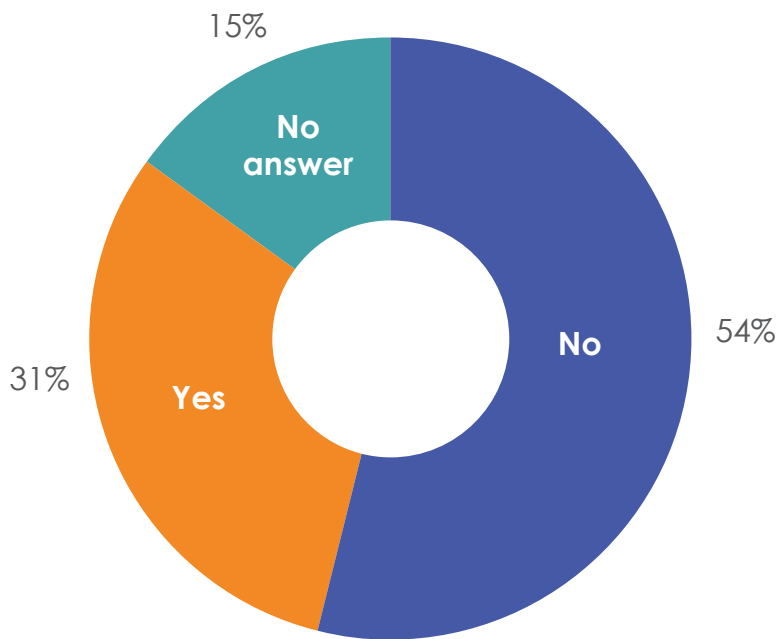


5.1.2. Responding to Right of Access Requests

Seven respondents reported that processing and responding to Right of Access requests was forwarded to a dedicated team which managed these requests, whereas five local authorities processed requests directly. One local authority varied its approach according to the nature of the Access request. Twelve local authority respondents reported that documented procedures about responding to Right of Access requests were available. However, only four had specific procedures for responding to requests from people with care experience.

The survey prompted local authorities to reflect on how their current services meet the needs of people with experience of care. Seven (54%) respondents felt that their processes did not meet people’s needs, two declined to answer, and only four (31%) considered their current service fit for purpose.

Figure 5. Does the records access service meet the needs of Care Experienced people?



5.1.3. Support Provided

Only five local authorities offered staff personal support with responding to challenging requests. Five local authorities provided support to care experienced people accessing their records. Only one local authority provided support to both staff and care experienced people. Four local authorities provided no support to staff or care experienced people.

We also asked local authorities if training about responding to Right of Access requests and associated data protection requirements was provided. All thirteen respondents offered training to staff. Twelve offered in-house training, seven sourced training externally and five provided certified training.

Only five local authorities provided guidance on their website about submitting Right of Access requests. Of these, only one provided specific guidance for care experienced people.

5.2. DOCUMENT ANALYSIS

Those accessing their records may be affected by their understanding of the Right of Access process. Moreover, record holders' understanding of the purpose and significance of accessing records, and the needs of care experienced people in particular may also impact the service provided. To explore what informs care experienced people's expectations and understandings of this process, and the guidance available to record holders about best practice, the project team analysed external and internal documents about the Right of Access process. We assessed publicly available resources including information provided on websites, and three internal documents intended to support and guide responses to Right of Access requests.

5.2.1. Public documents

We analysed 30 discrete web pages which provided information about data protection and submitting Right of Access requests.

Only two (6%) local authority webpages provided specific information for people with care experience accessing their records, which, while useful, varied considerably from webpage to webpage. For example, webpages often suggested that people access support while accessing their records but did not provide information about where to access this support.

Most local authorities provided a Right of Access request form on their website. However, to find these, the web-user had to search terms such as 'subject access request' or 'data protection.' Forms were not identifiable by searching for terms such as 'records.' On a minority of local authority websites, forms could be located via pages entitled 'Children and Families' and 'care experienced

Young People'. This may cause confusion as people may not be familiar with statutory terminology. Furthermore, adults seeking records may not assume that this information would be found in webpages about children and young people. This may create barriers for people understanding how to access their records.

5.2.2. Internal documents

We received internal documents from four local authorities. Three provided internal documents about the Right of Access process and associated resources, and one provided the form and cover letter used to respond to Right of Access requests. Within these documents, some content was consistent and recurring. However, we also observed significant variation in the content and detail of this information.

Most internal documents included detailed guidance about data rights legislation. Some documents included examples to demonstrate how data rights legislation could be implemented when responding to Right of Access requests. However, documents did not always refer to the specific purposes and needs of people requesting their records.

Some documents provided examples of how to address common issues such as locating historic records and redacting third-party information. On the other hand, some documents omitted notable challenges with responding to Right of Access requests, such as delivering records according to care experienced people's preferences. Documents provided guidance about posting records to the recipient but did not consider the specific circumstances of individuals with experience of care, who may receive sensitive and challenging information in their records. This can have a significant impact on people.

Some documents outlined processes to respond to Right of Access requests. This included the names and contact information of key contacts such as data management practitioners, and practitioners who could support people to access their records. Some documents provided information about teams involved in responding to Right of Access requests including information about their capacity, supervision and training needs, and budgets. Some documents also summarised the training programmes and resources available, as well as information about improvement programmes and relevant policies. The most detailed documents also provided links to webpages with publicly available advice for people with care experience about the Right of Access process.

These documents provided some guidance about good practice but did not provide comprehensive guidance about the full Right of Access process, reflecting the need for universal guidance for record holders about responding

to requests for records. Further work is needed to gain a more representative understanding of the context in which record holders are working. This section does however provide some examples of challenges which record holders face when responding to Right of Access requests. Our findings also highlight some variations in the information and support available to both record holders and care experienced people across Scotland.

6

Care Experienced Voice

6 Care experienced voice

6.1. THE MEANINGS AND IMPACTS OF ACCESSING RECORDS

“

“Being care experienced means there are records of every life event, every decision and even who you were at those times – a care record should provide the missing links of your fragmented self. They won't give all the answers, but they can help connect the dots. The record you are giving to a care experienced person is a missing piece of the fragmented self. In the “industry” we speak of person-centred care, holistic care, choice, safety and so on, but at what point do we consider that to truly offer such things we need to recognise the impact of recording data? Whose narrative are we speaking to and who's safety and choice are we promoting?

If this does not demonstrate the gravity and importance of your duties in writing records then it is something you should really sit with and ask – what would those records mean to you, if they were your life?”

Lee Davidson – Expert Reference Group Participant

6.1.1. What has accessing records felt like for care experienced participants?

- Accessing records is often a significant decision in a care experienced person's life.
- Deciding to access records often takes time and is prompted by different motivations.
- Accessing records can be positive. However, for most participants with care experience, accessing their records has had largely negative impacts e.g., resurfacing past traumas. However, distress can be managed effectively if the individual has support.

- Accessing records can positively or negatively affect people's relationships and perceptions of their relationships with others.
- Accessing records enables some to experience closure from their past experiences.
- For others, accessing records creates more questions than it answers which can generate or exacerbate feelings of anger, mistrust, and disenfranchisement, particularly when they do not obtain their full records.
- Overwhelmingly, people tell us that records hold great personal significance as a means of forming, understanding, and reclaiming ownership of their identities and that this experience can impact them in various and profound ways.

6.1.2. Overview

Life experiences play a vital role in forming a sense of identity, an important contributory factor to wellbeing (Haslam et al, 2009). While people generally learn about formative childhood experiences from family members, people with care experience can find it more difficult to answer questions about their past experiences.

As this section explores, accessing records can be deeply significant for people with experience of care. It can have both positive and negative impacts, including altering relationships and feelings of closure, traumatisation, anger and disenfranchisement.

6.1.3. 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 participant

Participants shared different contexts and motivations for deciding to access their records and described this decision as a significant moment in a person's life. Many participants experienced periods of mental ill health or sought to heal from past trauma in the lead up to this decision, which generally took some time to make. Some participants made this decision at a time when they were struggling with their mental health, because they hoped their records would clarify their experiences and aid their recovery.

Others waited until they felt secure in their personal circumstances and wellbeing before accessing their records because they anticipated that reading their records could cause distress. Others made this decision when they felt ready to move on from their past experiences and hoped to gain closure. Some participants had positive experiences of care, others had experienced trauma, which influenced their hopes and expectations for accessing their records. Regardless of context, participants described going through a period of deep reflection and in some cases turmoil before accessing their records, which impacted them in various ways.

6.1.4. The Impacts of Accessing Records

As seen above, people with care experience had different motivations for accessing their records. While people's individual circumstances may have affected how accessing their records impacted them, and the support most appropriate for them, some consistent themes emerged about the impacts of this experience.

59% of survey participants who had read their records (n=38) told us that this had a negative effect on them (either 'very negative' or 'quite negative'). 27% of participants told us that reading their records had neither a positive nor negative impact on them (n=17), and 14% (n=9) reported a positive impact from accessing their records (either 'quite' or 'very positive' impacts).

6.1.4.1 Trauma and Distress

Participants shared that reading records could be very distressing, particularly when individuals had experienced trauma in the past. Some participants described the difficult memories that reading their records evoked, and the negative impacts this had on their current circumstances, relationships, or mental wellbeing. Some also described feelings of deep pain, for themselves and for their families when reading their records.

“

“I don't think I realised that 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, accessed between one and two years ago

Where records disclosed information about family members, some participants discovered new information from their records about the circumstances of entering care, including emotive information about themselves or family members. A few discovered that abuse had happened to them within their families, often causing deep distress.

“

“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.”

Interview participant, accessed within the last year

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

“

I ended up in hospital. It was really bad, my mental health, when I was already in such a bad place before that. Aye it was horrendous.

Focus Group participant, accessed between one and two years ago

Some shared that support from a professional – whether an advocate, a lawyer, or another trusted person – with reading their records, helped this experience feel more manageable.

“

“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, accessed within the last year

6.1.4.2. Relationships

Some people described how this experience impacted their relationships with family members or carers, or how this experience altered how they perceived previous relationships with social workers, carers, and other professionals. This impact manifested in various ways. Where people received records containing familial information, some participants found that reading their records helped them understand the circumstances of their family members before or during their care.

“

“It allowed me to factually confirm what had happened to me as a child and fully move on from it. I can now stop feeling resentment towards my family.”

Survey respondent, accessed within the last year

Others who accessed this information found that this negatively affected their relationships, both past and present. In most cases this invoked feelings of being uncared for, and that their best interests were not prioritised by decision-makers.

“

“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, accessed between one and two years ago

“

“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, accessed between one and two years ago

6.1.4.3. Closure

Some participants whose records contained information about family members described gaining a better understanding of themselves, their families, and their care journey through reading their records. Some disclosed that learning about their childhood experiences helped them to understand themselves better, enabling them to gain closure from their past.

“

“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, accessed between two and five years ago

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 answers to the “many unanswered questions” about their past.

6.1.4.4. Anger, Mistrust, and Disenfranchisement

For some people, the experience of attempting to access their records – and reading their contents – engendered feelings of mistrust, powerlessness, disappointment and disenfranchisement.

“

“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, accessed within the last year

This response was particularly notable when participants had been unable to obtain access to their full records. While some participants managed to gain access to their full records, many of these individuals had worked with specialist record searching organisations to do so – indeed a few participants advised that it was only after seeking additional support that they obtained their records as they could not do it on their own. Others obtained only partial records or were unable to obtain any records at all.

“

“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, never accessed records

“I tried to access [my 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.”

Interview participant, accessed between two and five years ago

While a few participants had explanations for being unable to access their full records, most in this situation did not understand exactly why their full records could not be located. Some had been told their records may have been destroyed or were untraceable due to their age. Data protection regulations have changed over time, so it is possible that some records were destroyed in compliance with data protection legislation at that time. Nonetheless, participants often expressed frustration and confusion about why their records had been destroyed.

“

“[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.”

Interview participant, accessed within the last year

For a minority of participants, being unable to access their records was a positive experience. One participant shared why they felt it was positive that they had not been able to access their records when they first requested them.

“

“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.”

Tried to access records at 16, but told they were ‘lost in transit’ when an office move occurred. Interviewee, accessed between two and five years ago

Generally, not accessing records negatively impacted participants, who expressed feelings of disappointment, and more prominently, of anger, frustration, and 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.

“

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

Survey respondent, accessed more than ten years ago

6.2. REASONS FOR ACCESSING RECORDS

6.2.1. Why did people with care experience access their records?

- Participants believe that people with care experience have the Right of Access their records.
- Some sought to learn more about their time before and during being in care
- Understanding their childhood experiences to gain an insight into who they are now was very important to many
- Others were motivated to access their records for legal purposes
- Most shared multiple reasons demonstrating that motivations for accessing records are often complex and layered

6.2.2. Overview

Participants shared different reasons for deciding to access their records. Of those survey respondents who had accessed their records, 77% (n=49) did so to find out more about their time in care. 50% (n=32) shared that understanding more about themselves was wholly or partly the reason, while 23% (n=15) accessed their records for legal purposes.

6.2.3. Right to my record

“

“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.”

Survey respondent, accessed between one and two years ago

Participants 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. Participants generally felt that anything written about a person should be easily accessible by that individual.

“

“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, accessed within the last year

6.2.4. Putting the jigsaw together

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

“

“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, accessed more than ten years ago

Some participants sought records hoping to discover information about known or unknown family members. They wanted to learn about family members' circumstances or find information that might help them locate family members.

“

“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 but more about him.”

Interviewee, accessed more than ten years ago

6.2.5 Different perspectives'

People with experience of care may not always be able to gain a clear account of events from family members or people present in their earlier life, particularly given the potential complexity of these dynamics. Some participants hoped to gain an objective narrative about the events before and throughout their time in care through their records and shared the importance of this objectivity.

“

“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, accessed between one and two years ago

“My mum [...] has guilt, she will never be able to fully say to me what she did until she is okay with it, someone always has another agenda in the family, someone always has a hidden reason, or responsibility... I wanted that impartial person to tell me this is what happened, this is what your mum did, this is what your dad did.”

Focus Group participant, accessed between one and two years ago

Others accessed their records to understand the perspective of those involved with their care, and how they had perceived the care experienced individual and their circumstances. This minority of participants often felt they already understood what had happened to them, how this impacted them now, and had a sense of identity, and were motivated rather by a sense of curiosity.

“

“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, accessed between two and five years ago

6.2.6 Understanding 'Who I Am'

Understanding their childhood experiences and childhood identity felt significant to participants who wanted to understand how this contributed to who they are now. Participants often used phrases such as 'knowing who I am' when discussing the importance of records.

“

“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, accessed records unspecified length of time ago

Often, participants had no photographs of themselves as children and no sense of what they were like as children. They expressed hopes that their records would provide them this insight.

“

“...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, accessed between one and two years ago

6.2.7. Legal purposes

Just under a quarter of survey respondents accessed their records for a range of legal purposes, such as pursuing a criminal or civil case. One such respondent noted the Right of Access records is important.

“

“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, accessed between two and five years ago

6.3. ENGAGING WITH RECORD HOLDERS

6.3.1. What has engaging with record holders been like for care experienced participants?

- Participants felt that record holders did not recognise the significance of records for people with care experience
- Some reported receiving clear, consistent communication, and offers of support. Many others expressed feelings of unimportance, anxiety, and powerlessness in their engagement with record holders
- Participants shared various suggestions for how this engagement could be improved e.g., some suggested collating records from all local authorities in a centralised, online, government-funded system which would allow them to track the status of their application, and access support systems such as redress schemes and advocacy
- Ultimately, care experienced voices highlighted the importance of feeling informed, heard, and supported by record holders when accessing their records, as well as having some agency over the circumstances in which they read their records

6.3.2. Overview

Participants' experiences of engaging with record holders varied.

36% (n=23) of survey respondents who accessed their records felt 'quite,' 'somewhat,' or 'extremely' happy with communication with record holders, and used words such as words 'friendly' (16%; n=10), 'caring' (14%; n=9) and 'clear' (11%; n=7) to describe record holders.

64% (n=41) were 'not happy at all' or 'not very happy' with this interaction, and participants were most likely to describe their communication with record holders as 'slow' (33%; n=21), 'unclear' (28%; n=18), and 'confusing' (22%; n=14). This section explores participants' experiences of engaging with record holders from initial requests to the delivery of their records.

6.3.3. Starting the process

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

“

“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, accessed between one and two years ago

Many participants shared 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.

“

“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, accessed between one and two years ago

Some were supported by a social worker, therapist, and/or specialist record search organisation. 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 participants shared how important this support was.

“

“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, accessed within the last year

Participants stressed the importance of making it easier to access records by providing clear, accessible, and consistent guidance about how to access records, and suggested that having one point of contact from the start of the process would mitigate uncertainty and enable care experienced people to develop relationships with record holders. One participant suggested digitising this process.

“

“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, accessed unspecified number of years ago

6.3.4. Communication with record holders

Many participants described the record holders' tone of communication as generic. For example, many participants received an email or letter informing them that the record-holder had thirty days to respond to their request. Few participants had any further communication with record holders until they received their records, or their records were ready to be delivered. Those who did generally initiated this contact by enquiring about the status of their request. Many reported speaking to multiple different people, which caused them confusion. Two participants shared feeling as though the record-holder themselves did not know how to respond to their request, and others shared how the lack of communication left them feeling unimportant, uncared for and in some cases burdensome.

“

“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, accessed between two and five years ago

On the other hand, one participant shared the support they received through the process and how this positively impacted their experience.

“

“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.”

Interview participant, accessed within the last year

Participants suggested several ways that communication with record holders could be improved. They asserted that record holders taking the time to understand their purpose for accessing records and the records they hoped to receive and signposting them to available support would make the experience of accessing the records more manageable. Participants highlighted the importance of compassion, empathy, and awareness of the significance of a care record request.

“

“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, accessed between two and five years ago

6.3.5. Speed of accessing records

The word most often chosen to describe communication with record holders was 'slow.' Some did not receive any communication from the record-holder within the specified timeframe. Others were informed of a delay to meeting their request via email or phone.

The ICO requires record holders to respond to Right of Access requests within one month; where the request is complex, the record-holder can extend the time to respond by a further two months.

Participants generally understood delays, especially throughout the Covid-19 pandemic, and appreciated that record searches were administratively heavy and time-consuming. While some participants felt kept up to date by record holders despite long delays, those who did not receive updates reported feelings of anxiety and mistrust towards record holders. Participants emphasised the need for consistent, open communication between the record-holder and care experienced individual about the progress of their request.

6.3.6. Delivery of Records

65 survey respondents accessed their records and answered questions pertaining to their experiences of the process which are reported on in the section below. These participants shared their experiences of receiving their records, and this highlighted perceived inconsistencies in how record holders manage record delivery.

48% (n=31) of survey respondents who accessed their records were not asked how they would like to receive them. 11% (n=7) reported being asked but not receiving records in the way they asked, while 40% (n=25) were asked and received them in the way they had requested. Participants suggested that standardising providing choices about the delivery of records would enable people to feel in control over how they receive their records.

44% (n=28) of the survey respondents who accessed their records were not satisfied with how they received their records. 36% (n=23) of survey respondents received their records through regular post and received no notification that their records had been posted. One person had to pick their records up from their local postal depot when they missed their delivery because they had not been notified of dispatch, and two others opened their records without realising what they were.

“

“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, accessed between one and two years ago

One person had asked for their records to be sent to their advocate who they trusted to support them through reading their records. Instead, the records were delivered without notice to the individual's address, so they were opened without the planned support. This significantly impacted the individual's mental health.

“

“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, accessed between one and two years ago

There were a few instances where participants were only permitted to read their records in the presence of the record-holder.

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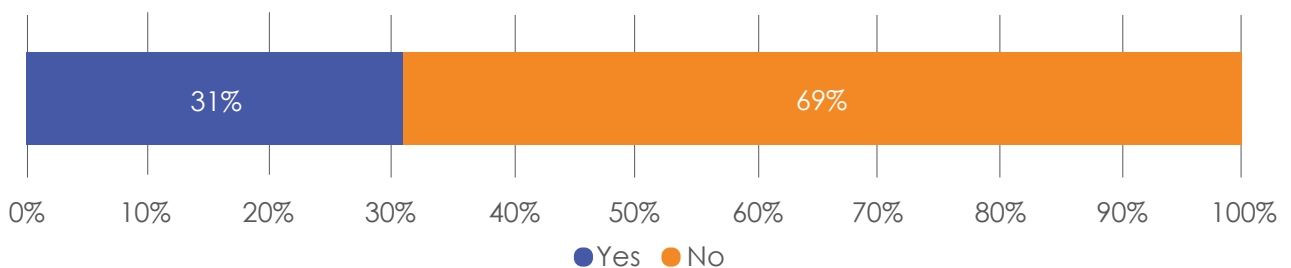
“I was handed a folder full of written records. I was left alone in a room to read them. I read some then walked out. I thought about taking them as they were the originals. I thought why should these strangers keep such records about me? No-one came after me, called or wrote to me to find out if I was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

Survey respondent, accessed unspecified number of years ago

Two participants were given a short amount of time to read their records and were not permitted to leave the premises with their records. In one instance, the social worker who had written the person's records was present when the person read their records, resulting in re-traumatisation for the person and the family members that were present.

Figure 6 (64 responses of 141 respondents)

Did you receive support when you accessed your records?



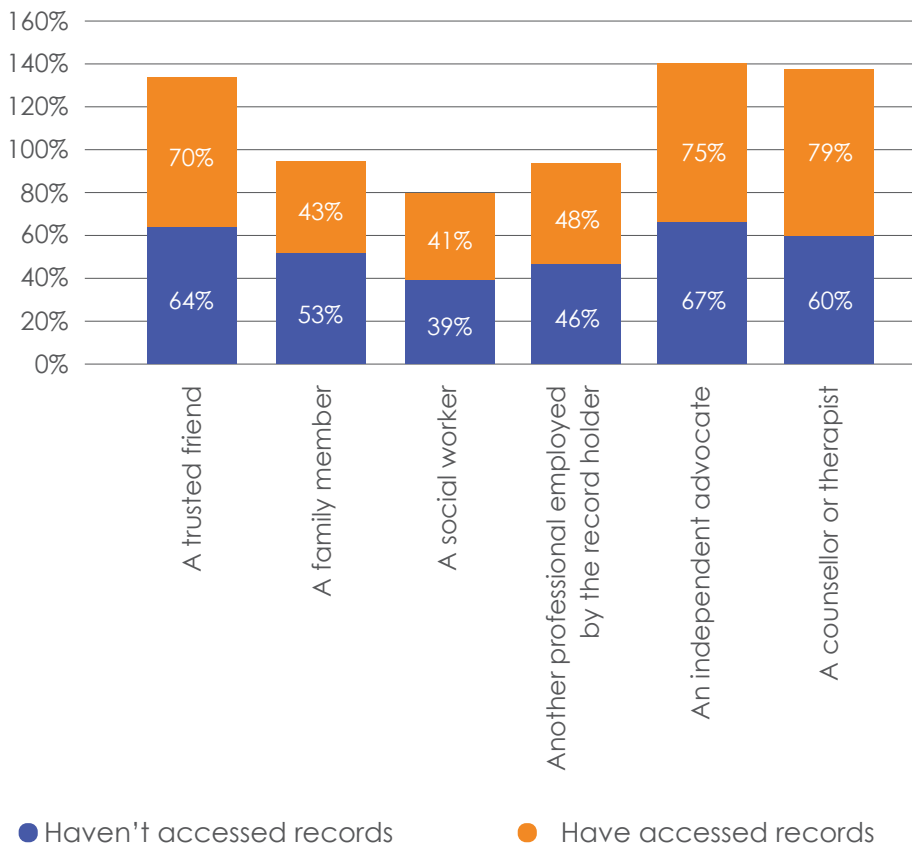
The majority of participants did not receive support when accessing their records. However, it is not known if individuals were offered or would have wished for support. Some participants spoke of needing support or expressed that that they would have liked to have been offered support. Of those who did receive support (n=20), 60% (n=12) were 'satisfied' with this, with 40% (n=8) saying they were 'extremely satisfied.' It is unclear whether this support came directly from the record-holder. Accounts of support from the record-holder were rarely discussed, whereas support outwith record holders was frequently discussed. Participants had primarily received support from people with whom they already had relationships – independent advocates, social workers, or other professionals like solicitors – who helped them to make requests, understand the process, and understand their records.

“

“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

Figure 7: Average helpfulness scores (n=141)



Survey respondents were asked how helpful a range of supports would have been when accessing records. Independent advocates, counsellors or therapists and trusted friends all scored highly, indicating that access to this kind of support is of value during the process of accessing one's records.

6.4. CONTENT AND PRESENTATION OF RECORDS

6.4.1. What do care experienced participants call for in respect of the content and presentation of records?

- Participants called for a consistent, transparent, and tailored approach to the redaction of records but shared differing views on what this could look like
- Understanding and being involved in the redaction process emerged as crucial to having a positive experience of this process
- Participants called for more careful, chronological organisation of records, and improving the legibility of records to make them easier to understand

- The content and presentation of records can result in feelings of powerlessness, distress, and mistrust, but appears also to have the potential to empower people to take ownership of their life story, stressing the significant impact of creating and presenting records with respect, dignity, and care

6.4.2. Overview

Participants' 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 redaction within records. We also heard some examples of people with care experience being informed and actively involved in the content and presentation of their records. This section explores the dominant themes participants raised, and how the content and presentation of records impacted people in different ways.

6.4.3. Understanding redaction

Care experienced participants had varied understandings of, and therefore reactions to, redaction within their records. Generally, participants understood the need for third-party data protection, but often expressed confusion about what this relates to and how record holders decide what to redact. For most participants, redaction was only explained in a letter which accompanied their records.

“

Question: Was redaction explained to you at any point?

“No, not at all. 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, accessed within the last year

A few participants had been supported to understand redaction before or during the process, meaning that they knew what to expect from their records.

“

“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, accessed within the last year

However, 73% (n=47) of the survey participants who received their records described themselves as 'not satisfied' with the redaction of their records for reasons explained below.

6.4.3.1. Inconsistent redaction

Many people felt that redaction was inconsistent and shared examples of third-party information being redacted in some parts of records while being accessible in others. While this may be due to misunderstanding redaction processes, perceived inconsistencies often caused people with care experience to feel that their records had been treated carelessly and that record holders did not appreciate the importance of their records.

“

“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, accessed unspecified number of years ago

6.4.3.2. Extensive redaction

Many expressed dissatisfaction with the volume of redacted information in their records. Many reported whole pages or sections of records which were redacted, invoking a range of responses. Some felt they were not able to achieve their initial purpose for seeking records. Others expressed shock, upset, and feelings of powerlessness or lack of ownership over their information.

“

“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, accessed between one and two years ago

“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, accessed unspecified number of years ago

6.4.4. Incomplete records

Many participants reported receiving incomplete records which provided little documentation representing significant periods of time in care. Some also described the impact of a lack of records about significant moments, like moving care institution, school, or foster family, generating feelings of unimportance and invisibility.

“

“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, accessed unspecified number of years ago

This speaks to practices around how records have been written historically. Participants highlighted that records may have been perceived by writers of records as an administrative or legal task, as opposed to a process of generating a coherent life narrative for, and if possible, with the care experienced person in question.

“

“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, accessed between two and five years ago

6.4.5. 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 often, due to child protection and safeguarding processes, from multiple organisations. Records may not be in chronological order due to the filing systems of the era. Records can be held in sections and therefore appear jumbled and disordered because the same type of reports will be together irrespective of age and stage. This may be confusing if the rationale is not explained. Records may therefore be stored in an ordered way that is not chronological, which demonstrates records management is not currently designed for life story work (Independent Care Review, 2020; 69).

Two thirds of survey respondents who could speak to this point were 'not at all satisfied' or 'not very satisfied' with how their records were organised. Contrary to expectations, most records were not arranged chronologically, and some had different types of records in the same file.

“

“[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, accessed between one and two years ago

6.4.6. Legibility of records

Some participants found it difficult to understand their records due to poor handwriting or faded type, making the process of reading their records time-consuming and frustrating. Most participants who experienced poorly handwritten records were older, yet one was aged under 25, suggesting this may not be an entirely historical issue.

“

“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, accessed within the last year

6.4.7. Language of Records

The manner in which records were written was often directed by regulation and legislation e.g. adoption records reporting the characteristics of the family. The law required, and still requires, a local authority to prove that the evidence threshold for removing parental rights has been reached. This can mean that the negatives were and are highlighted within the records, and the positives – the bits an adult child might most want, and which give a more real picture – much less so. This is important, for how records were written, and to highlight what needs to change – not only social workers writing of records but also the legislative and regulatory framework governing and surrounding those records.

80% (n=51) of survey respondents who had accessed their records were 'not at all satisfied' or 'not very satisfied' with how their records were written. Often people felt that their records reflected the opinions of the writer of records. People described reading impersonal or judgemental statements about themselves, their circumstances or family, where records included information about their family.

“

“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, accessed unspecified number of years ago

Again, this may reflect the dissonance between the intended audience of historical records, and how records can affect people with care experience in the present. Some participants highlighted the importance of writers of records taking care to frame circumstances and events using neutral or positive language which focuses on achievements rather than failings or deficits.

“

“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, accessed between one and two years ago

6.4.8. Inaccurate information

Some reported reading inaccurate information in their records, including addresses or dates of birth. A few reported events being recorded differently to their recollections. Some felt that information had been purposefully misrepresented in records to cover up events, such as abuse within institutions.

“

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, accessed within the last year

Some participants called for people to be able to contribute to their records.

“

“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

Some participants discussed the concept of a ‘digital passport,’ the idea that records should be co-created with the person with care experience, and stored in a mutually accessible digital location, to enhance the ownership people could feel over their life narratives.

“

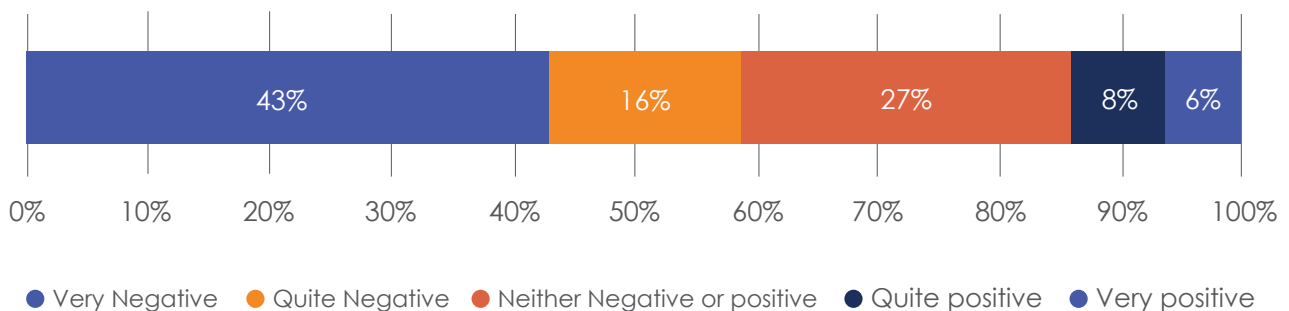
“My ideal is – everywhere we go as care experienced people, we take our records with us, and they carry on. Just like a health record book and whoever is looking after you is appointed to write in them.”

Focus Group participant, accessed unknown number of years ago

6.4.9. Impacts of Record Content and Presentation

Receiving records which were organised in a confusing way, illegible, incomplete, inaccurate, which used partial language or were redacted (without prior explanation) had significant, largely negative impacts on participants.

Figure 8: What type of impact did reading your records have for you personally? (n=64)



Some felt frustrated or deflated that their records could not offer the clarity or closure they had hoped for. A few shared how this had impacted them more profoundly.

“

“We understand that redaction must be done to protect those who've not given their permission for their information to be shared, but who does redaction really protect and who is protecting us from the impact of redaction? [...] redaction can reinforce our feelings of never knowing the truth, and that someone else is always going to be the gatekeeper of our story.”

Lynda Greig – Expert Reference Group participant

In some cases, this intensified mistrust of the record holder or care 'system'. For example, some participants shared suspicions that redaction was used by local authorities to withhold information about bad practice.

“

“It was the whole power dynamic and power over me. The people who have had power over me my whole life ... still do. 'We're still in control, not you'. It's like 'we've got information on you but we're not telling you' [...] That big cross just felt like it came down to power. If they are that worried about it, don't do it in the first place. There is definitely something about it to protect the system. To protect them from their failings.”

Focus Group participant, accessed between one and two years ago

Recurrently, participants expressed that the perceived lack of care taken with the content and presentation of their records created feelings of unimportance, anger, having more questions than answers, and disappointment.

7

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, 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

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, affect providing an explanation of what was recorded, the language used and the historic use of family files, recognises 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.

8

Conclusion

8. Conclusion

We hope that this report has enhanced your understanding of the experiences of people with care experience accessing their records in Scotland. We have explored what records mean to people, why they access their records, what it is like to engage with record holders and receive records, and the impacts of these experiences. In the context of The Promise, this creates a clear evidence base for changing how we understand and support access to records in Scotland.

The project also gave people with care experience the opportunity to share their experiences and their thoughts on how the challenges identified could be addressed. Each of the recommendations in the report is based on their contributions.

The report has also suggested avenues for future discussions about the Right of Access. A useful next step is to explore the ways in which record holders' capacity to implement the above recommendations is affected by resource limitations and other factors. Future research could also examine the conflict between data legislation and the right to understand one's childhood and be supported to recover from trauma.

Ultimately, this report is intended to provide the foundation for developing a consistent, trauma-informed framework for record holders responding to Right of Access requests: a Gold Standard Best Practice guide. This must be grounded in an understanding of people's experiences, thoughts and feelings.

9

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11

Appendices

11.1 PROJECTS

The project group has wide-ranging experience of supporting care experienced people to access their records.

CELCIS

CELCIS is the Centre for Excellence for Children's Care and Protection, based at the University of Strathclyde in Glasgow. We improve children's lives by supporting people and organisations to drive long-lasting change in the services they need, and the practices used by people responsible for their care. In our partnership work with carers, social workers, teachers, health workers, local authorities, charities, the police, local authorities, and the Scottish Government and other corporate parents, we work to understand the issues, opportunities and challenges to identify improvement in practice and develop solutions.

We have supported practice change to improve how people with care experience access their records, as well as practice change to improve how care records are written and stored. This includes facilitating round table events with corporate parents in 2019 and 2021, producing two briefings on the discussion and outcomes of these events, *Access to care records (2019)* and *Developing practice for care records in Scotland (2022)*.

In Care Survivors Alliance

The In Care Survivors Alliance was established in 2016 as part of a wider strategy developed by the Scottish Government to address the legacy of historic abuse in Scotland. The Alliance delivers two services: the Redress Support Service and Future Pathways. Future Pathways supports survivors of in care abuse and neglect to access a national support fund. The Redress Support Service provides trauma-informed emotional and practical support to people applying to Scotland's Redress Scheme. These services aim to fulfil recommendations made by the Scottish Human Rights Commission's Interaction Action Plan on Justice and remedies for Historic Abuse of Children in Care.

Access to records is a priority area: more than 1,257 people have sought help to access records of their time in care (October 2022), a trend that is expected to continue. The Alliance works in close partnership with two organisations with substantial expertise in this area, Birthlink and Wellbeing Scotland, to deliver access to recordssupport across Future Pathways and Redress Support Service.

Our impact and evaluation work across the Alliance shows the wide-ranging impact of record searches on individuals. The impact can be dependent upon on the person's state of mind, the outcome of the record search, the way people receive their records, and the content of the records received. We observe four key themes of impact:

- Record searches can support people to develop a more grounded and connected sense of identity.
- Record searches can facilitate significant mindset shifts in survivors which can result in tangible changes to people's day to day lives such as their choices around employment and their relationships.
- Record searches can enable survivors to access payments from Scotland's Redress Scheme which can, in turn, positively impact their life opportunities and those around them.
- When records contain difficult content, or when record searches are fully or partially unsuccessful, this can detrimentally impact people's mental health by causing feelings of distress, invisibility, and insignificance.

The Alliance observes that many people experience barriers to accessing their records. It is also clear that the complex process of seeking and receiving records could be improved. This project was an opportunity to look at this important area in more detail, in collaboration with organisations across different professions who are committed to improving how people are supported to access their records.

Aberdeen City Council

Write Right about Me

Aberdeen City Council is working alongside young people and care experienced people to support culture and practice change so that their voices and experiences are meaningfully captured in their records. This multi-agency project called Write Right about Me is changing the way the Council write and has a focus on voice and human rights for people in their records[1]. Access is an important part of this work, access in the form of participation in record creation, access as part of the Council's open records policy and access to records for care experienced people. Aberdeen City Council have also developed their D365 (information management system project) which will embed co-production of records with a focus on participatory record keeping and highlighting people's right of access to their records. As part of D365 readiness, the principles of participation, collaboration and access to records is being embedded into practice through learning, Recording Principles and Data Protection.

[1] The Write About Me Project includes: NHSG, Social Work, Education, Police Scotland, Children's Hearings Scotland, Scottish Children's Reporter Administration (SCRA), Barnardos, Aberlour, Includem, RAFT and Children's First, North East of Scotland College, Aberlour Futures, Robert Gordons University, Aberdeen University and The Open University WiSP.

ACC SCAI Team

In 2017 Aberdeen City Council set up its Scottish Child Abuse Inquiry Team, in 2018 becoming responsible for responding to Right of Access Requests from care experienced people. A whole systems review was undertaken and the process for engaging, responding to, and supporting people accessing their records was undertaken. A person centred approach has been developed and, care experienced people are involved in the process, support is offered through and after the journey and referral offered to specialist counselling and support services. Redaction is light touch and decisions are explained. Team members are trauma informed and receive specialist training to support them to carry out their roles. The impact of accessing records is recognised. Aberdeen City Council worked with the Scottish Children's Reporter Administration (SCRA), Police Scotland and NHS Grampian to streamline processes where other agencies records are held within the child's social work record.

The City of Edinburgh Council

To ensure that the Council could react positively to the National Inquiry, a temporary internal Scottish Child Abuse Inquiry response team was set up in February 2017 to manage and respond to the statutory requests for information from the Inquiry. The multidisciplinary team had members seconded and recruited from the Council's Information Governance Unit, Children's Services, HR, Internal Audit and Legal Services, with dedicated project management and administrative support. The team was led by the Information Governance Manager but reported to the Chief Social Work Officer.

With the removal of the Inquiry's reporting to the Scottish Parliament sunset date and the setup of the Advanced Payment and wider Redress compensation schemes, the Council recognised that there would need to be project team for the longer term. Given the developing expertise of this temporary team, the Council decided to give it the role of providing dedicated and specialised support around accessing historic social work records to those care experienced people who had suffered abuse during their time in its care and make its core permanent. The team currently comprises of two Archivists, two Information Asset Officers and a social work professional, with continued but ad-hoc support provided by HR and Legal Services when required. The SCAI Team sits within the Council's Information Governance Unit in recognition of the need to understand and maintain knowledge of historic record keeping practices over decades of social work provision when dealing, not only with the National Inquiry, but also supporting abuse survivors and care experienced individuals when they seek to access their life stories. The team aims to deal with such requests consistently, independently and transparently. Crucially, the team's social work professional now engages with abuse survivors and care experienced individuals as part of an increasingly integrated process of data protection procedure and social care support. Some key advantages of this team have been:

Better support for the care experienced – the team's knowledge of historic record keeping and trauma informed practice means that it can often more sensitively redact when responding to complex abuse related subject access requests. It can also provide bespoke support to those making the requests; helping to manage expectations and explain the context of records in a supportive and outcome focused basis. Having a dedicated resource for abuse survivors also aligns with national approach being developed in this area.

More independent monitoring of historic social work record keeping – the team also investigates historic files which have been identified as missing due to an Inquiry request or subject access request coming in. Missing file reports are produced, with recommendations on what changes could be made to stop the situation from happening again. Too many repeated mistakes around social work records have been uncovered over time, with such devastating impact upon survivors, to accept that these are isolated cases. Only with improved training around and monitoring of long-term social work record keeping can the likelihood that such failures will continue in the 21st Century be reduced. By having a reporting and advocacy role in the Council, the SCAI team has become key to its commitments in this area.

Social Work Scotland

Social Work Scotland is the professional body for social work leaders, working closely with our partners to shape policy and practice, and improve the quality and experience of social services. Professional leadership is critical in advancing change, and this report is a vital step in framing some of the Right of Access issues for leaders and practitioners at all levels who are closely involved in people's experience of care.

Our Historic Abuse subgroup has been leading and facilitating conversations in this area since 2018 and those conversations formed the basis of the work reflected within this report. We have been delighted to work alongside partners and particularly those with experience of accessing their records, to highlight the issues and suggest actions related to access to records. Along with our partners, we publish these results now in anticipation that they take the conversation forward to a place of practical action and improvement.

Who Cares? Scotland

All children need the same things to thrive. They need to feel safe, loved and supported by people who care about them. But for care experienced children and young people, this can't always be taken for granted.

At Who Cares? Scotland, we believe that care experienced people should grow up feeling loved, respected and equal. We were formed in 1978, as a voluntary forum for children and young people in the care system, to share their experiences. Over time, that developed into a professional independent advocacy service. Today, we deliver advocacy in every local authority in Scotland and support around 50 care experienced people to access their records every year, and others to access Redress services and supports. We therefore understand the significance of these record searches and some of the challenges care experienced people can face when trying to access their information about their lives.

Our campaigning roots date back to the late 1980s but in 2012, our campaigning and influencing work intensified, with a particular focus on amplifying the voices of care experienced people to decision makers with the power to change policy, practice and legislation.

In recognition of the growing movement of empowered care experienced people, we created a membership programme in 2014 and became known as the 'national membership body for care experienced people'. In the following years we prioritised campaigning activity and activism, as a route to positive change. This ultimately led to a series of historic changes to policy, practice and legislation.

Between 2018 and 2021, care experienced members of Who Cares? Scotland met regularly to discuss the meaning and significance of care records in their lives. The member-led Our Lives, Our Voices, Our Records campaign aimed to connect care experienced people with similar experiences and worked together to develop guidance about accessing records for care experienced people. This involved several workshops and conference inputs, as well as collaborative work with Aberdeen City Council and the Scottish Children's Reporters Administration (SCRA).

Evidence from our membership and those we support clearly tells us that many care experienced people encounter barriers to accessing their records. This project was an opportunity for our members, and the wider care experienced community, to work together with other organisations who were also committed to improving process and practice in the future.

11.2 Ethos Of Engagement

Project team members have experience of working with care experienced people, and therefore understand that care experienced people often face disadvantage, exclusion, and discrimination.

Members understand that accessing records can have profound and long-lasting impacts, particularly for care experienced people who have experienced trauma. We understand, both anecdotally and from existing research, that care experienced people can experience loss of identity, confusion, and distress throughout this process. Often written records may be assumed to be accurate. However, records can contradict care experienced people's memories, causing disorientation, overwhelm and many other emotional responses. Moreover, reading records can cause a person to re-live previous traumatic experiences, which can be retraumatising. This is particularly harmful when individuals do not have access to support, and/or have limited control over the process of accessing their records.

Considering this, we created opportunities throughout this project for participants to meaningfully contribute to the project's design, implementation, and outcomes. We felt it was integral to ensure participants felt heard and that they had agency over this process. We also put suitable safeguards, such as risk assessments, in place to ensure, as much as possible, that participating in this project would not have detrimental effects on participants.

Equity of voice

The project team endeavoured to ensure that all participants' voices were respected and valued, particularly in focus groups where unbalanced contributions can cause frustration. To mitigate this, we circulated and discussed a Participation Agreement with all focus group participants. This agreement emphasised the importance of support, non-judgement, and equality in focus groups.

Moreover, we facilitated focus group discussions in ways that included all participants. Before focus groups, we briefed facilitators on effective approaches to different focus group dynamics. After focus groups, we debriefed to identify and discuss any issues or adjustments required going forward.

Privacy and Confidentiality

Project partners created a Data Sharing Agreement for this project. This agreement clarified how data from this project was collected and stored. Only the project team had access to the secure platform where project data is stored.

Following transcription of interviews and focus groups, all participants' names were replaced with numbers to anonymise participants. Participants' names were retained only in a reference sheet, only available to the project lead, which linked participant names to their assigned number.

We provided participants with information and privacy notices in advance of interviews and focus groups, and we discussed these before beginning activities. These notices explained why participants' data was being collected, how data would be stored and analysed, how long data would be retained, and information about participants' data rights. Privacy information was summarised – and linked to in full – in the online surveys we sent to care experienced participants and record holders.

Consent

We asked participants clearly and explicitly for their consent at the beginning of the online survey. If participants withheld consent, we asked no further questions. We asked interviewees and focus group participants for written consent by email in advance of project activities and we confirmed consent verbally before interviews and focus groups. We reminded participants, before and after activities, that they could withdraw from this project at any point prior to this report being published.

Where project team members had existing relationships with participants, we took care to navigate underlying power dynamics and ensure participants understood that their engagement was voluntary, optional, and would not affect existing relationships.

Trauma-informed practice

Having worked extensively with care experienced people, the project team understood how trauma can profoundly affect how people understand themselves and the world, engage with peers and professionals, build relationships and experience social environments. We were also aware that accessing records can be a profound and challenging experience for care experienced people. We therefore embedded the principles of choice, collaboration, trust, empowerment and safety into the design and implementation of this project to reduce the risk of trauma-related distress.

We collaborated with the Expert Reference Group to design this project and to shape surveys, focus groups and interviews. We also included short grounding activities (such as mindfulness activities) in focus groups to support participants to feel calm and present. Focus group facilitators 'checked in' with participants as necessary during sessions and debriefed with participants after sessions to reflect and consider how sessions could be improved. In advance of interviews, interviewers had informal discussions with participants about the project, the content of the interview, and identified support needs. Before interviews began, interviewers had time to introduce the session and ensure the interviewees felt comfortable before progressing. During

focus groups and interviews, facilitators prioritised the needs of participants and responded to disclosures about traumatic experiences with empathy, compassion, respect, and kindness. After interviews, we encouraged interviewees to reflect on the experience and to plan a self-care activity. After participating in a focus group or interview, participants received an email thanking them for their contribution. We also provided contact details for a member of the project team, who participants could contact if they needed support or had any questions.

We developed a Risk Assessment which detailed further measures we took to mitigate risk including:

- A designated Safeguarding Lead oversaw all project activities and supported the project team to address welfare and safeguarding concerns
- Interview and Focus group facilitators received trained listener training
- During all interviews and focus groups, we made 1:1 support available to participants. These optional sessions were staffed by a trained listener or safeguarding professional
- We designed and distributed a digital Participation Agreement for focus group participants. This agreement communicated the project's ethos of engagement, and established ground rules for participation, including zero-tolerance for bullying
- We proactively checked in with participants after engagement to identify any negative impacts and respond appropriately
- We briefed all facilitators to ensure they were equipped to safeguard participants and themselves, and to respond appropriately to safeguarding concerns. We also provided opportunities for facilitators to debrief following focus groups

Inclusion

The project approach was developed with accessibility and inclusivity at its core. The online consultation was drafted in plain language and included definitions of key terms and phrases, while a simplified 'easy read' survey was made available. The focus group activities were designed to cater for a wide range of learning styles and to be adaptable to support the effective engagement of a broad constituency. Further, a high facilitator-participant ratio allowed for a tailored, responsive approach. Similarly, the semi-structured interview guide and trained, experienced interviewer team supported the safe and meaningful participation of participants of different ages and stages.

That withstanding, the team recognised that some people in the care experienced community may face additional barriers to engaging with projects such as this and that there are inherent limitations to the scope of this work. For example, those with Additional Support Needs or learning disabilities, or those for whom English is an additional language may have been precluded from completing the online survey, as were those without access to the internet.

Further, given the timescales involved and the recruitment methods employed (i.e., using existing contacts), those unknown to support services (which often includes those with intersectional barriers to access such as minority ethnicity, including Black, Brown and Gypsy, Roma and Traveller people) were also less likely to be represented.

Participant safeguarding

The project team applied child and adult safeguarding policies provided by Who Cares? Scotland and Future Pathways throughout this project. These policies identified the principles and responsibilities of child and adult protection and provided guidance about relevant legislation and best practice. For example, these policies provided definitions of abuse, exploitation, and neglect, and guidance about how to identify and respond to concerns. These policies were available to the project team and discussed at facilitation briefings when facilitators were encouraged to raise questions in advance of project activities. In accordance with these policies, where protection issues arose, project team members supported participants to identify the right support for them, and to have agency and choice in their next steps.

An Institute of Occupational Safety and Health (IOSH) Managing Safely trained assessor oversaw the project's risk assessments. Risk assessments identified hazards, those at risk of harm, and appropriate control measures such as a designated Safeguarding Lead being assigned to each project activity. Facilitators were fully appraised of risk assessments, reporting procedures, and their role in safeguarding participants during briefings. Facilitators were supported to respond swiftly and compassionately to concerns, and to prioritise the safety and wellbeing of participants throughout the project. All incidents and concerns were reported to the Designated Safeguarding Lead and then recorded. The Safeguarding Lead supported project team members to escalate incident reporting as appropriate.

11.3 Care Records Participant Information Focus Groups

ABOUT THE PROJECT

This is a collaborative research project organised collaboratively by Future Pathways, CELCIS, Who Cares? Scotland, Aberdeen City Council, West Dunbartonshire Council and City of Edinburgh Council.

Together we're aiming to establish a national evidence base for experiences of accessing records and further develop a Gold Standard best practice guide for record holders responding to records requests.

Our project has been developed using a participatory action research methodology, with an Expert Reference Group including those with lived experience of care coming together to support design and delivery. We are building on research which speaks to the importance of records in supporting care experienced people's sense of self, identity and autobiographical memory.

The project involves conducting an online consultation and a series of focus groups and interviews.

WHY ARE WE ASKING YOU TO PARTICIPATE?

We're collecting information on experiences of accessing care records to understand whether and to what extent record holders are meeting the purposes and needs of care experienced people making Subject Access Requests. This information will be used to create a research report and associated publicity materials. The report will include summaries of the information collected, composite case studies, recommendations for change and anonymous quotes. The report will inform the development of a Gold Standard Best Practice Guide for record holders, which should help improve experiences in future.

TAKING PART IN A FOCUS GROUP

You've been invited to take part a focus group. First of all, thank you. By sharing your experiences you will be helping to influence meaningful change. By now, you may have agreed a time and date for the group. This will take place on Zoom. In the session, you should feel respected and able to share your experiences without judgement and feel supported to do so.

[Insert specific details about Focus Group session]

DISCUSSION POINTS

There are no right or wrong answers to the questions that will be asked in the session. The researcher would like to hear about your experiences of accessing or attempting to access your records. The kinds of questions the researcher might ask you about are split into three categories:

1) EXPERIENCES

You might think about the process of accessing your records, for example communications with the record holder. If you had support from a person or service when you were accessing your records, what was this like. You might also think about the format of the records and whether the content was accurate and what you expected.

2) IMPACT

The research team are interested to hear how accessing or attempting to access your records has impacted your life.

3) IMPROVEMENTS

You might have some ideas about what could have made your experience better or different, and maybe some ideas in general about what needs to change in Scotland to make accessing records a better experience.

WHAT ARE MY RIGHTS IF I TAKE PART?

- It's totally up to you whether you take part. You can say yes or no without upsetting any one and without any impact to yourself.
- You have the right to be totally anonymous. We won't share any details that identify you (like your name or address) with anyone else. When we write our report, we might use quotes from what you shared, but never with your name.
- You have the right not to be judged when you share your story. We will listen to what you share with empathy, not judgment.
- You decide how much you share. We know we're asking people to speak about something that can be sensitive and emotional. We'll be led by you. You can choose not to answer questions that feel like too much - to take breaks - or we can stop if that feels right for you.
- You have the right for your data to be held securely. We care about your privacy and will protect your data – this is stored securely, will not be used for any purposes beyond this research and will only be retained for the duration of the project (present day - 30/07/2021). Data will be anonymised, and you will not be identifiable in the published reports.
- You have a right to change your mind, or 'withdraw consent,' at any time. This can be before, during, or after the session. If after the session you decide you don't want us to use what you shared, email recordsresearch@whocaresscotland.org and ask for us to delete your data off of our systems.

WHAT IF I HAVE QUESTIONS?

If you have any questions about this project and want to know more, including after the session, you can get in touch with a member of the research team at recordsresearch@whocaresscotland.org

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Additional Resources

12. Additional Resources

This report refers throughout to the below documents, all of which are available upon request:

- Digital Participation Agreement
- Focus Group session plans
- Semi-structured Interview guides
- Anonymised Interview transcripts
- Anonymised Survey results
- Data Sharing Agreement
- Information sheets and Privacy notices
- Project Risk Assessments
- Child and Adult Protection / Safeguarding policies

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Future Research and Information about the Project

Social Work Scotland - Leading the Profession

admin@socialworkscotland.org

Social Work Scotland is the professional leadership body for the social work and social care professions. We are a social work leadership body, led by our members. We work to influence policy and legislation and to support the development of the social work and social care workforce.

Social Work Scotland is committed to carrying forward the recommendations in this report to their members; managers and leaders, and the wider social work profession. They will be developing a coordinated programme of work to fully embed that learning.



