

# Children's Health in Care in Scotland (CHiCS)

## Main findings from population-wide research



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# CHiCS

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# Introduction

We all live public and private lives. When other people tell stories about our lives, they sometimes become very powerful and start defining us, becoming part of our identity. Certain groups have always been more susceptible to being defined by others. For example, historically, women have been defined by men as too emotional and unfit for reasoning and academic research. Disabled people have often been medicalised and seen through their particular disability, without private lives and experiences just as everyone else.

People with experiences of care have often faced disadvantage in childhood and, as a consequence, have poorer outcomes (e.g. in education, employment, health) as a group.<sup>1,2</sup> Subsequently, care experienced people have become defined by this in the public mind. In research they are predominantly viewed and studied through a problem-focused lens.<sup>3</sup> It can be difficult to see the young person for themselves. When negative stereotypes are repeatedly associated with one group of people it creates stigma, affecting people with experiences of care in all areas of life, including health.

This report describes only a fraction of the lives of children and young people, care experienced or not. We provide an aggregation of health outcomes across thousands of children, some of whom have been ill, maybe born with a health condition or who have become unwell over time. Some of these illnesses have been serious, some not, many children have recovered, very few have died. However, **most of the children included in this study have lived healthy lives and, with the right support, care experienced children and young people can attain excellent health that continues throughout their lives.**

The care system can facilitate positive health outcomes providing support to young people when they need it most. Our findings demonstrate that there are instances where children with care experience have poorer health outcomes than their peers, but this does not imply that being in care has caused this. **Poor health and health inequalities are not an inevitability, and our results and recommendations aim to provide a foundation for the delivery of better outcomes for care experienced children.**

We look at health outcomes that are recorded across different records, such as hospitalisations, prescriptions, and deaths (often referred to as objective health) and do not consider self-reported health or wellbeing (referred to as subjective health). People may be in good health but still feel that they are not healthy. Conversely, many children and young people with health conditions can successfully manage their illness, sometimes with the help of parents, carers, or health professionals, and live long and happy lives. In fact, our work shows that **many of the health problems faced by children and young people can be avoided and managed with better care.**

Population-wide analyses, such as this, aim to provide a large-scale overview of groups of people. These are necessary for monitoring change over time and developing policies to improve health and reduce health inequalities. Population-wide trends, as in mortality among children and young people or in prevalence of health problems, can tell us if our health is improving and whether measures intended to improve health are working. More detailed studies into the causes of deaths or diagnosis of illness tell us which areas of health need

more attention and what additional policies or services might be required. By comparing health outcomes of care experienced children to those in the general population our work aims to provide the first detailed population level overview of the differences between two groups of children with different life experiences.

Finally, parents, carers, social and health workers, and other people in children's lives have to be aware that they model and teach good habits and a healthy approach to life. Therefore, when considering the results presented in this report, **one should always remember that the health of children and young people reflect the society around them.**

## Summary of findings

We often expect children and young people to live longer, happier, and healthier lives compared to the previous generations but recent evidence in the UK and other high-income nations shows that this should not be taken for granted.<sup>4,5</sup> Our work brings together data collected by the NHS, local authorities, the Scottish Government, and the National Records of Scotland from 1990 to 2016 to study differences in health between children and young people with experiences of care and those without experience of care (referred to as the general population). A summary of recommendations based on this research is provided on pages 6-9.

We show that some children and young people in Scotland are more likely to experience poor mental health, hospitalisations, injuries and even deaths related to circumstances beyond their control and yet wholly avoidable. Unfortunately, care experienced children and young people are, on average, more likely to face adverse health events, including higher mortality, hospitalisations related to mental health, chronic conditions, and injuries, compared to the general population. These differences remain even after accounting for the fact that care experienced people are more likely to have been born into the most deprived areas of Scotland.

We also looked at how health and health service contact among care experienced children changes over the course of childhood and care placements, highlighting challenges that families and young people face at different stages of their lives and how care interacts with these to impact health. For example, chronic conditions, such as asthma or epilepsy, are often diagnosed at young ages before a child enters care. When these conditions prove challenging to cope with for the family, they may contribute to a child's entry into care. The higher prevalence of epilepsy among the care experienced cohort in this study may be an example of this. The prevalence of diabetes (type 1) and asthma is similar in the two cohorts, yet care experienced children are more likely to be hospitalised for all three chronic conditions. Importantly, for epilepsy and diabetes, hospitalisation rates tend to be lower while the child is in care, compared to before and after care. This again reflects the challenges faced by the family and the young person in managing chronic health conditions and highlights the support all families and young people experiencing chronic illnesses need.

Some care experienced children and young people are hospitalised for conditions that are uncommon among general population children, such as due to severe stress caused by exceptionally difficult life events or changes. This shows the unique challenges that care experienced young people face, and the need for services, including health, education, and social care, to better manage and support children in the already difficult transitions into care, between placements and out of care.

Health problems generally increase with age. Here, our work shows that in many cases this increasing trend is more pronounced among care experienced children and young people, widening the inequalities in health between the two cohorts. Some of this may be related to significant life events, for example starting independent life can be a difficult period for all young people in terms of managing their health and wellbeing. The transition into adulthood can be even more challenging for those with care experience as it coincides with leaving formal care. We find that hospitalisations for depression and poisonings from over-the-counter painkillers (analgesics) increase more sharply around the age of 18 for care experienced people, possibly reflecting the impact this transition has on them.

Ultimately, one of the most important findings from our work is that **many of the deaths and hospitalisations discussed here are completely avoidable**. While we cannot prevent the onset of type 1 diabetes, epilepsy, nor all cases of asthma or mental ill health, it is possible to manage these conditions and to avoid frequent hospitalisations or unnecessary deterioration of these illnesses. To do this successfully, children, young people, their parents and/or carers will often need more support and advice than they currently receive.



# Recommendations

## Before children enter care

Some chronic health conditions, including asthma, epilepsy and in some cases also diabetes (type 1), are likely to be diagnosed at fairly young ages, preceding entry to care. These conditions can be difficult to manage in young children and adolescents, requiring much closer attention from the whole family. It can be very challenging for parents and carers to cope with this while simultaneously also trying to care for other members of the family, retain employment and provide a safe home.

↳ Our work shows higher hospitalisation rates for chronic conditions before children enter care, suggesting that these illnesses may contribute to entering care in the first place. Our recommendation is that all families with children living with long-term and chronic conditions are offered more support to manage these conditions and keep families together.

While disabilities, including both physical, intellectual and learning, and neurodevelopmental conditions (e.g. ADHD) are generally rare in children, these are often diagnosed at young ages and can be challenging for the whole family. These conditions may also increase the risk of injuries and other mental and physical health conditions.

↳ The results presented here show that children who experience care at any point in their life have higher prevalence of injuries and poisonings at young ages, and disabilities and neurodevelopmental conditions likely that may be diagnosed before entering care, especially in severe cases. Our recommendation is again that families of children who experience disabilities or neurodevelopmental conditions receive more advice and support at an early age to learn to live with these conditions and manage them better.

## While children are in care

Care can be protective and a positive life change for children and young people. Our work shows that hospitalisations for chronic conditions are often reduced while children are in kinship or foster care, suggesting that they are receiving better support in managing their health.

↳ However, children and young people in residential care unfortunately often experience more hospitalisations, for both mental and physical health conditions, injuries, and poisonings. As of now, we do not know how pre-existing health problems affect the type of care placement children enter and it is possible that children with more complex and challenging health needs are also more likely to enter residential care compared to kinship or foster care. With respect to the future health of people in residential care, this really does not matter. The evidence clearly shows that much more attention and support should be given to those children and young people who experience residential care. More should be done to place children with families (in kinship or foster care) and where this is not possible, social, health and educational support for young people currently in residential care should be substantially increased.

While entering care can ultimately be a positive life change for children and young people, it no doubt is a very stressful event that can have a substantial impact on health.

↳ Our data shows that some children who are in care experience hospitalisations due to severe stress related to external environmental factors, something that is uncommon among children in the general population. We recommend that entering and moving between placements should be much more carefully managed to avoid adverse health outcomes related to this.

## After children leave care

Entering adulthood can be an exciting and yet a challenging time for all young people. Moving away from home (and sometimes living alone), forming new relationships, demands of further education or employment, and engaging with adult health services is not easy. Young people who have lived with their families often receive help and advice (including financial, emotional, and other practical guidance) from their families long after leaving home. Children who have been in care are perhaps less likely to have this support from their families or carers and often need to navigate leaving care and transitioning into adulthood on their own.

↳ The evidence presented here shows that when young people leave care many health problems increase sharply, this includes hospitalisations for chronic conditions as well as for depression and is unfortunately also associated with higher rates of avoidable deaths. Care and support should be extended well beyond ages 16-18 to help young people start independent life and prevent these wholly avoidable hospitalisations and deaths.

## Across the life-course

Many adverse health events that have affected the children and young people in this study are avoidable. This includes many of the hospitalisations for chronic conditions, mental ill health (such as related to substance use, stress, or depression), injuries, poisonings, and deaths related to external causes (including suicides and accidents). This also applies to the inequalities in health between care experienced and general population children and young people shown here.

↳ Some of these avoidable adverse health outcomes can be prevented with the right support provided specifically to families, children, and young people, such as in the case of chronic conditions. In other instances, the interventions need to happen at a community or national level, providing a safer and healthier environment for children to grow up. We recommend that more universal efforts across services should be made to improve the health of children and young people, including reducing substance abuse across Scotland.

Co-morbidities, the simultaneous presence of two or more medical conditions, are rare in children and young people. Yet, some conditions diagnosed at early ages can co-exist or are likely to lead to other mental or physical illnesses. Across our data we see that children and young people who are in care or have experienced care in the past are more likely to have multiple diagnosis, receive more different types of medication and have complex health needs. Based on this longitudinal data, we can say that in many cases these complex needs precede entering care. In other cases, these reflect the cumulative effects of adverse life experiences, which can include the reasons a child has been removed from home, or the challenges they face during or after care.

↳ Poor health and co-morbidities in children have a substantial adverse impact on society as a whole, as it can often limit educational attainment and employment, while incurring additional costs to the social and health care system. Addressing existing and preventing the development of co-morbidities in children and young people is not something that the social care system can achieve on its own. As has been highlighted by the Care Review, it requires a systematic approach, including an economic model that reduces socioeconomic inequalities and supports all young people to live healthy, safe, and happy lives.



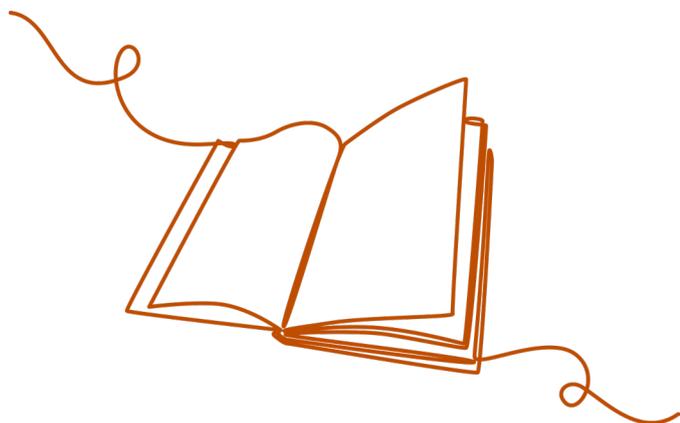
## Note on terminology

The term 'care experienced' refers to anyone who has experienced care at any point in their life, no matter how short or long, including residential, foster and kinship care, or being looked-after at home with a supervision requirement. The definition extends to children who are on the edges of care or informally in care, that is living with friends or relatives who have no legal parental responsibility for them and without local authority involvement. In this study, care experienced people include only those people who have been formally 'looked after' as defined by s17(6) of the Children (Scotland) Act 1995. This includes children and young people looked after at home (under a supervision order), in kinship or foster care, and in residential care at any point in their life, no matter the length of the care placement.

The data used here includes information on sex assigned at birth and we have no information on how the children and young people identify themselves. Thus, when referring to males-females, boys-girls, we are always referring to the sex assigned at birth. A recent guidance for public bodies by the Chief Statistician of Scotland noted that the terms sex and gender are sometimes used interchangeably by public authorities and there is typically limited detail on exactly what data is being collected.<sup>6</sup> There is also no standard way that data about sex and gender identity is being collected, either in Scotland or the UK. However, the guidance adds that since for the vast majority of people sex and gender identity questions will provide the same answer, results for most population-level statistical analysis will be the same regardless of which concept is used.

Throughout the report we use a few terms and acronyms that we wish to explain here also. In tables and figures we use the acronym GPC to denote general population children and CEC for care experienced children. The use of parentheses for age groups, such as [12,16) denotes the cut-offs between ages, such that the square parentheses include the age next to it and the round parentheses exclude the age next to it. The age group [12,16) includes everyone from the age 12 inclusive up to those just under the age of 16. Finally, we often refer to rates per 100,000 person-years (PY). These can be interpreted similarly to percentages and a rate of 45 per 100,000 PY means that we expect 45 events for every 100,000 children in a single year.

In health research we frequently talk about socioeconomic gradients. This gradient refers to the relationship between socioeconomic status, deprivation and/or economic disadvantage and health, health behaviours and/or health service contact. An increasing or a positive gradient refers to how health or health service contact becomes worse with an increase in deprivation. A reversed or a negative gradient describes the few instances where health and health service contact is improved with increasing deprivation.



# Acknowledgements

This report would not exist if it were not for the people and organisations that have helped us along the way. We would like to thank our project Advisory Group, who over the past two years have provided support and feedback as the research has progressed and who have also contributed to the writing of this report. These include many different people from the Scottish Government, Scottish Children's Reporter Administration (SCRA), Centre for Excellence for Children's Care and Protection, National Society for the Prevention of Cruelty to Children, and Professor Philip Wilson at the University of Aberdeen. We would also like to thank Who Cares? Scotland and the members of their National Representative Body for their feedback and time discussing this work.

In September 2021, we held an online knowledge exchange event that included hours of discussions with nurses, social workers, policy makers and others working with care experienced children. We would like to thank all these people who gave their time and input to these discussions, and we have included your thoughts in this report. Thank you also to our colleagues and students who helped facilitate these discussions – Emily, Danny, Esme, Ian, Keri, Marc, Anne, Daniel, Jessica, Kathryn, Ross, Roxana, and Sam. Most of you work with us at the MRC and CSO funded Social and Public Health Sciences Unit (SPHSU), but some volunteers also joined us from the University of Strathclyde and Queens University Belfast, demonstrating how important this area of research is to people across the UK. A big thank you also to all the guest presenters from SCRA and the universities of Swansea, Belfast, and Glasgow for sharing their work and findings on care experienced people.

Pulling together these data sets has been a very long process and again we owe a lot of gratitude to the organisations that have helped us get this far. Firstly, we would like to thank the Scottish Government and Public Health Scotland (PHS) who gave permission to use these data. Cecilia MacIntyre and Craig Kellock from the Scottish Government were also instrumental in working through many of the intricacies of the care history data. Morag Christie from the terminology team at PHS helped us harmonise the health data across the years. The data was linked by the National Records of Scotland and held at the National Safe Haven run by the electronic Data Research and Innovation Service (eDRIS). Our research coordinators at eDRIS, Amy Tilbrook, Dave Clark and Beth Bruce have also put in a lot of time to get this work finally underway.

We thank our colleagues Aoife and Enni at the SPHSU Knowledge Team who produced the final layout and design of the report and Laura from the SPHSU Places Team who developed the map in Figure 10.

While working on this report and planning for future research, we also worked with the Scottish Centre for Administrative Data Research (SCADR) who provided us with the opportunity to discuss our current results and planned work at a public panel meeting. We

found this meeting incredibly helpful for seeing how the public perceives our work and how we can communicate our work better.

Last but not least, the Urban Big Data Centre at the University of Glasgow has funded the data linkage and safe haven access for this project and the Economic and Social Research Council, together with the SPHSU, funded our time on this project.

All mistakes and inaccuracies in the report are our own and not due to any of the people and organisations mentioned here.



# Study background

All children need stability, love, and support in order to thrive. Children in care face more challenges than most but given the right support care experienced children and young people can succeed and flourish. For some, being in care is a positive experience leading to improved outcomes compared to the alternative of not being taken into care. Others may experience poorer educational outcomes or greater social and emotional difficulties.<sup>7</sup> Children and young people with care experience have consistently been found to have higher rates of poor health and wellbeing,<sup>8</sup> including greater mental health difficulties, often suffering from mental health problems that are more severe or complex than children in the general population.<sup>9,10</sup> These outcomes are likely related to the additional challenges faced in childhood, such as frequent moves between homes, schools, and/or doctors, and fewer advantages due to living in more deprived areas.

Most studies into the health of care experienced children and young people have been conducted outside Scotland and the UK and/or are based on evidence from small samples, sometimes do not account for socioeconomic characteristics or make no direct comparisons to the general population. Before this project, the only Scottish population-wide study of the health of care experienced children looked at dental health outcomes. It found that children in care had greater dental needs and less access to dental services than children in the general population and that these differences remained after taking into account levels of disadvantage across neighbourhoods.<sup>11</sup> Clearly, there is a need to provide high-quality national level evidence on the health of care experienced children in Scotland across a wider range of health issues such as asthma, epilepsy, diabetes or mental health.

## Developing the Children's Health in Care in Scotland study

The Children's Health in Care in Scotland (CHiCS) study sets out to examine how health, as measured across a wide range of outcomes, of care experienced children and young people in Scotland compares to the general population of children and young people (i.e. those who have not been in care). We are interested in whether there are differences between these two cohorts of children when we look at levels of neighbourhood disadvantage, their family circumstances at birth and whether the type of care someone experiences impacts their health.

The CHiCS study has been described in detail in a recent research paper.<sup>1</sup> Briefly, the study links together many data sets collected and held by government departments, local authorities, or public bodies such as the NHS. Such data can be useful in research as, unlike surveys, they cover whole populations. The study links 10 data sets in total, including data on children's social work statistics, school pupil statistics, health records, and birth and death records (see Appendix Table A1 for more information on the sources of

data included in this study). Data were linked using unique identifiers (including a Scottish Candidate Number (SCN), unique to each school pupil, and a Community Health Index Number, unique to each patient). Following linkage, all personally identifiable information is removed from the dataset. Confidentiality of the data is protected to ensure that no individuals in the study can be identified.

There are several strengths to the study design. Children and young people are followed up over a long period of time, from birth (1990-2004) until July 2016 (the latest available data at the time of study approval). This provides data richness that enables examination of the relationship between care experience and health. The study is Scotland-wide, allowing the opportunity to examine a wide range of health outcomes including relatively rare events. Health outcomes and care histories are recorded routinely and so are less likely to be subject to individuals' recollections. Through comparison of our cohorts with published national statistics (Children's social work statistics,<sup>12</sup> Scotland's 2011 census population aged 0-19, and Pupil Census statistics<sup>13</sup>) we were satisfied that we had captured a high proportion of children and young people in Scotland and that our cohorts were representative of the publicly-funded school-age population.

The study is not without its limitations though. As data were linked through the SCN, only children who were at school in 2009 were included in the study. Additionally, children educated at home or in independent schools were not included in the study due to not being recorded in school pupil statistics. Furthermore, our data only includes children and young people who are formally 'looked after' as defined by s17(6) of the Children (Scotland) Act 1995, including children and young people looked after at home (under a supervision order), in kinship or foster care, and in residential care at any point in their life. Children in informal care (e.g. living with close friends or relatives but not considered as looked after by the local authority) are excluded. In addition, data linkage is often a difficult and lengthy process; it took us several years from the inception of the CHiCS study to having all the data ready for research (Figure 1), meaning that these results are now a few years old.

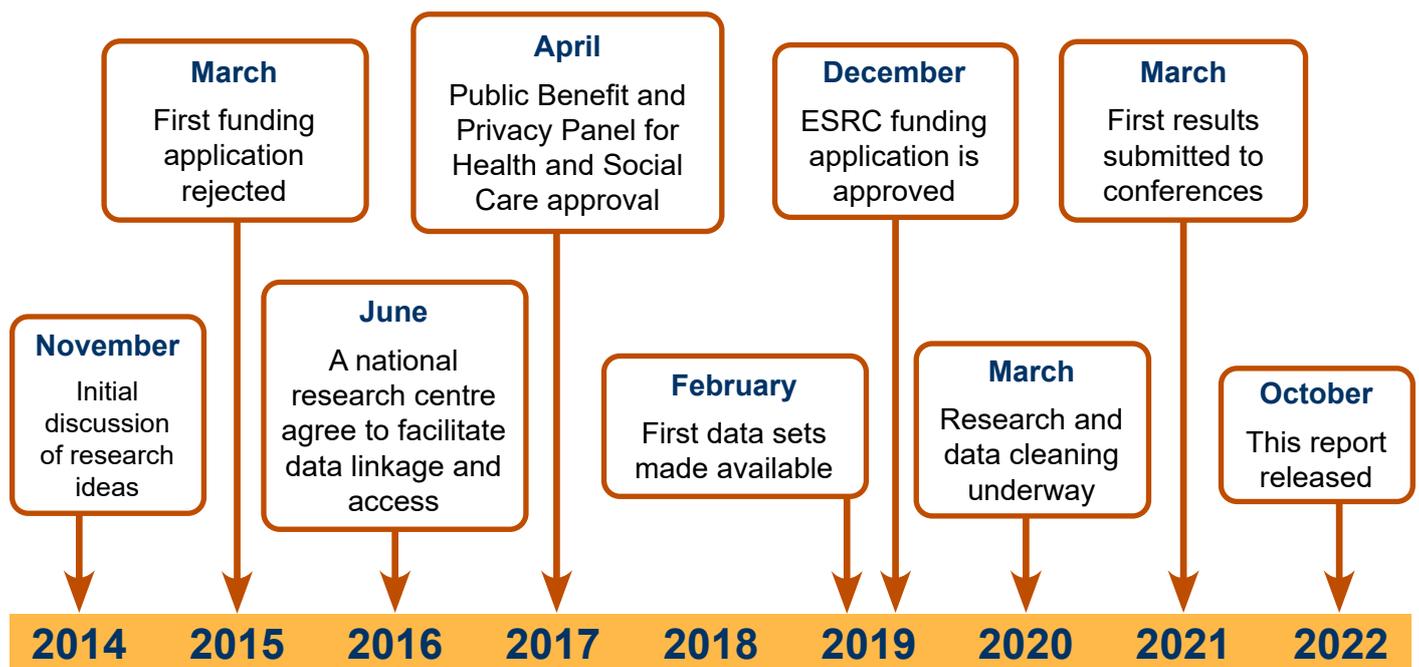


Figure 1. Timeline of study inception to this report.

## The children and young people in this study

All publicly funded school-aged children included in the 2009 Pupil Census in Scotland (and with a valid non-missing SCN) were followed up from birth until the end of the study in 2016. The group of children and young people with care experience are those who are included in the Children Looked After Statistics (CLAS) return in 2009/10; that is formally looked after at home or away from home in foster, kinship or residential care between 1st Aug 2009 and 31st July 2010. Children in the general population were those who were included in the 2009 Pupil Census but were not in any of the CLAS returns over the duration of the study (i.e. had not experienced care). The year 2009/10 was chosen as this is when linkage rates based on SCN first became reasonable.<sup>14</sup>

In all, 663,601 children and young people were included in the CHiCS study; 649,771 in the general population and 13,830 with care experience. Overall, 2.1% of children and young people in the study were care experienced. This ranged from 0.8% of children in East Dunbartonshire to 3.1% in Glasgow City. There were more males in care than females (see Figure 2), reflecting national statistics, which show that boys are somewhat more likely to experience care compared to girls.

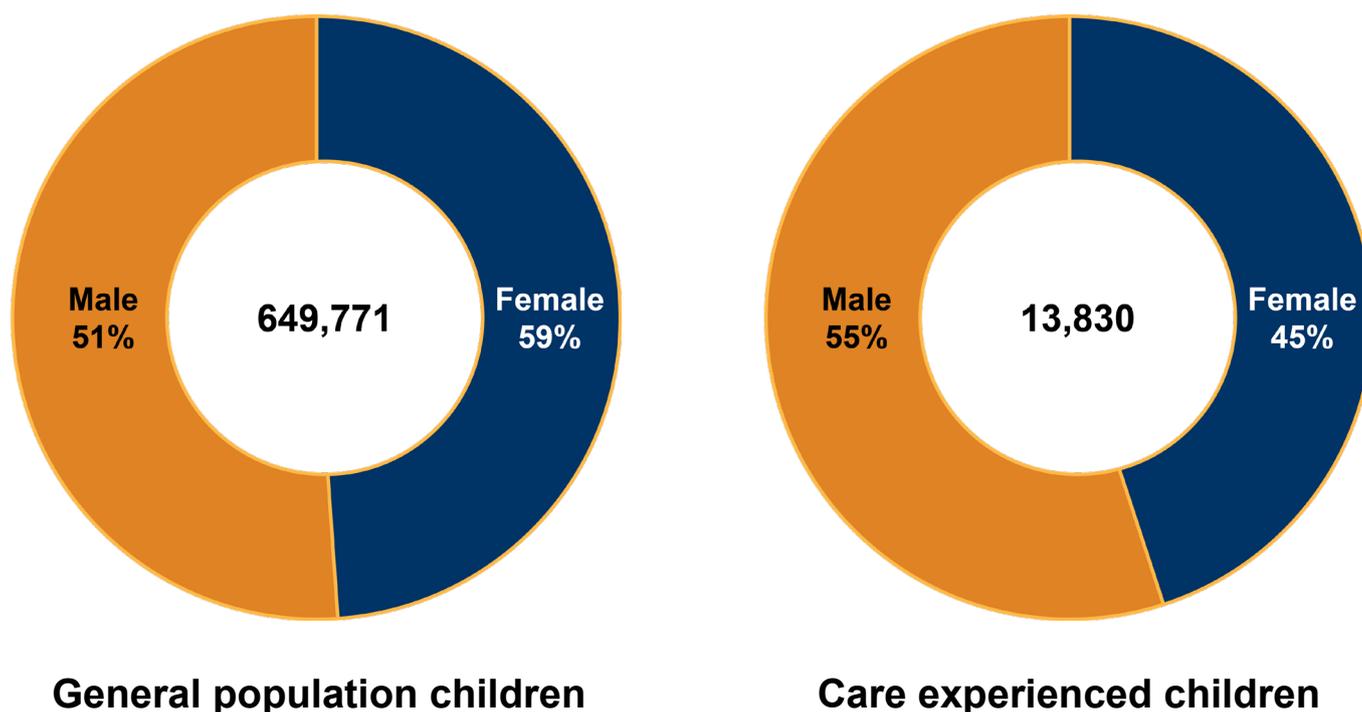


Figure 2. Number of children in the study by cohort and sex.

These children were born between 1990-2004 and aged 11-27 years at the end of follow-up in 2016. Figure 3 shows the distribution of year of birth of children in the care experienced cohort compared to children in the general population. Care experienced children included were more likely to be born in the early 1990s when compared to children in the general population meaning that care experienced children and young people were on average older (11 years and 3 months compared to 10 years and 10 months in the general population) in 2009 when the cohorts were drawn. We have accounted for the sex and age differences between the two cohorts in the analysis that follows.

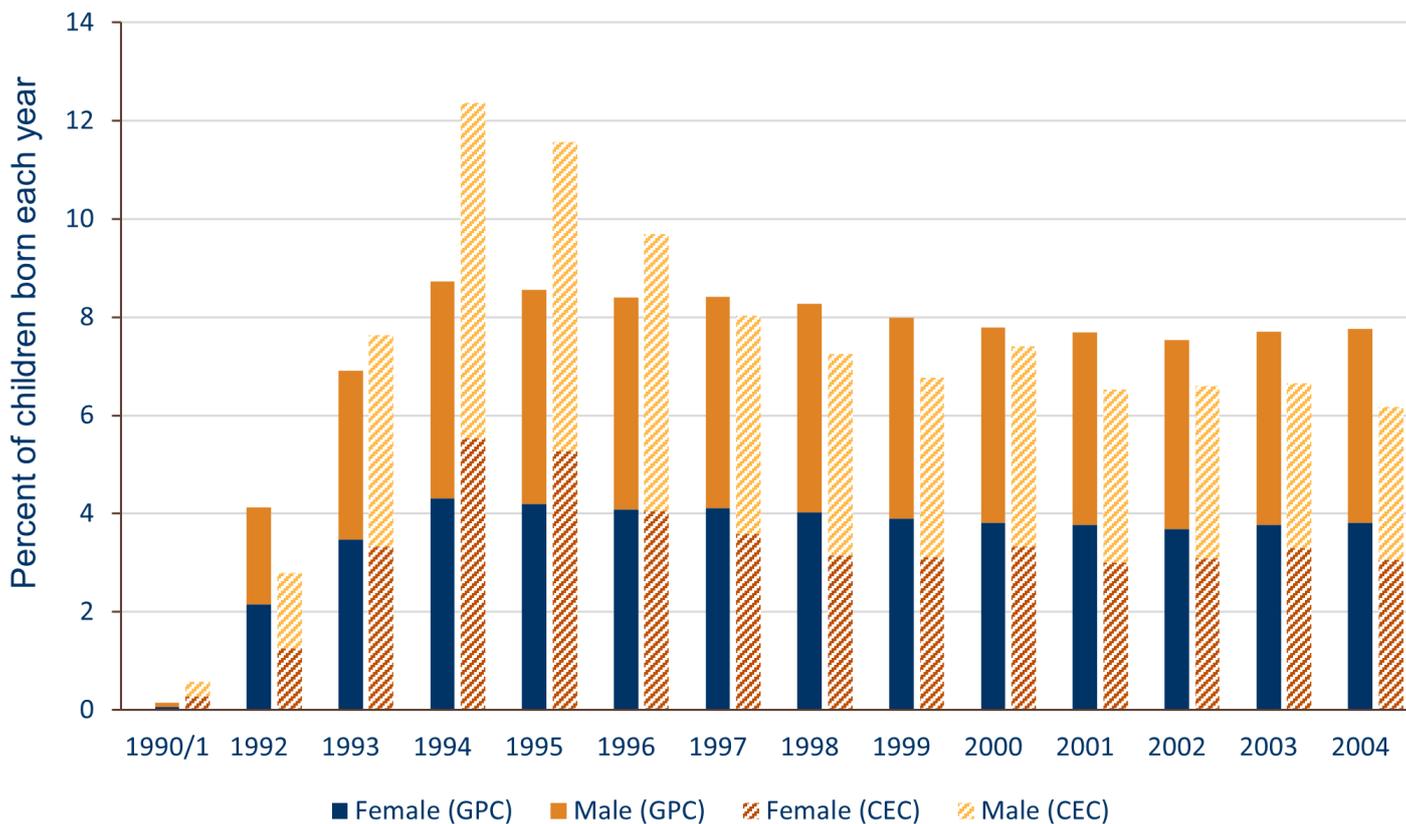
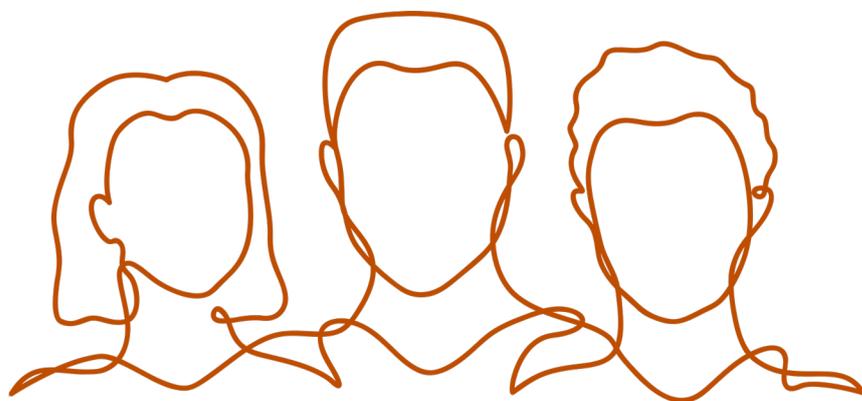


Figure 3. Percent of children born each year by cohort and sex. GPC – General population children; CEC – Care experienced children.



# Policy context of care in Scotland

The data analysed in this study relate to children formally 'looked after' in Scotland and cover a timeline from 1990 to 2016. Within that time, the policy and legislative landscape in Scotland has changed and developed with the aim to improve lives for people in care and who are care experienced. A timeline of key Scottish Government policies is highlighted in Figure 4. The timeline includes recent policies as well as those from around the time of birth of children in the CHiCS study and during the study follow-up period.

Historical studies<sup>15</sup> of legislation and policy in Scotland relating to 'looked after' children and young people show that there has been a move away from a reliance on social workers alone to a more integrated approach, extending responsibilities to other professions and universal services. This was particularly significant with the introduction of Corporate Parenting duties enshrined in law by Part 9 of the Children and Young People (Scotland) Act 2014. This includes Health and Social Care providers, such as the NHS and local health boards, who must understand the particular needs of care experienced people when designing and delivering their services.

The provision of care in Scotland has also changed over time, with national and local policy moving away from residential homes to community family-based care provision, as well as further work to strengthen routes to adoption and permanence for children. For full historical analysis, the Independent Care Review '[Evidence Framework](#)' (pp.198-223) provides a post-WW2 Scottish historical narrative of law and policy development up to the present day.

Currently in Scotland, section 17 of the [Children \(Scotland\) Act 1995](#) defines 'looked after' children as those in the care of their local authority – sometimes referred to as a 'corporate parent'. It is a legal status in which the local authority has specific duties, outlined in statutory guidance.

'Looked after' children in this study fall into two categories:

'Looked after at home' – where the child or young person has been through the Children's Hearings system and is subject to a Supervision Requirement (regular contact with social services) with no condition of residence.

'Looked after away from home' – where the child or young person has either:

- a. been through the Children's Hearings system and is subject to a Supervision Requirement with a condition of residence
- b. is subject to an order made or authorisation or warrant granted by virtue of [chapter 2, 3 or 4 of Part 2 of the Children \(Scotland\) Act 1995](#)
- c. is being provided with accommodation under [section 25 of Part 2 of the Children \(Scotland\) Act 1995](#) (a voluntary agreement)
- d. is placed by a local authority which has made a permanence order under [section 80 of the Adoption and Children Act 2007](#)

In these cases, the child or young person is cared for away from their normal place of residence, by foster or kinship carers, by prospective adopters, or in residential care homes, schools or secure units.

The key pieces of legislation and policy developments which relate to children included in the CHiCS study are listed below:

**Children (Scotland) Act 1995** - lays out many of the duties, powers and responsibilities Scottish local authorities hold in respect of care experienced children and young people, centring on the needs of children and their families defining both parental responsibilities and rights in relation to children. This Act marked a significant step in the development of legislation on the care of children in Scotland and came into force around the time the oldest children in our care experienced cohort (born in 1990 and 1991) were first starting school.

**Looked After Children (Scotland) Regulations 2009** - brought together care planning services for those looked after at home alongside those living in care away from home. They also reflect more detailed and consistent requirements when children are looked after by kinship carers. It includes provisions about care planning, fostering and emergency measures.

Amendments to the legislation noted above made following the end of the CHiCS study, include the Children (Scotland) Act 2020 and Looked After Children (Scotland) amendment regulations 2021, which aim to ensure that the views of siblings and their families are considered and that siblings are supported to stay together, where appropriate.

**Children and Young People (Scotland) Act 2014** - introduced Corporate Parenting duties (Part 9) for named public bodies involved in meeting the needs of care experienced children and young people. The Act also introduced Continuing Care (Part 11), giving young people in care the right to remain in their current care placement until 21 years old and extended provision of Aftercare support (Part 10). This Act came into force on 1st April 2015 affecting approximately 5,300 (or 38% of the) care experienced children in this study who were born on or after 1st April 1999. Future work comparing the young people who have been able to benefit from this change to those born earlier will be able to tell us if this has also had an impact on their health.

**Getting it right for looked after children and young people 2015** - built on the principles of getting it right for every child (GIRFEC) 2006, stressed the importance of quality relationships for children and young people and set out priorities around early engagement, early permanence and improving the quality of care.

Many of these policy developments will have impacted directly on the experiences of children and young people in care who are represented in the CHiCS study. The steps towards extending care beyond the age of 18 and building a more integrated approach to caring for children and young people in Scotland (inclusive of health, education and other professionals, and universal services) can help improve the health and wellbeing of children with experiences of care.

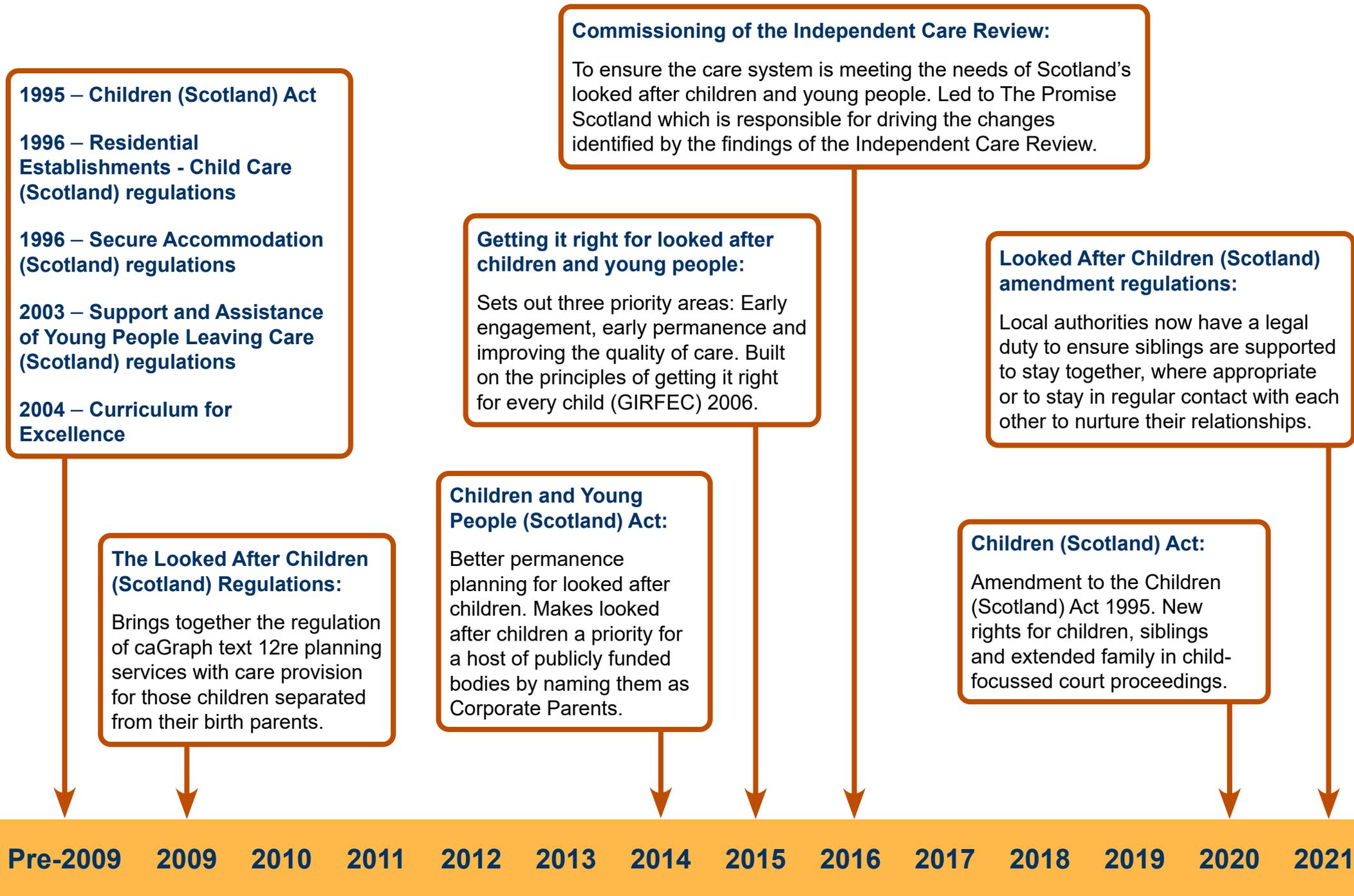


Figure 4. Timeline of key Scottish Government policies for children and young people in care.

## Our research and The Promise

In the years to come, the care system is likely to undergo further changes as a result of the [Independent Care Review](#). The Care Review, announced in October 2016 by the First Minister, made a commitment to identify and deliver lasting change in Scotland's care system by improving the wellbeing of infants, children, and young people. It began its work in February 2017 and concluded with the publication of seven reports, one of which was [The Promise](#).<sup>16</sup> *The Promise* sets out the vision for the future of the care system, resting on five foundations *voice, family, care, people, and scaffolding* – that should deliver better care and outcomes in the future.

Putting *The Promise* into practice is still in early stages and will take years to implement. Improving the health and wellbeing of children in care has been highlighted as a key commitment in the first phase of implementing change in the care system. Our results are therefore timely and highly relevant to achieving the envisioned improvements for children and young people in care. Below, we have highlighted how the five foundations of *The Promise* relate to health and health care, and what are the challenges to delivering the highest quality of wellbeing and care.

The five foundations of *voice, family, care, people, and scaffolding* emphasise the principles of listening to children and providing stable non-stigmatising support to both the children and the whole family through (universal) services. Listening and supporting children and their families will build trusting relationships with professionals. These aims are relevant for health service providers, as research has shown that people with adverse childhood experiences (ACEs) do not feel heard and have significant mistrust towards medical services.<sup>17</sup> Stable, non-judgemental and trusting relationships will enable children and young people to speak about their health and allow carers, nurses and doctors to “tune into” how the children are feeling, and notice their physical and emotional wellbeing. Poor relationships with health professionals, seeing different GPs or not being able to get an appointment with their preferred doctor have also been mentioned as reasons for missing appointments, disengagement with health services and not adhering to treatment.<sup>18–20</sup> Therefore, to establish good patterns of health-seeking behaviours and treatment adherence, children, young people, and their families should be able to establish good longer-term relationships with their GPs and nurses, feel supported and not judged when accessing these services.

Similar views were also expressed at our knowledge exchange event in September 2021 (Figure 5). The participants argued that children need a stable safe community of adults around them to have the confidence to speak about their health and the child should be allowed to determine who that safe adult is.

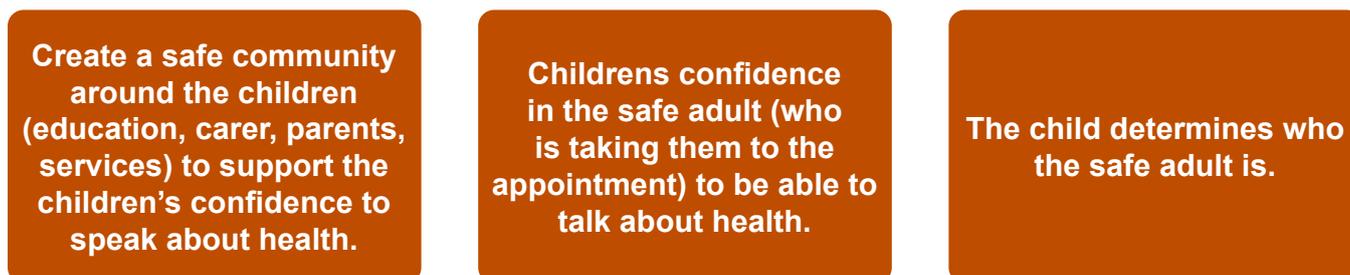


Figure 5. How to talk to children about health: participant views.

The Promise recognises that professionals who are in contact with children and families receiving care should also be provided with support and training to allow them to do their work better. This recommendation is supported by research, which shows that nurses and doctors can find it challenging to address issues of childhood adversity.<sup>21</sup> They may feel inadequate or lack the means necessary to explore child adversity at appointments or are afraid of further traumatising children. Addressing childhood adversity may also be emotionally difficult for the medical service provider, leading to avoidance in raising such questions.

This support system (*scaffolding*) of health, social, educational, and other universal services must be there when needed by children and families. Currently, children who enter care are required to have a health assessment, identifying their health needs, forming the basis of a health plan. However, it is not clear that these assessments always have the desired effect of improved health or better engagement with services among care experienced children. Both *The Promise* and the participants of our knowledge exchange event argued that forced contact with health services may do more harm than good.

Research or policies on health should not omit the role socioeconomic disadvantage has on our wellbeing. *The Promise* frequently emphasises the adverse effects of poverty and deprivation on the health and wellbeing of children and families. The overall poor health and high socioeconomic inequalities in health among the Scottish population have been widely documented.<sup>22</sup> Many children in Scotland, not just those in care, are at risk of poor health due to the family's economic circumstances. Different aspects of deprivation can lead to poor health, including inadequate housing, reduced access to nutritious foods or safe green spaces. Parents' time pressures, including working multiple jobs or unusual hours, financial and job insecurity, and lack of access to transport can also reduce contact with health services and lead to worse health.

To address deprivation *The Money*, also published by the Care Review, advocates for a wellbeing economy with the health and care of all children at its core.<sup>23</sup> Similar calls have been made by the World Health Organization and public health researchers.<sup>24</sup> A wellbeing economy highlights the need for putting people at the centre of policy instead of focusing primarily on economic growth. It is an economic growth model that is equitable and sustainable from the outset. The Care Review argues that this model makes economic sense – the human costs and the costs to offset the human costs of the care system are higher than current spending on the care system (i.e. the financial costs of the system). Its calculations show that if care experienced people had the same outcomes as the rest of the population it would realise an additional £732 million yearly through increased tax and national insurance contributions.<sup>23</sup>

*The Promise* also discusses the use of data and research into care experienced people and, as researchers working with some of these data, we strongly encourage a discussion on this. *The Promise* raises concerns with regard to the collection and use of data about children and their lives, is very critical about the quality and scope of available data and emphasises children's ownership of their data and their stories. Some of the participants of our knowledge exchange event thought that statistics and numbers seem an unfeeling, clinical or a dehumanising description of children's lives.



Figure 6. Participants' views on statistical evidence on care experienced children.

We understand this sentiment but believe that “big data” and large-scale population-wide evidence, such as this, are also instrumental in delivering the change envisioned by *The Promise*. Work like this gives us an understanding *when* in children's lives support is needed the most and *what* this support should look like. We are also committed to doing our work with care and sensitivity towards those most affected by our findings. We have pursued this work for years, it has not always been easy, but we have persisted because we believe that better outcomes for children and young people who have experienced care are possible.

Data science is also a form of power, it has been used to expose injustice and improve health outcomes.<sup>25</sup> Excluding minority or marginalised groups from analysis or not collecting adequate data on their experiences is a form of discrimination and can lead to further marginalisation. Of course, to fully incorporate diverse experiences in data collection and analysis, the views of these populations need to be heard at every stage of the data pipeline – from what to collect, to analysing and interpreting the results. Therefore, we support the proposal by *The Promise* for a participative guidance and criteria when planning policy development and academic research, and have ourselves engaged with organisations representing the rights of children and children who have experienced care. However, as most researchers will know, engaging young people about research into health and wellbeing, while rewarding, is also challenging and labour-intensive. Putting in place a structure that would better facilitate this, such as the [Cascade Voices](#), a group of care experienced young people who advise on research projects in Wales, would substantially improve collaboration between researchers and young people.

Current data sharing and linking mechanisms do have many weaknesses, especially with regard to marginalised populations. An example of these is the length of time it has taken us to do our research. Unfortunately, this project is not an isolated example and most researchers working with linked administrative data in Scotland have experienced substantial delays and confusion over if, when or what data can they access. To achieve improved data linkage recommended by *The Promise*, current difficulties in doing research need to be recognised. These obstacles are often not due to the laws and regulations

that govern data sharing and linking but are grounded more in how the data are collected, stored, and the systems in place for sharing data, including the willingness of different data controllers to proactively engage with researchers.<sup>26</sup> Resolving these issues requires considerable commitment from the Scottish Government, other public authorities and support from the Scottish public.

The change in the care system envisioned by *The Promise* is possible but will require substantial dedication. We asked the participants of our knowledge exchange event what it would take to achieve this change, how to reduce health inequalities and improve lives for care experienced children and young people (Figure 5). Participants expressed that there needs to be more commitment from key decision makers in order to help reduce inequalities. Some pointed out that it will take a joined-up and collaborative approach to ensure that care experienced children and young people's needs are met. And when planning targeted interventions, such as in the most deprived areas, we must be careful not to stigmatise children and young people in care.



*Figure 7. Participants' views on what can or should be done to reduce inequalities in health for care experienced children and young people.*



# The study cohorts

The following pages provide an overview of the socioeconomic, urban-rural, and regional background of the two cohorts and a description of the care histories of the care experienced cohort. Our cohort of care experienced children come from more deprived areas of Scotland compared to other children and were more likely to have unemployed parents at birth. The majority of care experienced children in our study only had one or two care placements and most commonly these were either at home, in kinship care or with a foster family. The proportion of children who experienced many placement changes, or residential care without a family environment, is small but still affected hundreds of young people in our study.

## Socioeconomic background of children

Socioeconomic status (SES) plays an important role in early life health with lower levels of SES associated with poorer physical<sup>27,28</sup> and psychological<sup>29–31</sup> health. Children in the poorest communities are also more likely to enter the care system.<sup>32</sup> It is therefore important to explore cohort differences by the SES measures available in this study.

The Scottish Index of Multiple Deprivation (SIMD) is a small area measure which uses area of residence to determine whether individuals live in areas of high or low deprivation. SIMD can be grouped into five categories (quintiles) from the least to the most deprived areas. We can compare deprivation levels of area of residence in 2009, when our cohorts were drawn, and at birth using information from children's birth registrations. Birth records were available for 571,702 (88%) children in the general population and for 12,249 (88.6%) care experienced children. Children with birth records were found to be representative of all children included in the study.<sup>1</sup> In total, 59% of care experienced children (with birth records) were born into the most deprived areas compared to 25% of children in the general population (Figure 8). In 2009, 41% of care experienced children (with birth records) were living in the most deprived areas compared to 22% of children in the general population. This suggests that when children enter kinship, foster or residential care, they often move away from the most deprived neighbourhoods to less deprived areas, but despite these moves are still more likely to experience socioeconomic disadvantage.



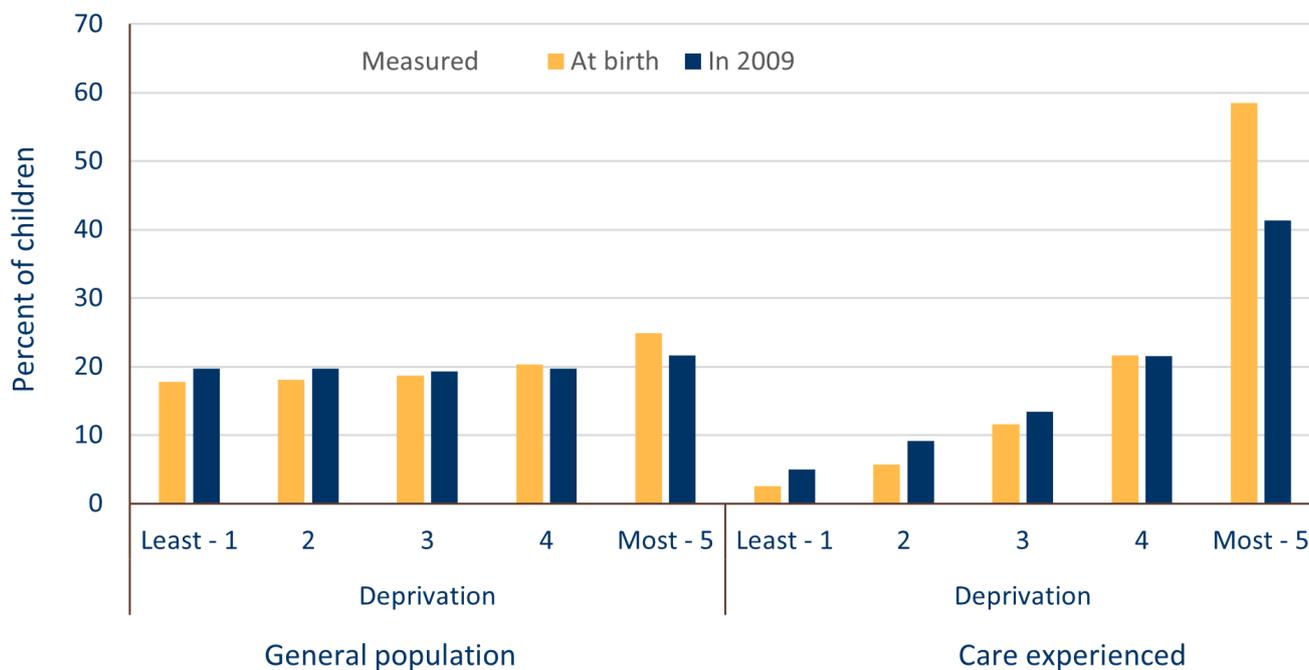


Figure 8. Percent of children (with birth records available) by deprivation at birth and in 2009.

Participants at our knowledge exchange event acknowledged the impact of deprivation and wider systemic issues faced by children and young people in care (Figure 9). They highlighted that, in addition to help given to individuals and their families by health, care and education services, wider issues relating to poverty and deprivation needed to be addressed. They also recognised that care experienced children and young people face different challenges from other children, over and above that of deprivation.

**Difficulties in being able to help individuals in some ways, but then being unable to address wider systemic issues around income, poverty, housing.**

**Hard to narrow the gap without addressing wider systemic equalities given deprivation underscores everything.**

**Data is showing that it's more than just the deprivation. CEC experience additional challenges.**

Figure 9. Describing the impact on care of wider systemic issues such as deprivation: participant views.

Children and young people with care experience were more likely to be born in large urban areas than children in the general population (51% compared to 39%). In 2009, the proportion of children in care living in large urban areas was similar to that of children in the general population (40% compared to 35%). Figure 10 shows the proportion of children and young people in the study living in each council area of Scotland in 2009. Just over 15% of children in care lived in Glasgow City, compared to 10% of children in the general population, likely reflecting the high proportion of deprived areas in Glasgow. This is in contrast to 5.8% of care experienced children living in Fife (compared to 7.1% in the general population) and 5.4% in North Lanarkshire (compared to 7.3% in the general population). In this study, 6.3% of care experienced children lived in the City of Edinburgh, compared to 6.4% in the general population. It is worth noting, however, that children with

care experience were more likely to have missing information on place of residence in 2009 (around 10% compared to <0.5% of the general population) and therefore the exact regional distributions may be somewhat different.

**% of children in cohort in each council area in 2009**

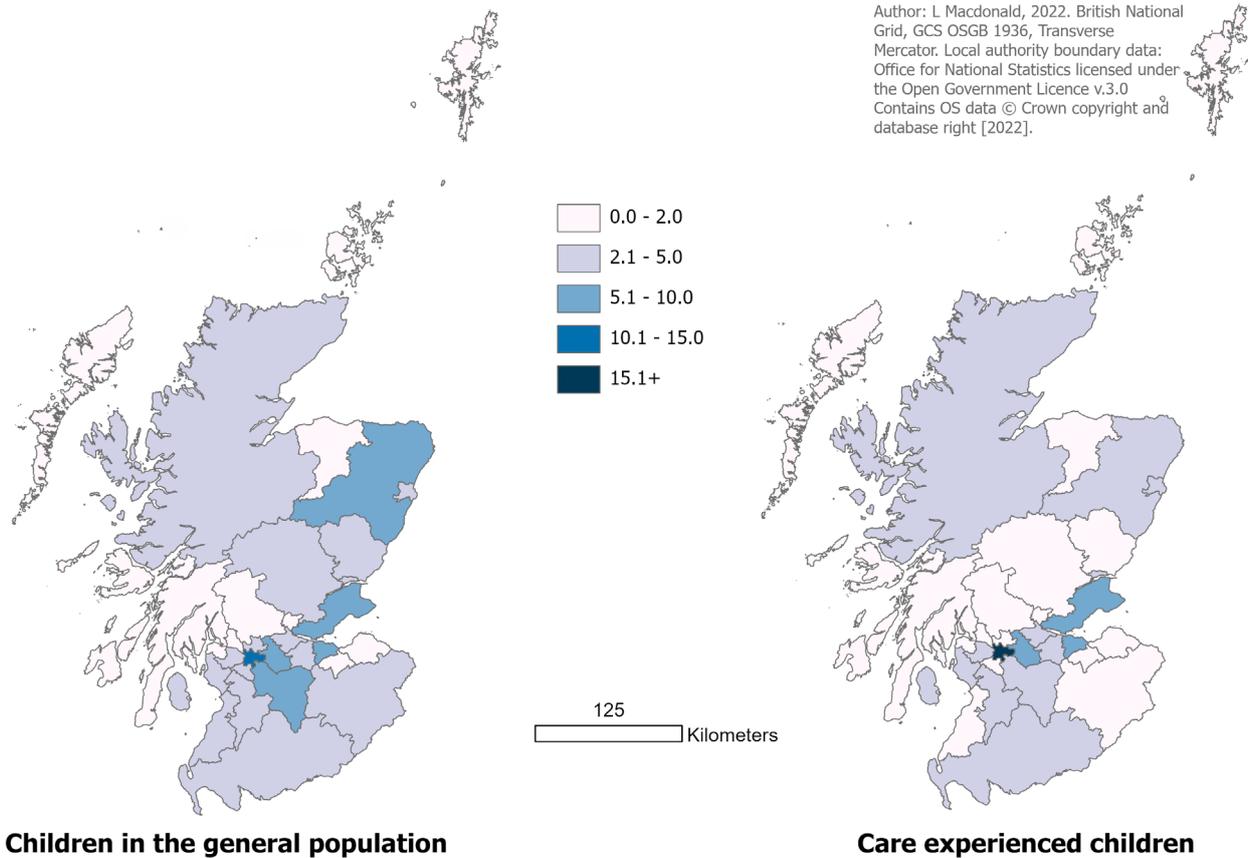


Figure 10. Council area of residence in 2009 of the general population and care experienced cohorts.

Information from birth records also included mothers' age and parental employment status at birth. Children with care experience were more likely to be born to younger mothers (Figure 11). For around 56% of care experienced children, maternal age was less than 25 years old (compared to 26% of the general population).

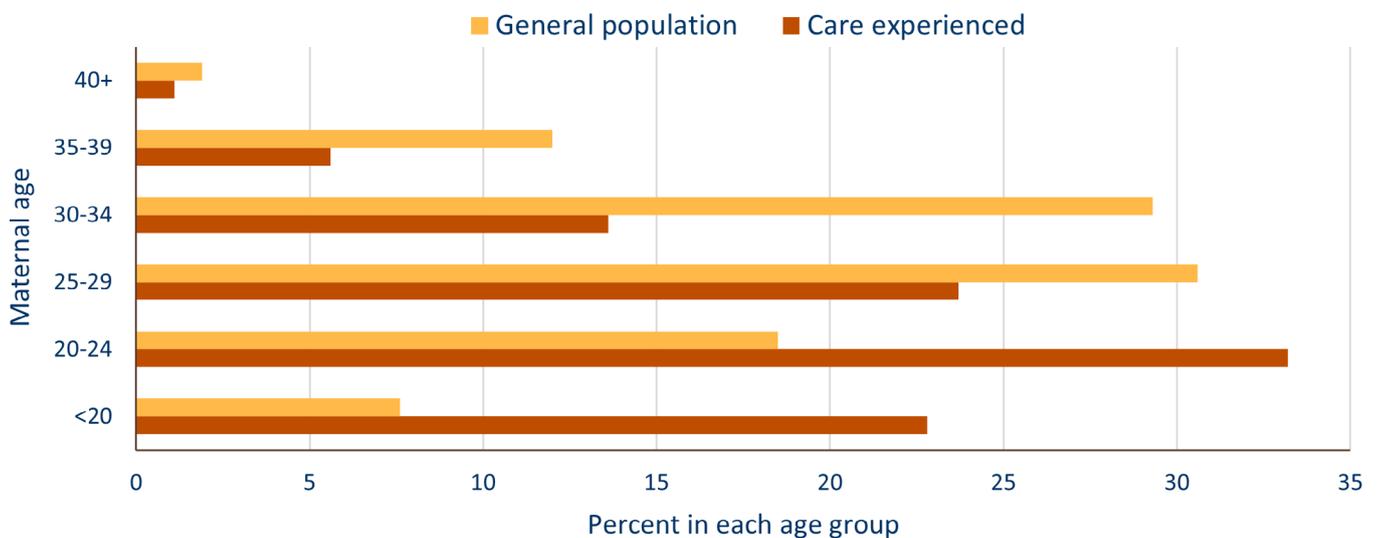


Figure 11. Percent of children (with birth records available) by maternal age group.

For children born prior to 1996, only one parent's occupation was recorded at birth (father's occupation if married, otherwise mother's occupation). From 1996 onward, both mothers' and fathers' occupation were recorded for all births registered by married couples or for births that were jointly registered by unmarried couples. For births prior to 1996 we report parental employment status and from 1996 we report mothers' employment status and fathers' employment status, if available. Parents of care experienced children were less likely to be in employment than parents of children in the general population (71% compared to 93%; see Table 1). From 1996 onwards, just 40% of mothers of children with care experience were in employment compared to 78% of mothers of children in the general population. Where fathers' occupation was recorded between 1996 and 2004, 62% of fathers of subsequently care experienced children were in employment, compared to 90% in the general population. Note that information on fathers' occupation was more likely to be missing between 1996 and 2004 for care experienced children (23% compared to 6% in the general population).

*Table 1. Parental employment status at birth.*

	General population		Care experienced	
	N	%	N	%
<b>Parental employment status (for births 1990-1995)</b>	<b>160,644</b>		<b>4,113</b>	
Employee	117,526	73.2	2,714	66.0
Manager / Supervisor	19,624	12.2	119	2.9
Self-employed (with or without employees)	11,874	7.4	94	2.3
Student / Unemployed / Not available	11,620	7.2	1,186	28.8
<i>Missing</i>	0	0.0	0	0
<b>Mother's employment status (for births 1996-2004)</b>	<b>411,058</b>		<b>8,136</b>	
Employee	271,711	66.1	3,138	38.6
Manager / Supervisor	37,516	9.2	97	1.2
Self-employed (with or without employees)	11,369	2.7	40	0.5
Student / Unemployed / Not available	90,425	22.0	4,861	59.7
<i>Missing</i>	37	0.0	0	0.0
<b>Father's employment status (for births 1996-2004)</b>	<b>411,058</b>		<b>8,136</b>	
Employee	274,748	66.8	4,467	54.9
Manager / Supervisor	57,315	13.9	191	2.3
Self-employed (with or without employees)	39,667	9.7	364	4.5
Student / Unemployed / Not available	15,889	3.9	1,227	15.1
<i>Missing</i>	23,439	5.7	1,887	23.2

The comparison of the socio-economic backgrounds of the two cohorts shows that care experienced children and young people in Scotland are more likely to be born into, and to live in, more deprived areas and were more likely to have unemployed parents at birth. This highlights the economic and financial challenges faced by many families, children and young people in Scotland and the effects these can have on raising children and keeping families together.

## Care histories of the cohort

The number of children who entered care before the age of five is low but increases steadily with age, reaching a first peak at the age of six (Figure 12). Between ages 7-13, the number of children entering care remains stable and then increases to its highest level at the age of 14. Up until recently, the legal age of leaving care was 16 and for this reason very few children enter care at the age of 16 or older. There are no sex differences in the age at which children entered care.

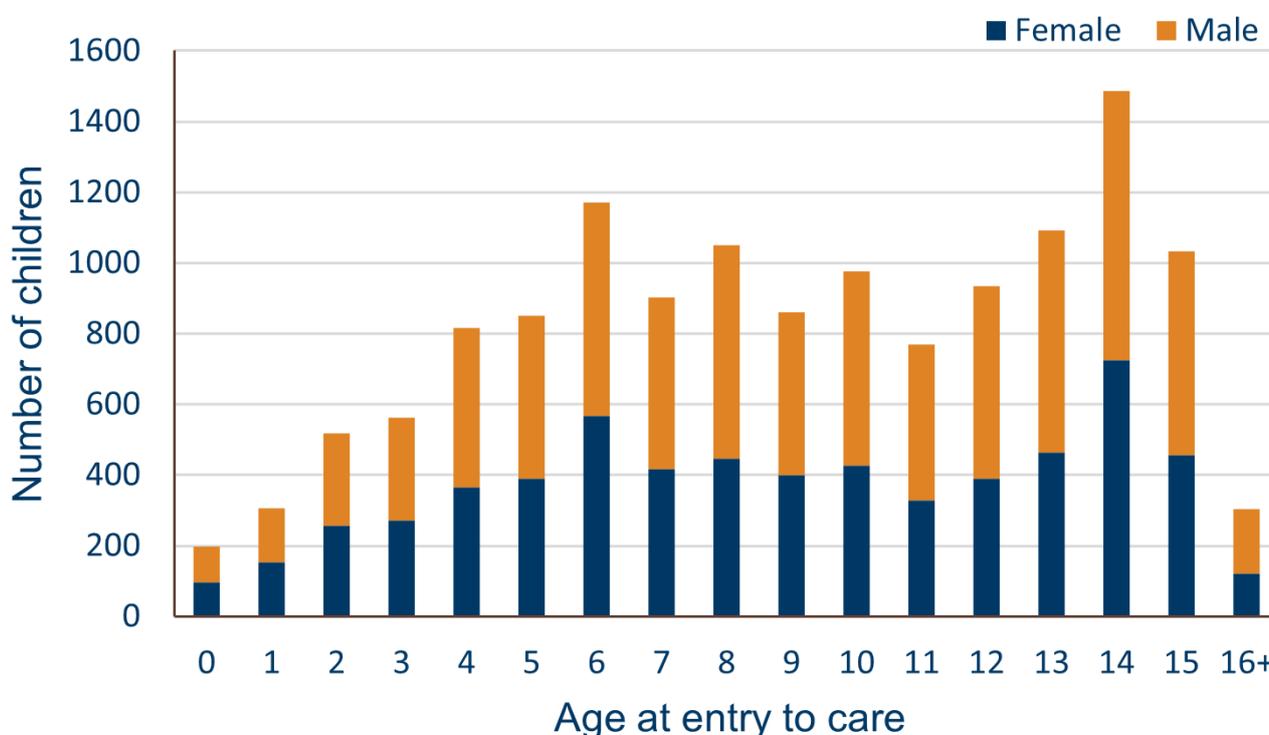


Figure 12. Number of children by age of entry to care and sex.

There can be many explanations to the age pattern observed in Figure 12. First, between 2003 and 2010 the proportion of children starting to be looked after aged under 5 years has increased from 25% to 37% and has remained broadly stable since. On the other hand, the proportion of children becoming looked after in the 12-15 age bracket has been steadily decreasing from 39% in 2003, to 26% of all children starting to be looked after in 2020. That is, children today are entering care at an earlier age.<sup>33-35</sup> Most children in our study were born before the year 2000 and the more recent trends of younger ages at care entry would not be reflected in our cohort.

Secondly, it is possible that health visits and other support services, available before children reach primary school age, provide support for families to stay together but if these

services do not continue into school-age families may face increasing challenges that can lead to relationship breakdown. Third, primary schools may also be the first point at which difficulties faced by the family also become visible to public services, including to teachers. Fourth, as children become older, they are more able to express themselves in a way that allows services and other adults to pick up on problems children may face at home, or to challenge their parents in a way that creates conflict. Finally, the transition to primary school and later to secondary school are big milestones which can put pressure and expectations on children and families, leading to breakdown or deterioration of family relationships.

Children who enter care can go into very different types of placements. In this study, we have grouped placements into four major types: at home, kinship care, foster care (including a very small proportion with prospective adoptive parents), and residential care. Residential care includes very different types of accommodation but given the small number of children who have had any of the residential placements, it was not possible to provide any results by these separately.

The types of first placements children in this study had depends very much on the age the child entered care (Figure 13). Younger children, aged less than five, are more likely to enter foster care as the first placement, while those entering care at an older age are more likely to remain at home or enter residential care. There is some variation in the first placement type by sex. Among children aged 0-5, females are more likely to stay at home or be in kinship care and males are more likely to enter foster care. At ages 5 and above, males are more likely to remain at home and females are more likely to enter kinship or foster care. Across all age groups, males are more likely to enter residential care as the first placement. The differences between sexes are more pronounced for ages 12 and above, but overall, differences between boys and girls in the first placement type are small, especially compared to the differences by age.

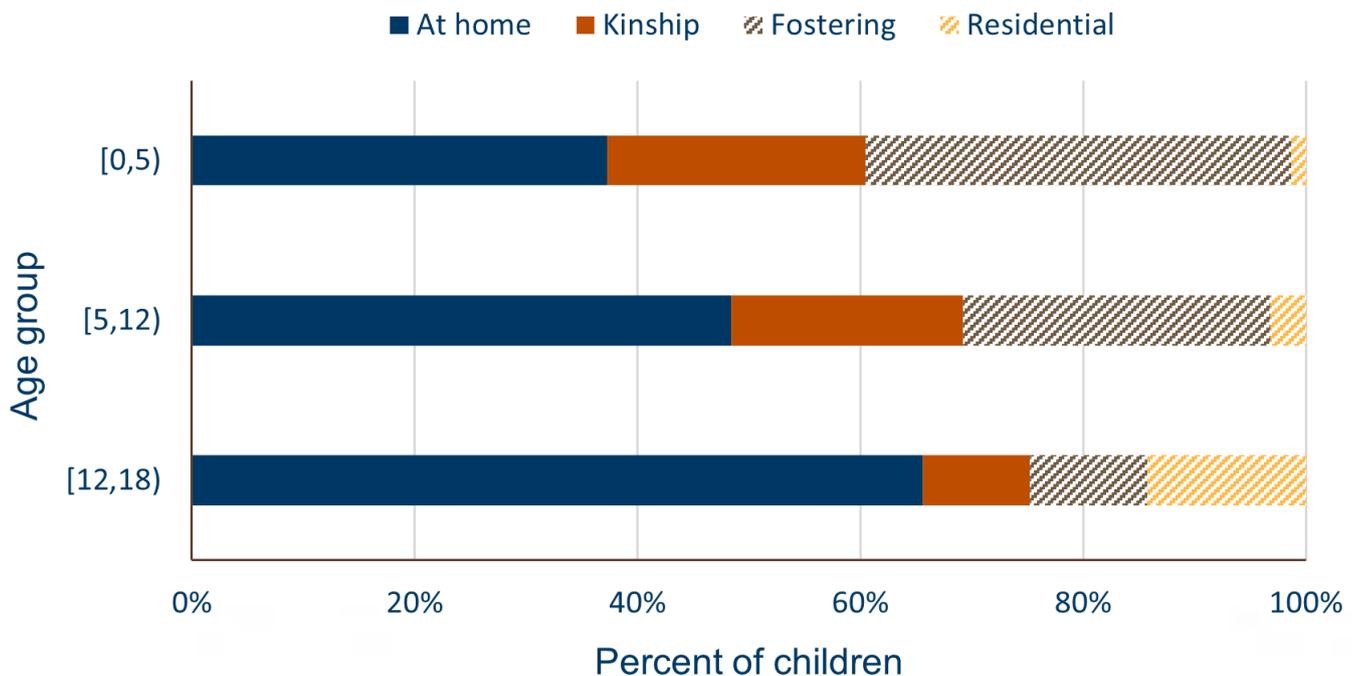


Figure 13. Children by age of entry to care and first placement type.

The majority of children in our study only had one (40%) or two (17%) care placements from birth to the end of 2016. However, that still leaves a substantial number of children who had multiple care placements (Figure 14). This includes 3.4%, or nearly 500 children, who had 10 or more placements. Children who entered care at a younger age had more placements compared to those who entered at an older age. For example, only 23% of children who entered care before the age of five had one placement during the study, while this percentage was 57% among children aged 12 or above. We did not find any differences in the number of care placements between female and male members of the cohort.

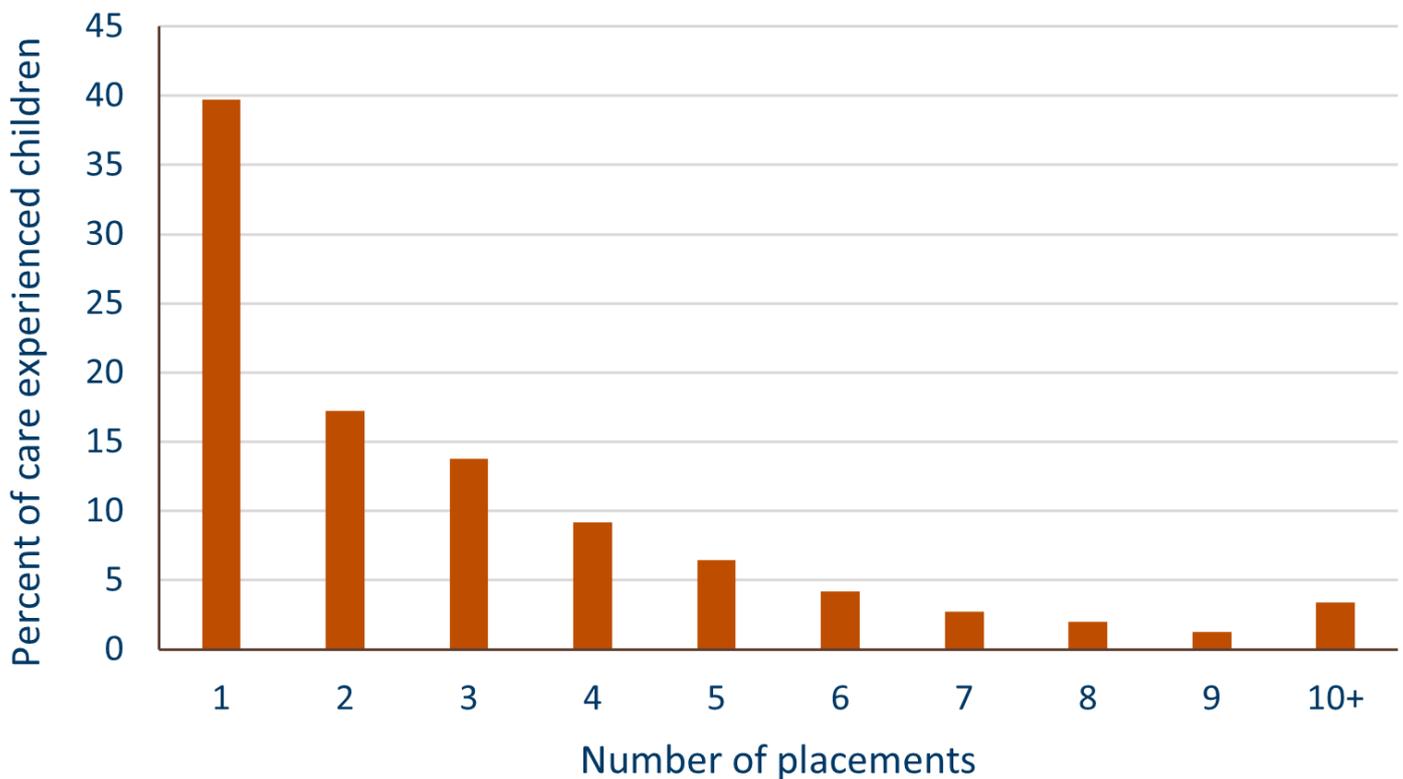


Figure 14. Percent of care experienced children by the number of placements.

We estimate that about 55% of children in our study will have left care permanently by the end of 2016. The rest, while not always in care at the end of the study, were young enough that they could still return to care. This means the final number of care placements the children in the study will have had by the time they permanently leave care may be higher than reported here.

The different types of placements a child is likely to have over the course of their care depends again on the age they enter care (Figure 15). As with the first placement, children who enter care at a younger age are more likely to have fostering placements and few residential placements. Those who enter care at the age of 12 or older are more likely to remain at home or have residential care placements.

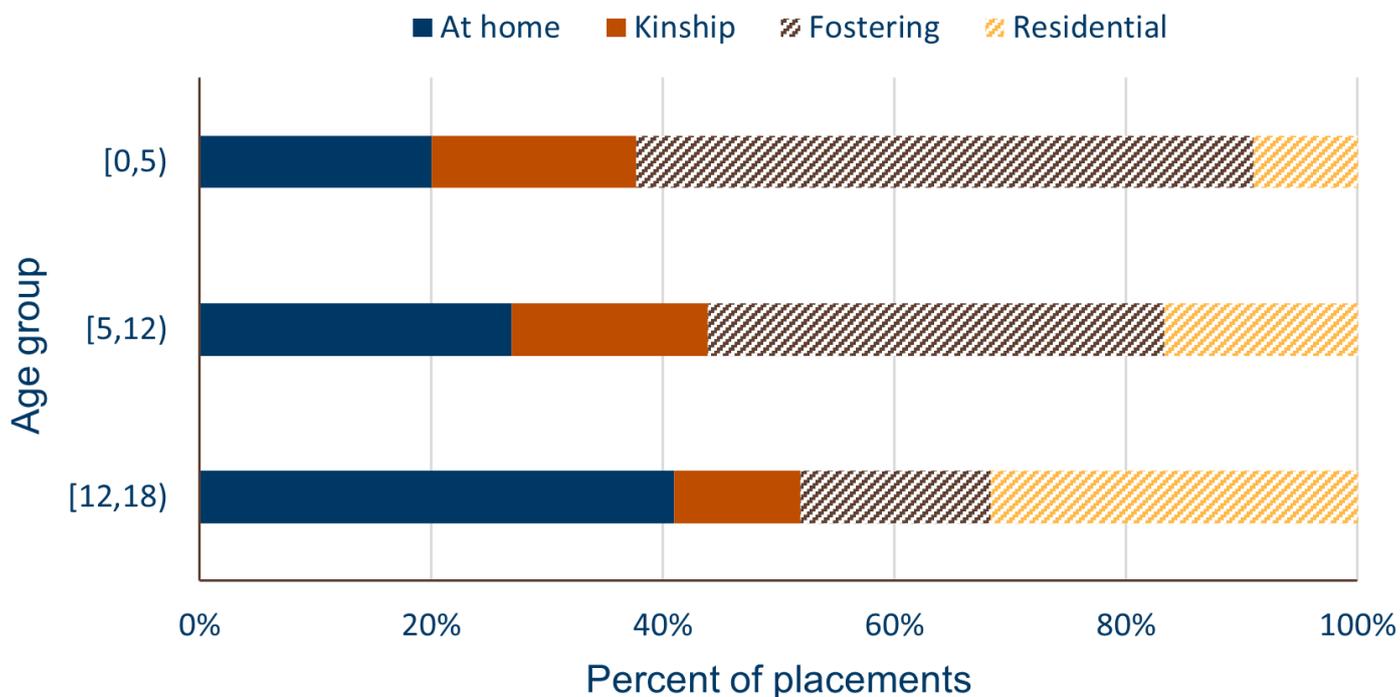


Figure 15. Distribution of all placements by placement type and age of first entry to care.

Scottish Government statistics show that the types of placement children experience over the course of care in each age group has changed over the past two decades. The proportion of children looked after at home by parents has been falling across all age groups, while the number of children looked after by friends or relatives has been increasing. Additionally, the proportion of children looked after by foster carers in the 12-15 year old and 16-17 year old age brackets has also increased, and the proportion of 12-15 year old children in residential care has decreased.<sup>36,37</sup> According to Children’s Social Work Statistics, in 2021 the most common placement types across all age groups were either with friends/relatives or being looked after by foster carers.<sup>37</sup> Therefore, the oldest and the youngest members of our cohort are likely to have experienced quite different practices and placement decisions made for them.

Given the changes in the past decades in the age at which children enter care and the types of care they experience, our results presented here may not reflect the care experiences and health outcomes of children who are currently in care. But our results are representative of people born in Scotland between 1990 and 2004, young people who are now starting independent life, entering higher education, beginning their working careers, and forming new families. These are people who still have most of their lives ahead of them and whose health and childhood experiences will be impacting Scottish society in the decades to come.



# Health outcomes in the cohorts

We have only discussed some aspects of health in this report. In choosing the topics we considered the extent of differences between the cohorts, the avoidability of the outcomes, and their immediate policy relevance. Our initial work highlighted that the largest differences existed in deaths, and mental, sexual and reproductive health.<sup>1</sup> Here, we have looked at deaths and mental health (including hospitalisations and prescriptions), while sexual and reproductive health will be the focus of our future research. The coding schemas for all health outcomes are given in Appendix Table A2.

The care experienced cohort have more hospital visits that can be avoided with better care and treatment, including hospitalisations for chronic conditions such as asthma, epilepsy, and diabetes. In addition, care experienced children and young people are more likely to be hospitalised for injuries and poisonings, again causes that are avoidable with better overall care. However, we should highlight here that many of these avoidable hospitalisations do not happen while the child is in formal care but rather before or after formal care placements, emphasising the need for better support for all children and young people.

The evidence presented here is a step towards understanding the health and health behaviours of care experienced children at the population level in Scotland. So much of our work still remains to be done and in the final chapter we have discussed our plans for next steps, including further research into sexual and reproductive health.

## Deaths

The death of any child or young person is a tragedy, and measures to prevent or reduce unnecessary deaths should be a priority. Children who have spent time in care have a higher risk of dying prematurely compared to children without care experience,<sup>10,38–40</sup> and that lasts into middle age.<sup>41–43</sup> This does not have to be the case. It is estimated that around a quarter of deaths of children in Scotland could be prevented each year.<sup>44</sup>

We look at mortality outcomes for children and young people over a seven-year period from 2009-2016. In total, there were 824 deaths over this time period (Table 2); 746 (0.11%) in the general population and 78 (0.56%) in the care experienced cohort. Although relatively small percentages, there is a clear difference between the two groups.

It is important to understand the causes of death in children and young people in order to focus efforts on reducing early deaths. In the general population the three most common causes of death were accidents, cancer, and suicides. For children with care experience these were suicides, accidents, and diseases of the nervous system (which included deaths due to cerebral palsy and epilepsy). Deaths are often described as due to internal (such as a disease or illness) or external (such as drug misuse, suicide, self-harm, and

traffic accidents) causes. Overall, 68% of deaths in the care experienced cohort were due to external causes compared to just over 40% in the general population. External causes of death are less likely to be anticipated deaths (e.g. due to a life-limiting condition or terminal illness) and more likely to be unexpected, sometimes due to risk-taking behaviours.

*Table 2. Premature mortality among children and young people in the general population and the care experienced cohorts.*

	General population	Care experienced
Number in cohorts	649,771	13,830
Deaths in cohort	746	78
Percent	0.11	0.56
Leading causes	Accidents (24%) Cancer (16%) Suicide (16%)	Suicide (29%) Accidents (27%) Nervous system (10%)
External causes	41%	68%

We used regression analysis to compare the mortality rates of those in the care experienced group to those in the general population (Figure 16). Calculating the rate ratio allows us to compare the incidence rates of death in the two groups. A rate ratio of 1 indicates equal rates in the two groups, a rate ratio less than 1 would indicate that rates of death were higher in the general population and a rate ratio greater than 1 would indicate that rates of death were higher in the care experienced population.

For children and young people included in the CHiCS study, we wanted to look at the extent of any differences in rates of death between the care experienced cohort and the general population, and whether any differences in these could be explained by differences in the age and sex composition of the two groups, by deprivation or disability. Directly comparing the two groups (i.e. not accounting for any other factors), premature deaths were almost 5 times as high for children and young people in the care experienced cohort. Accounting for age, sex and deprivation explained a little of this difference in rates and reduced the rate ratio to 4.3. Accounting for disability in children reduced the differences in rates the most. After accounting for age, sex, deprivation and having a disability, death rates remained 2.7 times as high for care experienced children. It is possible that there are other circumstances, not included here and not relating to the care system, that could explain this difference between the two groups.

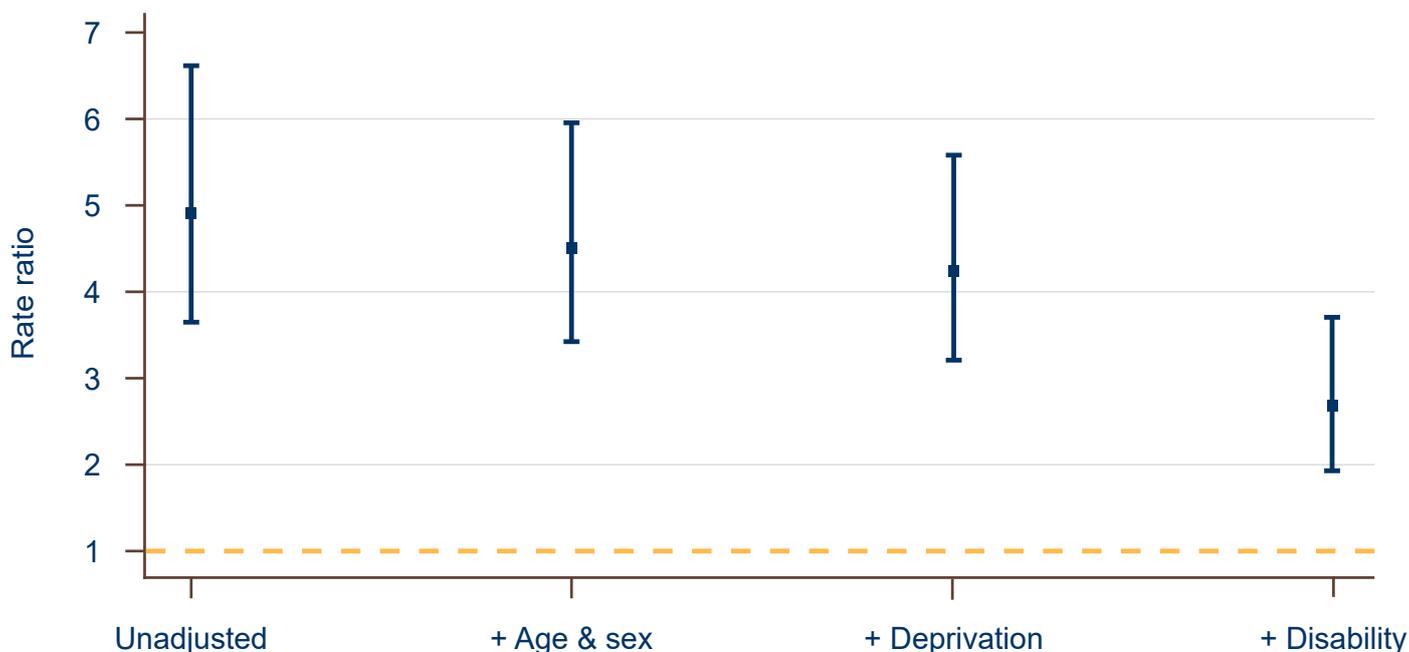


Figure 16. Rate ratios of premature mortality for care experienced children and young people compared to children and young people in the general population. We first show the rate ratio for the unadjusted model. We then adjust for age and sex, deprivation, and then for having a disability. The bands around rate ratios indicate confidence intervals (CI), the range of values that is likely to include the true population value. Since the CI's do not include the value 1, we can conclude that our results are not obtained by chance.

Our measure of disability for children and young people is rather a simplistic one. It comes from the Pupil Census and records whether pupils were assessed (by a qualified professional) as having a disability, yes or no, with no breakdown of the type of disability. Children in the care experienced cohort were more likely to have a disability (8.6% compared to 2.2% in the general population). In total, 1.6% of those assessed disabled in the care experienced cohort died, compared to 1.2% in the general population. There was a larger difference in the group without an assessed disability; 0.09% of the general population died compared to 0.47% in the care experienced cohort.

A more detailed measure of disability is available in the CLAS returns recorded prior to 2015/16 (after 2015/16 disability is recorded simply as yes/no). Having this is useful as it allows us to understand more about a child's health. Based on these data we estimate that 11.6% of the care experienced cohort had a single disability and 1.4% had multiple disabilities. This sums to 13% in total and is substantially higher than what is estimated by the Pupil Census (8.6%). Of those who died, 19.2% had a single disability and 14.1% had multiple disabilities. The most common types of disabilities among care experienced children are social, emotional, and behavioural problems (39% - percentages from those with a disability) and learning disabilities (20%). Autism spectrum condition is recorded in 6% of cases. Chronic conditions and physical disabilities (e.g. hearing or visual impairments) are noted for 14% of care experienced children and young people with a disability included in this study.

Table 3. Care experienced children by the number of disabilities (based on CLAS returns).

	All children		Children who died	
	N	%	N	%
No disability	12,029	87.0	52	66.7
Single disability	1,602	11.6	15	19.2
Multiple disabilities	199	1.4	11	14.1
<b>Total</b>	<b>13,830</b>	<b>100</b>	<b>78</b>	<b>100</b>

In both cohorts, more than half of all deaths occurred at age 18 years or older. Three quarters of all care experienced children and young people who died were not in a care placement at the time of death, suggesting that children moving out of care or permanently leaving care may need additional support to thrive.

It is important to continue to review and learn from the deaths of all children and young people, including deaths of children and young people with care experience. Healthcare Improvement Scotland and the Care Inspectorate have recently announced the development of a National Hub to review the deaths of all children in Scotland up to age 18, or until age 26 for care leavers in receipt of continuing care or aftercare.<sup>44</sup> One of the main aims of the review is to reduce the risk of preventable deaths. Our work showed that 362 children across both cohorts died from avoidable external causes (such as accidents and suicide); 44% of all deaths among children in the study. Although mortality rates for children and young people in Scotland are higher than in the rest of UK and Western Europe, Scotland tends to have a relatively low rate of deaths from external causes in adolescence and early adulthood compared to many other countries in Europe.<sup>5</sup> Unfortunately, among care experienced children and young people, 68% of deaths were due to external causes. Scottish children and young people, including those who have experienced adversity or a significant life change such as leaving formal care, require more support with respect to their mental and emotional wellbeing needs to successfully navigate these challenging events.

## Mental health and neurodevelopmental disorders

As in many parts of the world, mental ill health among children and young people is of growing concern in Scotland. Between 2013/2014 and 2017/2018, referrals to specialist services increased by 22% from 27,271 to 33,270 among those aged under 18, posing a significant health burden and making it a public health priority.<sup>45,46</sup> The importance of identifying mental health issues and providing appropriate support for psychological wellbeing at an early age cannot be underestimated. Mental ill health can continue into adulthood and have an adverse effect on many aspects of life, including physical health, educational achievement, and employment.<sup>47-49</sup>

While evidence shows an increased need for mental health services, less is known about the prevalence of different diagnosable mental health conditions (e.g. depression, anxiety, substance misuse) affecting children and young people in Scotland and the UK. In 2004,

a UK-wide study estimated that around 1 in 10 children and young people (three in every classroom) have a diagnosable mental health disorder, with half of all mental health problems beginning before age 14.<sup>50,51</sup> The most recent 2018 Health Behaviour in School-Aged Children (HBSC) Study in Scotland found that 14% of young people aged 11-15 may be at risk of depression.<sup>52</sup>

Our ability to distinguish between different conditions is important for conducting research, to document the prevalence of a condition, predicting outcomes, and influencing public health service planning, including resource allocation decisions and research priorities. It is also relevant for those experiencing mental ill health because it allows clinicians, social services, carers, and young people to better communicate information and allows doctors to select the most effective treatment and intervention.<sup>53-55</sup>

The evidence presented here is unique as we are able to give an indication of the prevalence of different mental health conditions experienced by children and young people in Scotland. We also look at neurodevelopmental conditions, specifically attention deficit and hyperactivity disorder (ADHD). Neurodevelopmental conditions affect how the brain functions and how a person understands and experiences the world around them, their communication, behaviour and/or motor skills. It is not uncommon for children with neurodevelopmental conditions to also experience mental ill health, including anxiety, depression, personality, eating, and substance use disorders.<sup>56,57</sup>

We compare mental health between the two cohorts by looking at outpatient psychiatry visits, inpatient hospitalisations with a mental health diagnosis, and central nervous system (CNS) prescriptions related to mental illness and neurodevelopmental disorders. Like physical health problems, mental ill health should be treated and from this perspective seeing a psychiatrist or receiving medication is a good thing and outpatient psychiatric visits or prescriptions should not necessarily be viewed as a negative.

It is not possible to conclude from these data how much unmet need for mental health services and treatment there is among either of the two cohorts. However, one indicator of this might be inpatient hospitalisations for mental health diagnosis. Ideally, timely outpatient consultations, support services, including counselling, or medications should meet many mental health needs. While in some cases this may not be sufficient, in others inpatient hospitalisations can indicate that needs are not met in a timely or adequate manner, leading to children and young people being hospitalised. Inpatient mental health hospitalisations and the differences in this between the cohorts may therefore reflect more significant inequalities in mental health.

Mental health hospitalisations can also include the diagnosis of intellectual disability, assessed by standardised intelligence tests. (This is different to a learning disability.) A hospital diagnosis of intellectual disability affects very few children included in this study (less than 0.5% in both cohorts). In the below analysis, we have excluded inpatient hospitalisations for intellectual disability because the vast majority of these hospitalisations are for respite care, allowing family and carers to take a break from caring. Hospitalisations for respite care are rare for any other mental health diagnosis.

All our data related to mental health suggest that prevalence of mental health problems is higher among the care experienced cohort (Table 4). For example, 29.5% of the care experienced cohort visited a psychiatrist and 30% had a prescription for antidepressants,

hypnotics or anxiolytics (sedatives), substance dependence, psychosis, or ADHD. In the general population, only 7.3% of children saw a psychiatrist and 12% had any of the five CNS prescriptions. Together these data suggest an approximately 2.5-4 times higher prevalence of mental ill health among care experienced people (Table 4, prevalence ratio).

Since we do not know if unmet need varies between the cohorts, some of this difference may be explained by access to services (e.g. via legislated health assessments among the care experienced cohort). If care experienced children have better access to mental health services, the estimated 2.5-4 times higher prevalence may be an overestimate. However, the differences between cohorts are greater (6-fold) for inpatient hospitalisations, with 5% of the care experienced and 0.8% of the general population having had at least one hospitalisation for mental and behavioural disorders. This suggests that there is a higher need for specialist mental health care among care experienced children and young people.

In both cohorts, a higher proportion of males have had an outpatient psychiatry visit while more females have received a prescription for a mental health condition, but there are no sex differences for inpatient hospitalisations within the cohorts. Overall, differences in the prevalence of mental health problems between males and females within the two cohorts are much smaller than the differences between the two cohorts.



Table 4. Number and percent of children with at least one mental health related hospital visit or prescription by cohort and sex.

	General population				Care experienced				Prevalence ratio CEC:GPC		
	Number	Percent			Number	Percent			Total	F	M
		Total	Female	Male		Total	Female	Male			
Total children	649,771	100	100	100	13,830	100	100	100			
Psychiatry outpatient visit	47,228	7.3	6.9	7.6	4,077	29.5	26.1	32.3	4.1	3.8	4.3
Any of the five CNS prescriptions	76,486	11.8	14.3	9.3	4,178	30.2	32.5	28.3	2.6	2.3	3.0
Children by the type of prescription:											
Antidepressants	52,905	8.1	11.2	5.2	2,725	19.7	25.7	14.7	2.4	2.3	2.8
Hypnotics & anxiolytics	26,852	4.1	4.9	3.4	1,483	10.7	11.5	10.1	2.6	2.4	3.0
Substance dependence	8,334	1.3	1.5	1.1	937	6.8	8.7	5.2	5.3	5.8	4.8
ADHD	7,684	1.2	0.4	1.9	829	6.0	1.9	9.4	5.1	4.8	4.8
Psychoses	4,307	0.7	0.6	0.7	503	3.6	3.3	4.0	5.5	5.2	5.6
Any MH hospitalisation*	5,225	0.8	0.8	0.8	701	5.1	5.0	5.1	6.3	6.4	6.2
Children hospitalised by diagnosis:											
Substance use	2,088	0.3	0.3	0.4	446	3.2	3.1	3.4	10.0	11.4	9.0
<i>Of this: Alcohol**</i>	1,672	80.1	86.9	75.4	345	77.4	82.3	73.6			
<i>Other (e.g. caffeine)</i>	135	6.5	5.9	6.9	39	8.7	8.9	8.7			
<i>Cannabinoids***</i>	61	2.9			15	3.4					
<i>Opioids</i>	29	1.4			16	3.6					
Mood disorder	772	0.1	0.1	0.1	73	0.5	0.6	0.4	4.4	4.4	4.7
<i>Of this: Depression</i>	614	79.5	83.3	74.1	58	79.5	79.5	79.4			
<i>Bipolar disorder</i>	88	11.4	11.4	11.4	10	13.7					
Neurotic disorder	681	0.1	0.1	0.1	84	0.6	0.7	0.5	5.8	5.4	6.7
<i>Of this: Anxiety</i>	324	47.6	44.7	52.4	17	20.2					
<i>Severe stress</i>	217	31.9	34.9	26.8	32	69.0	68.9	69.2			

\*Hospitalisations for ICD-10 chapter V, excludes a very small number of children hospitalised for intellectual disability.

\*\*Percentages for the italicised diagnosis are calculated from the main diagnosis (e.g. percentage for alcohol use is from substance use).

\*\*\*Distribution by sex is excluded for some diagnosis due to statistical disclosure control.

The biggest differences between cohorts are evident for hospitalisations due to substance abuse and medications for substance dependence (Table 4). While very few young people are hospitalised for mental and behavioural disorders due to substance abuse, this is about 10 times higher in the care experienced cohort (3.2% compared to 0.3% in the general population). In both cohorts, most of these hospitalisations are due to alcohol abuse, but among males, particularly those with care experience, hospitalisations due to abuse of cannabinoids and opioids make up a more substantial proportion of substance abuse hospitalisations.

A small number of children have also been hospitalised for mood disorders and, in both cohorts, this is most commonly for depression. Again, care experienced children are more likely to be hospitalised for mood disorders and the differences are about 4-fold (Table 4, prevalence ratio). Differences in the prevalence of hospitalisations for neurotic and stress-related disorders are almost 6-fold between the two cohorts. Here, we can also note a difference in the specific diagnosis at hospitalisation – care experienced children are more often hospitalised due to severe stress, such as caused by an exceptionally stressful life event or a significant life change, while this diagnosis is quite rare among general population children and young people. This difference clearly highlights the importance of better managing transitions into, between and out of care.

In both cohorts and for both sexes, antidepressants are the most prevalent medications, followed by sedatives (hypnotics and anxiolytics; Table 4). Antidepressant prescriptions are nearly twice as prevalent in females compared to males. For females in both cohorts, the third most common medications are for substance dependence (including for nicotine dependence) but for males in both cohorts the third most common medication is for ADHD. Nearly 10% of care experienced males received ADHD medication between 2009-2016 while this was 2% among general population boys and care experienced girls and only 0.4% among general population girls.

In addition to having higher prevalence of mental ill health, members of the care experienced cohort are also more likely to have had multiple prescriptions and hospital visits, including more different types of centrally acting medications and mental health diagnosis (Figure 17). Of those with any of the five CNS prescriptions, 41% of the care experienced cohort had more than one type of prescription compared to 26% among the general population. Of those hospitalised for mental health conditions, 15% of care experienced and 8% of general population children were hospitalised for two or more separate diagnosis. This evidence suggests that the care experienced population has more complex mental health needs and are more likely to experience multiple different mental health challenges.



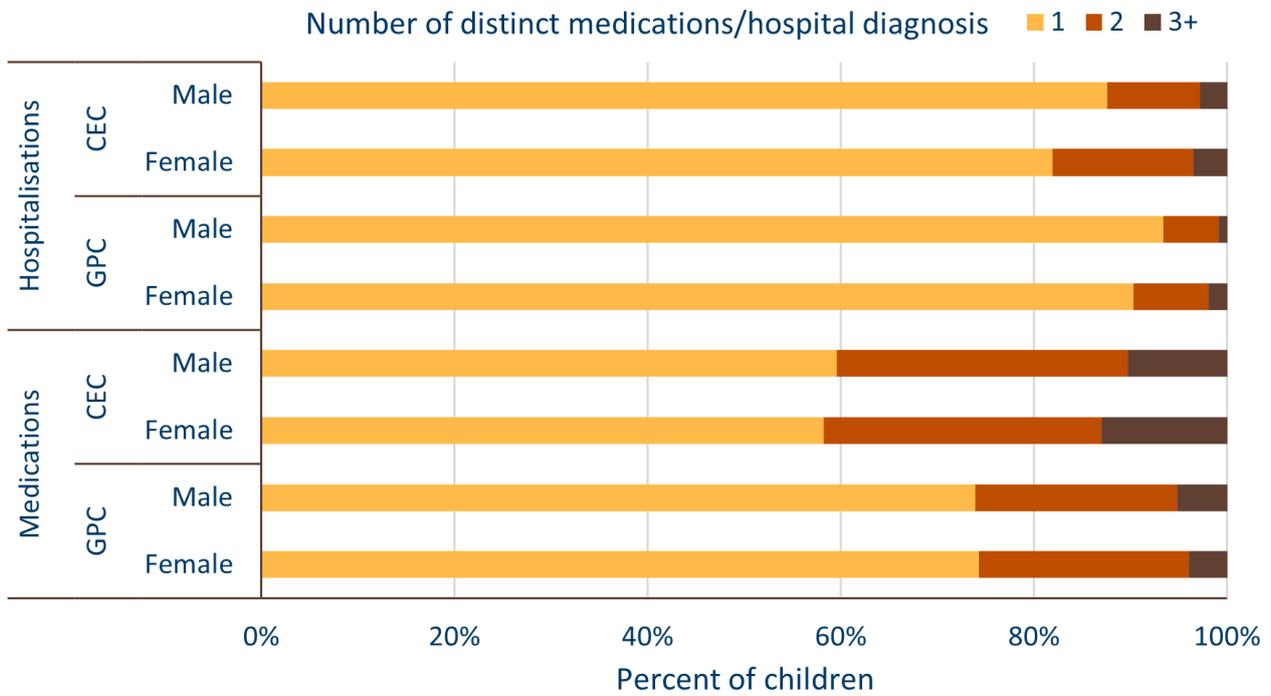


Figure 17. Percent of children by sex, cohort and the number of distinct CNS medications and diagnosis. GPC – General population children; CEC – care experienced children.

CNS prescription and hospitalisation rates increase with age in both cohorts, but this is slightly different for boys and girls. Generally, rates for in- and outpatient hospitalisation, and prescriptions, are higher among boys before the age of five (before school-age) and become higher for girls around the age of 12 (example for inpatient hospitalisations in Figure 18). This applies to both the care experienced and general population children and is a commonly noted finding for depression and other indicators on mental wellbeing.<sup>52,58</sup>

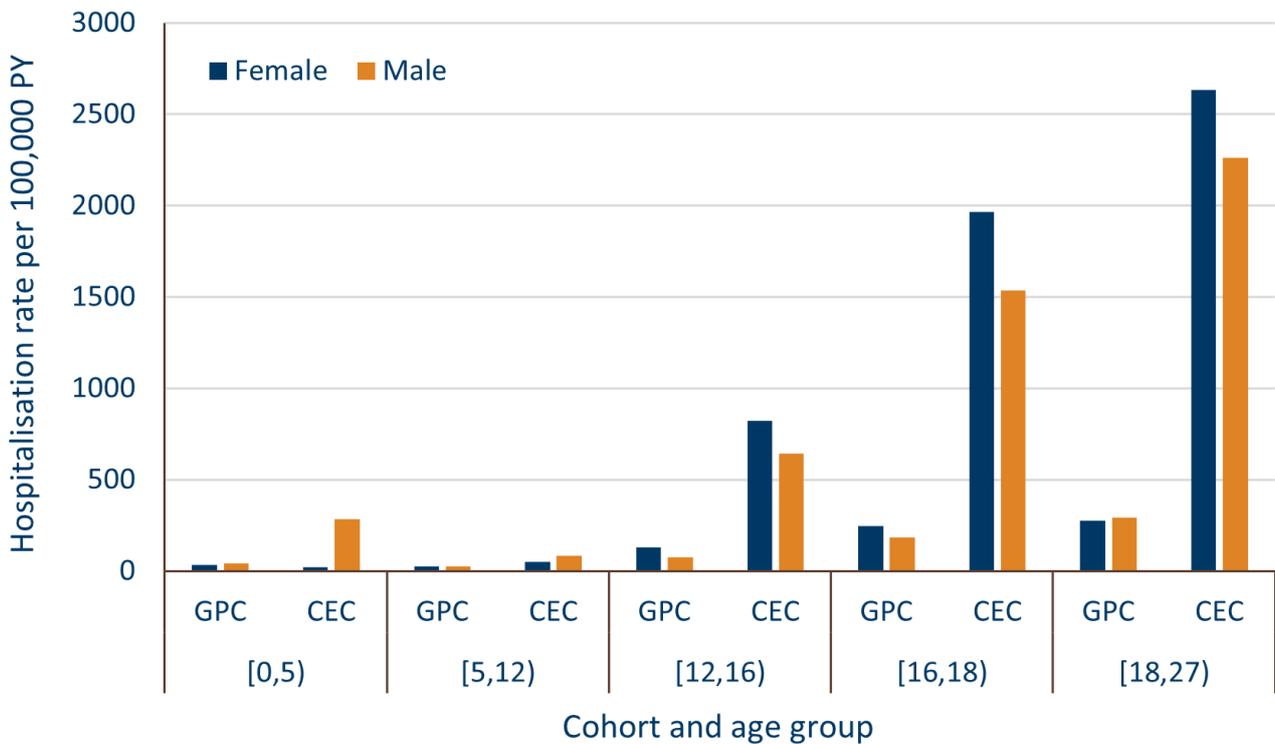


Figure 18. Inpatient hospitalisation rates for mental health conditions by age and cohort. GPC – General population children; CEC - care experienced children.

The above figure also suggests that inequalities between cohorts in mental ill health increase with age. Before the age of 12, care experienced children are about 2-4 times more frequently hospitalised compared to general population children, but this increases to about 8-9 times by ages 18 and above. This shows, first, that adverse childhood experiences can have a long-term impact on health if not properly addressed. Second, the need for mental health services among care experienced people is higher at an age where young people leave care, start independent life, and try to access adult mental health services.

Among the care experienced cohort, hospitalisation rates vary substantially by care placement type. For example, hospitalisation rates for mental and behavioural disorders due to substance use (primarily due to alcohol) are highest before entering care, during care at home and in residential care (Table 5). Rates are much lower while in kinship or foster care, and after leaving care. Unfortunately, many children in Scotland witness alcohol and drug abuse in their wider community. This can lead to substance use and hospitalisation at very young ages, and eventually to being removed from home.

*Table 5. Inpatient hospitalisations for mental and behavioural problems due to substance abuse by cohort, age, and care placement. GPC – General population children; CEC - care experienced children.*

Age group	GPC		CEC						
			Overall CEC		Care placement type				
	N	Rate	N	Rate	Before	At home	Kinship/ fostering	Residential	After care
[0,12)	57	0.7	26	15.7	13.8				
[12,16)	1015	48.2	246	528.9	693.7	683.3	355.3	1312.9	135.1
[16,27)	1338	78.0	331	802.9		2118.2	376.7	1173.5	774.4
Total N	2410		603		73	103	73	81	273

The patterns in hospitalisation rates by care placement type vary by diagnosis. Hospitalisations for mood disorders (primarily depression) are highest after leaving care while hospitalisations for neurotic and stress disorders (including severe stress related to external factors) often occur during care. This indicates that care experienced children and young people are facing different challenges at different stages in their lives and care experiences. The high rates of hospitalisations for severe stress during care episodes is indicative of the trauma caused either by events that lead to removal from home or by entering and/or changing care placements. Increased hospitalisations for depression after leaving care are likely evidence of the difficulties care leavers face when having to start independent life.

For the general population, our data suggest an increasing prevalence of mental health problems as deprivation increases. For example, the percent of children who have visited a psychiatrist is higher in the most deprived areas (Figure 19) and this increase is more notable for males. Differences between the least and most deprived areas are greatest in relation to substance abuse and tend to increase with age, indicating deepening

socioeconomic inequalities with age in the general population of children and young people.

Among the care experienced cohort, there is no obvious relationship between mental health hospitalisations (neither inpatient or outpatient), prescriptions and deprivation. Often the prevalence of prescriptions and hospitalisations is highest for those born in areas of average deprivation and lowest in areas of highest deprivation (Figure 19).

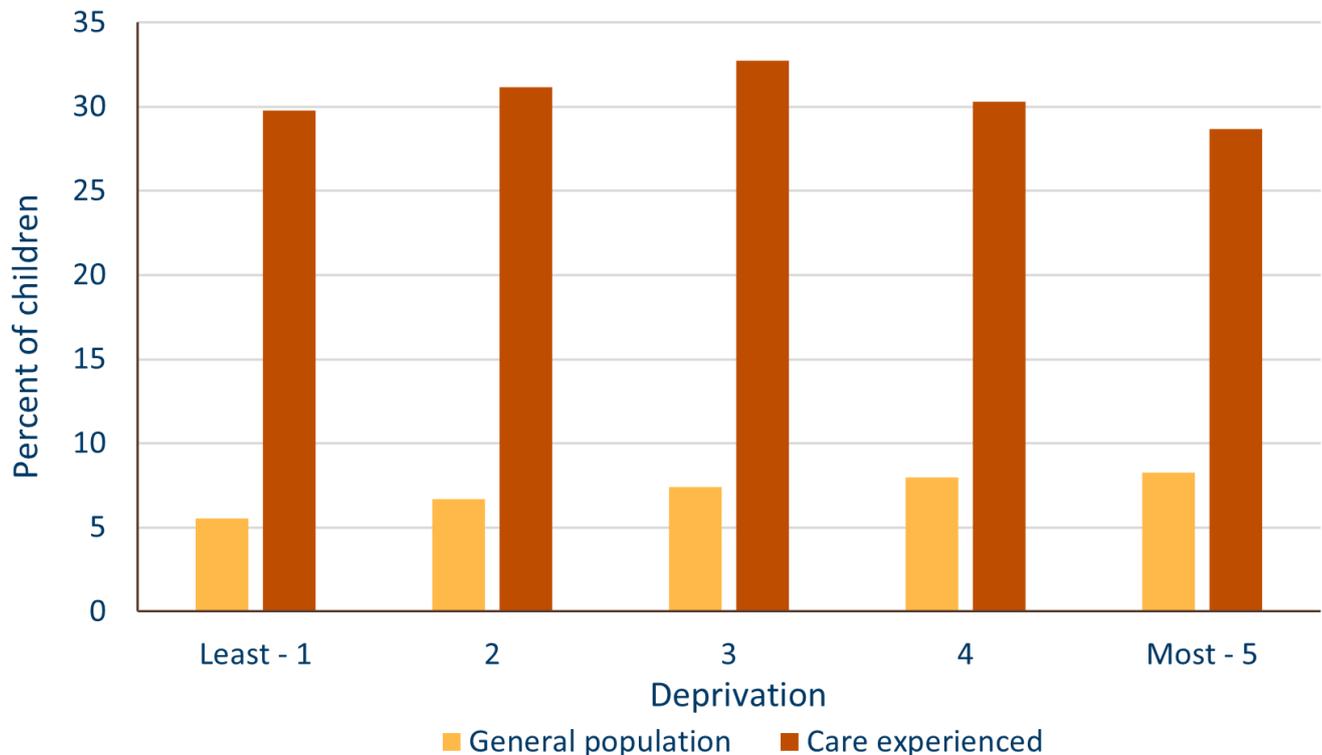


Figure 19. Percent of children with an outpatient psychiatry visits by deprivation at birth and cohort.

The above figure also shows that prevalence of mental health problems and the rates of prescriptions and hospitalisations are always higher among the care experienced cohort, even in comparison to the general population born into the most deprived areas. While area level deprivation, such as the SIMD, impacts health and health behaviours, it cannot explain all the differences in health outcomes between the care experienced and the general population children. Disadvantages that affect health are cumulative and multifaceted, and while deprivation significantly contributes to poorer health outcomes, it is one of many social and environmental factors that does this.

Everyone can be at risk of poor mental health and some conditions may be unavoidable. In other cases, life experiences or external circumstances increase the likelihood of developing mental ill health. For example, many studies, including this one, show that children and young people who experience socioeconomic disadvantage are more likely to experience mental ill health. Care experienced children are likely to have faced additional challenging life events, and as shown here, have a higher prevalence of mental illnesses and more complex mental health needs.

However, many of these mental and behavioural disorders could be completely avoided. In both cohorts, the most common reason for hospitalisations relate to substance abuse.

These hospitalisations and prescriptions for substance dependence are also where differences between the cohorts are biggest. Children and young people should not witness substance abuse in their communities nor have access to alcohol and drugs. Reducing substance dependence across Scotland is important for improving health and life outcomes for all children.

The most common CNS prescriptions in both cohorts are antidepressants and for care experienced people, there is a notable increase in hospitalisations related to depression after they leave care. Becoming an adult can be an exciting and yet a challenging life transition for everyone and lacking stable, trusting, and safe relationships and support can make this even more difficult. The increase in mental health difficulties after leaving care highlights the need for continued support for many years after legally becoming an adult.

There are also differences in the types of mental ill health experienced by the cohorts. For example, care experienced children are much more likely to be hospitalised for severe stress brought on by external factors or life changes. These incidences happen during care, highlighting the need for better management of transitions into and between care episodes.

Our analysis shows that deprivation cannot explain the differences between the two cohorts. In the general population, mental health disorders tend to increase with deprivation, but there is no obvious relationship between deprivation and mental health among the care experienced population. Care experienced children have a higher prevalence of mental health problems, even when compared to children born in the most deprived areas.

## Injuries and poisonings

Injuries and poisonings are a common cause of death and emergency hospital admission for children. In Scotland, there were 7,143 emergency admissions to hospital and 12 deaths registered due to unintentional injuries for children under 15 years in 2019/20. Although trends fluctuate each year, boys in all age groups are more likely to be admitted to hospital than girls. In 2019/20, emergency hospital admission rates per 100,000 population were 950.1 for boys, and 693.7 for girls, with under 5 year olds having the highest rates among children.<sup>59</sup> The most common unintentional injury types for which children are hospitalised vary within the UK nations. In Scotland, in 2019/20 these included - among others - head injuries, arm/hand injuries, leg/foot injuries, and poisonings.<sup>59,60</sup> Many injuries are avoidable and understanding the extent of this problem is important for finding a way to address and prevent them.

Table 6 shows that, taken together, injuries and poisoning are twice as prevalent among the care experienced children compared to children in the general population, 34.8% and 16.9% respectively. In both cohorts, males are more likely than females to experience injuries, but hospitalisations related to poisonings are more common among females. The differences between cohorts are bigger for any poisoning compared to any injury (Table 6, prevalence ratio), and the differences between sexes are more pronounced in the care experienced cohort for both injuries and poisoning.

Table 6. Number and percent of children with injury and poisoning by cohort and sex. GPC – General population children; CEC - care experienced children.

	General population				Care experienced				Prevalence ratio CEC:GPC		
	N	%			N	%			Total	F	M
		Total	Female	Male		Total	Female	Male			
Total children	649,771	100	100	100	13,830	100	100	100			
Any injury or poisoning	109,923	16.9	14.1	19.7	4,818	34.8	31.5	37.6	2.1	2.2	1.9
Any injury*	98,439	15.1	11.9	18.3	3,928	28.4	22.8	33.1	1.9	1.9	1.8
Any poisoning*	15,293	2.4	2.8	2.0	1,495	10.8	13.2	8.8	4.6	4.8	4.5
Of this:											
Poisoning due to drugs and medications	12,579	1.9	2.4	1.5	1,292	9.3	12.0	7.22	4.8	5.0	4.8
Other, not due to drugs or medications (includes alcohol)	2,915	0.4	0.4		262	1.9			4.2		

\*Some children may have had more than one type of injury or poisoning and thus the numbers do not add up to the total number with any injury or poisoning.

The most common types of injury among children in both cohorts for both sexes are head injuries, followed by arm and hand injuries (Figure 20). Boys are more likely to experience all types of injury, this applies to both cohorts, but the difference between sexes is more marked in the care experienced cohort.

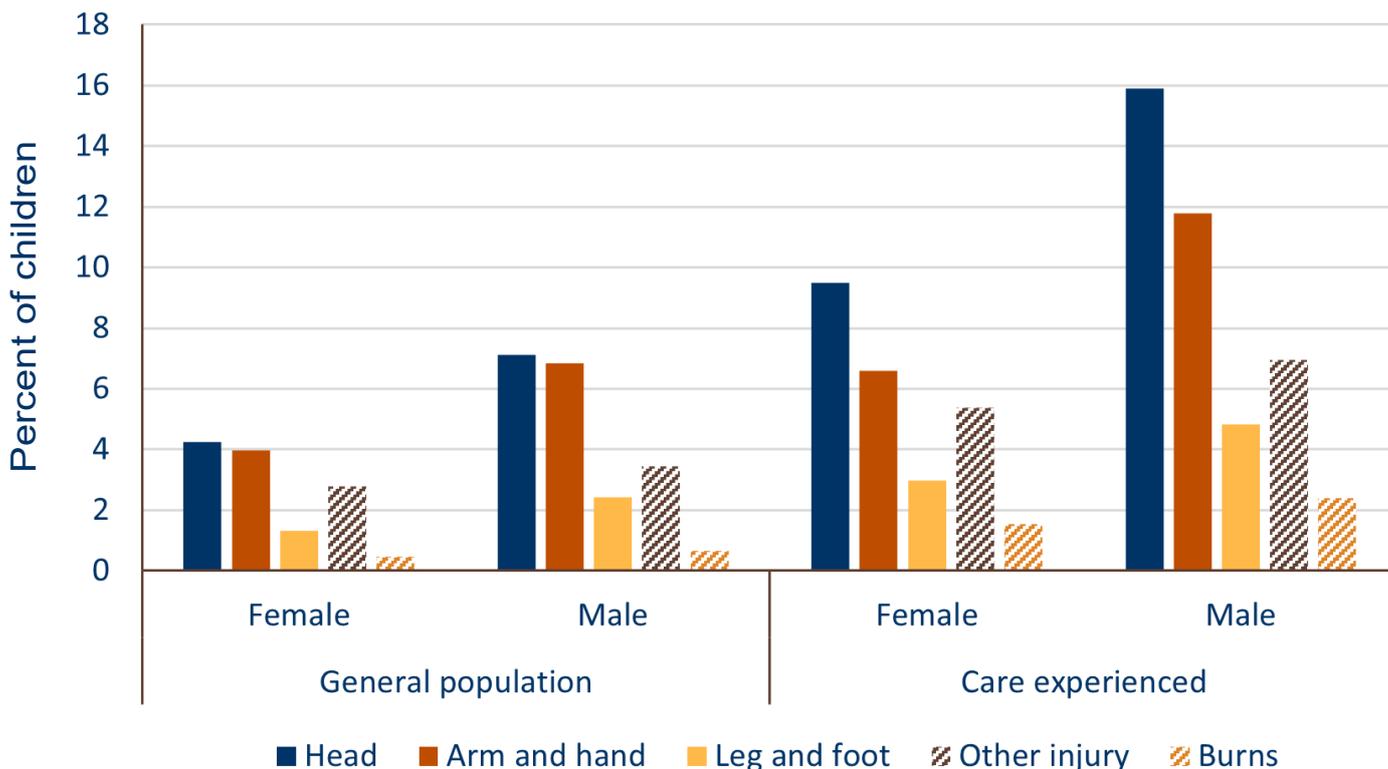


Figure 20. Prevalence of injuries by injury types, sex, and cohort.

Compared to injuries, poisonings are less common in both cohorts. The vast majority of poisonings are related to drugs and medications, with 2% of the general population and 9% of the care experienced cohort having been hospitalised for this (Table 6). The distribution of children by the type of medication causing the poisoning is shown in Figure 21. Most children were hospitalised for poisoning by analgesics (over-the-counter painkillers) or psychotropic medication (e.g. antidepressants), followed by antiepileptics, and narcotics (e.g. opium, heroin). In both cohorts, the differences between sexes are most evident for analgesics and antiepileptic drugs. Poisoning by analgesics is 1.4 times higher for girls in the general population cohort, and 1.7 times higher for girls in the care experienced children, compared to boys. Poisoning due to antiepileptic drugs is 1.5 times higher for boys in both cohorts.



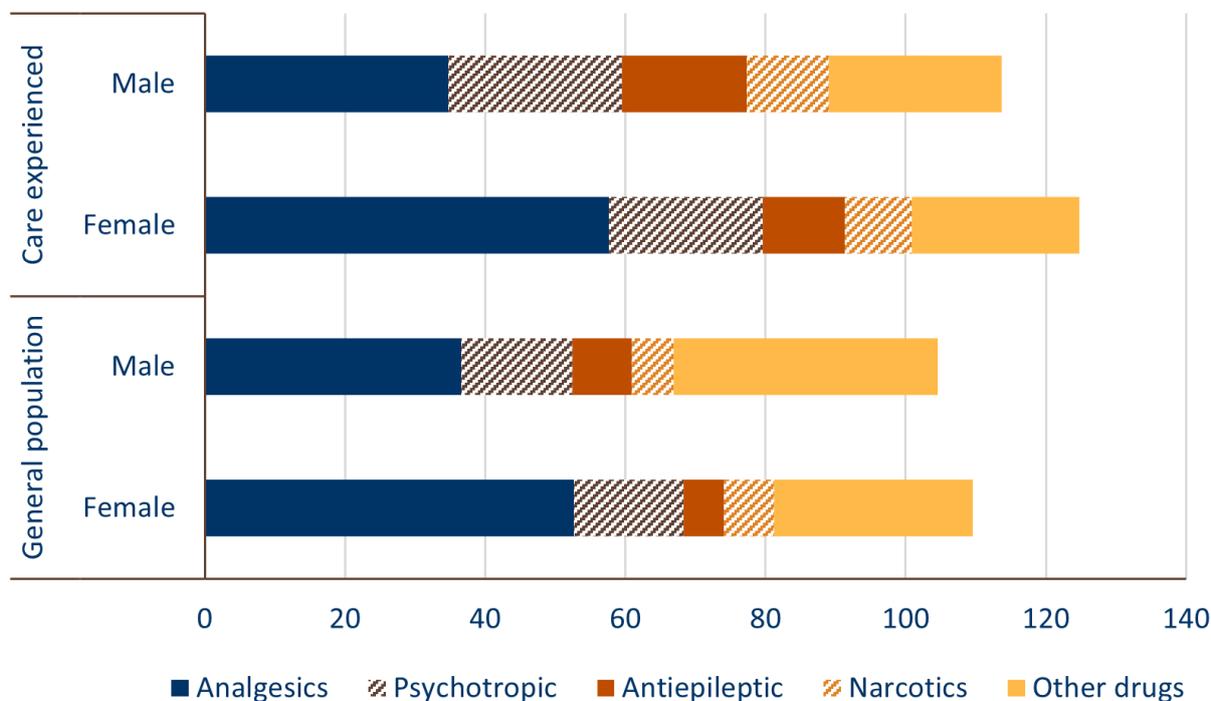


Figure 21. Percent of children by the type of poisoning from all children hospitalised for poisoning due to drugs and medications. Note that some children may have had more than one type of poisoning thus the total percentages are greater than 100%. The bars that reach further beyond 100% indicate higher numbers of children hospitalised for more than one type of poisoning.

In our cohorts, the majority of children are hospitalised only once for any injury or poisoning (Figure 22). Repeated hospitalisations for injury are more common for boys in both cohorts, and notably more common among care experienced boys. Differences in the prevalence of repeated hospitalisations are most obvious for head injuries. Specifically, 13.6% and 20.8% of care experienced girls and boys, respectively, have been hospitalised more than once for a head injury, compared to 8.3% and 12.2% for general population girls and boys. The difference in repeated hospitalisations between cohorts is less evident for burns and all other injuries.

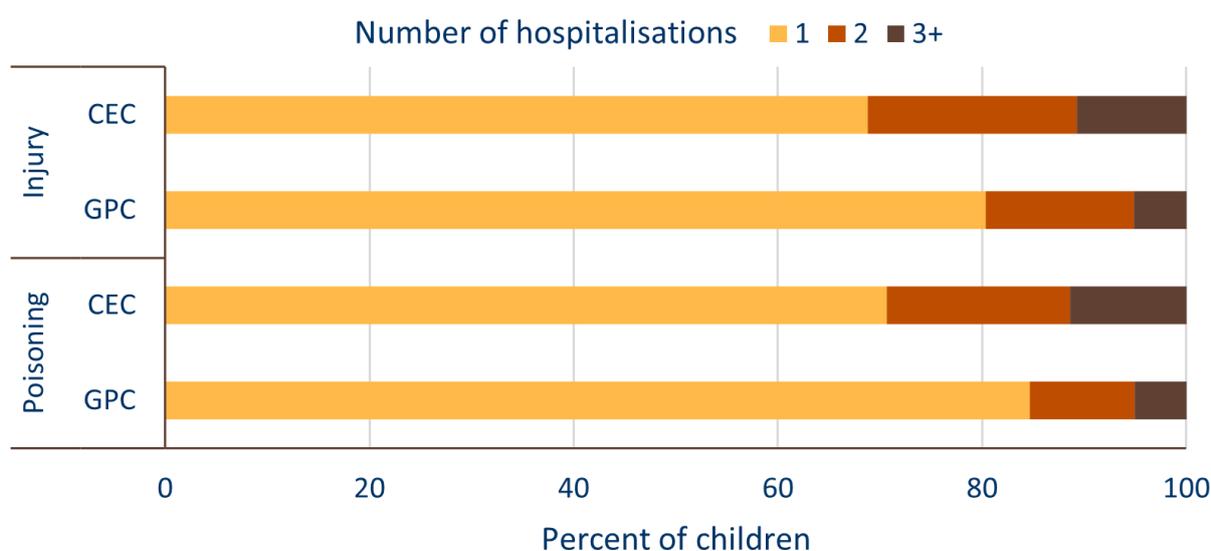


Figure 22. Percent of children with injury or poisoning by the number of hospitalisations and cohort. CEC – Care experienced children; GPC – General population children.

Repeated hospitalisations for poisoning are also more common in the care experienced cohort (Figure 22). Girls in both cohorts, but especially care experienced girls, are more likely than boys to be hospitalised more than once for poisoning. Differences in repeated hospitalisations between cohorts are most notable for analgesics and psychotropics (for girls), and less notable for antiepileptic, narcotic, and for poisonings not related to drugs or medication.

We also look at how the proportion of children who experience injury or poisoning changes with deprivation. In the general population, the proportion of children who are hospitalised for injury increases with deprivation, from 13.5% in the least deprived to 17.6% in the most deprived quintile. Hospital admission rates for poisoning increases from 1.7% in the least deprived quintile to 3.1% in the most deprived areas. However, among the care experienced cohort, there is no obvious gradient for injuries. For poisoning, there is a reversed gradient, that is, as deprivation increases the proportion of children admitted to hospital decreases from 13.5% in the least deprived to 10.2% in the most deprived areas. This reversed gradient is more notable among females, than males.

Figure 23, shows that hospitalisation rates for injury at first decrease with age in both cohorts, however, this decrease is more pronounced in the care experienced cohort. From the age of 5 years old, rates remain broadly stable in the general population cohort, but for care experienced children an increase is observed from age 12. In both cohorts, and across all age groups hospitalisation rates for injury are higher among males compared to females. Differences between the cohorts increase with age for head, arm, and hand injuries but less so for other injuries.

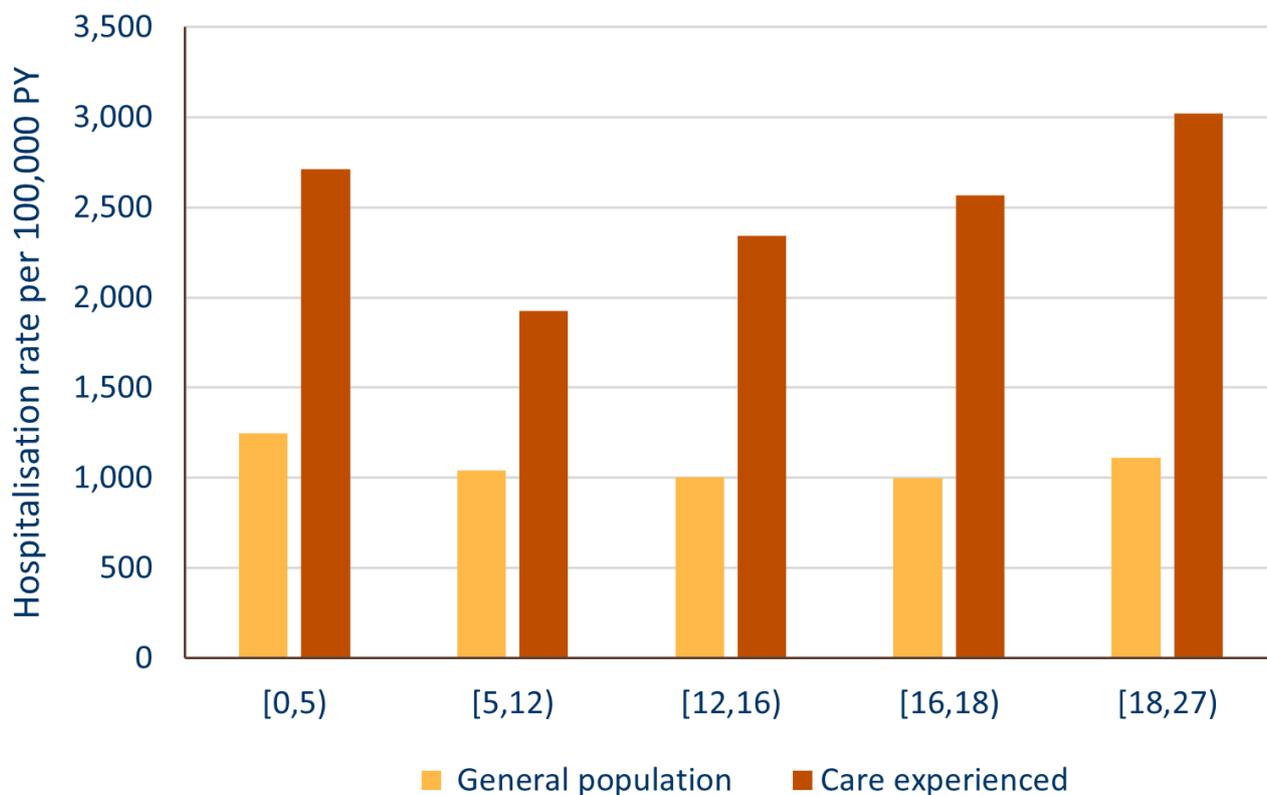


Figure 23. Hospitalisation rates of injury by age and cohort. PY – person-years.

Similar to injuries, hospitalisation rates of poisoning first decrease with age in both cohorts and increase again at age 12 (Figure 24). As rates increase, so too do the differences between the cohorts, and the increase is much more prominent for care experienced children than for the general population cohort (nearly 9-fold by ages 18 and over). In both cohorts, prior to age 12 poisoning rates are higher for males but higher for females from age 12 onwards. These presented patterns are driven by poisonings due to drugs and medication. Poisoning due to substances other than drugs and medications is more common among very young children but not after the age 5.

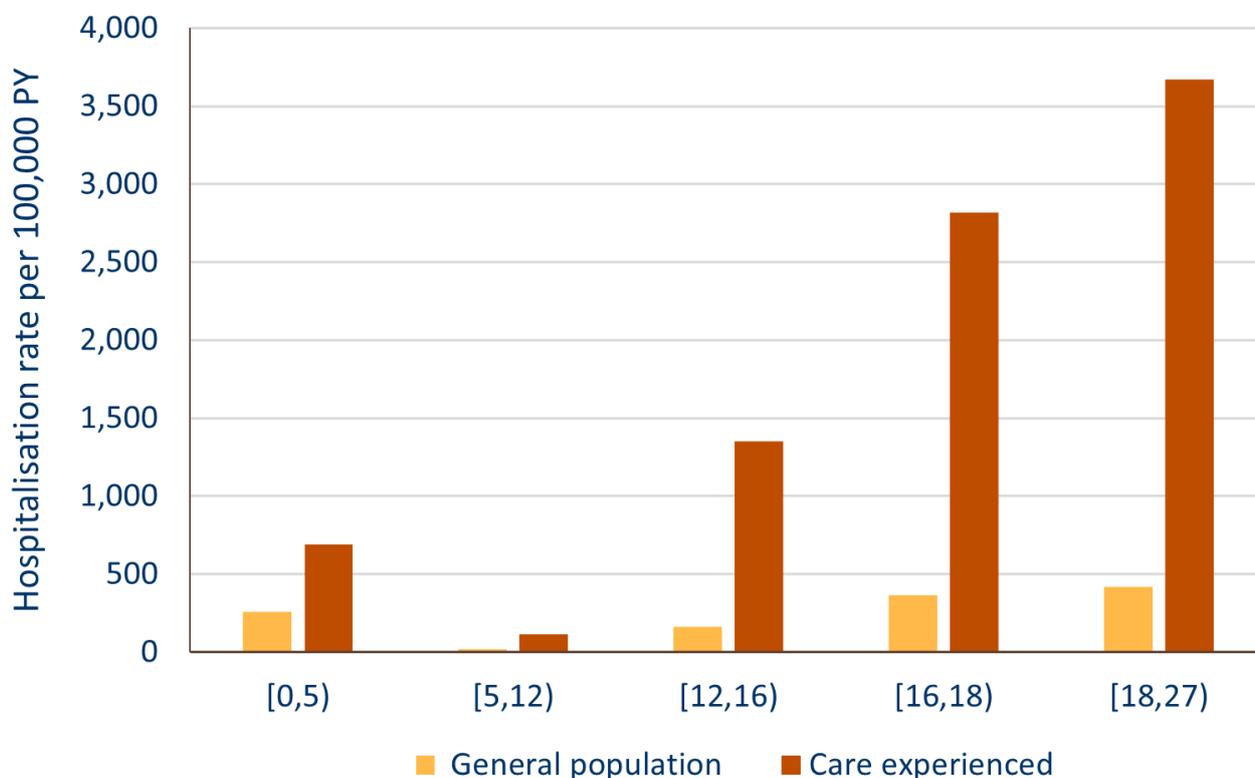


Figure 24. Hospitalisation rates of any type of poisoning by age and cohort. PY – person-years.

## Hospitalisations for chronic conditions

Many hospitalisations, both among children and adults, can be avoided with better care. In health research, conditions, and diagnoses for which timely and effective primary care can help reduce the risks of hospitalisation by either preventing the onset of an illness or condition, controlling an acute episodic illness or condition, or managing a chronic disease, are known as ambulatory care sensitive conditions (ACSC). Among children, these chronic illnesses generally include asthma, epilepsy, and diabetes (type 1). In addition, many common infections, including ear, nose and throat infections, and dental health problems, such as tooth decay, should not lead to hospitalisations among children and young people. Here, we have compared the prevalence and hospitalisation rates of the three most common chronic conditions among children – asthma, epilepsy, and diabetes.

To estimate the prevalence of all three conditions, we use both prescription and hospitalisation data. This is a common method also used in other studies. It has some

limitations, for example, not all children diagnosed with these conditions will have been hospitalised, meaning that we will underestimate the prevalence. Including prescription data allows us to capture more individuals who might have asthma, epilepsy, or diabetes, but sometimes medication commonly used for asthma or epilepsy may also be prescribed for other conditions. This means that our results may be an overestimate. In the below sections, we have compared our results to those published by others to assess the accuracy of our work. Coding schemas for these conditions are provided in Appendix Table A2.

## Asthma

Like in other UK nations, the prevalence of asthma in Scotland is high compared to the rest of the world. In 2019, approximately 10% of children aged 0-15 were reported as having doctor diagnosed asthma in Scotland, with increasing prevalence with age.<sup>61</sup> Among the youngest children, boys are more likely to have asthma compared to girls, but this changes with age and becomes more common among women in adulthood. According to Scottish Health Survey data, current asthma prevalence among children is lower than it was in 2003 (16%),<sup>62</sup> however, it is still the most common long term condition affecting children and young people, which can reduce the quality of life, requires regular treatment, and as of now, is incurable.<sup>63,64</sup> However, some children do grow out of asthma.

Table 7 shows the number and percent of children who are estimated to have had asthma at any time during the study by cohort and sex. The prevalence ranges from about 14-17% by cohort and sex but is broadly similar. Asthma prevalence in this study is slightly higher compared to most recent Scottish estimates but similar to earlier estimates cited above. Given that our data span quite a long timeframe from 1990-2016, our results are in line with what is known about asthma prevalence among children and young people.

We also looked at how prevalence and hospitalisation changes with deprivation. Among general population children prevalence increases slightly with deprivation, from 12.5% among children from the least to 15.9% for those from the most deprived areas. For the care experienced cohort, we did not note any clear patterns for asthma prevalence by deprivation.

*Table 7. Number and percent of children with asthma and hospitalised for asthma by cohort. GPC – General population children; CEC – care experienced children.*

	Children					Hospitalisations				
	GPC		CEC		Prevalence ratio CEC:GPC	GPC		CEC		Ratio of means CEC:GPC
	N	%	N	%		N	Mean	N	Mean	
Asthma	94,700	14.6	2,242	16.2	1.1	15,695	0.35	478	0.47	1.3
Female	44,376	13.9	1,057	16.8	1.2	5,785	0.30	174	0.35	1.2
Male	51,324	15.5	1,185	15.7	1.0	9,910	0.39	304	0.58	1.5

The table also shows the numbers of, and mean, hospitalisations (across children with asthma) for both cohorts and by sex. The mean number of hospitalisations ranges from 0.3-0.6 by cohort and sex, and most children with asthma are never hospitalised for this condition in our cohorts. In all, 83% of general population children and 78% of care experienced children were never hospitalised (Figure 25). Being hospitalised for asthma more than once is somewhat more common among care experienced children. In both cohorts, males are more likely to be hospitalised for asthma and repeated hospitalisations are highest for care experienced boys. While general population boys are hospitalised an average of 0.4 times, care experienced boys are hospitalised 0.6 times over the study period (Table 7).

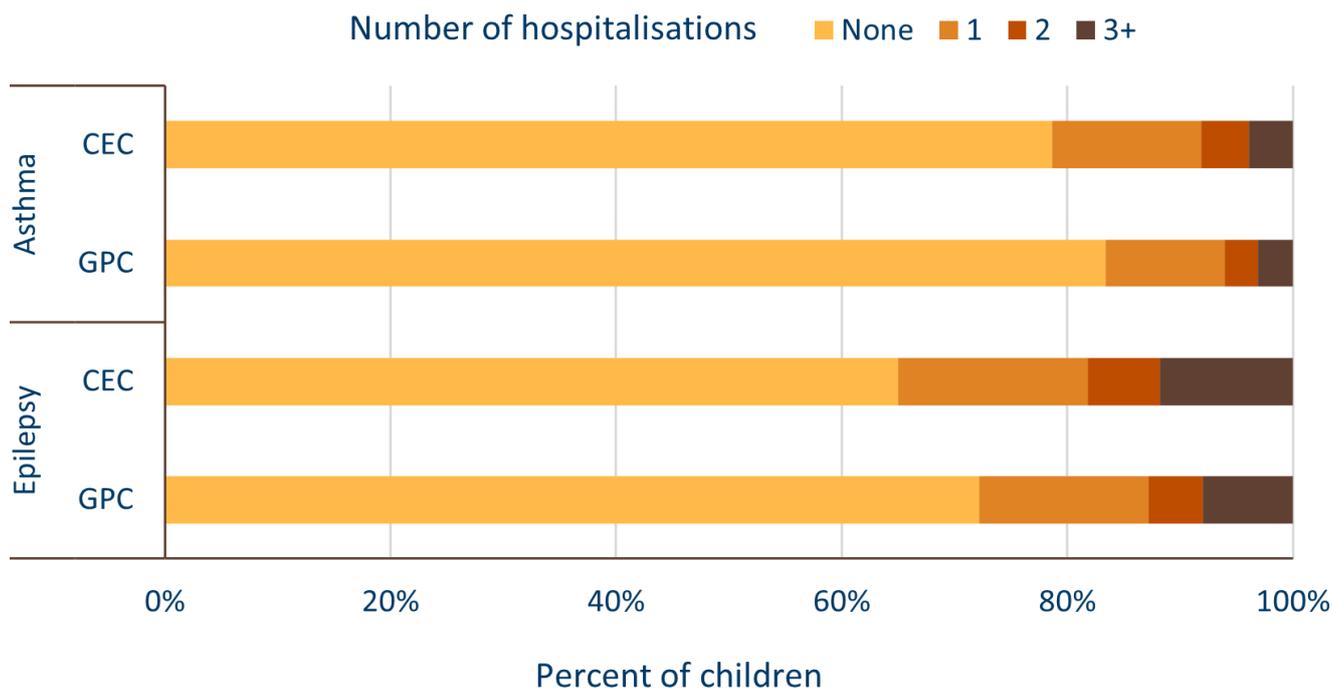


Figure 25. Percent of children with asthma or epilepsy by the number of hospitalisations and cohort. CEC – Care experienced children; GPC – General population children.

In the general population children, mean hospitalisations and hospitalisation rates increase as deprivation increases, but for care experienced children this trend is not visible.

Figure 26 shows that hospitalisation rates decrease with age for general population children. For the care experienced cohort, while these initially decrease with age they increase again at the age of 16, around the time young people leave care. In both cohorts, hospitalisation rates are higher for males before the age of 12 but become higher for females after that. The increase in hospitalisations with age for asthma among care experienced people is mostly driven by increasing hospitalisation rates for women aged 16 and older.

For care experienced children, asthma hospitalisation rates do not vary much depending on if these occur before, during, or after care, or by care type. Hospitalisation rates are highest in the youngest age groups, regardless of care placement type. However, three quarters of first hospitalisations for asthma happen before entering care, meaning that

children are likely to have been diagnosed with asthma before care. It is therefore very unlikely that being in care has contributed to developing asthma, rather, having asthma may play some role in entering care.

Overall, our data suggests that there are not very big differences in asthma prevalence between the two cohorts of children and young people. However, hospitalisations for asthma are somewhat more common among the care experienced cohort and do not decline with age in the same way compared to the general population children. Noticeably, care experienced young women have increased hospitalisations from the age of 16.

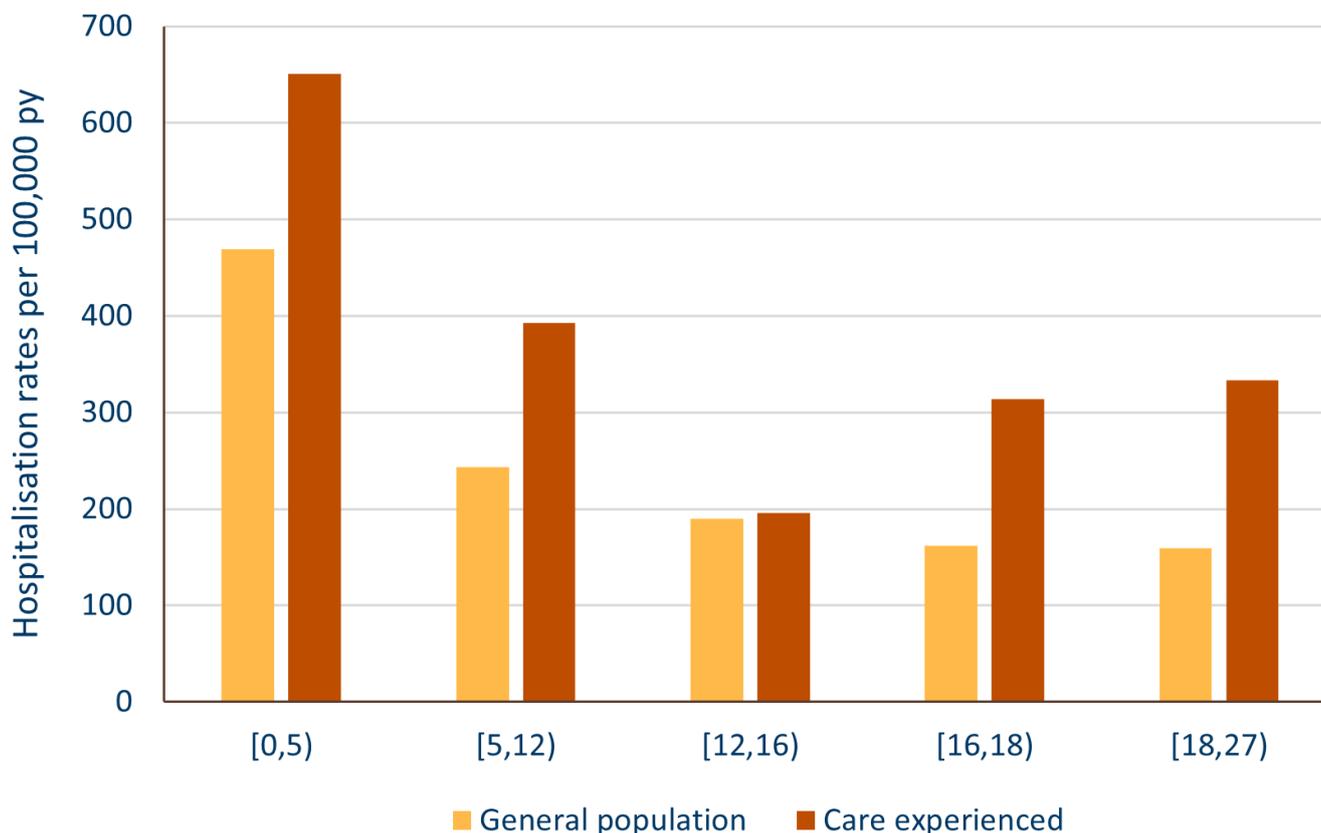


Figure 26. Hospitalisation rates for asthma by age and cohort. PY – person-years.

## Epilepsy

Epilepsy is the most common brain disorder among children worldwide with serious consequences for personal health and lifestyle<sup>65</sup> but currently there are no accurate prevalence figures for Scotland. The Scottish Paediatric Epilepsy Network estimates that in 2005 epilepsy affected around 4,200 children under 18, with 820-1,000 new epilepsy diagnoses being made each year.<sup>66</sup> This suggest that epilepsy affects around 0.4% of Scotland's under 18 population while other studies put this figure closer to 1%. Based on a report from a sample of 60 Scottish general practices, in 2012/13 an estimated number of 170 under 4 year olds, and 590 children aged 5-14 years, consulted a GP or a nurse for epilepsy at least once during the year.<sup>67</sup> Although these numbers are relatively low compared to the number of registered patients, the prevalence of epilepsy in these age groups is likely to be considerably higher as those with well-managed epilepsy do not consult GPs frequently and are not included in these figures.<sup>68</sup> Ultimately, epilepsy is a very

serious condition, associated with increased risk of mortality, including sudden unexpected death in epilepsy (SUDEP), mental health issues (such as depression and anxiety), and increased risk of hospitalisation.<sup>69–71</sup> Therefore, increased awareness and management of epilepsy are important to improve health outcomes and quality of life.

In our data, the estimated prevalence of epilepsy is about 1.7% among the general population and 3.3% among care experienced children and young people (Table 8), which is much higher than estimated in other studies. Our estimates are partly based on prescriptions and since antiepileptic medications are increasingly prescribed for conditions other than epilepsy<sup>72</sup> this could explain the higher prevalence estimated here. Only including hospitalisations will put epilepsy prevalence in the general population at 0.5% (same for men and women) and 1.2% for care experienced people (0.9% in girls and 1.3% in boys), which is close to previous estimates.

Both prevalence estimates suggest that care experienced people are about twice as likely to have epilepsy (Table 8, prevalence ratio including prescriptions). The prevalence of epilepsy (using both prescriptions and hospitalisations) increases with deprivation among the general population children; from 1.4% in the least deprived quintile to 2.0% in the most deprived areas. For the care experienced cohort, the gradient is reversed – prevalence is higher among children from the least deprived areas (5.7%) and lower among those from the most deprived areas (3.0%).

*Table 8. Number and percent of children with epilepsy and by cohort and sex. GPC – General population children; CEC – care experienced children.*

	Children					Hospitalisations				
	GPC		CEC		Prevalence ratio CEC:GPC	GPC		CEC		Ratio of means CEC:GPC
	N	%	N	%		N	Mean	N	Mean	
Epilepsy	11,334	1.7	457	3.3	1.9	9,633	0.8	643	1.4	1.7
Female	6,571	2.1	218	3.5	1.7	4,549	0.7	205	0.9	1.4
Male	4,763	1.4	239	3.2	2.2	5,084	1.1	438	1.8	1.7

As with asthma, hospitalisations for epilepsy are rare, and in both cohorts most children with epilepsy have not been hospitalised for it (Figure 25). However, the mean number of hospitalisations is just under one for the general population children and around 1.4 for the care experienced cohort (Table 8). These differences in mean hospitalisations are mostly driven by boys who have been hospitalised repeatedly. The percent of children who have been hospitalised once is only slightly higher for those with care experience, but when looking at the percent of children with two or more hospitalisations, the inequalities are more notable (18% among care experienced children compared to 13% in the general population, Figure 25).

While the prevalence of epilepsy changes with deprivation, increasing for the general population and decreasing for the care experienced people, hospitalisation rates are not affected by deprivation in our data. Hospitalisation rates decrease with age in both cohorts and this decrease is more pronounced for care experienced children and young people, meaning that differences between cohorts are reduced with age. However, at age 18 hospitalisations increase again in the care experienced cohort, reflecting the need for more support among care leavers.

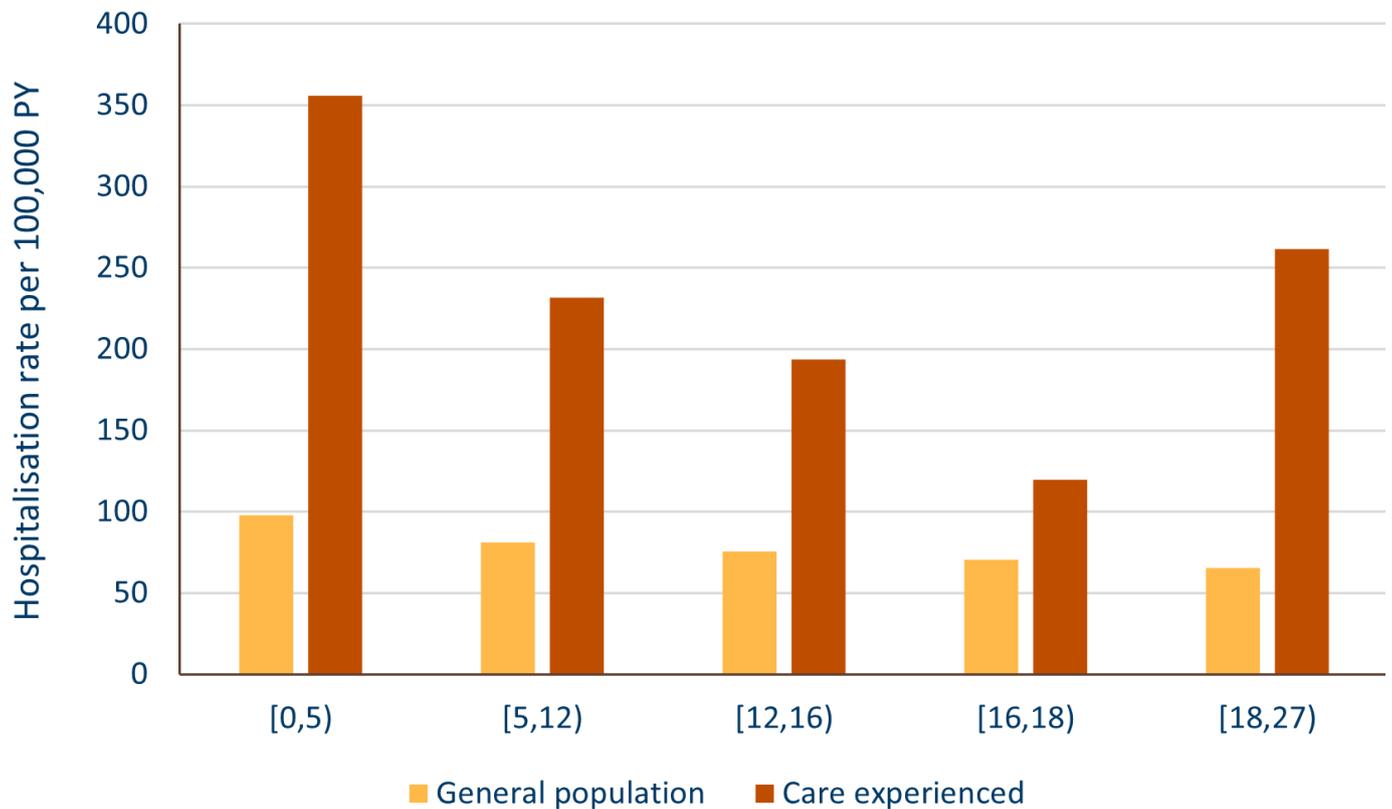


Figure 27. Hospitalisation rates for epilepsy by age and cohort. PY – person-years.

Our data do not allow us to identify the age at first diagnosis of epilepsy, but we are able to look at the age at first hospitalisation. The median age at first hospitalisation is 10 years for both cohorts and sexes. Among the care experienced cohort, the majority of first hospitalisations (64%) occur before the child enters care. This means that in most cases epilepsy will have been diagnosed before entering care and may have contributed to this. This may explain the higher prevalence of this condition among care experienced children and young people. In all age groups, epilepsy hospitalisations tend to also be higher before entering care compared to during care, suggesting that being in care may have helped to manage this condition better.

## Diabetes

The number of people with diabetes has risen steadily in Scotland and in the other UK nations in the past decade, and these increases have been observed across age groups and for both type 1 and type 2 diabetes.<sup>73,74</sup> Among children and young people, the vast majority of diagnoses are for type 1 diabetes, for which the causes are still not fully

known.<sup>75</sup> Diabetes has been linked to a range of other adverse mental and physical health outcomes (including cardiovascular and kidney disease, amputation, tooth decay, asthma, and depression),<sup>73,76–78</sup> and therefore proper management of diabetes is crucial for long-term health.

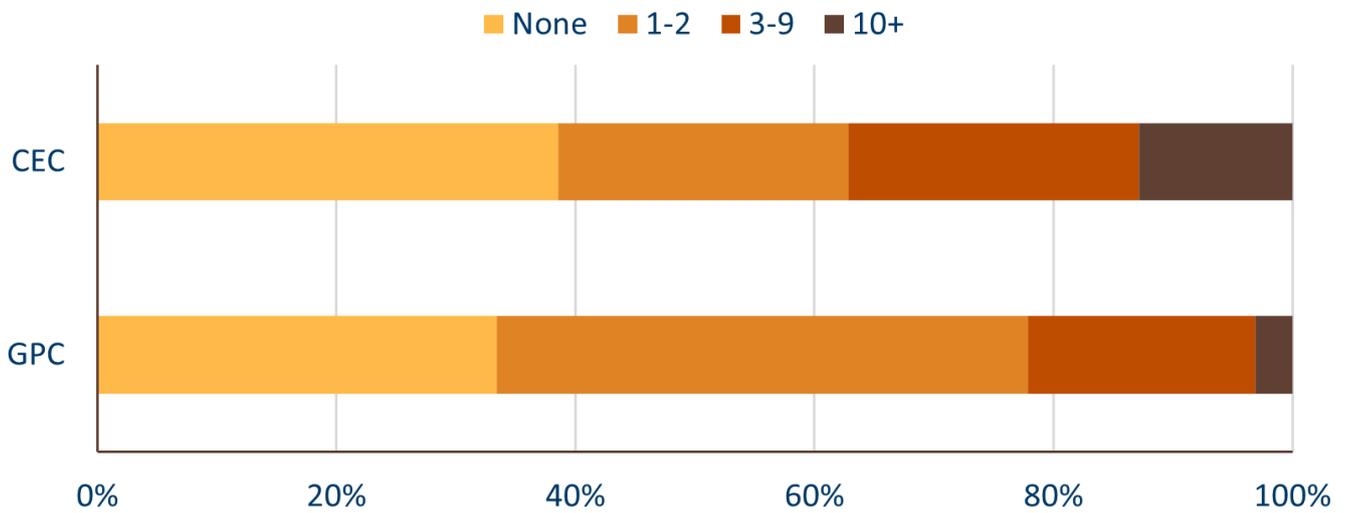
We estimate that less than 1% of all children in this study have diabetes by the time they reached ages 11-27 (Table 9). Prevalence is slightly higher among the care experienced cohort and among females, but the differences are not notable. In the below analysis we do not distinguish between the type of diabetes but, based on hospitalisation data, we can say that in about 90% of cases it will be type 1 diabetes, which is more prevalent among children and young people. This is in line with national statistics and research published in Scotland and in the UK for these age groups.<sup>73</sup>

While similar proportions of children and young people have diabetes, hospitalisations for diabetes are much more common among the care experienced cohort (Table 9). The mean number of hospitalisations for each diagnosed child is 4.5 for the care experienced cohort and 2 for the general population, meaning that the mean number of hospitalisations is 2.2 times higher among the care experienced children (Table 9, ratio of means). Differences are three-fold for boys and young men, an average 6 hospitalisations for the care experienced cohort compared to 2 in the general population.

*Table 9. Diabetes prevalence and hospitalisations in the two cohorts. GPC – General population children; CEC – care experienced children.*

	Children					Hospitalisations				
	GPC		CEC		Prevalence ratio CEC:GPC	GPC		CEC		Ratio of means CEC:GPC
	N	%	N	%		N	Mean	N	Mean	
Total	5,472	0.8	140	1.0	1.2	11,167	2.0	628	4.5	2.2
Female	2,946	0.9	87	1.4	1.5	6,150	2.1	311	3.6	1.7
Male	2,526	0.8	53	0.7	0.9	5,017	2.0	317	6.0	3.0

This difference is driven mostly by children and young people who are hospitalised repeatedly for diabetes (Figure 28). For example, the percent of those who have not been hospitalised is similar in the two cohorts and even slightly higher for the care experienced children. About 44% of general population children with diabetes are hospitalised 1-2 times, but this is only 24% among those who have been in care. While only 3% of general population children have been hospitalised 10 or more times, nearly 13% of care experienced people have been hospitalised that often. Differences between cohorts are bigger for males compared to females.



Percent of children by the number of hospitalisations

Figure 28. Children by the number of diabetes hospitalisations and cohort. CEC – Care experienced children; GPC – General population children.

Unlike for asthma and epilepsy, hospitalisation rates for diabetes increase with age. This is expected as the prevalence of diabetes increases with age and type 1 diabetes is often diagnosed around ages 10-14. For the care experienced cohort, the increase in hospitalisation rates is much more notable, leading to increased inequalities in hospitalisations between the two cohorts with age (Figure 29). While there are only small differences in hospitalisation rates before the age of 12, these become 4-fold by ages 18 and over.

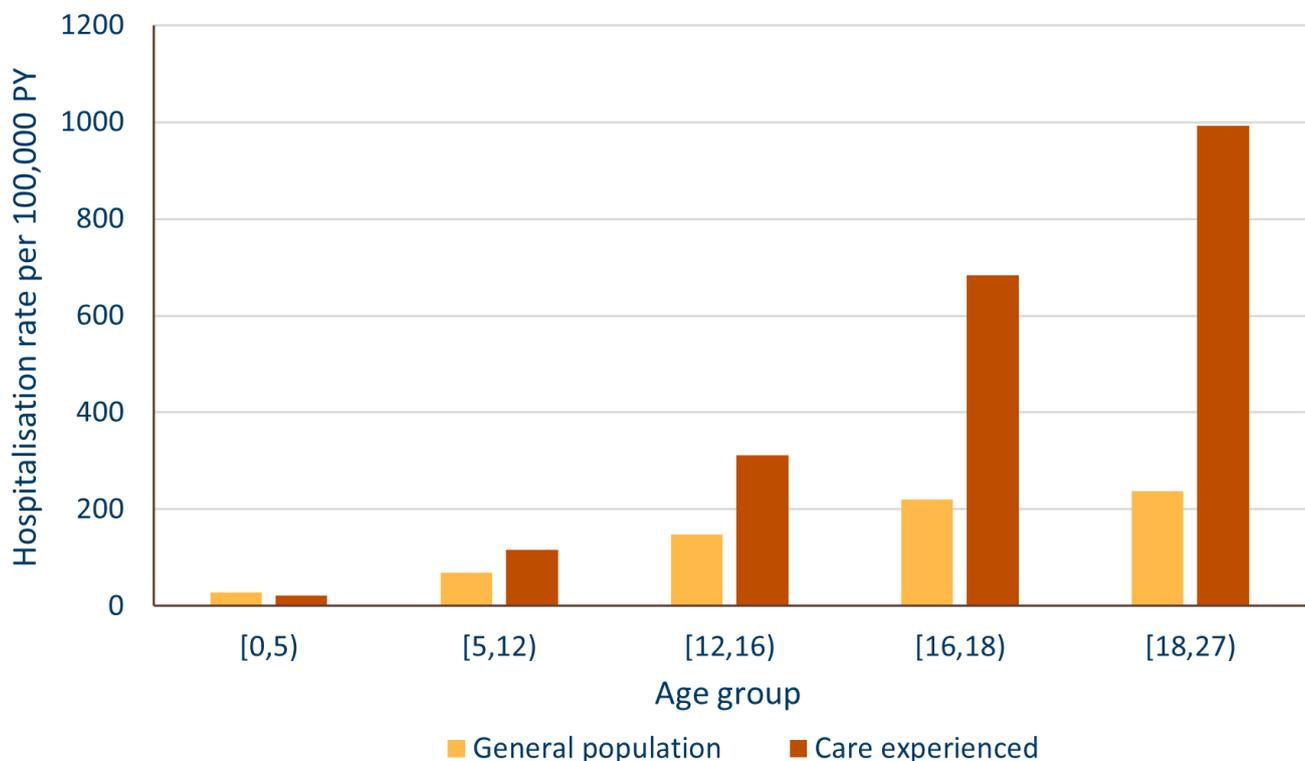


Figure 29. Diabetes hospitalisation rates by age for both cohorts. PY – person-years.

Using slightly larger age groups, we were also able to look at hospitalisation rates for care experienced children by the timing of these events relative to the journey through care. What we can note is that hospitalisation rates are often higher outside care episodes (Table 10). For example, at ages 12-16, hospitalisation rates are nearly three times as high before the child enters care compared to during a care episode and rates increase again after the child leaves care. When comparing diabetes hospitalisation rates between types of care placements, rates are generally lowest for foster care and highest for residential care. This relationship might be related to children in residential care having more complex health needs.

*Table 10. Diabetes hospitalisation rates (per 100,000 person years) before, during and after leaving care by age.*

Age group	Before entering care	During care	After leaving care
[0-12)	80.3	71.2	70.8
[12,16)	645.0	212.9	342.1
[16,27)	N/A	737.3	889.9

Our analysis of asthma, epilepsy, and diabetes (type 1), the three most common chronic conditions in children and young people, has shown that care experienced children have higher hospitalisation rates for all three conditions. The higher hospitalisation rates among care experienced people, often peaking before and after care, may be indicative of the difficulties people with chronic conditions experience. It also highlights the support all families and young people need in coping with these conditions.

Very few children in our data are likely to have two or all three of these chronic conditions at the same time, among general population this is less than 0.6% and among care experienced children just over 1%. While co-morbidity is very rare among children, having more than one chronic health condition is more common in the care experienced cohort. As we have noted, these conditions (particularly asthma and epilepsy) will have in most cases been diagnosed before the child entered care. Thus, they may have contributed to entering care in the first place. The data do not suggest that care has caused these conditions or that being hospitalised for these conditions is more likely while in care compared to before or after care.



# Conclusions

The UK government considers it our moral, social and economic duty to give everyone the opportunity to flourish, live longer lives, and benefit from rises in living standards and wellbeing.<sup>79</sup> The Scottish Government has promised that all children, including those in care, will be listened to, have a right to safe, loving relationships, and can access a supporting system to help them and their families in times of difficulty.<sup>16</sup> Both of these commitments include the rights of care experienced children and young people to have the same chances as everyone else to live healthy, safe and happy lives.

Unfortunately, evidence across the UK shows that care experienced children and young people have higher rates of ill health and mortality compared to children and young people who have not been in care.<sup>1,2,43</sup> This research has highlighted inequalities in mortality, mental health, chronic health conditions, such as asthma, epilepsy and diabetes, and injuries. In many of these examples, the differences between cohorts are quite stark and cannot be explained by the lower socioeconomic background of care experienced children and young people. Children who enter care have faced adversity or trauma in their lives over and above socioeconomic disadvantage, and these negative experiences have a strong relationship to health across the life span.

The care system can help children flourish, overcome the experienced adversity and improve health. Our work has shown that sometimes health outcomes are better while the child is in care, for example, hospitalisation rates are lower for diabetes, epilepsy, and mental health due to substance abuse while the child is in care. However, for some conditions, such as due to severe stress, hospitalisations are highest while in care, emphasising the need for carefully managing transitions into care and between placements. Our results also show that hospitalisations can increase after young people leave care, such as for depression and chronic conditions, emphasising the need for more support after formal care.

It can sometimes be difficult to determine the direction of causality between experiencing care and poor health. Children with underlying health conditions may be more likely to enter care in the first place, which may be one of the reasons we see a higher prevalence of some chronic conditions (e.g. epilepsy) and illnesses among care experienced children. This highlights the support all families with children experiencing additional health needs require.

Improving the health and lives of children has a substantial impact on the future economy and wellbeing of the society. The World Health Organisation has called addressing childhood health inequalities “the most effective means of improving population health and reducing inequities”.<sup>80</sup> This is especially true for children who been in care or faced other adverse childhood experiences (ACEs) as they are more likely to have ill health and reduced life-expectancy. The combined ACE attributable costs in the UK have been estimated to be 78.6 billion USD, approximately 2.8% of GDP.<sup>81</sup>

Our report has described a selection of health outcomes among children born in Scotland between 1990-2004. These are young people who are now starting independent life,

entering higher education, beginning their working careers, and forming new families. They still have most of their lives ahead of them and their health and experiences will be impacting Scottish society in the decades to come. If deprivation, drug abuse, poor health behaviours (lack of exercise, smoking and harmful drinking) and mental ill health are what children witness around them, it will be difficult for them not to be affected by this. Improving the economic circumstances for these young people and reducing income inequalities will have a substantial impact on health outcomes and on what Scotland will look like in the future.

## Strengths and limitations

The CHiCS project is the first national longitudinal data collection in the UK that compares the health of care experienced children to that of general population children. In addition to the large population-wide sample and a long follow-up, other main strengths of the work include the wide range of health outcomes we can look at and the high quality and representativeness of the data. Together, these strengths have and will allow for robust and detailed analysis that can be used to make recommendations to improve health and other life outcomes for people with experiences of care.

The work presented here also has limitations. For example, we exclude children who have been informally looked after, that is living away from their parents, with friends or relatives, but without formal social care intervention. These and other children on the edges of care are not recorded in data collections that could be linked to health outcomes. The outcomes and contextual factors we have been able to include in this analysis are limited by what data is systematically and uniformly collected by public authorities. It currently lacks information on parents, their education and health, and children's relationships with friends and families.

Our work is representative of people born in Scotland between 1990-2004 and the study ended in 2016. The results presented here do not reflect recent changes and might not reflect health outcomes of children who are currently in care or the inequalities between care experienced and general population children. It is possible that children's health has improved over time and differences between children have reduced, but this can only be concluded with any certainty with new research.

We did not cover the period of the COVID-19 pandemic or the national lock-downs, which have had a substantial impact on all of our lives. It is too early to conclude what effect this event has had on the health of children and young people, but participants at our knowledge exchange event raised concerns over reduced access to services (Figure 30). Again, future research will be able to tell us what effect the pandemic and lock-downs had on children's and young people's health.

**COVID: online services didn't work for everyone and face to face appointments were needed**

**Pandemic will reduce the availability of resources at a time when there will be even greater need**

*Figure 30. Participant views on the effects of Covid-19 pandemic and lock-downs on children's services.*

Despite this, we have been able, for the first time, to show relevant, population-wide, and representative evidence on the health of care experienced children compared to the general population. Our hope is that the CHiCS study acts as a source of information for future change planned by the Scottish Government, PHS and Care Review. The findings of our study provide the evidence base that clearly shows the need for transformational change in how we care for children and can be used to monitor change over time to understand if progress towards reducing health inequalities is being achieved.

## What next?

After years of working on this research project, it feels strange to say that we are really just at the beginning in understanding the health outcomes for care experienced children and young people, but this is the truth. This report has only looked at a few outcomes and work to study the differences in other areas of health is ongoing. Our next focus will include sexual and reproductive health for which data is primarily only available for the young women in our cohorts. We hope that additional results on these outcomes will be available within a year.

A worthwhile direction for future research would be to identify and explore the issues faced by unaccompanied minors in Scotland who are 'looked after' by local authority social services. In the last decade, the overall number of asylum applications lodged by unaccompanied minors in the UK has risen from 1,513 applications in 2010 to 4,382 in 2021, with most applications being made by males.<sup>82,83</sup> Although the exact number of unaccompanied minors in Scotland is unclear, it is estimated that at least five unaccompanied children under the age of 18 arrive in Scotland and claim asylum each month.<sup>84</sup> Referrals to the Scottish Guardianship Service (SGS) also provide some estimates of the numbers. For example, between 2010 and 2021 the SGS has supported 750 unaccompanied children.<sup>85</sup>

Unaccompanied children arriving in the UK and seeking asylum are entitled to the same level of support and services as all looked after children and have similar needs in terms of health, education, and safety. However, compared to UK-born care experienced children, unaccompanied minors are also subject to immigration laws, which can make planning for their future difficult.<sup>86</sup> They may also have additional mental and physical health needs related to adverse events they have experienced prior to their move and during their journey. For example, indicators of human trafficking and exploitation have been present for almost sixty percent of all unaccompanied children referred to the SGS.<sup>85</sup> Communication issues due to language barriers can also be present, and in many cases, this slows down the process of accessing and engaging with the services they are entitled to.<sup>87</sup> Although having access to interpreting and translation services can be helpful, effective communication is not always possible due to the issue of trust as children might not share needed information when an unknown third party is introduced.<sup>88</sup>

Finally, we have requested permission to extend the study, both in terms of the follow-up period, taking this to the end of 2022 (including the national lock-downs) and in scope, such as including childhood vaccinations, maternal health and health behaviours before birth, and birth outcomes for the two cohorts of children and young people. This will allow us to better understand how preventive health care and early life health affects outcomes in later life and whether these contribute to entering care in the first place.

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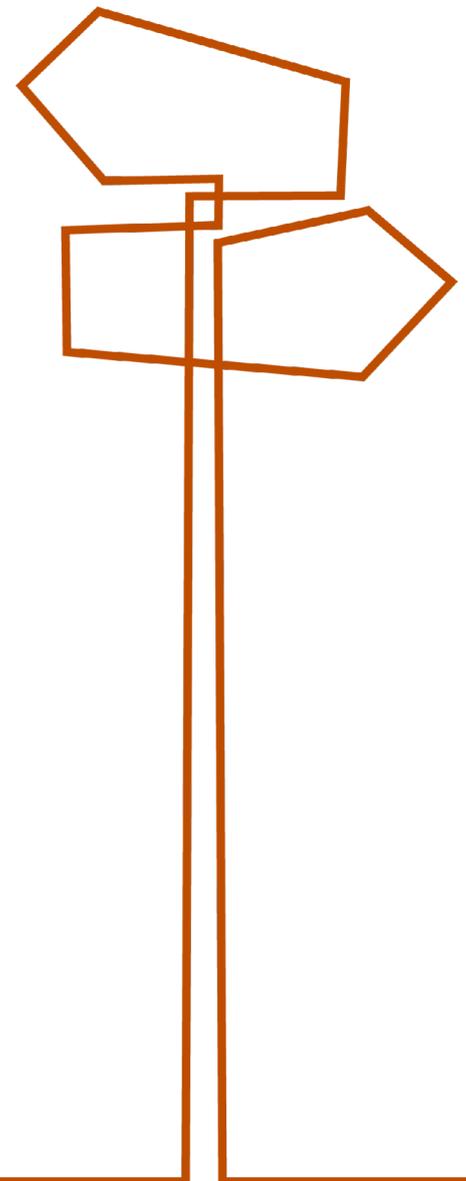
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# CHiCS



## Study details

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## Ethics

Ethical approval was obtained from the University of Glasgow College of Medicine, Veterinary and Life Sciences Ethics Committee [Project No: 200160031].

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# Appendix

Table A1. Sources of data included in the CHiCS study.

Data set	Time period	Brief description of data
<a href="#">Children Looked After Survey</a> <sup>1</sup> (CLAS)	From 2009/10, for each year until 2016/17	Individual level survey data on Looked After Children. Includes information on sex, age in months, disability, care episodes, placement type and duration and number of placements. Children in care were included in the study if they were formally looked after at home or away from home in foster, kinship or residential care between 1st August 2009 and 31st July 2010.
<a href="#">Pupil Census</a> <sup>1</sup>	From 2009, for each year until 2016	The annual school Pupil Census collects data on pupil characteristics. Data from the Pupil Census linked in this study includes information on sex, date of birth, disability, and area of residence. Children and young people in the general population were those who were included in the 2009 Pupil Census but were not included in any of the CLAS returns over the duration of the study.
<a href="#">Birth registrations</a> <sup>2</sup>	1990-2004	Children's own birth registrations includes information on sex, area of residence at birth, maternal age and parental employment status at birth.
<a href="#">Death registrations</a> <sup>2</sup>	2009-2016	Deaths are recorded for all children and young people in the study. Data includes age at death, underlying cause of death and area of residence at the time of death.
<a href="#">Scottish Morbidity Records</a> <sup>3</sup> (SMR 00, 01, 02, 04)	1990-2016	Scottish Morbidity Records contain information on hospital admissions in Scotland. This study links to outpatient attendance (SMR00), general/acute inpatient and day case (SMR01), maternity inpatient and day case (SMR02) and mental health inpatient and day case (SMR04) records. These are available from 1990 allowing for consideration of children's health from birth.
<a href="#">Accident and Emergencies</a> <sup>3</sup> (A&E)	Mid 2007-2016	Provides information on the number of accident and emergency attendances per year for each child and young person in the study.
<a href="#">Prescribing Information System</a> <sup>3</sup> (PIS)	2009-2016	Data on all prescriptions prescribed and dispensed in the community in Scotland. Data is provided on the number of prescriptions, given by British National Formulary (BNF) chapter and section code.

<sup>1</sup> Data provided by the Scottish Exchange of Data (ScotXed) within the Scottish Government

<sup>2</sup> Data provided by National Records of Scotland (NRS)

<sup>3</sup> Data provided by NHS Scotland

Table A2. Coding rules for health outcomes.

Diagnosis	Deaths and hospitalisations		Prescriptions	
	ICD-10, from 1996	ICD-9, pre 1996*	Prescription type	BNF section codes
Deaths				
External causes	Based on the four causes below			
Suicide	X60-X84, Y10-Y34, Y87			
Drugs	F11-F16, F18-F19			
Accidents	V01-V99, W00-X59, Y85-Y89, excl. Y87			
Assault	X85-Y09			
Mental health	Chapter V minus intellectual disability		Mental health	
Any MH hospitalisation	F00-F69, F80-F99	290-316	Antidepressants	4.3
Substance use	F10-F19	291, 292, 303, 304, 305	Hypnotics & anxiolytics	4.1
Of this: Alcohol	F10	291, 303	Substance dependence	4.1
Other (e.g. caffeine)	F13-F19	292, 304, 305	ADHD	4.4
Cannabinoids	F12		Psychoses	4.2
Opioids	F11			
Mood disorder	F30-F39			
Of this: Depression	F32, F33			
Bipolar disorder	F30-F31			
Neurotic disorder	F40-F48	300		
Of this: Anxiety	F41			
Severe stress	F43			
Injuries and poisoning				
Any injury	S00-T35	800-959, 990-999		

Of this: Head	S00-S09	800–804, 830, 850–854, 870-873, 910, 918, 920-921, 925, 930-932		
Arm and hand	S40-S69	810–819, 831-834, 840-842, 880–887, 912-915, 923, 927		
Leg and foot	S70-S99	820-829, 836-838, 844-845, 890-897, 916-917, 924, 928		
Other injuries	S10-S19, S20-S29, S30-S39, T00-T07, T08-T14, T15-T19, T33-T35	805-809, 835, 839, 843, 846-848, 860- 869, 874-879, 900-909, 911, 919, 922, 926, 929, 933-939, 950-959, 990-999		
Burns	T20-T32		940-949	
Any poisoning	T36-T65		960-989	
Of this: Drug poisoning	T36-T50		960-979	
Analgesics	T39		965	
Psychotropics	T43		969	
Antiepileptic	T42		966, 967	
Narcotics	T40			
Other drugs and medications	T36 - T38, T41, T44 - T50		960-964, 968, 970-979	
Poisoning not related to drugs and medications	T51-T65		980-989	
Alcohol	T51		980	
Chronic conditions				Chronic conditions
Asthma	J45-J46		493	Asthma** 3.1, 3.2, 3.3
Epilepsy	G40-G41		345	Epilepsy 4.8
Diabetes	E10-E14		250	Diabetes 6.1

\* No deaths and a small proportion of hospitalisations occurred before 1996 and therefore not all ICD-10 codes were mapped to ICD-9.

\*\* If prescribed more than once in a 12-month period.