# Scoping the feasibility of a new longitudinal birth cohort study of children supported by the child welfare system: Recommendations for next steps

Nuffield Family Justice Observatory

CENTRE FOR
LONGITUDINAL
STUDIES

Recommendations paper

# Background

## Context

Nearly half a million children under the age of five live in households with domestic abuse, parental mental health problems, or parental drug/alcohol abuse.[1] There is a significant and growing body of evidence that these experiences have harmful effects on children's well-being, development in early childhood and later life outcomes.[2]

Moreover, the proportion of newborns involved in infant care proceedings has doubled in recent years from 15 to 35 per 10,000 children between 2007 and 2017.[3] While we now have more robust evidence on the predictors of abuse and neglect, as well as the impact on children[4], we still know very little about the early physical, cognitive, social and emotional development of children supported by the child welfare system in the UK.

The recently published *Independent Review of Children's Social Care* therefore makes the case for a new cohort study of care experienced children.[5]

*"Better data is needed on the health outcomes of care experienced people. Its absence limits policy making and demonstrates that society places too little value on the health outcomes of care experienced people."* (p36)

*"Government should also launch a new cohort study which tracks the health outcomes of care experienced people and helps to gather other missing data on housing, education and employment outcomes."* (p175)

There is also a critical gap in our understanding not just of the later health, housing, education, and employment outcomes of children in need or experiencing care, but also in our understanding of the environments in which they are raised, and their developmental trajectories, especially during the very critical and formative periods of development in early life and across childhood.

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[1] Children's Commissioner for England. (2021). Local vulnerability profiles [online]. Children's Commissioner for England. Available from: www.childrenscommissioner.gov.uk/vulnerable-children/local-vulnerability-profiles

[2] Asmussen, K., Fischer, F., Drayton, E., and McBride, T. (2019). Adverse childhood experiences: What we know, what we don't know, and what should happen next. London: Early Intervention Foundation.

[3] Broadhurst, L., et al. (2018). Born into care: newborns in care proceedings in England. London: Nuffield FJO. Available from: https://www.nuffieldfjo.org.uk/resource/born-into-care-newborns-in-care-proceedings-in-england-final-report-october-2018

[4] Radford, L., Corral, S., Bradley, C., and Fisher, H. L. (2013). The prevalence and impact of child maltreatment and other types of victimization in the UK: findings from a population survey of caregivers, children and young people and young adults. Child Abuse & Neglect, 37(10), pp. 801–813; Ashton, K., Bellis, M. A., Davies, A., Hardcastle, K. A., and Hughes, K. (2016). Adverse childhood experiences and their association with chronic disease and health service use in the Welsh adult population. Cardiff: NHS Wales.

[5] MacAlister, J. (2022). The independent review of children's social care: Final report. The independent review of children's social care. https://childrenssocialcare.independent-review.uk/final-report/

Such evidence is needed to answer vital questions about the needs and circumstances of parents and their children, and when services can best intervene to support better outcomes for young children.

This evidence has not previously been available because babies and young children who are especially vulnerable, such as those looked after or on the edge of care are generally absent from national longitudinal studies of child development. Although the UK has a world-leading portfolio of longitudinal population-based studies, there is a critical gap when it comes to children supported by the child welfare system. This is largely due to the challenges of identifying, recruiting, and retaining them, given the difficult and often unstable circumstances that highly vulnerable infants and young children experience.

Deficiencies in administrative data and lack of linkage of social care administrative data into cohorts, the underrepresentation of these children in cohort studies to date, as well as the relatively few qualitive studies tracking processes and journeys from different perspectives, serve to limit the ability to create evidence-informed policy**.**

# Scoping study and the Early Life Cohort

The Nuffield Family Justice Observatory and Centre for Longitudinal Studies have therefore carried out a scoping study to understand the need for, and feasibility of, setting up a new longitudinal birth cohort study of vulnerable children in their early years. Our focus is largely on a quantitative study, given the separately funded strand of work within the Early Life Cohort Feasibility Study on qualitative approaches.

Together we carried out an initial research-based scoping exercise to investigate how vulnerable children have been captured in previous national and local birth cohort studies, the key challenges arising, and identified a number of ongoing studies in the UK and elsewhere with valuable relevant experience.

Two workshops were held during 2022. The written outputs of the work to date have been two participant briefings (one for each workshop) and a summary of the second workshop, which was circulated to stakeholders. These are available in the annex to this document, and contain the outputs from the detailed scoping work undertaken which supported the workshop discussions and the recommendations we have made. The agenda and participant attendee list for each workshop is also available in the annex.

## Workshop 1

Workshop 1 in June 2022 brought together academics and other experts working in the field to discuss potential challenges and to share examples of best practice. The focus of the workshop was on how vulnerable children could be identified, recruited and retained prior to entry into the formal school system. Eleven academics and experts attended in addition to the six organisers/speakers. Following an introduction to the context and aims of the workshop, the discussion was divided into four parts:

1) Experiences of the successes/challenges of existing birth cohorts with recruiting vulnerable children followed by a discussion on possible sampling, recruitment,

retention and data access strategies. The group heard about the identification of vulnerable children and mothers from administrative data, and the experiences of the Permanently Progressing study.

2) The possibilities of using linked data to study vulnerable children with lessons learned from ALSPAC.
3) Adopting innovative approaches to measurement and filling evidence needs (including lessons learned from other studies)
4) Next steps regarding timing, scales, cost and risk.

## Workshop 2

Workshop 2 in November 2022 brought together key stakeholders in UK government departments, devolved nations' governments, practitioners, and funding bodies, along with academics and experts working in the field, to further develop our understanding of evidence needs, and to consider some specific design options for taking forward a longitudinal study of vulnerable children. There were 26 attendees in addition to the 9 speakers/organisers. There were three parts to the workshop:

1) The evidence gaps (and what kind of study could fill these gaps) from a government perspective
2) Key challenges for a future study including issues and alternative approaches for identifying and sampling those under 5. The group heard about research using the E-Child study on identifying children at risk, and the E-Risk study which sampled young mothers with twins. It also heard about the experiences of the Permanently Progressing study and the Care Pathways and Outcomes Study in Northern Ireland.
3) Next steps including the key feasibility questions, the prospect of obtaining a sample, the scale of the sample frame, cost, methods and possible funding.

# This report

The purpose of this document is to set out recommendations for next steps, based on the scoping work carried out (see introduction, and annexes). In summary, we recommend that should a main Early Life Cohort (ELC) study be commissioned, this should include a boost of young mothers, ideally identified as being young at first birth. A key feasibility issue here relates to the potential for further sampling of vulnerable children in addition to a young mother boost, which is discussed in detail in Recommendation 2, on sampling, below. Recommendations 3 and 4 cover approaches to data collection and measurement, and sample sizes and cost.

Note that these recommendations will be further explored in a new project 'Scoping the feasibility of a new longitudinal birth cohort study of children at risk of poor outcomes across the UK' led by Professor Lucy Griffiths at University of Swansea. This work is funded by the ESRC's "Transforming data collections infrastructure for social science" grant, and will run between 1st July 2024 and 30th June 2025.

# Recommendations

## Recommendation 1. Scientific and policy evidence needs

Having established that there are major evidence gaps in our understanding of vulnerable children and their families (see Box 1, below), it was evident from Workshop 2 and follow-up discussions with the Department for Education (DfE) that a more granular understanding of what a new study would be for, what problems it will solve, and which policy issues it will address is now needed in order to make the case within government for such a study.

**Box 1. Summary of findings on scientific and policy evidence needs from workshop 1 and 2**

**Why is a new longitudinal study of vulnerable children needed?**

- To understand the early health and developmental pathways of vulnerable children from birth (preferably before birth).
- To inform what services, including early interaction with health and care services, might serve their needs better – with early prevention as well as early mitigation as key aims.
- To better understand the environments in which children are living and their pathways over time – e.g.
    - What are the backgrounds, experiences, relationships and support networks of birth parents, siblings and other carers?
    - What are the challenges families face in looking after their children?
    - What happens to families when they are stepped down from social care?
    - What happens to children who leave social care to be adopted or are on an SGO?
- Why are services more effective for some families than others? How is this affected by the quality/type of services they access?
- What are parents' experiences of children's services and interventions, their expectations and unmet needs? What other services are they receiving?
- How do the needs of vulnerable children and their families develop over the life course and what are the critical times when children may require specific interventions to support their success and well-being as they progress through childhood and adolescence?
- What are the long-term outcomes of care experienced people, and how are these shaped by their childhood experiences?

### Recommendations and delivery:

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| **Recommendation 1a.**<br>Government policy evidence needs – these could be scoped by government departments, or could be set up as a facilitated workshop by the ELC study or other commissioned team. |
| **Recommendation 1b.**<br>Non-government policy and practice stakeholders – a discovery workshop should be held focusing on evidence needs and specific research questions. |
| **Recommendation 1c.**<br>Scientific needs – an academic consultation could be carried out (but this could also potentially be deferred to a later stage, e.g. post-commissioning, and focused on content rather than design). |

# Recommendation 2. Target population and sampling strategy

One key area of discussion in the workshops was to determine the population of interest, given the main drivers of scientific need: it was determined that this should be vulnerable children in their early years who are *at heightened risk* of experiencing a range of adversities, which would include, but is not necessarily limited to, children/families in contact with child welfare services. Targeting children *at risk* rather than only those realising certain adversities, enables important research on prevention strategy.

Another key aspect of the work was to discuss possible approaches to sampling, given the target population. Overall, we identified three main approaches to sample design and sampling (see Box 2, below), and more detailed investigations are now required to establish the acceptability and feasibility of each of these three main sampling approaches.

**Box 2. Summary of findings on target population and sampling approach**

Our primary concern is children whose early life experience is significantly disadvantaged because they are maltreated and/or living in circumstances which are likely to have a profound and lifelong impact on their health and wellbeing.

### Defining vulnerability

We initially started by defining the target population as children who have had some contact with child welfare services, but through workshop discussions we recognised this is too narrow (see 'how to define vulnerability, workshop 2 summary'). The kind of adversities the group were concerned about included physical abuse, sexual abuse, emotional abuse, witnessing domestic violence, neglect, having a close family member who misuses alcohol or drugs, having a close family member with mental health problems, living with someone who has gone to prison, or losing a parent through divorce, death or abandonment. This means that while many of the children experiencing these will be known to children's services, some are not (e.g. lots of children are in kinship care, some are living in adversity but not seen by children's services, and around 25% of referrals to children's services result in no action). It is also important to have a wider sample beyond those who have come to the attention of children's services, because it helps us to understand the relative impact of social care intervention, as well as why some children in adverse circumstances do better than others. Additionally, it is useful to study populations of children who are at risk of these adversities, but where these risks are not realised, to be able to inform prevention strategies.

## Sampling

It is evident from existing studies that population cohorts that do not over-sample families or children who are highly vulnerable do not capture sufficiently high numbers of these children. Th group identified three main approaches to sampling that could be taken in order to sample children at disproportionately high risk of experiencing such adversities. Options A and B seek to identify vulnerable mothers who have a higher risk of having children who experience adversities. Option C involves directly recruiting vulnerable children. All the approaches discussed so far relate to England and the full UK approach still needs to be fully determined.

### Approach A: sampling vulnerable mothers through birth/health records

One option would be to identify vulnerable mothers, who are identifiably at higher risk of having children who experience adversities. This approach, which doesn't rely on the emergence of damaging behaviour in order to be sampled for the study, generates a broader sample of children and is also less stigmatising for those taking part in the study, which will also assist with recruitment and retention.

#### Option 1:

Sampling teenage or young (e.g. up to age 25) mothers, ideally *at first birth*. This would require sampling from birth registration data (ideally linked to maternity records as in ELC-FS). One case where this was successfully done was for the E-risk study, where the ONS identified those who had a prior teenage birth from whom they sampled twins; how this would be done with linked ONS HES data provided by NHS England would need to be determined.

#### Option 2:

Mothers whose vulnerability status is based on prior admissions to hospital relating to violence/drug or alcohol issues, self-harm or mental health or behavioural conditions. By augmenting maternal age with other information obtained from prior health records, Hospital Episode Statistics maternity data would provide more characteristics (besides age) on which the sample could be drawn.

### Approach B: sampling vulnerable mothers through DfE records

Option 1:

Mothers whose vulnerability status is based on DfE records of if they were exposed to children's social care services while a child. Births would be sampled from among mothers who were CiN or CLA and/or had Special Educational Needs (SEN) support during primary and/or secondary school. Women whose pupil matching reference numbers had been flagged based on their SEN/social care history could then be identified using either the ECHILD linkage spine, or by linkage by personal identifiers to their birth registration via ONS/NHS England. However, in practice this approach will restrict the study to young mums because of data longevity (e.g. CiN complete only from 2012 such that in 2024 CiN history would exist for 11-16 on women delivering aged 25 or below; SEN can be used further back – but still <30 (this will need to be confirmed).

Option 2:

Mothers whose vulnerability status is based on an attainment measure for skills (e.g. in school census year 10 or 11, but few GCSEs (e.g. 18% have <5 GCSEs grade A* to C – but could use other thresholds – hardly any have no qualifications). This might be less sensitive and more acceptable as the research might be more obviously linked to interventions preconception and pre-parenting for girls lacking qualifications/with limited skills. Or a joint strategy of any births to mums <20 (as per a i) AND births in sampling years to older mums with low qualifications.

### Approach C: Sampling children using child welfare records

Vulnerable children: sampling at the national level using child welfare records. Note that scientifically, restricting the cohort to children in contact with social care would focus less on prevention and more on mitigation and social care responses.

Option 1:

The DfE collects CiN and CLA data for children of all ages, but do not have the names and addresses of pre-school children. The DfE could request names and addresses from local authorities of CiN and CLA children age under 5 and there appears to be a legal gateway that would enable this. However, there are concerns about the burden of undertaking this work (and the resource implications) for both local authorities and the DfE. It could be undertaken as a one-off request, or a more general change to the way that children in need data is collected.

Option 2:

Sampling from specific local authorities: partnership model. Note if recruiting through local authority staff, then recruitment could also be considered based on a broader definition of referral+assessment (and not only CiN and CLA children).

For a UK cohort study with sampling across all four nations, it will be important to identify how similar records will be sampled in Scotland, Wales, and Northern Ireland.

## Recommendations and delivery

**Recommendation 2a: sampling vulnerable mothers using health records**

***Regarding Option A1 (sampling young mothers)***

- Given the need for a pan-UK approach, using birth records to identify young mothers was considered to be the simplest and most feasible strategy that could be straightforwardly incorporated into the ELC-FS, noting 12-14% of children in the general population will be CiN by age 5, but we would expect this to be much higher in those born to younger mums. We therefore recommend exploring with NHS England the feasibility of boosting the main ELC sample of births from linked birth register and maternal health records with an oversample based on prior teenage/young births (based on age of mother at first birth).
- We also recommend assessing the data quality and distribution of maternal age variables on the ELC-FS sampling frame, and response rates and key data fields relating to maternal age and child adversity risk in ELC-FS and Children of the 2020s (COT2020s).

***Regarding Option A2 (sampling mothers based on hospital admissions)***

- To understand whether health records could be used for sampling vulnerable mothers, we recommend exploring with NHS England the feasibility (public acceptability, ethics, legal gateways and overall willingness of data owners) of drawing a sample of births from linked birth register and maternal health records based on more sensitive characteristics drawn from maternal health records on prior admissions to hospital relating to violence/drug or alcohol issues, self-harm or mental health or behavioural conditions. Given the sensitivity of the information used to define this target sample, recruitment into the survey would need to be done on an opt-in (rather than opt-out) basis.
- The number of births and potential sampling strategies that could be adopted using de-identified data within ECHILD should be further explored.
- The potential role of ECHILD linkage spine for identification of the sample for this purpose should be explored.

**Recommendation 2b: sampling vulnerable mothers using DfE records**

- Our recommendation is that mothers selected through this route are those exposed to children's social care services while they were children; or mother had very low attainment. Regarding the former, analysis of the

ECHILD cohort shows 35% of 16-year-olds have received social care or SEN support during their secondary school years, with 15% either CiN or CLA during that period. These populations have poor mental health, high hospital admission rates etc and so you would likely capture a high proportion of vulnerable children in this sample.

- To understand feasibility, we should explore further the number of births and potential sampling strategies that could be adopted using de-identified data within ECHILD.
- We recommend exploring with NHS England and DfE the potential for linkage of DfE and NHS/ONS records as a bespoke linkage for sampling purposes.
- We recommend exploring the potential role of E-CHILD linkage spine for identification of mothers who were CiN or CLA and/or had SEN support during primary and/or secondary school; or had very low attainment

**Recommendation 2c: sampling vulnerable children**

***Regarding Option C1 (sampling children using DfE records)***

- While the DfE collects CiN and CLA data, they do not have the names and addresses which would be needed for a cohort survey when the children are under 5. Our recommendation is therefore to explore with DfE the potential to request names and addresses from local authorities of CiN and CLA children age under 5 as a one-off request, or a more general change to the way that children in need data is collected.

***Regarding Option C2 (partnering with specific local authorities)***

- To understand the feasibility of a partnership model, further discussions with Birmingham City Council and potentially other councils/local authorities: to discuss potential for locally-based studies, including approach to sampling parents and other carers, what information can be linked on the services that they are receiving, and methods and modes of engagement and data collection.

**Recommendation 2d: UK considerations**

- For a UK cohort study with sampling across all four nations, it will be important to identify how similar records will be sampled in Scotland, Wales, and Northern Ireland. We therefore recommend desk-research and consultation is carried out on how to enact similar approaches in Scotland, Wales, and Northern Ireland.

# Recommendation 3. Approaches to data collection and measurement

Depending on evidence needs and sampling approach identified through recommendations 1 and 2, we would then recommend developing a high-level scientific protocol that has some alignment of content with the main ELC study and ELC qualitative scoping studies, but also specialised question areas/measures where needed. This should include key design decisions around informants and mode.

**Box 3. Summary of findings relating to data collection and measurement**

Previous studies suggest that in order to recruit and retain participants, data collection must be face-to-face home visits. This requires persistence and flexibility in approach.

Existing studies (Permanently Progressing, E-Risk, Care Pathways and Outcomes Study) all reveal the intensive relationship-building required to enable the study to be effective in recruiting and retaining participants and keeping professionals on board who support access to the families.

In terms of survey content, data on the services and interventions families receive was deemed necessary to make policy and practice conclusions.

## Recommendations and delivery

**Recommendation 3:**

- Develop a high-level scientific protocol covering key considerations about engagement, mode, incentives and questionnaire content. We recommend testing some of these methodologies or conducting further qualitative work to establish their likely success.
- Examine whether and how this can be aligned within the ELC studies

# Recommendation 4. Size/scale and costs required

A key requirement for funders would be understanding the scalability of the approaches identified in recommendations 1-3, and the size of the study needed to be sufficiently powered to inform policy and practice.

A further key requirement from funders would be providing indicative costs of such a cohort. Part of this will also be understanding to what extent the work could align within the Early Life Cohort project and funding.

## Recommendations and delivery

**Recommendation 4:**

- Create sample size scenarios, informed by scientific needs and power calculations
- Understand additional consultation and public engagement costs.
- Understand costs relating to sample frame access in each country.
- Understand project staffing costs.
- Understand fieldwork costs, relating to key study design features identified through recommendations 1-3 (e.g. need for piloting, sample sizes, data collection mode, interview length).

# Annex to recommendations report

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# Annex contents

# Annex 1

# Workshop 1 Briefing

# A new national birth cohort study of vulnerable children: What would it involve, and can it be done?

Nuffield Family Justice Observatory

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# Contents

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# 1. Rationale and aims

Babies and young children who are especially vulnerable, such as those looked after or on the edge of care, are generally absent from national longitudinal studies of child development. Although the UK has a world-leading portfolio of longitudinal population-based studies, there is a critical gap when it comes to children supported by the child welfare system. This is largely due to the challenges of identifying, recruiting, and retaining them, given the difficult and often unstable circumstances that highly vulnerable infants and young children experience.

During 2022, we are holding two stakeholder workshops to further understand whether these challenges can be addressed, by examining the enablers and barriers to recruitment and engagement, as well as appropriate methods and tools for assessment of young children supported by the child welfare system in their early years.

The workshops aim to assess the feasibility, and the challenges of, implementing a new longitudinal birth cohort study of vulnerable children – defined as those supported by the child welfare system. These workshops form one part of the Early Life Cohort Feasibility Study project, funded by ESRC.

This scoping work has strong interest from the Department for Education (DfE), Department for Health and Social Care and other government departments.

The first workshop will be a closed workshop of academics with direct experience of research and data collection among vulnerable young children. Insights gathered at this stage will be presented at the second stakeholder workshop, which consists of potential government funders, alongside research council representatives and other funders of research in this space, to discuss potential paths to commissioning a new pilot study.

# 2. Parameters

In this programme of work, we define children supported by the child welfare system as those classified as children in need (or Wales/Scotland/Northern Ireland equivalent), on protection plans, and looked after children in care.

Our focus is on the early years, namely how such children could be identified, recruited, and retained prior to entry into the formal schooling system.

# 3. Workshop times and summaries

**Workshop 1 – Scoping the feasibility of a new longitudinal birth cohort study of children supported by the child welfare system**.

Morning (10:30 – 13:30) 21 June 2022

An initial session for **academics and practitioners** working in this space will discuss evidence needs, and share best practice, challenges, and solutions in a closed forum.

To develop a blueprint for a proposal that would feed into Workshop 2 (with government stakeholders and funders).

**Workshop 2 – Why is a longitudinal birth cohort study of children supported by the child welfare system needed?**

Morning (10:00 – 12:30) 21 November 2022

A follow up session combining **government stakeholders and funders** will enable a two-way exchange about policy-evidence needs, and how a proposed new study could support those needs.

# 4. Context

It is estimated that some half a million children under the age of five live in a household with domestic abuse, parental mental health problems, or parental drug/alcohol abuse.[6] While less is known about trends in underlying prevalence of child abuse and neglect, much more is known about the profile of children being supported by child welfare and family justice systems, and how this cohort has changed over time.

Recent analysis has found that just under one in four children in care proceedings in England is an infant under one year old. We also know that a greater proportion of care proceedings concerning infants have been issued for newborns in recent years, with the incidence rate in England more than doubling from 15 to 35 per 10,000 children between 2007 and 2017.[7]

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[6] Children's Commissioner for England. (2021). Local vulnerability profiles [online]. Children's Commissioner for England. Available from: www.childrenscommissioner.gov.uk/vulnerable-children/local-vulnerability-profiles

[7] Broadhurst, L., et al. (2018). Born into care: newborns in care proceedings in England. London: Nuffield FJO. Available from: https://www.nuffieldfjo.org.uk/resource/born-into-care-newborns-in-care-proceedings-in-england-final-report-october-2018

There is a large and growing body of research on the detrimental impact of abuse and neglect in early childhood.[8] Recent research on adverse childhood experiences (ACEs), such as maltreatment or exposure to domestic abuse, has built on an established base of literature and collated the evidence on the harmful effects that these experiences have on well-being, development in early childhood, and further outcomes throughout life.[9]

Our understanding of abuse and neglect in early childhood has grown substantially in recent decades. We now have more robust evidence on the predictors of abuse and neglect, as well as some evidence on the later life outcomes for this group of children.[10] Yet, we still know very little about the *early* physical, cognitive, social and emotional development of children supported by the child welfare system in the UK.

The recently published *Independent Review of Children's Social Care* makes the case for a new cohort study of care experienced children.[11]

*"Better data is needed on the health outcomes of care experienced people. Its absence limits policy making and demonstrates that society places too little value on the health outcomes of care experienced people."* (p36)

*"Government should also launch a new cohort study which tracks the health outcomes of care experienced people and helps to gather other missing data on housing, education and employment outcomes."* (p175)

We would add to this that there is a critical gap not just in our understanding of the health outcomes and later housing, education, and employment outcomes of children in need or experiencing care, but also in our understanding of both the environments in which they are raised, and their developmental trajectories, especially during the very critical and formative periods of development in early life and across childhood.

Such a study is needed to answer vital questions about the needs and circumstances of parents and their children, and when services can best intervene to support better outcomes for young children. Deficiencies in administrative data and lack of linkage, the underrepresentation of these children in cohort studies to date, as well as the relatively few qualitive studies tracking processes and journeys from different perspectives, serve to limit the ability to create evidence-informed policy**.**

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[8] Wilkinson, J. and Bowyer, S. (2017). The impacts of abuse and neglect on children; and comparison of different placement options: evidence review. London: DfE.

[9] Asmussen, K., Fischer, F., Drayton, E., and McBride, T. (2019). Adverse childhood experiences: What we know, what we don't know, and what should happen next. London: Early Intervention Foundation.

[10] Radford, L., Corral, S., Bradley, C., and Fisher, H. L. (2013). The prevalence and impact of child maltreatment and other types of victimization in the UK: findings from a population survey of caregivers, children and young people and young adults. Child Abuse & Neglect, 37(10), pp. 801–813; Ashton, K., Bellis, M. A., Davies, A., Hardcastle, K. A., and Hughes, K. (2016). Adverse childhood experiences and their association with chronic disease and health service use in the Welsh adult population. Cardiff: NHS Wales.

[11] MacAlister, J. (2022). The independent review of children's social care: Final report. The independent review of children's social care. https://childrenssocialcare.independent-review.uk/final-report/

# 5. Vulnerable children in existing longitudinal population studies – what are the challenges?

We know that vulnerable children are typically difficult to study using population longitudinal survey research for several reasons.

In population studies that aim to be representative of a population as a whole, the most vulnerable children are typically relatively small in number and so even with completely successful random sampling (or related stratified methods) at the national or local level, relatively few may be sampled in the first place. Depending on the approach to sampling, they may also appear in reduced numbers in the sampling frame (or not at all): for example, in recent major locally-based birth cohort studies, such as Born in Bradford, participants have been recruited through antenatal clinics, which women with the most dysfunctional lives were least likely to attend.[12]

Once sampled, for a range of reasons, their families are less likely to be recruited, and if they are recruited, they are at greater risk of dropping out over time.[13]

As well as issues around sampling, recruitment and retention, there are also important challenges around identification of children in need when children are sampled from a general population. Vulnerability is dynamic and self-report from parents or interviewer observations cannot necessarily be relied on to surface major issues of abuse or neglect, while where children are not cared for by parents, their early vulnerability is also often missed in research as measures of early-life experiences are often captured only from parental questionnaires and interviews.

Given the difficulties of identification via prospective data collection, much of the existing evidence we do have derives from retrospectively collected information. In cohort studies that follow people across their lives, adult cohort members have often been asked to recall periods of care, and are also directly asked to recall their experiences of abuse, neglect and other adverse circumstances in childhood, spawning a rich literature about the long-term outcomes of adversity in childhood.[14] In some studies of children, parents of study members are also asked to retrospectively recall their own experience of social care support, which enables research about their own outcomes, and approaches to parenting.[15]

Another important source of information in this context is record linkage, which provides one approach to identification and would also be vital for sampling for any new study specifically of young children supported by the child welfare system.

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[12] Biehal,N.,Baldwin, H., Cusworth, L., Wade, J. & Allgar, V. (2018) 'In-home support or out of home care? Thresholds for intervention with abused and neglected children.' *Children and Youth Services* Review 89, June 2018, pp. 263-271.

[13] Teyhan, A., Boyd, A., Wijedasa, D., & Macleod, J. (2019). Early life adversity, contact with children's social care services and educational outcomes at age 16 years: UK birth cohort study with linkage to national administrative records. *BMJ open*, 9(10), e030213.

[14] Radford

[15] See upcoming study: https://cls.ucl.ac.uk/wp-content/uploads/2017/02/CLS-briefing-paper-Resources-available-to-mothers-who-experienced-out-of-home-care-in-childhood.pdf

# 6. The use of administrative data for sampling, identifying and retaining ‘looked after’ and other vulnerable children in cohort studies?

Children who have contact with social services, either because they are ‘in need’ (with a social services referral), or ‘looked after’ (in local authority care, usually in foster care), have many administrative records. A central source of such records is DfE administrative records for children in need (CIN) and children looked after (CLA) (see Annex 1, provided by DfE).

Attempts have been made to link social care records of cohort members into longitudinal studies, allowing researchers to identify vulnerable children in the cohort without reliance on parental reports. For example, in the Avon Longitudinal Study of Pregnancy and Childhood (ALSPAC), CIN and CLA, data held by DfE has been linked into the cohort data in order to understand more about educational outcomes at 16 years old for those who had involvement of social services during their adolescent years.[16] In Born in Bradford, a partnership was formed directly with the local authority in order to provide a bespoke match between cohort study members (between 50 and 100 months of age) and data held by the authority.[17] Administrative data is also potentially useful for informing tracing and contact strategies to help ensure vulnerable children can be retained in cohorts once they have been recruited.

While this research has been useful in flagging vulnerable children within existing cohort studies, and keeping in touch when circumstances change, it does not address the difficulties of recruitment of the most vulnerable children in the first place. In the workshop, we will discuss further how administrative records could be used to sample vulnerable children into a bespoke new study, designed specifically for this purpose, and examples of where this is being tried.

# 7. Scoping research

We are currently undertaking a scoping exercise of existing general population studies, and specialised studies in the UK and abroad, whose samples contain vulnerable children in their early years, in order that we can understand their strengths and limitations, and any lessons learned. We would benefit from your knowledge and expertise in completing this scoping work. We will be circulating a draft in due course and will ask for your contribution.

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[16] Teyhan et al. (2019) Ibid.

[17] Teyhan et al. (2019) Ibid.

# Appendix 1 – DfE administrative records for children in need (CIN) and children looked after (CLA)

## Provided by Michael Dale, DfE, June 2022. Prepared for UCL regarding vulnerable children cohort study considerations (sampling frame).

DfE collects data on **all** children who are looked after by local authorities, including care leavers aged 17-21. Local authorities submit an annual return during April-June each year (relating to the previous year ending 31 March). Local authorities update the database every year, including making amendments to previous years' records where there have been changes. The records for each child are linked - using a unique child ID - to any supplied by the same local authority in preceding years (from 1992 onwards). This creates a longitudinal database with one record for every episode of care.

We publish statistics on the numbers of children in care, numbers starting to be looked after and numbers ceasing to be looked after (and much more!) here:

https://explore-education-statistics.service.gov.uk/find-statistics/children-looked-after-in-england-including-adoptions

We also match social care data with data on outcomes such as absence, attainment, and destinations, and this is published each year here:

https://explore-education-statistics.service.gov.uk/find-statistics/outcomes-for-children-in-need-including-children-looked-after-by-local-authorities-in-england

A subset of looked after children data is matched into the National Pupil Database (NPD) every year. A Unique Pupil Number (UPN) is used to match at child level and as UPN is generally only created for a child when they start school only looked after children of school age will appear in the NPD.

CLA is a subset of CIN, so it is broadly similar picture for CIN. We collect data on all children referred to local authority social care services in an annual census:

https://www.gov.uk/guidance/children-in-need-census

However, unlike CLA, CIN is not longitudinal. We collect information for each collection year (1 April to 31 March), but once the data is collected for each year, we do not update it.

We collect data on age for all children and since CIN includes unborn children, we collect expected date of birth as well. Information on age is included in the annual CIN statistics publication:

https://explore-education-statistics.service.gov.uk/find-statistics/characteristics-of-children-in-need

NPD hold the overwhelming majority of information we collect in the census, including age for all CIN. However, when NPD match data they can only do so if a child is school age and therefore has a UPN (and hence a PMR). This means any data extracts they produce which involve matching data largely exclude children below school age; there would likely be no data to match to for these children in any case.

# Annex 2

# Workshop 2 Briefing

# **Scoping the feasibility of a new longitudinal birth cohort study of children supported by the child welfare system**: Key challenges and possible approaches

Nuffield Family Justice Observatory

CENTRE FOR LONGITUDINAL STUDIES

# 1. Background and aims of the workshop

Babies and young children who are especially vulnerable, such as those looked after or on the edge of care, are generally absent from national longitudinal studies of child development. Although the UK has a world-leading portfolio of longitudinal population-based studies, there is a critical gap when it comes to children supported by the child welfare system. This largely due to the challenges of identifying, recruiting, and retaining them, given the difficult and often unstable circumstances that these highly vulnerable infants and young children experience.

In this work, we define children supported by the child welfare system as those classified as children in need (or Wales/Scotland/Northern Ireland equivalent), on protection plans, and looked after children in care. Our focus is on the early years, namely how such children could be identified, recruited, and retained prior to entry into the formal schooling system.

This is the second workshop in a series of two, which aims to bring together key stakeholders in UK government departments, devolved nations' governments, practitioners, and funding bodies, along with academics and experts working in the field, to develop our understanding of evidence needs, and options for taking forward a longitudinal study of vulnerable children (those supported by the child welfare system, or some broader measure of vulnerability), as a stand-alone study. This second workshop follows a first closed workshop of academics and experts in the field, held in June 2022, which undertook detailed discussion of barriers and enablers for conducting such a study.

The aims of this second workshop are:

- To enable a two-way exchange about policy-evidence needs, and how a proposed new birth cohort study could support those needs.
- To recommend next steps needed in order to establish the feasibility a new longitudinal birth cohort study of children in need, with a view to future commissioning.

# 2. Why is a new cohort study needed and what knowledge gaps could it fill?

The recently published *Independent Review of Children's Social Care* makes the case for a new cohort study of care experienced children.[18]

*"Better data is needed on the health outcomes of care experienced people. Its absence limits policy making and demonstrates that society places too little value on the health outcomes of care experienced people."* (p36)

*"Government should also launch a new cohort study which tracks the health outcomes of care experienced people and helps to gather other missing data on housing, education and employment outcomes."* (p175)

There is a critical gap not just in our understanding of the health outcomes and later housing, education, and employment outcomes of children in need or experiencing care (as specified in the Independent Review), but also in our understanding of both the environments in which they are raised, and their developmental trajectories, especially during the very critical and formative periods of development in early life and across childhood.

Such a study is needed to answer vital questions about the needs and circumstances of parents and their children, and how services can best intervene to support better outcomes for young children. Deficiencies in administrative data and lack of linkage, the underrepresentation of these children in cohort studies to date, as well as the relatively few qualitive studies tracking processes and journeys from different perspectives, serve to limit the ability to create evidence-informed policy**.**

In this context, such a study is needed to:

- Provide a comprehensive account of the experiences of young children supported by the child welfare system.
- Measure a range of children's developmental outcomes over time, including while they are in care and beyond.
- Identify determinants of these outcomes.
- Developmentally trace children and young people in care compared to population norms.

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[18] MacAlister, J. (2022). The independent review of children's social care: Final report. The independent review of children's social care. https://childrenssocialcare.independent-review.uk/final-report/

- Identify differences in needs over the life course and the critical times when children may require specific interventions to support their success and well-being as they progress through childhood and adolescence.
- Inform policy makers and service managers on how best to tailor services to the developmental needs of young children.
- Assess whether current service provision can adequately respond to the developmental needs of the population they are designed to serve.

# 3. What are the key challenges in sampling and identification among this group?

**Sampling from the general population:**

We know that vulnerable young children are typically difficult to study using standard methods in population longitudinal survey research for several reasons:

- In general population studies the most vulnerable children are typically relatively small in number, and so with random sampling (and related stratified methods) at the national or local level, relatively few are likely to be sampled in the first place.
- Once sampled, for a range of reasons, their families are less likely to be successfully recruited, and if they are recruited, they are at greater risk of dropping out over time as they move between different homes, and/or their main caregiver or other respondent (foster carer/social worker) changes between waves.
- Identifying which children within a general population sample are in need is especially difficult, due to challenges with obtaining prospective self-reports from families/carers, and multiple difficulties with data linkage, which would be the ideal mechanism for identification.

**Sampling from a national database of children in the welfare system:**

To overcome some of these problems, sampling in larger numbers than their population prevalence from a database of children in the welfare system would be ideal. In Wales and Scotland, such sampling should be possible at the national level (and the situation in Northern Ireland tbc). However, in England there are particular problems in identifying young children through existing national administrative data, which has implications for sampling young children in need:

- Currently it is difficult to identify all children under 5 in Department for Education (DfE) data, as children under 5 are not allocated a Unique Pupil Number (UPN). The 2005 Act allows the DfE to request full identifiers from local authorities as part of their annual returns – this would allow better identification (for potential sampling) and linkage of children social care data to other administrative datasets.
- Work is underway by the DfE to explore the feasibility of establishing a new Consistent Child Identifier (CCI) at a national level.

A national approach to sampling would have the advantage of being representative of a known target population at a national level, and would allow robust profile comparisons with cohorts in existing national cohort data. However, depending on how the study is then implemented, drawing a sample at a national level could make it more difficult to develop strong relationships at the local level, with potential implications for recruitment, retention and data quality.

### Sampling from individual local authorities:

Instead of sampling at a national level, partnerships with local authorities could also be formed so that sampling could be undertaken at a local level instead, in specific local authorities.

- There are benefits to a local design, in particular due to the opportunities for strong relationship-building in the delivery of the study, with local authorities and individual social workers, that are likely to be positive for recruitment and retention, and data quality.
- Some local authorities are especially well-placed to deliver such a partnership, given a history of strong research collaborations (e.g., Bristol, Bradford) and/or current active work in this space.
- By its design, this approach would not lead to a nationally representative sample.

### Sampling from parents considered to be vulnerable/high-risk:

An alternative approach to sampling could be to identify participants based on the vulnerability of mothers from administrative data, rather than of children, since a high proportion of children born to vulnerable mothers end up being supported by the child welfare system. One example would be recruiting from a pool of mothers who had been in care themselves. Another would be focusing on young (e.g. teenage) mothers, potentially in deprived areas (the E-risk approach). There are a number of issues with such an approach:

- Defining ‘vulnerability’. How are vulnerable mothers defined? Any definition chosen would have major implications for the population of children reached.
- Only a minority of those children born to vulnerable mothers become in need themselves, and many children not born to vulnerable mothers would not be reached.

- Identification of children in need – unlike drawing from an administrative sampling frame from which all children are by definition in care or on the fringes of care, this sampling approach entails the same difficult issues around identification of problems that exists in the general population (i.e. the weaknesses of prospective self-reporting for uncovering maltreatment/abuse are also relevant here).

## 4. What are the key considerations for recruitment and retention?

Irrespective of the approach taken to sampling (above), partnership building will be especially critical to the success of a new study. This includes a strong need for very skilled and credible data collectors that have knowledge of the field, and can build a good relationship with participants, who may be especially wary of researchers. Employing data collectors who are highly skilled, from the communities involved, and/or potentially using social work professionals (this may have both pros and cons) to undertake data collection is likely to be necessary.

For a longitudinal study to succeed, there needs to be a strong relationship of trust between the study and its participants. Such trust can be built in a number of ways including through strong and transparent communication, using engaging methods, including qualitative approaches in which participant voices are heard. Retention issues can also be minimised by having short intervals between waves and keeping participants informed of results between waves, as well as using effective tracing methods, and incentivisation.

## 5. What are the most appropriate data collection approaches?

**Informants: Parent/carer/child information:** Depending on the exact research questions, the prospective study will need to gather information on potentially a wider variety of informants supporting the child than 'standard' population studies. Studies have focused on gathering the views of adoptive, foster and birth parents (Permanently Progressing – Scotland, Care Pathways and Outcomes – Northern

Ireland). Others have also gathered insights from social workers and other family support professionals.

**Survey data collection mode and measurement:** Any new study is likely to combine quantitative survey and/or qualitative data collection, and may employ a variety of modes, however face-to-face contact with participants will be especially important to maximise response and establish relationships. For children who move between carers, establishment and renewal of these relationships on an ongoing basis will also be important.

**Quantitative data collection: scales and measurements:** The study would need to choose scales and measurements that are well harmonised to other studies, to enable comparisons and benchmarking, especially to general population studies. There is strong potential for alignment to the key survey and other instruments adopted by the main/core Early Life Cohort Study. They would also need to be developmentally sensitive and attuned to the particular needs and issues facing vulnerable children.

**Qualitative and mixed method approaches:** Qualitative information is considered to be especially important among this population, to examine the personal experiences of children in care, and for engaging participants.

**Administrative data linkage:** Linkage to administrative data is also required, especially since self-report from parents and carers, or interviewer observations cannot necessarily be relied on to surface the major issues of abuse or neglect that many have been subject to. This is especially the case when children are no longer cared for by their parents, and their early vulnerability would also be not necessarily be picked up by carer questionnaires and interviews. Administrative data is also very important for enabling tracing of children over time, especially as children potentially will move between different carers. However, obtaining access to, and securing sufficient coverage and quality of linked data remains a major issue for all studies of this kind (with potentially different issues occurring at the national vs. local level, depending on the study's design).

# 6. Ethics and consent

Sampling and recruiting children who are currently in care raises a number of ethical and consent issues that need to be addressed.

**Sampling and initial contact**: In order to establish a new study, ethical and other permissions to draw a sample in order to make initial contact, to invite participants to take part in the study, is required.

- In the Northern Ireland Care Pathways and Outcomes study, an ‘opt-out’ consent approach was initially used, and a letter informed parents/carers that they should ring a specified representative in the authority if they did not consent to the research team receiving their contact details. Parents/carers consented for themselves and their children to take part, and during each visit, written consent was sought.
- In the Building Blocks trial, [19] an ‘opt-in’ model to consent was used. In the trial, potential trial participants were contacted via a current caregiver. The participants were then asked to complete a referral slip if they agreed for details to be passed to the local researcher. During the recruitment visit they were then provided with an information sheet explaining the trial. Informed, written consent was obtained by the researcher before any trial surveys were carried out.

**Who provides consent for children in foster care?** There is a specific issue for children who are in foster care, as to who is able to provide consent. Usually the parent retains legal responsibility, but it is shared with the local authority (depending on the care order), which can create some serious complications for participating in research. For example – can a foster carer give consent on behalf of the child? Does the local authority need to? Does the parent? These issues would need to be very carefully resolved.

## 7. Study scale, and costs

One key consideration (closely related to the design issues highlighted above) is the intended study scale and cost.

- The smaller the sample, in general the more intensive the data collection efforts can be, favouring for example employing highly trained social workers as interviewers, using qualitative data collection approaches, and/or including relatively expensive observations and bio-measures.
- The larger the sample, the better for statistical inference, and sub-group analysis, but at the expense of resource intensive data collection approaches.

In both Permanently Progressing and the Northern Ireland Care Pathways and Outcomes Study, there have been different sub-samples accessed for different research questions or during different waves of study, which has largely been a

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[19] More information on the Building Blocks trial is available here: https://www.cardiff.ac.uk/__data/assets/pdf_file/0009/504729/Building-Blocks-Full-Study-Report.pdf

result of cost, resourcing and capacity issues given the highly resource intensive nature of working with this study population. For example, the Northern Ireland Care Pathways and Outcomes Study explores the care history of the whole sample in Wave One when exploring care files (administrative data) of participants but limited the sample to around a third of the whole sample in Wave Three when interviewing parents and caregivers.

# 8. Key questions/future feasibility questions to be addressed

- What is the prospect for obtaining a national sample of children in the welfare system?
- Even if a national sample could be obtained, should the study be locally clustered, through partnerships with specific local authorities?
- Would a sample design based on parent vulnerability deliver the evidence needs required?
- What is the ideal balance between cost per case (enabling more intensive relationship-focused recruitment, retention and data collection approaches), and sample size, to fulfil evidence needs?
- Would a relatively small, qualitative-only study ever be sufficient?

# Appendix 1: Potential approaches to sampling and recruitment, and current UK examples of practice

### Approach/Option 1

**A national approach: Identifying parents/carers of vulnerable children through national administrative data on the circumstances of the child, and recruiting through an independent data collection agency at a national level. Or, if feasible, highly trained researchers employed by the study team.**

Description:

- Children identified using existing administrative data, then recruited directly via parent/carer at a national level from this cohort using an independent data collection agency.
- Data collection could potentially be undertaken by university-employed researcher-interviewers.

Previous example (proof of concept):

- **The Pathways of Care Longitudinal Study (POCLS) – Australia. 2010-present**. This is the first large-scale prospective longitudinal study of all children and young people (of all ages) entering out-of-home care (OOHC) between May 2010 and October 2011 in Australia.[20]
  - The survey cohort consists of children and young people whose carers agreed to have their contact details passed from New South Wales Department of Family and Community Services (FACS) to an independent data collection agency and then were invited to participate and surveyed.

Key challenges:

- Currently, identifiers are not supplied with Child in Need or Children Looked After data in England under 5 (except date of birth, sex, local authority), making it impossible to sample directly and to link to children's social care and other administrative education data.
- A UPN is currently not assigned until a child first starts state school in most cases (children under 5 are allocated a UPN if they attend a maintained nursery school attached to a state primary (around one in six children according to the latest DfE data).
- Difficult to maintain contact with children and their caregivers as they move homes or once children have been adopted.
- Issues around gaining consent to share contact details and data with an independent data collection agency.
- Data collection by staff not yet known to participant families. Lack of specialist staff in national agencies to intensively build relationships.
- National representation/geographic spread makes deploying university-employed researcher-interviewers logistically challenging, and expensive.

Pros:

- Significantly less pressure on the administrative teams of local authorities to administer surveys (compared to Option 2 – below).

### Approach/Option 2

### A local approach: Identifying parents/carers of vulnerable children in (national or) local administrative data on the circumstances of the child, and recruiting participants through local authorities and administer surveys via social workers.

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[20] More information on the Pathways of Care Longitudinal Study is available here: https://www.facs.nsw.gov.au/resources/research/pathways-of-care/about-POCLS

Description:

- Project team gather ID number and the date of birth, gender, and other identifiers from either nationally or locally-held administrative data to identify a potential sample. These lists are either given to, or already held by, the local authorities who identify the child, their social worker and main caregiver.
- Communication and engagement with individual local authorities.
- Surveys administered by social workers or other trusted local authority representatives.

Previous example (proof of concept):

- **Permanently Progressing - Scotland. 2014 – present.** A longitudinal study gathering early outcomes, pre-care experiences and pathways for all 1,836 children who became looked after in Scotland when aged 5 or younger in 2012-13.
    - See Table 1 below for more information on sampling and recruitment.
- **Care Pathways and Outcomes - Northern Ireland**. **2000-2019.** A longitudinal study that has been following all 374 children who were under 5 years old and in care in Northern Ireland on 31 March 2000.
    - See Table 1 below for more information on sampling and recruitment.
- **BeST? Services Trial - England**. **2021 – present.** A longitudinal follow up following a randomised control trial (RCT) of the New Orleans Intervention Model (NIM) for infants and young children entering care. The research team plan to recruit approximately 390 families across the intervention sites. They will be randomly allocated to NIM or optimised services as usual and followed up to 2.5 years post-randomisation.[21]
    - This study uses the novel recruitment and retention strategy of employing experienced social workers, who receive additional specific training in Good Clinical Practice, to screen for eligibility and conduct our study information and consent meetings with potential participants.
    - In addition, in each site, efforts have been made to build good relationships with the most senior social worker in charge of child protection and to involve that person in the local steering group.

Key challenges:

- Labour intensive – lots of work needed to establish and maintain relationships with individual local authorities and Directors of Children's Services.
- Relies on buy-in from individual social workers to contact and administer surveys.

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[21] More information about the BeST? Services Trial is available here: https://trialsjournal.biomedcentral.com/articles/10.1186/s13063-022-06007-3

- Conflicting information about a child may be shared by caregiver/social worker.

Pros:

- Allows study to maintain connection with child even after moves in and across local authorities.
- Buy in from social workers who then 'sell' the benefits of the study to children and families – resulting in lower attrition rates.

### Approach/Option 3

### An approach based on mother (or parent/older sibling) vulnerability, identified through national administrative data.

Description:

- Project team gather identifiers of children based on the characteristics of their mothers (other parents/siblings) from national administrative data to identify a potential sample.

Previous example (proof of concept):

**E-Risk study:** Used ONS birth register for sampling. Mothers aged 15-20 at first birth were sampled (which would not necessarily be the study child's birth), given young maternal age at first birth is a statistical predictor of a whole host of concerning child outcomes. 600 mothers enrolled whose first birth was under age 20, and target children were twins, first recruited at age 5 (living with mother at age 5).

All data collection in home visits, by specially recruited and trained team of graduates with at least a 2.1 degree from a good university, young women selected for their combination of high intelligence, strong extroversion, and radiant warmth.

Key challenges:

- Defining 'vulnerability'. How are vulnerable mothers defined? Any definition chosen would have major implications for the population of children reached.
- Only a minority of those children born to vulnerable mothers become in need themselves, and many children not born to vulnerable mothers would not be reached.
- Identification of children in need – unlike drawing from an administrative sampling frame from which all children are by definition in care or on the fringes of care, this sampling approach entails the same difficult issues around identification of problems that exists in general population (i.e. the

weaknesses of prospective self-reporting for uncovering maltreatment/abuse are also relevant here).

Pros:

- Broader population of interest, not just those under welfare services; potential comparisons between children in high-risk families who do become in need of care, and those who don't.
- Extremely high retention rates.
- Potential for a hybrid approach – sampling on a range of characteristics, e.g., mothers who had experienced care, young mothers, etc.

**TABLE 1: Longitudinal studies of children in care in the UK**

| Country | Study name | Duration | Waves | Sampling | Participants (numbers) | Participants (profile) | Recruitment and data collection | Outcomes measured |
|---|---|---|---|---|---|---|---|---|
| Northern Ireland | Care Pathways and Outcomes Study (CPOS) | 2000–2019 | **Background information** (Age 5) | National sample from administrative data. | 374 children. | All children under 5 years old and in care on 31st March 2000. | Case file analysis. | Background, family history, coming into care. |
| | | | **Carers perspectives** (Age 8-10) | Sub-sample – limited by responses to survey. | 110 caregivers of children (adoptive, foster, and birth parents) (29% of total sample). | Carers perspectives strand: | Invitation letter distributed by local authorities. Subsequent survey and in-person interview. | Carers perspectives strand: |
| | | | **Children's perspectives strand** (Age 9-14) | Sub-sample children chosen to be representative of five placement types (adoption, foster care, kinship care, residence order, birth parents). | 77 children (21% of total sample, 57% of sub-sample). | 77 of the young people (at that stage aged 9 to 14 years), who had been living in long-term placements (longer than three years), in addition to their parents and carers. | Invitation letter distributed by local authorities. Subsequent survey and in-person interview. | Attachment, behaviour, parent/carer stress. |
| | | | **Children's perspectives stand (adolescence)** (Age 18 -22) | National sample from administrative data. | 354 children - administrative data (95% of total sample)<br>39 children – interview data (11% of total sample). | All children in sample - under 5 years old and in care on 31st March 2000.<br>Sub-sample who responded to request for interview. | Children's social care placement data.<br>Interview data | Placement stability.<br>Belonging, behaviour, reasons for placement |

| TABLE 1: Longitudinal studies of children in care in the UK | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| **Country** | **Study name** | **Duration** | **Waves** | **Sampling** | **Participants (numbers)** | **Participants (profile)** | **Recruitment and data collection** | **Outcomes measured** |
| | | | | | | | | breakdown (interview data). |
| Scotland | Permanently Progressing | 2014-present | **Early childhood** (aged 5 and under) | Pathways strand:<br>National sample from administrative data. | 1,836 children. | All children who became looked after during the year 1 August 2012 - 31 July 2013 when they were aged 5 and under. | No direct recruitment. Analysis of national administrative data. | Children's pathways into and through the looked after system over four years from 2012-16, including the route and timescales to permanence. |
| | | | | Outcomes strand:<br>National sample, limited by number of participating LAs (19). | 643 caregivers of children (166 kinship carers/foster carers/adoptive parents (42% response rate). and 433 social workers of participating children (67% response rate). | Caregivers of children looked after away from home 2012-2013 and remained looked after away from home at end of year 2. | Direct engagement with information managers and liaison Local via social workers. Providing up-to-date information on children.<br>a) Social worker questionnaire in participating LAs.<br>b) Caregivers' questionnaire distributed by LA | Characteristics of the children and birth family. Progress and outcomes for the children three to four years after they became looked after away from home, including their health and development and educational progress. |

TABLE 1: Longitudinal studies of children in care in the UK

| Country | Study name | Duration | Waves | Sampling | Participants (numbers) | Participants (profile) | Recruitment and data collection | Outcomes measured |
|---|---|---|---|---|---|---|---|---|
| | | | | Linkage strand: National sample, limited by matching during linkage process. | 1,000 children (54% of total sample). | Sub-sample of total population where linkage was successful. | No direct data collection. Linkage of CSC and court data. | Prior pathways and journeys through the children's social care system. |
| | | | | Children and parents' experiences strand: Sub sample, limited by responses to invitation to interview. | Play and talk sessions with 10 children and interviews with 20 kinship carers/foster carers/adoptive parents | The participants in this study were a sub-sample drawn from the Outcomes strand in which 433 social workers and 166 carers/adoptive parents completed detailed questionnaires | Direct engagement with parents/caregivers who had indicated they wanted to be contacted in the previous outcomes strand. Play and talk sessions with children, face to face interview with caregivers. | Belonging and permanence.<br>Contact.<br>Transitions. |
| | | | - Middle childhood (age 7+). | TBC | TBC | TBC | TBC | TBC |
| | | | - Late childhood adolescence | TBC | TBC | TBC | TBC | TBC |

# Annex 3

## Workshop 2 summary

## The case for, and feasibility of, developing a new national birth cohort study of children supported by the child welfare system: Practical challenges and next steps

**Monday 21 November 2022**

**10:00-12:30**

Nuffield Family Justice Observatory

CENTRE FOR LONGITUDINAL STUDIES

# Why we need a cohort study of vulnerable children

Cohort studies are vital as a source of information to help develop new policy and practice, refine existing policy and practice, help to solve big strategic policy questions and enable rapid understanding of the impact of changing circumstances (e.g. tracking changes during and following a pandemic). Officials from the Department for Education (DfE), Department of Health, Department for Work and Pensions and the Scottish Government expressed the need for such a study.

A birth cohort study of vulnerable children is important because:

- We need to understand how to better support vulnerable families from birth (or preferably before birth).
- We lack an understanding of the early health and developmental pathways of vulnerable children, and therefore how early interaction with health and care services might respond to their needs better.
- We have some child-level data, but need to understand the context in which children are living – e.g.
    - What are the backgrounds, experiences, relationships and support networks of birth parents and siblings?
    - What are the challenges families face in looking after their children? What happens to families when they are stepped down from social care?
    - What happens to children who leave social care to be adopted or are on a Special Guardianship Order (SGO)?
    - What are parents' experiences of children's services and interventions, their expectations and unmet needs? What other services are they receiving?
    - Are there any patterns regarding those parents who seem able to change sufficiently or not following services/interventions? How is this affected by the quality/type of services they access?

# The case for investment

While there are many challenges for a vulnerable children cohort and the solutions require disproportionate efforts and funding compared to general population cohort studies, this is the wrong benchmark. Disproportionate amounts of funding and policy are targeted at the most vulnerable and ideally, this should be mirrored in research terms. We have the *least* developed longitudinal data in relation to the *most* important subgroups of children and there are ethical and financial reasons to address this. Any investment needs to produce data that will help to inform future policy – data on services and use, family circumstances, experiences and children's outcomes.

# How to define vulnerability

Our primary concern is children whose early life experience is significantly disadvantaged because they are maltreated and/or living in circumstances that are likely to have a profound and lifelong impact on their health and wellbeing. Because of the potentially chaotic nature of their family life and circumstances, they are largely absent from cohort studies. They are among the most vulnerable children in our society, but we know least about them.

We started by defining vulnerability as having some contact with child welfare services, but we recognise this is too narrow as, while many of these children are known to children's services, some are not (e.g. lots of children are in kinship care, some are living in adversity but not seen by children's services, and around 25% of referrals to children's services result in no action). It is also important to have a wider sample beyond those who have come to the attention of children's services, because it helps us to understand the relative impact of social care intervention, as well as why some children in adverse circumstances do better than others.

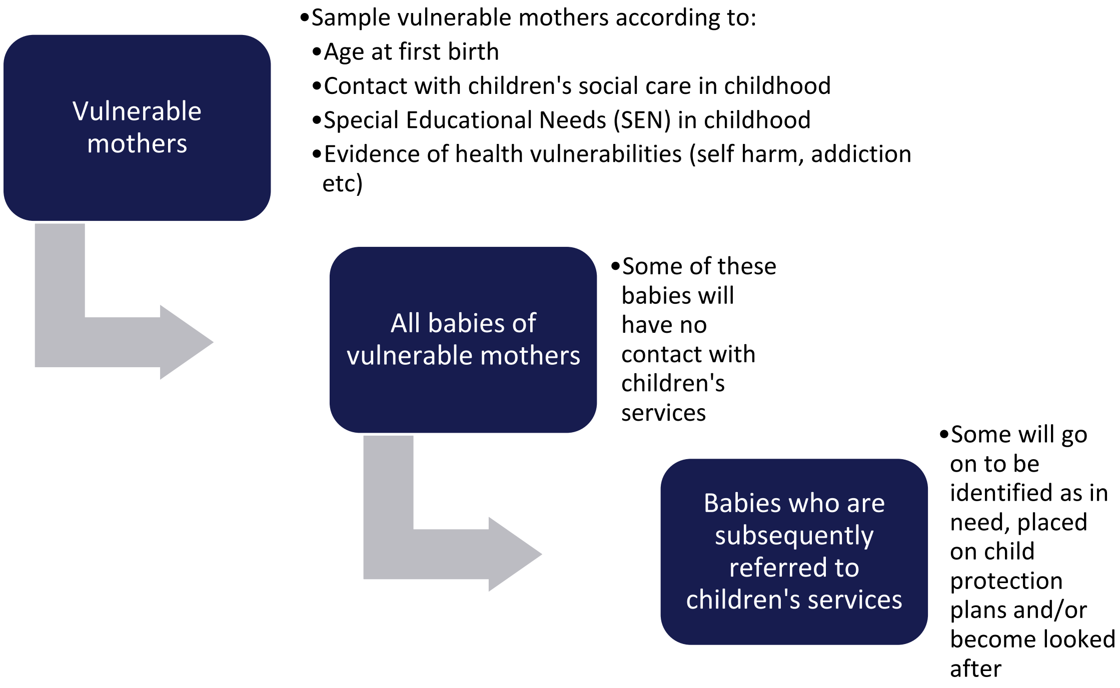
However, in defining vulnerability more broadly than those who experience children's services, we need to make sure we have a big enough sample size of those who are referred to children's services, in need, on child protection plans or looked after, so we can undertake sufficiently powered analysis of their circumstances and trajectories, and also so that we can capture the impact of these interventions. More than half of children in care are in care for short periods of time, most commonly in the pre-school period. Incident rates are rising – more children are in care. In 2017, 0.9% of infants had been in care in their first year of life. There are big variations by ethnicity – over 3% of Black or Mixed ethnicity children are in care before the age of 5, compared to around 1% of White or Asian children (McGrath, PhD Thesis 2017).

We cannot assume that vulnerability is greatest for those children who are looked after – we need to define vulnerability by the adversity that children actually experience rather than by what services they receive.

The kind of vulnerabilities we are concerned about include physical abuse, sexual abuse, emotional abuse, witnessing domestic violence, neglect, having a close family member who misuses alcohol or drugs, having a close family member with mental health problems, living with someone who has gone to prison, or losing a parent through divorce, death or abandonment.

We cannot sample children on the basis of these events having already happened, so we need to define a population of vulnerable children who are at heightened risk of experiencing such adversities.

By comparing two twin studies: the Environmental Risk Longitudinal Twin Study (E-Risk), which over-sampled on young mothers with twins, and the Twins Early Development Study (TEDS), which did not, it is evident that population cohort studies that do not over-sample on families or children who are highly vulnerable do not capture sufficient numbers of vulnerable children. The prevalence of children's mental health, rate of childhood obesity and number of children leaving care with no qualifications was much higher in the E-Risk, which deliberately oversampled vulnerable mothers.



Vulnerable mothers

- Sample vulnerable mothers according to:
  - Age at first birth
  - Contact with children's social care in childhood
  - Special Educational Needs (SEN) in childhood
  - Evidence of health vulnerabilities (self harm, addiction etc)

All babies of vulnerable mothers

- Some of these babies will have no contact with children's services

Babies who are subsequently referred to children's services

- Some will go on to be identified as in need, placed on child protection plans and/or become looked after

# Sampling issues

There is a need for a sufficiently powered sample (of subgroups as well as whole sample) in order to have an impact on policy and practice – high-quality evidence is needed.

(a) Sampling by vulnerable mothers

One option would be to identify vulnerable mothers, who are identifiably at higher risk of having children who experience adversities of the kind identified above (including physical abuse, sexual abuse, emotional abuse, witnessing domestic violence, neglect, having a close family member who misuses alcohol or drugs, having a close family member with mental health problems, living with someone who has gone to prison, or losing a parent through divorce, death or abandonment). Such an approach will capture children who become in need, on child protection plans or looked after, but will also capture a larger pool of children, both those who are vulnerable but not subject to a social welfare intervention, and many who grow will up without any identifiable vulnerabilities despite the earlier challenging circumstances of the mother.

There are multiple potential avenues for identifying such vulnerable mothers. The approach taken by the E-Risk study was to use the ONS birth register to identify the age of the mother at her first birth, and to over-sample on teenage mothers. This approach, which doesn't rely on the emergence of damaging behaviour in order to be sampled for the study, generates a broader sample of children (as above) and is also less stigmatising for those taking part in the study, which will also assist with recruitment and retention.

Vulnerable mothers could be identified and sampled by using DfE data to identify mothers who had been exposed to children's social care services – Children in Need (CiN) or Children Looked After (CLA) – and/or SEN support (the two are linked: roughly 85% of children in care will have special educational needs) during their secondary school years. Analysis of the ECHILD cohort shows 35% of 16-year-olds have received social care or SEN support during their secondary school years, with 15% either CiN or CLA during that period. You would need to sample in relation to their whole secondary school experience (i.e. from Year 7 onwards) because some will fall out of education. If you looked at social care involvement and SEN during primary school years, the size of the sample would increase. This population has poor mental health, high hospital admission rates etc and so you would likely capture a high proportion of vulnerable children in this sample.

In order to identify which of those who have had a SEN/social care intervention also become mothers, this could be achieved by linking these records to hospital (HES) data linked to birth registration data through ECHILD. Women whose pupil matching reference numbers had been flagged based on their SEN/social care history could then be flagged using either the ECHILD linkage spine, or by linkage by personal identifiers to their birth registration via ONS, in order for their personal contact details to be released so that they could be invited to take part in the study. One approach using ECHILD would be to include all mothers whose first birth was before age of 25, which would generate a substantial number. [N.B. face-to-face surveys of parents would also need some cross referencing with whether the family is having contact with children's social care?]

Another option would be to identify children born to mothers up to the age of 25 whose vulnerability status is based on prior admissions to hospital relating to violence/drug or alcohol issues, self-harm or mental health or behavioural conditions, or having had a prior teenage birth. ONS might also be able to provide a sample based on mother's age at first birth (like in the E-Risk study) but linkage to HES maternity data would provide more characteristics (besides age) on which the sample could be drawn.

Any approach that relies on access to NHS records would require permissions in place to re-identity a sample using de-identified data. There is a precedent for this – the NHS DigiTrials led by the University of Oxford have sampled people with cardio-vascular indicators for recruitment into trials. Postnatal and perinatal mental health is a major public health issue and justification on those grounds could be seen as stronger than a more narrow approach related only to social care services.

Sampling options therefore seem to be (either single or combination of these):

- Age of mother at first birth. In ECHILD around 4% of births <20 and another 7.9% were prior teenage mums – so quite large samples.
- Mother's experience of social care intervention during secondary school (or primary and secondary).
- Mother's SEN status during secondary school (or primary and secondary).
- Mother's vulnerability status based on prior admissions to hospital relating to violence/drug or alcohol issues, self-harm or mental health or behavioural conditions.

(b) <u>A hybrid approach</u>

If you sample on the basis of vulnerable mothers, you are still likely to get a fairly small sample of children who are subject to child welfare services. The E-Risk study found one third of the sample experienced maltreatment, two-thirds did not (although the study sampled mothers whose first birth was aged 20 or under; if you sampled on the basis of younger mothers, you would be likely to get higher proportion of maltreatment).

One way to boost the child welfare sample would be to adopt a hybrid approach – by sampling by vulnerable mothers in the general population AND oversampling using child welfare records.

### c) Sampling using child welfare records

The DfE collects CiN and looked after children (LAC) data for children of all ages but do not have the names and addresses of pre-school children, so only records for school age children can be used for sampling purposes. And yet 20% of children who are only looked after in the pre-school period, so we are missing a fifth of all vulnerable children when a school-age sampling frame is used.

CiN and LAC records for school-age children have been used for sampling purposes in the past, so there is a precedent. The DfE could request names and addresses from local authorities of CiN and LAC children age under 5 and there appears to be a legal gateway[22] that would enable this. However, there are concerns about the burden of undertaking this work (and the resource implications) for both local authorities and the DfE. It could be undertaken as a one-off request, or a more general change to the way that children in need data is collected. The establishment of a Unique Child Identifier development work might be a back-up option.

**Note re: four nations**

For a UK cohort study, you would sample across all four nations, with booster samples in Wales, Scotland and Northern Ireland. It is important to identify how you would sample the same records in Scotland, Wales and Northern Ireland as those in England.

# Recruitment and retention

Previous studies suggest that in order to recruit and retain participants, data collection must be face-to-face home visits with no self-completion questionnaires. This requires persistence and flexibility in approach.

Existing studies (Permanently Progressing, E-Risk, Care Pathways and Outcomes Study) all reveal the intensive relationship-building required to enable the study to be effective in recruiting and retaining participants and keeping professionals on board who support access to the families.

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[22] The Department for Education is already processing their personal data, just not names and addresses, under 83 of the children’s act https://www.legislation.gov.uk/ukpga/1989/41/section/83

Home visits need two researchers per visit, partly for safety and partly to separate parents from children during data collection.

## Services data

Data on the services and interventions families receive needs to be as good as the data on the families themselves, so we can draw policy and practice conclusions. It is not yet clear how you would gather data on interventions and service use.

## Learning from other studies

### The E-risk Longitudinal Twin Study

The E-risk study succeeded in recruiting high-risk families in which many children were maltreated and some eventually went into care. The study sustained a 94% participation rate up until the most recent wave, when the children were 18 years old. After three decades, the cohort still very closely represents the UK population, for example each of the 10 levels of the Index of Multiple Deprivation that holds 10% of the UK population also holds approximately 10% of the E-risk cohort today. The study has recently received funding from the Medical Research Council to carry out a follow up when the children are age 30.

E-Risk recruited its families in 1998. The study had access to ONS multiple birth register as its sampling frame. The birth register contains mother’s age at her first birth. The goal in sampling was to avoid the cohort being too affluent and well educated. With twin births, the mother is usually older, better educated, and has often conceived using assisted reproduction. The study deliberately drew 562 families with twins born to a young mother and twins who were conceived naturally. The study sampled mothers’ age at the time of their FIRST birth (i.e. aged 15 to 20 at birth of her first child, which would not necessarily be the study child’s birth). The decision to sample young mothers was guided by the literature showing young maternal age at first birth is the best statistical predictor of a range of poor child outcomes. In addition, the study also sampled another 560 families with mothers over 20.

Targeting young mothers resulted in a less affluent sample where most had an income under £10K, lived in council housing, had no father living at home, lived in a family where there was no employed adult, or where the mother had diagnosed depression.

Families were recruited by sending out research workers in person to homes to knock on doors. Of the 562 mothers whose first birth was under age 20, at least half had one or more characteristics that made them poor candidates for data collection modes that are not in-person: e.g. they tested at a reading level below grade 7, frequent address changes in past five years, a home-visit research interviewer rated this mum as having poor ability to understand and fill in questionnaires, the mother had not responded to repeated postal surveys sent to them by Plomin's TEDS study.

The study found that young mums were not more difficult to recruit or interview than older mums, but they did require home visit data collection (and they liked the visit). Note the study recruited families when the target children, a pair of twins, were age 5 years, not at birth. Also, the target children were living with their biological mother. Recruiting mothers of twins was felt to be easier than recruiting mothers generally, however, since mothers recognized their children were 'special' and were not suspicious of or resistant to the idea of a study.

In terms of the full cohort of 562 young mums and 562 older mums (totalling about 2,200 children):

- Of families who had a child go into care by age 18, 73% had a young mum.
- Of families who had a child physically/sexually abused between birth and 12, 70% had a young mum.
- Of families who had a teenager physically/sexually abused between age 12 and 18, 76% had a young mum.

This means, by recruiting on young mother's age, it was possible to capture most of the children who will later be maltreated or go into care.

Considering maltreatment outcomes of children of just the 562 young mums:

- Between age 5 and age 18: 5% were formally taken into care for child protection. This compares well with administrative data showing 3.3% of children born in the 1990s who went into care by age 18.
- More children experienced maltreatment than went into care. Between birth and age 12, 15% had evidence of probable physical or sexual child abuse, and a further 8% had evidence of definite serious physical or sexual abuse. By age 12-18, a further 10% had physical, sexual abuse or neglect.
- In total, 33% of the 562 families were involved in child maltreatment at some time.

This means that by recruiting on young maternal age you will get about one third of the cohort who is involved in maltreatment. But you will get two thirds who are not involved in child maltreatment; they are equally poor and disadvantaged, but they provide warm and loving homes for their children. However, it also means that sampling based on young maternal age will not generate a large number of cases in care, because care is such a rare outcome. You would need to oversample or enrich the sample for children in care.

These families were followed with 94% participation until the children were age 24, with last contact in 2021. Ways to keep them in the study have been:

- All data collection is oral, carried out during home visits; there is no self-completion, ever.
- Home visitors are a specially recruited and trained team of graduates with at least a 2.1 degree from a good university, young women selected for their combination of high intelligence, strong extroversion, and radiant warmth. The study team meet with the interviewer team bi-weekly to problem solve, and there is enormous team morale, such that the 1998 team still meets for dinner annually. This is not territory for NatCen-type staff.
- The home visitors bring lots of really nice gifts for the children, which means a lot to these deprived families.
- The study takes 24 months to run a follow-up, so if any mum sounds reluctant, the home visitors can hang up and ring back in three to six months when she might be less stressed and more able to host a home visit. It is important not to hem yourself in with a narrow recruitment or assessment window.
- If the team cannot easily book a home visit, they do pop-ins – just going to the home and knocking on doors, checking with neighbours to ask if the family has moved, etc. The team completed lots of home visits spontaneously by just showing up at the door.

It is a costly approach, but less costly than losing the most at-risk families to attrition. The E-Risk team can provide a budget for per/family costings, if needed.

### Permanently Progressing

The study explores the decision-making, pathways and outcomes for all children in Scotland who became looked after in 2012/13, when they were aged 5 and under. The sample includes 1,836 children (1,355 children looked after away from home, 481 looked after at home). Phase One (2014-2018) explored early childhood and Phase Two (2020-2024) is exploring middle childhood. Phase Three is planned for 2026-2030.

The study involves analysis of administrative data, plus surveys (of local authorities, social workers, and care givers) and qualitative research (involving children, kinship carers, and birth parents).

The challenges concerning recruitment and retention echo the experience of the E-risk study: it is all about maintaining relationships – both with research participants and partners. It involves a lot of time, persistence, and patience. Communication and dissemination of findings as you go along is key. It is also important to give careful consideration to how you communicate/what you give families.

### Care pathways and outcomes study

Longitudinal prospective study following a population of children (n=374) who were under the age of 5 and in care on the 31 March 2000. Four waves of study to date.

In terms of costs, learning from Wave Three (four-year study, rich quantitative and qualitative data, with detailed engagement with advisory groups, piloting, innovative development, PLUS placement profiling) cost = was £400k (@80% FEC). This involved 75 families = 150 face-to-face interviews, so approximate cost £5k per family.

Advice is to cost key individuals in gatekeeping organisations into the budget (through secondments etc) to support recruitment process etc. Also to consider financial incentives for families to take part, recognising their value and input.

### Brown et al (2016)

See also the experience of Brown et al (2016). Eight-year-olds identified in infancy as at risk of harm: report of a prospective longitudinal study. DfE.

### BaBi e-cohort network

This is a network of studies pooling local level admin data from the NHS and local authorities. BaBi stands for Born and Bred in. Five areas now established and using this approach, and others are interested and coming on board. If we are looking to do some feasibility testing with local authorities it would be worth contacting these local authorities as they are already ahead of the game.

### National Survey of Child and Adolescent Wellbeing

National Survey of Child and Adolescent Well-Being (NSCAW) | The Administration for Children and Families (hhs.gov), which is a similar size study to the Care pathways and outcomes study but involves a wider population of children where there's been a child protection investigation.

The National Survey of Child and Adolescent Well-Being (NSCAW) is a nationally representative, longitudinal survey of children and families who have been the subjects of investigation by Child Protective Services. NSCAW examines child and family well-being outcomes in detail and seeks to relate those outcomes to experience with the child welfare system and to family characteristics, community environment, and other factors. NSCAW includes first-hand reports from children, parents, and other caregivers, as well as reports from caseworkers and teachers.

To date, there are three cohorts of NSCAW:

- NSCAW I, the landmark study, was launched in 1997 and continued through 2007;
- NSCAW II was initiated in 2006 and completed in 2014; and
- NSCAW III began in 2015 and is ongoing.

The first cohort included more than 6,200 children aged birth to 14 years who were followed for five to six years. The second cohort included more than 5,800 children aged birth to 17.5 years who were followed for three years. Survey data from children in the second cohort was linked to child welfare administrative data on maltreatment re-reports, out-of-home placements, and adoptions.

## The funder perspective

ESRC and other funders would need to see:

- Establish that you can access a sample.
- Clarity about what we mean by vulnerability, what is the group of interest? (identify any trade-offs between different options).
- Identify the policy questions that are a priority to answer and methods needed to answer (for example need quantitative estimates with certain degree of precision).
- Clarity about sampling approach, how to collect the data and get a sufficient sample size.
- Identify cost and likely funders (a funding approach similar to that for the Millennium Cohort Study might be suitable).
- What extent does the work align scientifically, logistically, administratively with the Early Life Cohort study. Some of the work is likely to take longer than the timeframe for the Early Life Cohort.

Some of the above could be tested via a feasibility study.

## What would a feasibility study test?

A feasibility study would test:

- The practicalities of various sampling methods (nationally for vulnerable mothers, locally for CiN sampling).
- The practicalities of data collection methods (locally – in several local authorities) – how do you access parents and other carers, what information can you collect on the services that they are receiving.
- The likely scalability of these approaches.
- Whether you could generate a sufficiently powered sample to inform policy and practice.

Before a feasibility test is undertaken you would need permission to:

- Identify a sample of mothers by age of first birth and SEN/social care status.
- Identify a sample of children under 5 who were in CiN census (i.e. local authorities to provide names and addresses).
- Work with a selection of local authorities to test data collection methods.
- What size of various subgroups are needed to provide a sufficiently powered sample in order to have an impact on policy and practice – what does success look like?
- Clarify whether some or all of this can be conducted under the auspices of the Early Life Cohort.
- How much would a feasibility study cost?

# Who attended the second workshop

**Dr Adam Staines** (Associate Director– Cross-Council Partnerships and Infrastructure, Medical Research Council)

**Dr Alison Teyhan** (Research Fellow, Bristol Medical School, University of Bristol)

**Professor Alissa Goodman** (Director, UCL Centre for Longitudinal Studies)

**Amanda Farineau** (Families Analysis Team Leader, DWP)

**Aoife O'Higgins (**Director of Research, What Works for Children's Social Care)

**Catherine Bromley** (Deputy Director Data Strategy and Infrastructure, ESRC)

**Charlotte Edney** (Researcher, Nuffield Family Justice Observatory)

**Dr Dominic McSherry** (Reader in Psychology, Ulster University)

**Edward Martyn** (Economist, DWP)

**Erin Hawkins** (Principal Research Officer, Department of Health and Social Care)

**Harriet Ward** (Emeritus Professor, Rees Centre, Oxford University)

**Joas Flynn** (Senior Social Researcher, DfE)

**Jonathon Blackburn** (Head of Impact and Evaluation, Early Intervention Foundation)

**Professor Jonathan Scourfield** (Professor of Social Work, Cardiff University (CASCADE))

**Josh Hillman** (Director of Education, Nuffield Foundation)

**Professor Julie Selwyn** (Professor of Education and Adoption, Rees Centre, Oxford University)

**Professor Leon Feinstein** (Professor of Education and Children’s Social Care and Director, Rees Centre, Oxford University)

**Dr Linda Cusworth** (Research Fellow, Lancaster University)

**Professor Lisa Calderwood** (Senior Survey Manager, UCL Centre for Longitudinal Studies)

**Lisa Harker** (Director, Nuffield Family Justice Observatory)

**Michael Dale** (Senior Research Officer, DfE)

**Dr Orla McBride** (Reader in Psychology, Ulster University)

**Professor Pasco Fearon** (Chair in Developmental Psychopathology, UCL)

**Paul Bradshaw** (Director, Scottish Centre for Social Research)

**Peter Heath** (Department for Education)

**Rashid Jussa** (Chair, National Performance and Information Managers Group (NPIMG))

**Richard White** (Lead Analyst Children's Services, DfE)

**Rob Street** (Director of Justice, Nuffield Foundation)

**Professor Ruth Gilbert** (Professor of Clinical Epidemiology, UCL)

**Sarah Newton** (Principal Researcher, Scottish Government)

**Professor Terrie Moffitt** (Professor of Social Development, King’s College London and Professor of Psychology, Duke University)

**Wendy van Rijswijk** (Principal Research Officer, DfE)

# Annex 4

# Workshop 1 Agenda

## A new national birth cohort study of vulnerable children: What would it involve, and can it be done?

21 June 2022, 10:30 – 13:30

**10:30 – 10:45**

**Introduction and aims** (Lisa Harker)

- Short introduction from the workshop chair outlining the aims referencing briefing paper
- Expected outcomes from the workshop, including link to Workshop 2 (policy makers and funders)

**10:45 – 11:00**

**Context for this workshop: The Early Life Cohort Feasibility Study** (Alissa Goodman)

- The Early Life Cohort Feasibility Study
- Potential DfE and ESRC interest in further funding

**11.00 – 11.45**

**Part 1: Initiating a longitudinal cohort study of vulnerable children. Experiences of implementing birth cohort studies, what has and hasn't worked, and any challenges to be overcome**

- **Presentation 1 – Recruitment and retention:** Permanently Progressing study – using innovative methods to establish and maintain a longitudinal study of looked-after children (Helen Whincup)
- **Presentation 2–** Sampling from administrative data in England (Ruth Gilbert)
- **Discussion**
  - **Q1 Sampling, recruitment and retention**: What innovative approaches to sampling can we draw on for this cohort of children and families? How do we keep families in the study when their address and contact details may frequently change and other challenges to retention?

  - **<u>Q2 Data access</u>:** What are the key data access issues especially for sampling and how tractable are these barriers? Even where there is a legal gateway there are also usually major barriers including capacity issues in public bodies needed.

**11:45-11.55**
**Break**

**11:55-12:35**

### Part 2: Linking data collected in birth cohort studies

- **Presentation 2 – Linkage in ALSPAC:** Lessons learned – with a focus on linkage of ALSPAC data to the Children in Need census (Dr Alison Teyhan)
- **Discussion**
  - **<u>Q3 Linkage</u>**: Understanding the potential usage and ongoing blockages associated with data linkage between longitudinal survey and children's social care data. How can we make it easier to link records in future studies? What needs to be done to ensure adequate linking rates?

**12:35-13:05**

### Part 3: Adopting innovative approaches to measurement and filling evidence needs

- **Discussion**
  - **<u>Q4 Content:</u>** What are the most pressing evidence needs? Should this be the same as a mainstream study or adapted?
  - **<u>Q5 Measurement:</u>** What are the most appropriate measurement modes and tools for this cohort?
  - **<u>Q6 New opportunities and approaches:</u>** What can we learn and adopt from new domestic and international studies?

**13:05 – 13:25**

### Part 4: Next steps

- **Discussion**
  - Looking forward. Degree of risk, timing, scale, and cost

**13:25-13:30**

## Close: Thoughts, next steps and concluding remarks

- Summary from chair with reflections from Nuffield FJO (Lisa Harker) and ELC-FS project (Alissa Goodman)

# Annex 5

# Workshop 2 Agenda

## The case for, and feasibility of, developing a new national birth cohort study of children supported by the child welfare system: practical challenges and next steps

21 November 2022

10:00-12:30

**10:00 - 10:15**

**Introductions** (Lisa Harker)

**10:15 - 10:35**

**Part 1: Evidence needs from a government perspective** (Michael Dale and Richard White)

**Discussion points:**

- Are there any further evidence gaps?
- What kind of a study would help fill these gaps?

**10:35 - 11:35**

**Part 2: Key challenges for a future study**

Target population and sampling

- Issues with identification and sampling among the under 5s (Ruth Gilbert)
- Alternative approaches to sampling/population of interest (Terrie Moffitt)

**Discussion points:**

- What are the possible approaches to sampling?
- What feasibility testing is needed?

**Learning from existing studies**

- Permanently Progressing, including approach to recruitment, retention, data collection and linkage (Linda Cusworth)
- Care Pathways and Outcomes Study (Northern Ireland), (Dominic McSherry)

**Discussion points:**

- Further exemplars of innovative approaches to recruitment, retention, data collection and linkage (including from local national and international studies)
- What further feasibility testing is needed?
- Are there further challenges we have not yet considered?

### 11.35-11.45

### Break

### 11:45-12:25

### Part 3: Feasibility and next steps

- What are the next steps for this work?
- Key areas of feasibility to be tested
- What is the prospect for obtaining a national sample of children in the welfare system?
- If a national sample could be obtained, would it be preferable to recruit at a national level or through partnerships with specific local authorities?
- If a national sample cannot be obtained, would a national sample based on mother or parent vulnerability deliver the evidence needs required?
- What is the ideal balance between cost per case (enabling more intensive relationship-focused recruitment, retention, and data collection approaches), and sample size, to fulfil evidence needs?
- Would a relatively small, qual-only study be sufficient? Or would a joint quant and qual-approach be needed?
- Is there appetite to fund or work collaboratively on a feasibility study?

### 12.25-12.30

### Round up and reflections: including from ESRC

### Concluding remarks and close

# Annex 6

## Workshop 1
## June 21, 2022
## Participants

**Speakers/organisers:**

- **Dr Alison Teyhan** (Senior Research Associate for PEARL, Bristol Medical School, University of Bristol)
- **Dr Helen Whincup** (Senior Lecturer, University of Stirling)
- **Professor Ruth Gilbert** (Professor of Clinical Epidemiology at UCL Great Ormond Street Institute of Child Health)
- **Professor Alissa Goodman** (Director of the UCL Centre for Longitudinal Studies)
- **Lisa Harker** (Director, Nuffield Family Justice Observatory)
- **Jordan Rehill** (Researcher, Nuffield Family Justice Observatory)

**Attendees:**

- **Dr Linda Cusworth** (Research Fellow at the Centre for Child and Family Justice Research, Lancaster University)
- **Dr Lucy Griffiths** (Associate Professor of Health Data Science, Swansea University).
- **Dr Orla McBride** (Reader in Psychology at Ulster University)
- **Dr Rachel Hiller** (Department of Psychology, Centre for Applied Autism Research, University of Bath)
- **Karen Crawford** (Senior Trial Manager, University of Glasgow)
- **Martin Wood** (Director of Longitudinal Surveys, NatCen)
- **Professor Barbara Maughan** (Professor of Developmental Epidemiology, KCL)

- **Professor Lorraine Dearden** (Professor of Economics and Social Statistics in Social Research Institute, UCL)
- **Professor Marion Brandon** (Professor of Social Work and Director of the Centre for Research on Children and Families, University of East Anglia)
- **Professor Lisa Calderwood** (Senior Survey Manager, UCL Centre for Longitudinal Studies)
- **Mary Ryan** (Associate, Nuffield Family Justice Observatory)

# Annex 7

## Workshop 2
## November 21, 2022
## Participants

**Speakers/organisers:**

- **Dr Dominic McSherry** (Reader in Psychology, Ulster University)
- **Dr Linda Cusworth** (Research Fellow, Lancaster University)
- **Lisa Harker** (Director, Nuffield Family Justice Observatory)
- **Michael Dale** (Senior Research Officer, DfE)
- **Professor Alissa Goodman** (Director, UCL Centre for Longitudinal Studies)
- **Professor Lisa Calderwood** (Senior Survey Manager, UCL Centre for Longitudinal Studies)
- **Professor Pasco Fearon** (Chair in Developmental Psychopathology, UCL)
- **Professor Ruth Gilbert** (Professor of Clinical Epidemiology, UCL)
- **Professor Terrie Moffitt** (Professor of Social Development, King's College London and Professor of Psychology, Duke University)

**Participants:**

- **Dr Adam Staines** (Associate Director– Cross-Council Partnerships and Infrastructure, Medical Research Council)
- **Aimee Watts** (Department for Work and Pensions)
- **Dr Alison Teyhan** (Research Fellow, Bristol Medical School, University of Bristol)
- **Amanda Farineau** (Families Analysis Team Leader, DWP)
- **Aoife O'Higgins (**Director of Research, What Works for Children's Social Care)

- **Catherine Bromley** (Deputy Director Data Strategy and Infrastructure, ESRC)
- **Charlotte Edney** (Researcher, Nuffield Family Justice Observatory)
- **Martyn Edward** (Economist, DWP)
- **Erin Hawkins** (Principal Research Officer, Department of Health and Social Care)
- **Harriet Ward** (Emeritus Professor, Rees Centre, Oxford University)
- **James Neal** (Head of Family Hubs and Food Research and Analysis, DfE)
- **Joas Flynn** (Senior Social Researcher, DfE)
- **Jonathon Blackburn** (Head of Impact and Evaluation, Early Intervention Foundation)
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# Nuffield Family Justice Observatory

Nuffield Family Justice Observatory (Nuffield FJO) aims to support the best possible decisions for children by improving the use of data and research evidence in the family justice system in England and Wales. Covering both public and private law, Nuffield FJO provides accessible analysis and research for professionals working in the family courts.

Nuffield FJO was established by the Nuffield Foundation, an independent charitable trust with a mission to advance social well-being. The Foundation funds research that informs social policy, primarily in education, welfare, and justice. It also funds student programmes for young people to develop skills and confidence in quantitative and scientific methods. The Nuffield Foundation is the founder and co-funder of the Ada Lovelace Institute and the Nuffield Council on Bioethics. Nuffield FJO funded the development of this briefing paper. Any views expressed are not necessarily those of Nuffield FJO or the Nuffield Foundation.

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