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Experiences and Perspectives of Minoritised People on

Routine Enquiry of Adverse Childhood Experiences

A thesis submitted in partial fulfilment of the requirements for the Doctorate in Clinical Psychology

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Declaration

This thesis has not been submitted to any other institution, or for the purpose of obtaining any other qualifications.

Structure and Word Counts

Section One: Literature Review

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Section Two: Research Report

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Overall Abstract

In recent years, several services have been considering routine enquiry of Adverse Childhood Experiences (ACEs). This is happening in a context where few Black and minoritised people have been included in ACEs research.

The first section contains a scoping review that aimed to understand how research has been conducted in the area of routine enquiry of ACEs and identify any gaps in knowledge. This was done by describing the methods of research on routine enquiry of adverse childhood experiences (ACEs), briefly summarising the main findings of the research, and evaluating whether race and ethnicity has been considered in the research. Systematic searches of online research databases were conducted, searching for all relevant research on the topic of routine ACE enquiry. The data was extracted from relevant studies and presented in a descriptive manner. Twenty-nine studies on practitioner views, service user views and feasibility were identified. Most studies were quantitative, conducted in the US, and used a variety of ACE measurements. Both practitioners and service users generally found ACE enquiry acceptable. Several studies did not report any demographics, and only a handful of studies seemed to have considered the ethnicity of their participants in any depth. It was concluded that there were several gaps in knowledge, including most studies being set in the US, a lack of qualitative research and a lack of demographic information. The lack of racial and ethnic equity considerations in research limits generalisability and transferability of research on routine ACE enquiry.

Secondly, a research study was conducted to explore the experiences of Black people of being asked about ACEs, their perspectives on being asked about ACEs with a typical tool, and their perspectives on how services should be asking about ACEs. This study used a qualitative methodology, with a critical realist reflexive thematic analysis approach. Ten

people who had been asked about ACEs previously were interviewed about their experiences and perspectives. The interviews suggested that participants found trust and safety to be key when being asked about ACEs, and that it was important that practitioners take the time to build a relationship before asking about ACEs. Participants found it important to be asked about ACEs, but reported several experiences of clinicians or services making it difficult to do so. Participants did not want to be asked about ACEs using a questionnaire.

Acknowledgements

Firstly, I would like to say a huge thank you to the people who signed up to be participants in this study. I am immensely grateful for the time and effort you put into our interviews. I learned so much from you all, and it was a privilege to hear your insights.

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Section One: Literature Review

Methods and Diversity in Research on Routine ACE Enquiry: A Scoping Review

Abstract

Objectives

This scoping review sought to describe the characteristics and methods of research on routine enquiry of adverse childhood experiences (ACEs), briefly summarise the main findings of the research, and understand whether race and ethnicity has been considered in the research. The aim of this was to understand how research has been conducted in this field and identify potential knowledge gaps.

Methods

In December 2020, systematic searches were conducted in PsychInfo, MEDLINE and CINAHL, following the mneumonic Population, Context and Concept. The search terms included the concept of routine enquiry of ACEs, and the population and context were left open to keep the search wide. The data was extracted from relevant studies and presented in a charting table and a descriptive summary.

Results

Twenty-nine studies on practitioner views, service user views and feasibility were identified. Most studies were quantitative, conducted in the US, and used a variety of ACE measurements. Both practitioners and service users generally found ACE enquiry acceptable. Several studies did not report any demographics, and only a handful of studies had included an in-depth consideration of the ethnicity of their participants.

Conclusions

There are several gaps in knowledge based on the findings from this scoping review. Recommendations for future research includes conducting more qualitative research in a wider range of settings, and for research in this area to consider racial and ethnic equity.

Practitioner Points

- There are several knowledge gaps in this area, including most studies being set in the US, a lack of qualitative research and a lack of participants' demographic information.

- Lack of racial and ethnic equity considerations in research limits generalisability and transferability of research on routine ACE enquiry.

Methods and Diversity in Research on Routine ACE Enquiry: A Scoping Review

Introduction

Trauma-informed practice has been gaining traction in recent years, and many public health services are starting to realise the importance of considering clients' past experiences when they are accessing support. Harris and Fallot (2006) provided the initial background work for the trauma-informed practice model, which has been developed into a model that is now used in, for example, Scotland's public health services (Homes & Grandison, 2021). This model advises that public health services are grounded in an understanding of how trauma can affect people's psychological, social and biological development. The main tenet of the trauma-informed model is to move away from people feeling scared or controlled in services, and instead feel safe, empowered and able to hold services accountable (Concetta, 2018). When an organisation is trauma-informed, it works on the assumption that people who have experienced trauma might need particular attention from the services they are accessing in order to be able to develop trusting relationships with service providers, and so the organisations need to be structured in ways that prevents re-traumatisation and distrust (Homes & Grandison, 2021). The Scottish government toolkit for trauma-informed practice suggests that screening people accessing the service for traumatic experiences is an important part of the work (Homes & Grandison, 2021). Some practitioners suggest that service providers should not be concerned with screening for trauma, but that they should instead treat everyone as if they might have experienced trauma (Tello, 2018). Others again recommend that health care providers should make screening people for current or past trauma a part of their routine provision (McGregor et al., 2010; Roberts et al., 1999).

The idea of screening people for traumatic experiences has gained momentum since the first large-scale Adverse Childhood Experiences (ACEs) study by Felitti, Anda and Nordenberg (1998). This American study established ten ACEs that were linked to poor

mental and physical health outcomes (Felitti et al., 1998). These ten ACEs are physical, emotional or sexual abuse; physical or emotional neglect; family experiences of domestic abuse, substance abuse, mental illness, parental divorce, or a parent being in prison. Since this study, several researchers and practitioners have suggested that screening for ACEs can form an important part of trauma-informed practice, and that practitioners being aware of people's ACEs can help them provide better, more sensitive care (Hardcastle & Bellis, 2019; Larkin & Cairns, 2020; Gillespie & Folger, 2017).

In the US, routinely asking people accessing services about their ACEs has become increasingly common, particularly in primary care and paediatric care (Felitti, 2019). In the UK, there has been growing interest in incorporating this practice, and these ideas are now sometimes referred to as the "ACE movement" (Larkin & Cairns, 2020; Walsh, 2018). As part of becoming trauma-informed, the Scottish government has focused on becoming ACE-aware and are called the first "ACE-aware nation" by some (Walsh, 2018).

Challenges to the idea that being trauma-informed and enquiring about ACEs are closely-knit concepts, include suggestions that experiences of adversity does not always equal trauma, as it is the *experience of the event* as opposed to the event happening in itself, that determines the impact on a person (Barrett, 2018). Counting the number of ACEs might therefore not be enough to understand the impact this would have on a person accessing services. Others have commented that ACE screening might not be helpful if there are not enough resources to respond to the needs that arise when we understand the true impact of trauma (Finkelhor, 2018), and it has also been noted by a past review that there is not enough evidence to conclusively suggest whether routine ACE enquiry is useful and feasible (Ford et al., 2019). The methodological heterogeneity and the limited settings in which the research was conducted, were the main reasons provided as to why it was not yet possible to draw conclusions. In order to combat these criticisms, there seems to have been a very recent

increase in research on the feasibility, acceptability and experiences of routine ACE enquiry. Given this is a rapidly developing field, the current review sought an understanding of the methods and approaches of the now available research, which includes research published in the last three years since the searches of the Ford et al. (2019) review was conducted.

Some researchers have also noted that the original ACE study included a sample of primarily White, college-educated people, with a majority of participants being over the age of 50, which is not representative of the general population (Goldstein et al., 2017; Johnson et al., 2017). The second reason for this review being conducted, is therefore to understand whether the criticisms regarding the lack of representability in the original ACE studies has been addressed specifically in the area of routine ACE enquiry. This is important because screening for adverse experiences should be 'culturally appropriate' (Homes & Grandison, 2021). In order to ensure this, the demographics of people included in research needs to be representative of the demographics of those who might access public health services. However, people from minoritized ethnicities are generally less represented in research than their White counterparts (Smart & Harrison, 2017). This is despite the fact that since 2001, UK researchers have been asked by the Department of Health to include a diverse range of participants in their research, and, since 1993, US researchers have been required to disclose the race, ethnicity and gender of their participants in order to receive government funding (Department of Health, 2005; National Institutes of Health, 1993). The US National Institute on Minority Health and Health Disparities also recommend that ethnicity is not only reported on, but that researchers also investigate potential differences between ethnicities. Furthermore, they also recommend that such differences are considered in terms of potential underlying factors such as culture and socioeconomic status, rather than immediately attributed to genetic difference. The Institute suggested that by conducting research in this way, it would not only lead to better quality research, but it would also contribute towards

social justice and equality (Perez-Stable, 2018). Whilst minoritized people have argued for more diversity in research for a long time, it seems the Black Lives Matter movement, and the increase in discussions on racism and equality following the events of 2020, have prompted more researchers and research organisations to take a closer look at their policies and practice in regard to diversity (UK Research and Innovation, 2021). It is therefore particularly timely to use this momentum to consider how representative the current research is.

In order to evaluate the racial and ethnic representativeness in the available research, the researcher created a racial and ethnic equity checklist. This was informed by a working paper on racial equity in research by ChildTrends, a non-profit, non-partisan research centre, and the author of the current review has extrapolated the main points that were applicable to the research area in question and, from this, created a checklist of points to review in each paper (Andrews et al., 2019). The checklist can be found in Table 2. below.

In order to meet these objectives, it was judged that a scoping review would be the most appropriate tool, as the objectives are about understanding *how research has been conducted* in the area and identifying potential knowledge gaps in relation to the representativeness of the participants, which are questions best addressed by a scoping review (Munn et al., 2018). The scoping review will include a brief summary of the findings of the available research. As scoping reviews are focused on systematically describing and summarising, the review will summarise the methods and settings of the available research, divided into themes of studies on practitioner and service user views on ACE enquiry, and feasibility studies. Furthermore, the review will provide a description of the demographics of both practitioners and service users involved in the research. It will then use a checklist to understand to what extent the research available has considered ethnicity in their studies.

Aims

The review aimed to understand how research has been conducted and identify potential knowledge gaps by:

- Describing the characteristics and methods of currently available studies on routine enquiry of ACEs.

- Briefly summarise the main findings of current research on routine enquiry of ACEs.

- Understand whether race and ethnicity has been considered in the research on routine enquiry of ACEs.

Method

Protocol Registration

The protocol for this scoping review was registered with OSF (https://doi.org/10.17605/OSF.IO/Q2SZ7).

Search Strategy

Following scoping review guidelines, a systematic search was conducted (Peters et al., 2015). Preliminary searches using Google Scholar and Scopus were conducted in November 2020, for the researcher to familiarise themselves with the topic area. From these preliminary searches, the final search terms were determined based on commonly used words in titles and abstracts. The search terms of a previous scoping review on routine ACE enquiry were also used to inform the present search strategy (Ford et al., 2019). The preliminary searches also included checking that no similar scoping reviews in progress were registered with Prospero or OSF.

In December 2020, systematic searches were conducted in PsychInfo, MEDLINE and CINAHL. The search terms followed the PCC (Population, Concept, Context) mnemonic, which is the recommended search strategy for scoping reviews to allow for a wide search

(Peters et al., 2015). The concept to be researched is routine enquiry of adverse childhood experiences, which has been included in the search terms. The population and context have been left open, to keep the search as wide as possible. The search terms used were ("adverse childhood experience*" OR "adverse childhood event*" OR "childhood adversit*" OR "childhood trauma") AND (enquir* OR screen* OR inquir*). The Boolean operators OR and AND were used to combine the terms, and an * or $ was used to search for singular or plural versions of a word. The terms were searched for in abstracts and titles. Non-English papers were excluded during the search stage, by using the database filter functions.

Searches of grey literature were also conducted, using Google and a website specifically for grey literature, www.opengrey.eu. Relevant government and public health websites were also searched.

Inclusion Criteria

- All available research on feasibility, acceptability, experiences and perspectives of routine enquiry of ACEs was included. Routine enquiry was defined as a process of asking a large proportion of service users a set of questions to understand which ACEs they have experienced.

- Qualitative, quantitative and mixed-method peer-reviewed studies, as well as unpublished theses, were included.

- Research that focused on prevalence or validity, but also included participant experiences of routine ACE enquiry, were included.

- As this was an exploratory review, no specific measures related to ACEs were excluded. For the same reason, no method of gathering data was excluded. This meant that papers where perspectives on ACE enquiry had been gathered "ad-hoc" and not as the main focus of the paper, were included.

- Research published in for example a public health setting, but not published in a journal, was considered grey literature, and was included (Adams et al., 2016).

Exclusion Criteria

- Reviews, meta-analyses or case studies were excluded. Summary papers or opinion papers were also excluded. Furthermore, research that focused solely on the prevalence of ACEs or solely on the validity of an ACE questionnaire, was excluded. Research that focused only on current practice, such as asking how many practitioners were currently asking about ACEs, but did not include anything about the experience of this or barriers to doing so, were excluded.

- Grey data, such as Tweets and blogs, were excluded (Adams et al., 2016).

- Any papers not written in English were excluded.

Study Selection

After searches had been conducted, duplicates were removed. The author manually screened titles and abstracts for relevant studies and excluded those that did not fit the criteria. The author used the inclusion and exclusion criteria listed above to go through full-text versions of the narrowed-down list and excluded further papers. In May 2021, the author also conducted forwards and backwards citation searches, in order to identify further relevant research.

Data Analysis and Summary

This scoping review wished to focus on examining how research is conducted on a certain topic and identify any knowledge gaps in the area (Munn et al., 2018). Scoping reviews do not traditionally include a methodological quality appraisal of the studies in the form of a risk of bias tool (Arskey & O'Malley, 2005; Peters et al., 2015), and as the aim of this review was to describe how research is conducted, rather than understanding how reliable the current evidence base is, a formal risk of bias tool was not included. However, the study

does take a critical perspective of the methods employed by the included research and utilises a checklist that considers the quality of included studies in terms of racial and ethnic equity.

As the focus of a scoping review is to describe the data, the process of data extraction is called "charting", and this includes creating a "descriptive numerical" and analytical summary (Arksey & O'Malley, 2005; Peters et al., 2015). The charting table for this review is presented in Table 1 below. Scoping review guidelines suggest including study design, year of publication, study population and outcomes, in addition to other data that will be relevant in answering the research question (Peters et al., 2015). The process of adding data to answer the question is an iterative one, which meant that additional data points were added to the table during the process of charting, in order to capture the most important aspects of the studies (Levac et al., 2010). The data was also described narratively by dividing it into meaningful themes (Levac et al., 2010).

As one of the aims of this scoping review was to describe the approaches to research in the area with a particular focus on ethnicity, another table charting the considerations that has been made regarding ethnicity in each study was created. The checklist addressed in this table was based on the previously mentioned recommendations from ChildTrends on racial equity in research (Andrews et al., 2019). The author has not included important elements such as community engagement in the planning and dissemination phase of the research, or diversity in the demographics of the research team, as this information is often not readily available, and therefore difficult to comment on in a review. In any instances where this has been mentioned in a research paper, this has been noted and commented on as an additional point in the results section. Table 1 includes information on whether participants with a range of socioeconomic status, gender, age and ethnicity has been represented in the research. The second table (Table 2) considers the following questions:

1. Have potential researcher biases been explored or commented on?

2. Has oversampling of underrepresented groups been done?

3. Has intersectionality of ethnicity/race and other factors been explored? Intersectionality is defined as the interconnectedness of aspects such as ethnicity, gender and class.

4. Have different ethnical/racial groups been conflated?

5. Has difference in ethnic/racial groups been commented on?

6. Have quantitative data been disaggregated by ethnicity/race, and has qualitative themes been filtered by demographics for larger samples?

7. Have root issues regarding differences based on ethnicity/race been explored? This is defined as researchers attempting to understand potential underlying reasons for their results.

The answers to these questions for each study has been collated in Table 2 and will be expanded on below.

Results

Study Selection

Using the search strategy described above, 821 studies were screened. The PRISMA diagram in Figure 1 below demonstrates the process of study selection and the reasons for excluding papers at each stage (Moher et al., 2009). After the titles and abstracts were manually screened, 47 papers remained. Full text searches of these 47 papers were then conducted, which led to the exclusion of 18 studies. This left 29 studies to be included in this review.
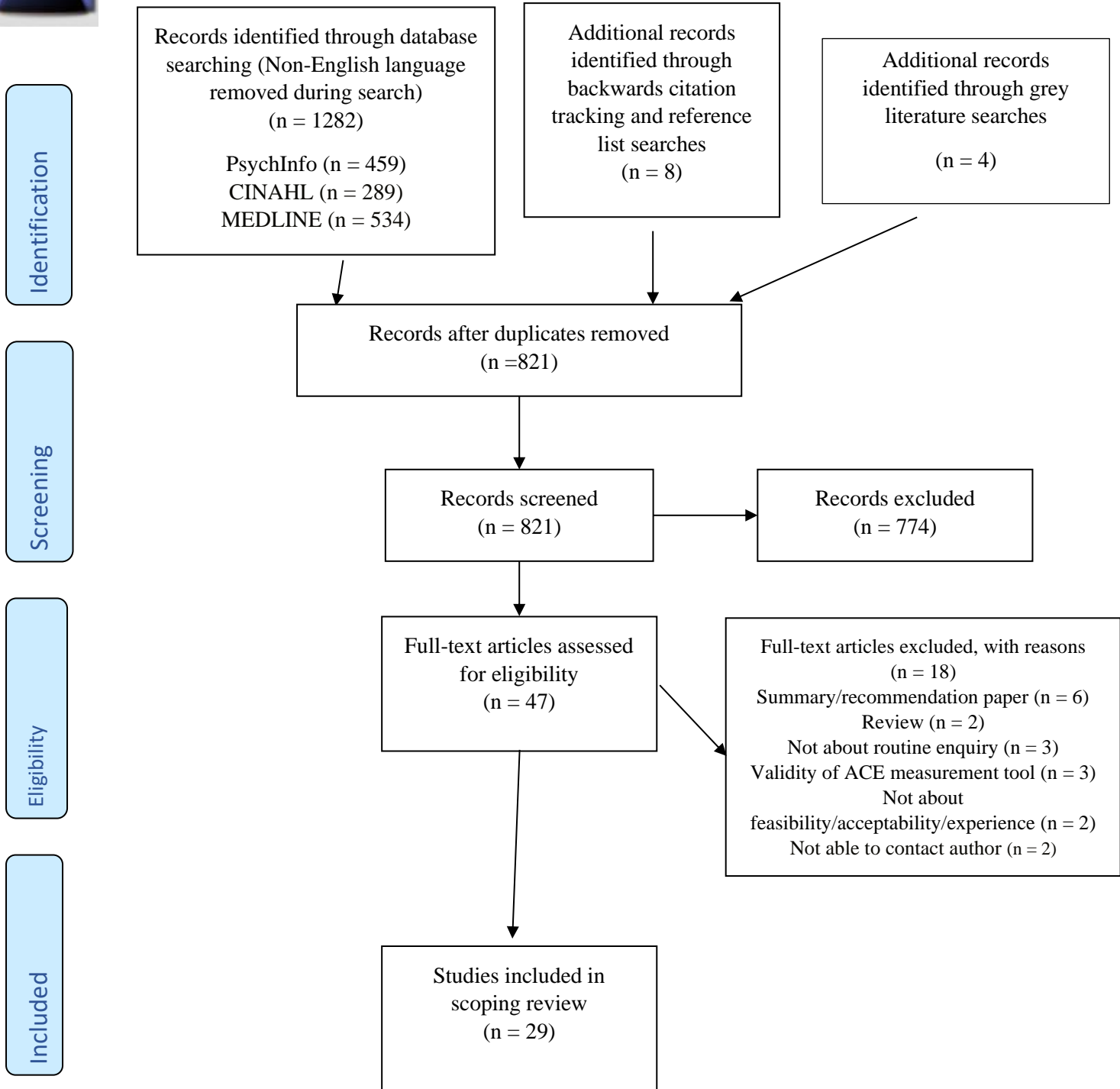
PRISMA 2009 Flow Diagram

Identification

Records identified through database searching (Non-English language removed during search)
(n = 1282)

PsychInfo (n = 459)
CINAHL (n = 289)
MEDLINE (n = 534)

Additional records identified through backwards citation tracking and reference list searches
(n = 8)

Additional records identified through grey literature searches
(n = 4)

Records after duplicates removed
(n =821)

Screening

Records screened
(n = 821)

Records excluded
(n = 774)

Eligibility

Full-text articles assessed for eligibility
(n = 47)

Full-text articles excluded, with reasons
(n = 18)
Summary/recommendation paper (n = 6)
Review (n = 2)
Not about routine enquiry (n = 3)
Validity of ACE measurement tool (n = 3)
Not about feasibility/acceptability/experience (n = 2)
Not able to contact author (n = 2)

Included

Studies included in scoping review
(n = 29)

Figure 1. *PRISMA (Preferred Reporting Items for Systematic Reviews and Meta Analyses;*

Moher et al., 2009) diagram of study selection process.

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Charting Data

      29 studies were included in this review. The charting table below (Table 1.)

summarises these studies, including country of study, method, sample size and population,

setting, ACE enquiry tool, data collection method, findings and demographic information.

Authors and year	Country	Method	Sample size and population	Setting	ACE enquiry tool	Data collection method	Findings	Socioeconomic status*	Age*	Gender*	Ethnicity/race*
Bright et al., 2015	USA	Mixed method	210 paediatricians	Paediatric office serving low-income families	12 ACEs from different tools	Survey	Most participants think some ACE screening is necessary. 50% of providers reported that they screen for or discuss all forms of child maltreatment with children.	Not provided, but all participants are employed doctors	Not provided	Male 102 (51%)	Hispanic 67 (39.9%) White, non- Hispanic 54 (32.1%) Black, non- Hispanic 11 (6.5%) Asian/ Pacific Islander 31 (18.5%) Other 5 (3.0%)
Bryant et al., 2020	USA	Intervention study	59 primary care providers (2 nurses, 57 medical residents)	Paediatric primary care clinic	CYW ACE-Q	Survey	After an educational intervention, most providers used the ACE screening tool. Providers reported feeling they do not have enough time to screen.	Not provided, but all participants are nurses or medical residents	24-63 years, mean age 30.8 years	Female 45 (76.3) Male 14 (23.7)	White 44 (74.6%) African American 5 (8.5%) Asian 9 (15.3%) Other 1 (1.7%)
Chandler et al., 2018	USA	Mixed method	30 adult service users	Substance misuse clinic	ACE screening interview	Interview, survey	Participants felt encouraged to speak about ACEs after understanding the link with substance misuse.	Education completed: Grade school – 8 GED - 4 High school - 15 College – 3 80% of participants not currently working.	21-30years 14 31-40years 7 41-50years 5 50+ years 4	Male 11 (36%) Female 19 (64%)	White 14 (46%) African American 14 (46%) Hispanic 2 (8%)
Chokshi et al., 2020	USA	Qualitative	16 adolescent service users	Adolescent health centre	CYW Teen ACE-Q SR	Semistructured interviews	Participants found it important to talk about ACEs. Participants made several suggestions of how to make ACE conversations better.	Largely low-income	Adolescents	Not provided	Not provided

Conn et al., 2018	USA	Qualitative	15 parents	Paediatric clinic	Original ACE tool	Semistructured interviews	Parents want to discuss ACEs and receive help and guidance. It is important to ensure that paediatricians have the training, skills and know about available resources.	Not provided	18–25 years 42% 26–34 years 33% 35–44 years 25%	Female 93%	Black 46% White 8% Hispanic 8% Multiracial 38%
DiGangi et al., 2020	USA	Observational	7056 children	Well-child visits at medical centre	CYW ACE-Q	Questionnaire	Despite some challenges, particularly with follow-up for those screening positive for ACEs, screening was feasible.	Not provided	3-year-olds 3241 5-year-olds 2761 10-year-olds 545 13-year-olds 509	Not provided	Not provided
Farrow et al., 2018	USA	Observational	145 obstetrician-gynaecologists	Fellows of the American College of Obstetricians and Gynecologists	Not specified	Survey	The majority of providers believe that assessment of abuse history is important and relevant, but few reported screening regularly. Barriers included lack of time and lack of referral resource.	Not provided, but all participants are obstetricians or gynaecologists	Mean age 52.5	Female 68.8% Male 31.3%	White 119 (85%) Asian 11 (8%) Black 8 (6%) Hispanic 4 (3%) Pacific Islander 1 (1%) Native American/Alaskan 1 (1%)
Flanagan et al., 2018	USA	Mixed-methods pilot	375 pregnant women 26 clinicians	Paediatric clinics	8 ACE exposures assessed in a shortened Behavioral Risk Factor Surveillance System Questionnaire	Survey, and focus groups (providers only)	ACE screening mostly feasible and acceptable to pregnant women. Providers said screening is dependent on referral resource.	Service users: Median neighbourhood income: Over $40k – 26 $40-80k – 144 $80-110k – 172 Over $100k – 50	Service users: Median age of those who answered ACE questions – 30 years. Median age of those who did not answer – 31 years.	Service users: Female 375 (100%)	Service users: White 167 (44%) Asian/Pacific Islander 54 (14%) Hispanic 63 (17%) Black 63 (17%) Other/unknown 16 (4%)

Study	Country	Design	Sample	Setting	Tool	Method	Key findings	Income	Age	Gender	Ethnicity
Gillespie et al., 2017	USA	Mixed-methods	1,308 parents 19 clinicians (pediatricians and nurse practitioner)	Paediatric clinics	Original ACE-10 with 4 ACEs added after initial review, both item-level and aggregate-level	Survey (parents) and qualitative survey (providers)	Providers and parents seem receptive to ACE conversations. Parents appear to be more likely to disclose ACEs with aggregate-level reporting.	20% of patients at the clinic use Medicaid (support for low-income families) 80% pay privately	Not provided	Not provided	A subset of 460 service users: Race: White 52.2% Hispanic 16.1% Asian 8.7% African American 1.1% Less than 1.0% American Indian and Pacific Islander 325 of the subset provided ethnicity data: Hispanic / Latino 30.5% non-Hispanic 69.5%
Glowa et al., 2016	USA	Observational	111 adult patients 7 primary practice clinicians	Primary care	Original ACE-10	Questionnaire	Feasible to incorporate ACE screening during routine primary care. Managing ACE risks can be part of primary care interventions.	Not provided	Service users: Mean age 51.9 years	Service users: Female 61%	Not provided
Goldstein et al., 2017	USA	Observational (cross-sectional)	152 adult patients	Primary care safety-net clinic	Original ACE-10	Questionnaire	Most primary care patients found ACE screening acceptable. Screening helps identify patients who may need further support.	Income under $10,000 – 50 $10 – 30,000 – 73 Over $30,000 - 28	18-34 years – 44 35-64 years – 98 Over 65 - 10	Female 98 (66%) Male 52 (34%)	Latino 96 (63%) White non-Hispanic 11 (7%) Other 18 (12%)
Hardcastle et al., 2019 (a)	UK	Mixed methods pilot	321 parents 14 health visitors	Heath visiting service	Adapted ACE-10	Survey (parents) Interviews (health visitors)	Parents found ACE enquiry acceptable and important. Health visitors also found it feasible and acceptable.	Not provided	Not provided	Service users: Female 321 (100%)	Not provided

Hardcastle et al., 2019 (b)	UK	Mixed methods pilot	549 adult patients 12 practitioners	GP surgeries	Adapted ACE-10	Questionnaire (patients) Focus groups and interviews (practitioners)	Most patients and practitioners said Ace enquiry was important and acceptable.	Not provided	Service users: 18-30 yrs - 76 (13.8%) 31-50 yrs - 163 (29.7%) 51-70 yrs - 196 (35.7%) ≥71 yrs - 114 (20.8%)	Service users: Male 216 (39.3%)	Not provided
Johnson et al., 2017	USA	Observational	110 parents	Home visit programme	Original ACE-10	Questionnaire	Parents reported feeling it was acceptable to be screened for ACEs during home visit.	One of the clinics studied covered "low-income families" specifically	Not provided	Female 101 (91%) Male 9 (9%)	Not provided
Kalmakis et al., 2017	USA	Mixed method	188 nurses	Nurses near Massachusetts	Not specified	Survey and focus groups	Only a third of nurses enquired about ACEs, lack of time and confidence were reported as main barriers.	Not provided, but all participants are employed nurses	Not provided	Female 98%	White 94% African American 2% Hispanic 1% Asian 1% Multiracial 1%
Kalmakis et al., 2018	USA	Observational	71 adult patients	Primary care	Adapted 19-item ACE	Questionnaire	Findings support screening is feasible in primary care.	Not provided	21–30 years - 6 31–40 years - 14 41–50 years -11 51–60 years - 21 61–70 years - 13 71–80 years – 6	Female 49(69%) Male 22 (31%)	White 71 (100%)
Kia-Keating et al., 2019	USA	Mixed method	151 parents 9 clinicians	Well-child visits	Adapted ACE questionnaire	Questionnaire (patients) Semistructured interview (clinicians)	Providers and parents found ACE screening acceptable and useful.	Low-income families	Child: Mean age 5.77 months	Child: Female 50.3% Male 49.7%	Child: Latinx 76.8% Other 18.5% Not reported 4.6%
Mansfield et al., 2017	Australia	Mixed method	57 mental health practitioners	Mental health services	Not specified (Child sexual abuse)	Survey	Low enquiry rates for child sexual abuse. Lack of confidence in enquiry and response was one of the main barriers.	Not reported, but all participants employed as mental health professionals	26–35 years - 15 36–45 years - 13 46–55 years - 15 56–65 years - 8	Not provided	Not provided

Study	Country	Design	Sample	Setting	Measure	Method	Key findings	SES	Age	Gender	Ethnicity
Marsicek et al., 2019	USA	Longitudinal study	1,206 parents 24 clinicians	Well-child visits	CYW ACE-Q	Questionnaire (patients) Survey (clinicians)	ACE screening feasible, with 60% of children screened. Providers felt uncomfortable discussing ACEs.	Not provided	Not provided	Not provided	Not provided
Maunder et al., 2020	Canada	Observational	89 family physicians, 46 psychiatrists and 48 other specialists.	Online survey	Not specified	Survey	Psychiatrists screened more routinely for ACEs than others. Barriers to screening were lack of resources and time, lack of confidence and concern about causing distress.	Not provided, but all participants employed as doctors	Not provided	Female 103 (43%)	Not provided
Mejia et al., 2018	Poland	Observational	110 parents 18 physicians	Paediatric clinic	CYW ACE-Q	Questionnaire (parents) Survey (clinicians)	ACE screening indicated families in need of support. Almost half of parents unsure if they would be comfortable discussing ACEs. Barriers to screening identified by physicians.	Family demographics: Below average 12 Average 72 Above average 24	Child: 1–4 years - 10 5–9 years - 33 10–13 years - 44 14–17 years - 22	Not provided	Not provided
Mersky et al., 2019	USA	Observational	1,678 parents or pregnant women 161 home visitor providers	Home visiting programme	Original ACE-10	Questionnaire	Most parents do not report extreme discomfort. Compared with non-Hispanic White people, American Indians had higher mean discomfort levels, and Hispanic people were less likely to report any discomfort.	Service user: "Low income" Any postsecondary education 449	Service user: Mean age 24.4 years	Service user: Female 1,678 (100%)	Service user: White 749 (44.6%) Hispanic 350 (20.9%) African American 324 (19.3%) American Indian 167 (10.0%) Other race/ethnicity 88 (5.2%)

Study	Country	Design	Sample	Setting	Tool	Method	Findings	Insurance	Age	Sex	Ethnicity
Pearce et al., 2019	UK	Qualitative	7 health and social care practitioners	Health and social care	Not specified	Semi-structured interview	The emerging themes were: change in knowledge, perception and practice; the emotional impact of hearing and responding to disclosures; confidence in asking and responding appropriately; making sense of the impact for clients; how and when to ask.	Not provided, but all participants employed in health and social care	Not provided	Not provided	Not provided
Popp et al., 2020	USA	Observational	48 family and paediatric practitioners	Family and paediatric clinics	13 ACE questions	Survey	Less than half of practitioners screened for ACEs. Barriers were lack of education on ACEs, lack of time and lack of appropriate screening tools.	Not provided, but all participants were employed health practitioners	Not provided	Female 31 (64%)	Caucasian 40 (95%) Asian/Pacific Islander 5 (11%) American Indian 2 (4%)
Selvaraj et al., 2019	USA	Observational	2569 families	Well-child visits	Addressing Social Key Questions for Health Questionnaire	Survey	Most families felt comfortable with ACE screening.	Subset: Medicaid 437 (76.7%) Private 67 (11.8%) Self-pay 31 (5.4%) Other 35 (6.1%)	2 wk-11 mo - 841 (32.74%) 1-4 y - 768 (29.89%) 5-11 y - 582 (22.65%) 12-14 y - 199 (7.75%) 15-17 y - 173 (6.73%)	Female 1328 (48.3%) Male 1328 (51.7%)	Subset: African American 352 (54.9%) Hispanic/Latino 137 (21.4%) Caucasian 49 (7.6%) Asian/Pacific Islander 30 (4.7%) Other 73 (11.4%)
Stevens, 2021	USA	Observational	28 adults	Well-child visits	Original ACE-10	Survey	Most participants felt comfortable being asked about their ACEs.	Not provided	Not provided	Female 19 (68%) Male 9 (32%)	Not provided

Author	Country	Study design	Sample	Setting	Measure	Method	Key findings	Recruitment	Age	Gender	Ethnicity
Thomas-Nawaz et al., 2015	UK	Qualitative pilot	6 clients 8 practitioners	Third sector mental health and wellbeing organisations	Not specified	Interviews	Practitioners feel they gain valuable insight from ACE enquiry. Researchers noted "no detrimental effect" to clients due to ACE screening.	Not provided	Aged between 21-60 years	Service users: Female 6 (100%)	White 4 Pakistani 1
Tink et al., 2017	Canada	Observational	112 family medicine residents	Family medicine residency programme	Not specified	Survey	Most participants did not routinely screen for ACEs, and main barriers were concern about offending patients and feeling uncomfortable asking about psychosocial issues.	Not provided, but all participants were medicine residents	Not provided	58% female	Not provided
Weinreb et al., 2010	USA	Observational	313 physicians	Academy of Family Physicians	Not specified	Survey	Providers who felt more confident were more likely to screen routinely. Being female, or reporting fewer barriers to screening, was associated with increased screening.	Not provided, but all participants were doctors	Not provided	Female 157 (51%) Male 154 (49%)	Race: White 268 (85%) Black 3 1%) Asian 32 (10%) Native American 3 (1%) Other 8 (2%) Ethnicity: Non-Hispanic 302 (96%) Hispanic 6 (4%)

CYW ACE-Q – Centre for Youth Wellness ACE Questionnaire

*Reported as provided by the paper

Descriptive Summary

Methodology of All Included Studies

The methods and characteristics of the included papers are summarised below. They have been divided into themes of studies including practitioner views and service user views, and feasibility studies. The service user views studies have also been divided into themes of disclosing their own ACEs and disclosing their children's ACEs. Where studies have included both practitioner and service user views and/or feasibility, the relevant part of the study has been included in each section, meaning some studies will be covered in several themes. If a study has used a mixed method, and practitioner views have been collected qualitatively and service user views has been collected quantitatively, the method noted under each theme will relate to the way data was collected for that specific participant group.

Methodology of Studies on Practitioner Views. Twenty out of the twenty-nine studies included in this scoping review contained information on practitioner views on ACE enquiry. The majority of these twenty studies were based in USA, with twelve studies originating from the USA. In addition, four studies were from the UK, two from Canada and one each from Poland and Australia.

Half of the twenty studies utilised a quantitative approach, three studies used a mixed-method approach, and the remaining seven studies were either qualitative (two) or were mixed-method studies that included a qualitative part for the practitioner views (five).

The setting for twelve of the twenty studies were related to children's health, such as family medicine, paediatrics, or health visitors. The remaining eight studies covered various settings such as GPs, mental health services or third sector charities.

The ACE tool used to consider practitioner views on ACE enquiry, was not specified in eight out of the twenty studies. Only two of the studies utilised the original ACE-10 questionnaire (Felitti et al., 1998). Three studies used the more recently developed CYW

ACE-Q, which aimed to be a more inclusive questionnaire with experiences such as neighbourhood violence, discrimination and deportation added as ACEs (Burke Harris & Renschler, 2015). One study used a shortened version of the Behavioural Risk Factor Surveillance System Questionnaire (CDC, 2021), and the remaining six studies used their own adapted versions of ACE questionnaires.

In conclusion, the majority of studies that included practitioner views, were quantitative studies that originated in the USA and focused on children's health services. The ACE questionnaires used were highly variable.

Methodology of Studies on Service User Views.

Disclosing Own ACEs. Eleven studies included service user views on being asked to disclose their own ACEs. Eight of these studies were conducted in the USA, and three of the studies were conducted in the UK.

The majority of service user views were gathered using quantitative methods, with eight studies utilising this approach. Two studies used a mixed-methods approach, and one study was qualitative.

Similar to studies including practitioner views, most of the service user views studies were conducted in children's services, with six studies being done in health visitor or paediatrics settings. The remaining studies were conducted in settings such as GPs and substance misuse clinics.

The ACE tools used were different from those used in practitioner views studies, and only one study did not specify their ACE tool. Four studies used the original ACE-10, and three studies used an adapted version of this. The remaining three studies used the CYW ACE-Q, the Behavioural Risk Factor Surveillance System and an ACE interview screening tool.

Disclosing Children's ACEs. Only three studies considered service user views on being asked to disclose not their own ACEs, but their children's ACEs. Two of these studies were conducted in the USA, and one of these studies was conducted in Poland. Two of the studies were quantitative, and one study was qualitative. They were all set in children's services, with two being set in paediatric clinics and one during well-child visits. One of these studies used the CYW ACE-Q tool, whereas one study used the original ACE-10 questionnaire, and one study created their own ACE measure.

Disclosing Own or Children's ACEs. Lastly, one study asked parents to provide their children's ACEs if their children were under the age of 12, and they asked children to provide their own if they were over the age of 12. This study was quantitative and set in the USA. It was conducted during well-child visits and used an adapted ACE questionnaire.

Summary Service User Views. In summary, out of the fifteen studies that considered service user views, most of them were also conducted in children's services in the USA. They were overwhelmingly quantitative, and they mostly specified which tools they used.

Methodology of Feasibility Studies. Four studies considered the feasibility of delivering routine ACE enquiry, without asking for service user views on this. Two of these studies asked for people to disclose their own ACEs, one asked people to describe their children's ACEs, and one asked people to disclose both their own and their children's ACEs.

All these studies were conducted in the USA. They were also set in children's services, with two being set in primary care and two being set during well-child visits. Two studies used the CYW ACE-Q tool, one used the original ACE-10, and one study used an adapted ACE questionnaire.

Demographics of Participants

The included studies have used varied language to describe the demographics of their participants. This scoping review mostly uses the language that each individual study has

utilised. It will however consider whether the language used is conducive to inclusive

research. Regarding reports of gender demographics, if a study has only provided the data for

one gender, for example the percentage of female-identifying participants, the review has

only reported this data in the data charting table. The review will not assume that the

remaining participants were cisgender if not reported, however the review does acknowledge

that it is likely the researchers assumed the remaining participants to be male if they only

reported number of female participants. The reporting of socio-economic status has also been

considered with any available information in the study, and the review has kept the definition

of what represents socio-economic status relatively open in order to record any information

provided.

Practitioner Demographics. Considering the twenty studies that included

practitioner demographics, none of these studies gave information on their participants'

socioeconomic status. However, as all the participants would need to be employed, usually as

doctors or nurses, it is possible to infer a certain level of income and status. Only three of the

studies reported the age of their participants, so it is not possible to draw any conclusions

about the representability of the ages of practitioners included. Eleven of the studies also did

not report the genders of their participants. Five of the remaining studies only reported the

amount of male or female participants, but in all but one of the studies which reported gender,

there were more female than male participants, and one study had 98% female participants

(Kalmakis et al., 2017).

Fourteen of the studies also did not report the ethnicity or race of their participants.

Due to the different language used to report demographics, it is difficult to calculate the exact

number of participants for each ethnicity provided. For example, some studies have conflated

Asian people and Pacific Islanders, which means it is not possible to calculate how many

people who identified as Asian and how many identified as Pacific Islanders. However, five

of the six studies that reported on ethnicity, had more than 60% White non-Hispanic participants. This is a useful benchmark for representability, as most the studies were conducted in the US, and 60% of the US population is White (US Census Bureau, 2019).

Service User Demographics. Out of the nineteen studies that included service users as participants, nine studies did not report socioeconomic status. Out of the ten studies that did provide this information, seven of the studies provided information that suggested low socio-economic status. The remaining three reported high or average status. Regarding the age of participants, five studies did not report this information. Ten of the studies that did report age information, had fewer than 16% of participants over the age of 65. This is useful as a benchmark, as 16% of the US population is over 65 (US Census Bureau, 2019). Again, five studies did not report information on gender identity. Of those that did report gender, three studies only reported the percentage of one gender. All of the fourteen studies that reported gender, had more female than male participants. Four of these studies had 100% female participants.

Nine of the nineteen studies did not report ethnicity or race. Of the remaining ten studies, seven had less than 60% White participants. Black or African American people and Latinx people were particularly represented in those studies.

Brief Summary of Findings

Practitioner Views. In all the studies with practitioners as participants, most practitioners concluded that it was useful and feasible to routinely ask service users about ACEs, with their views expressed either through scaled survey-answers or qualitative interviews. However, in the studies where practitioners were asked how often they enquired about ACEs, few practitioners routinely enquired even when they felt it would be useful to do so. The barriers to asking about ACEs reported by practitioners included lack of resources (Bright et al., 2015; Farrow et al., 2018; Flanagan et al., 2018; Maunder et al., 2020), lack of

time (Bright et al., 2015; Bryant & Van Graafeiland, 2020; Farrow et al., 2018; Kalamakis et al., 2017; Maunder et al., 2020; Popp et al., 2020) lack of tools (Bright et al., 2015; Popp et al., 2020), lack of confidence (Kalamakis et al., 2017; Mansfield et al., 2017; Maunder et al., 2020; Pearce et al., 2019), feeling uncomfortable or worried about upsetting the service users (Marsicek et al., 2019; Mansfield et al., 2017; Pearce et al., 2019), and a lack of education on ACEs (Popp et al., 2020).

Service User Views. Most of the papers which included service user views on routine ACE enquiry, considered service users being asked about their own ACEs by a practitioner. In general, people found it acceptable to be asked about ACEs, and some people expressed that it was important to be asked (Chandler et al., 2018; Chokshi & Skjoldager, 2020; Hardcastle & Bellis, 2019). Some studies merely concluded that there was "no detrimental effect" to being asked about ACEs (Thomas-Nawaz et al., 2015) or that it did not cause "extreme discomfort" for service users (Mersky et al., 2019). Two studies included recommendations from service users, which included ensuring practitioners have training, skills and familiarity with resources when asking about ACEs (Conn et al., 2018), and that practitioners are non-judgemental, establish trust, and offer choice in whether to discuss ACEs (Chokshi & Skjoldager, 2020).

The studies that asked service users to provide their children's ACEs scores, as opposed to their own ACEs scores (Conn et al., 2018; Mejia et al., 2018; Selvaraj et al., 2019), mostly concluded that parents or caregivers felt comfortable discussing their children's ACEs. However Mejia et al. (2018) found that half of the parents asked were unsure whether they would feel comfortable to disclose. In addition, the one study that asked parents to provide their children's ACEs for them if they child was under 12, also concluded it was acceptable and useful to ask about ACEs (Kia-Keating et al., 2019).

Feasibility Studies.

The four studies on feasibility all found it feasible to conduct routine enquiry of ACEs, meaning services tested large-scale delivery and found that a majority of clients were answering ACE questions (DiGangi & Negriff, 2020; Glowa et al., 2016; Kalamkis et al., 2018; Marsicek et al., 2019). However, it was noted that there were some challenges in how to respond to those people who disclosed having experienced ACEs (DiGangi & Negriff, 2020).

Racial and Ethnic Equity Checklist

The extent to which the included studies considered racial and ethnic equity in their research, is summarised in a checklist in Table 2 below.

Table 2. *Racial and ethnic equity checklist.*

Study	Participants	Biases considered	Over-sampling	Inter-sectionality considered	Conflation of ethnic groups	Comments on differences	Data disaggregated/filtered	Root issues regarding differences explored
Bright et al., 2015	Providers	No	NP*	No	Yes	No	No	N/A**
Bryant et al., 2020	Providers	No	NP*	No	Yes	No	No	N/A**
Chandler et al., 2018	Service users	No	NP*	No	No	No	No	N/A**
Chokshi et al., 2020	Service users	No	NP*	No	N/A***	No	No	N/A**
Conn et al., 2018	Service users	No	NP*	No	No	No	No	N/A**
DiGangi et al., 2020	Service users	No	NP*	No	Yes	Yes	Yes	No
Farrow et al., 2018	Providers	No	NP*	No	No	No	No	N/A**
Flanagan et al., 2018	Service users and providers	No	NP*	No	Yes	Yes	Yes	Yes
Gillespie et al., 2017	Service users and providers	No	NP*	No	No	No	No	N/A**
Glowa et al., 2016	Service users and providers	No	NP*	No	N/A***	No	No	N/A**
Goldstein et al., 2017	Service users	No	Yes	Yes****	Yes	Yes	Yes	No

Hardcastle et al., 2019 (a)	Service users and providers	No	NP*	No	N/A***	No	No	N/A**
Hardcastle et al., 2019 (b)	Service users and providers	No	NP*	No	N/A***	No	No	N/A**
Johnson et al., 2017	Service users	No	NP*	No	N/A***	No	No	N/A**
Kalmakis et al., 2017	Providers	No	NP*	No	No	No	No	N/A**
Kalmakis et al., 2018	Service users	No	NP*	No	No	No	No	N/A**
Kia-Keating et al., 2019	Service users and providers	No	Yes	Yes****	Yes	Yes	No	Yes
Mansfield et al., 2017	Providers	No	NP*	No	N/A***	No	No	N/A**
Marsicek et al., 2019	Service users and providers	No	NP*	No	N/A***	No	No	N/A**
Maunder et al., 2020	Providers	No	NP*	No	N/A***	No	No	N/A**
Mejia et al., 2018	Service users and providers	No	NP*	No	N/A***	No	No	N/A**
Mersky et al., 2019	Service users and providers	No	NP*	No	Yes	Yes	Yes	No

Pearce et al., 2019	Providers	Yes	NP*	No	N/A***	No	No	N/A**
Popp et al., 2020	Providers	No	NP*	No	No	No	No	N/A**
Selvaraj et al., 2019	Service users	No	NP*	No	Yes	No	Yes	No
Stevens, 2021	Service users	No	NP*	No	N/A***	No	No	N/A**
Thomas-Nawaz et al., 2015	Service users and providers	No	NP*	No	No	No	No	N/A**
Tink et al., 2017	Providers	No	NP*	No	N/A***	No	No	N/A**
Weinreb et al., 2010	Providers	No	NP*	No	Yes	No	No	N/A**
Total number		1 Yes	2 Yes	2 Yes	9 Yes	5 Yes	5 Yes	2 Yes
		28 No	27 NP	27 No	8 No	24 No	24 No	4 No
					12 N/A			23 N/A

*No information provided

**This is N/A if the study has not disaggregated or commented on any differences by ethnicity

***N/A as no ethnic groups were provided

****Not considered in the analysis, but considered in the recruitment

Biases Considered. Only one out of the twenty-nine studies included, had researchers being explicitly reflexive about any biases they might bring to the work (Pearce et al., 2019). The study was qualitative, and there is a longer tradition for researchers being reflexive about their potential biases when conducting qualitative research, however it has been argued that quantitative researchers should also consider the impact interviewer demographics might have on people's survey responses (Davis et al., 2010).

Over-Sampling. Over-sampling of minoritised people was only done in two of the included studies (Goldstein et al., 2017; Kia-Keating et al., 2019). Goldstein et al. (2017) consciously chose to do their research in a medical centre they knew served majority low-income, Latinx people. Kia-Keating et al. (2019) specifically discussed the disproportionate impact of ACEs on people who are Latinx and have low incomes, and therefore aimed to understand the feasibility and acceptability of routine enquiry with this population. They also went one step further by working in collaboration with the community being served, and they also included bilingual and bicultural wellness navigators that connected service users to a variety of resources.

Intersectionality Considered. Two of the included studies considered intersectionality in their research (Goldstein et al., 2017; Kia-Keating et al., 2019). Goldstein et al. (2017) and Kia-Keating et al. (2019) considered it by deliberately seeking out participants who would be both ethnically minoritized and have low incomes, but they could have gone further by considering intersectionality in their analyses (Andrews et al., 2019).

Conflation of Ethnic Groups. Regarding conflation of ethnic or racial groups, twelve studies did not report any demographics on ethnicity or race, and therefore this question did not apply to these studies. Nine studies did conflate ethnic groups, most commonly by using the term "other" as a racial or ethnic category. It is not known whether participants were asked to tick a box that said "other" if they did not identify with any of the

supplied ethnicities, or whether the researchers conflated the data later if there were not many people from some ethnic groups. Eight studies did not conflate groups and reported each individual participant's ethnic or racial group.

Comments on Differences. Twenty-four out of the twenty-nine included studies did not comment on any difference between ethnic or racial groups. Five studies did make comments regarding potential differences, even if they did not all explore this through analysis (DiGangi et al., 2020; Flanagan et al., 2018; Goldstein et al., 2017; Kia-Keating et al., 2019; Mersky et al., 2019). DiGangi et al. (2020) commented that young Black people were screening positive for ACEs at higher rates than other ethnic groups. Goldstein et al. (2017) however, did not find any difference in ACE reporting according to ethnicity in their samples. As previously mentioned, Kia-Keating et al. (2019) hypothesised that Latinx people would be disproportionately affected by ACEs, and Mersky et al. (2019) suggested that American Indians reported more discomfort in disclosing ACEs than White Americans.

Flanagan et al. (2018) note that women who reported their ethnicity as "other" were less likely to complete the ACE screening, and they speculate whether this reflects a cultural gap between service users and practitioners, greater stigma, or lower levels of engagement among minoritized people. They also wonder whether women who prefer not to disclose their ethnicity, might also be less likely to disclose their ACEs. Whilst it is useful to comment on potential reasons for lower engagement levels, it also highlights the issue with using the "other" category, as we do not know whether these women had an option to identify as anything but "other", and by them being identified as "other", we cannot learn anything about cultural preferences. It therefore seems that Flanagan et al. (2018) have not provided enough rationale for speculation about cultural gaps or stigma, when they do not know what this supposed culture is. It further demonstrates the importance of researchers being reflexive, as the researchers have not considered whether these women in fact felt literally othered by

being given the category "other" and whether this might have contributed to how much they wished to engage with the service.

Disaggregating or Filtering Data. Five out of the twenty-nine studies disaggregated or filtered their data in some way according to ethnicity or race (DiGangi et al., 2020; Flanagan et al., 2018; Goldstein et al., 2017; Mersky et al., 2019; Selvaraj et al., 2019). As mentioned above, Mersky et al. (2019) explored whether ethnicity or race in addition to number of ACEs reported, impacted on how comfortable participants felt in disclosing ACEs, and DiGangi et al. (2020) and Goldstein et al. (2017) considered whether ethnic groups had different rates of ACEs. Flanagan et al. (2018) looked at likelihood of completing ACE screenings according to reported ethnicity, and Selveraj et al. (2019) filtered their participants by ethnicity when considering whether ACEs were a risk factor for toxic stress.

Exploring Root Issues. Only two studies explored potential root issues for any difference between ethnic or racial groups (Flanagan et al., 2018; Kia-Keating et al., 2019). Kia-Keating et al. (2019) suggest that there might be additional stigma attached to visiting behavioural health services for Latinx people. Flanagan et al. (2018) also considers that stigma might be impacting on people's engagement with ACE questions, and they also speculate whether there is a cultural gap between service users and practitioners that contributes to this.

Note on Language and Other Minoritised Groups. Most studies conflated people's racial or ethnic identity to a certain extent, for example by using terms such as Asian, rather than specifying region or even country. This is not directly discouraged by APA guidelines, but it is suggested that it is preferable to be as specific as possible when it comes to people's racial or ethnic identity (American Psychological Association, 2019). Some studies used language that would be directly discouraged however, such as the term Caucasian (Popp et al., 2020; Selvaraj et al., 2019). This term stems from the days of "racial classification" and

segregation, and the term is therefore considered outdated and potentially offensive. APA guidelines recommend using White or European instead (American Psychological Association, 2019). More generally, the guidelines recommend being as precise as possible and allowing participants to self-identify. Therefore, terms such as "other" does not appear to fit with the guidelines.

Furthermore, the reporting of only one gender under participant demographics, imply that there are only two genders, which is discouraged by APA guidelines. Researchers are also encouraged to be explicit when identifying the gender of their participants, rather than assuming cisgender (American Psychological Association, 2019).

Lastly, none of the studies included gathered demographics on sexuality or disability, which means they may have further missed opportunities to understand intersectionality.

Summary Racial and Ethnic Equity Checklist. Only three studies scored three or more on the list of racial and ethnic equity (Flanagan et al., 2018; Goldstein et al., 2017; Kia-Keating, 2019), indicating that there is limited consideration of racial and ethnic equity in routine enquiry of ACEs research.

Discussion

This review sought to describe the characteristics and methods of research on routine enquiry of ACEs, briefly summarise the main findings of the research, and understand whether race and ethnicity has been considered in the research. The aim of this was to understand how research has been conducted in this field and identify potential knowledge gaps. This scoping review built on a previous review on the topic of routine enquiry of ACEs (Ford et al., 2019) by including several more recent studies, searching grey literature, and focusing on the demographics and racial and ethnic equity in the research.

The review showed a fairly equal divide of studies that considered practitioners'

views and studies that considered service users' views, as well as a smaller number of

feasibility studies. The research showed that both practitioners and service users generally

found ACE enquiry acceptable. There were however very few studies regarding service user

views that utilised a qualitative methodology to understand people's perspectives. It was also

clear that most studies were conducted in the USA. Several studies did not report any

demographics, particularly for practitioners, and only eight out of the twenty-nine studies had

less than 60% White people in their samples. Only a handful of studies seemed to have

considered the ethnicity of their participants in any depth.

The lack of racial and ethnic diversity in the sample demographics and lack of equity

considerations in most of the research on routine enquiry of ACEs is a significant gap in

knowledge. The two studies with most consideration for ethnic and racial equity according to

the checklist, both had a majority of Latinx participants (Goldstein et al, 2017; Kia-Keating et

al., 2019). Whilst these studies represent positive steps, more research with other racially

minoritised groups will be important in order to understand whether routine enquiry of ACEs

is acceptable to most people.

It could also be considered a gap in knowledge that there are fewer qualitative papers

in this area, particularly of service user views, considering the subject matter is related to

people's experiences and perspectives – which are topics well-suited to qualitative research.

The lack of qualitative papers might also explain why few researchers considered the biases

and assumptions they might be bringing into the research, as this is more commonly done in

qualitative research (Braun & Clarke, 2019).

Furthermore, the heterogeneity in methodology and particularly questionnaires used,

might make it difficult to conduct systematic reviews to judge the robustness of the current

evidence base. The way that ACE questions are asked, might have an impact on how acceptable the questions are to service users. For example, participants in one of the studies talked about the important of clinicians being non-judgemental, building trust and providing choice when asking about ACEs (Chokshi & Skjoldager, 2020).

Another noteworthy aspect of this review is that there were more women than men in most studies. Usually, women are underrepresented in research compared with men (Perez, 2019). However, it is possible that there were more women overall in these studies, as many of them were conducted in paediatric or health visitor settings, where it is more likely that women will accompany their children. This means there might be a gap in knowledge both in terms of the acceptability of ACE questionnaires for men, but also in terms of which settings it feels acceptable to ask about ACEs in. It is possible that people are generally receptive to discussing ACEs in settings with children, as it might appear directly relevant to their child's wellbeing, and therefore easier to discuss (Conn et al., 2018). However, there is potentially a gap in knowledge regarding how people find both asking and being asked about ACEs in settings where it might not appear as directly relevant. This will be important to establish if trauma-informed care is to be implemented widely (Homes & Grandison, 2021).

The studies in this review conformed to the norm with regard to under-representation of elderly people in research (Vitale et al., 2017). Again, this might be related to some of the settings in which the research was conducted, as elderly people will be less likely to access paediatric services or have well-child visits. However, this does highlight another knowledge gap, as there is less understanding of the willingness of elderly people in disclosing ACEs. It is possible that elderly people find it less acceptable, as demonstrated by one of the included studies which found that nearly 30% of those people aged 71 or over who were asked about their ACEs, declined to take part (Hardcastle & Bellis, 2019).

An area where the studies included in this review does not conform to the norm for ACE research generally (Cronholm et al., 2015), is that out of the studies that did report socioeconomic status, several studies included people with low incomes. It is possible that there is an assumption by researchers that poorer families will have more ACEs, and some research has suggested this might be the case (Marryat & Frank, 2019). However, it is worth noting that out of the ten studies that provided socio-economic status, seven of those included many participants with low incomes, and six of those studies again, were the studies with higher representation of minoritised people. This might lead to questions about researchers potentially being influenced by stereotypes of racially minoritised people living in poorer conditions when deciding whether or not to report certain demographics, and thereby fuelling these stereotypes.

In general, there are many studies that do not report demographic information, without providing specific reasons for not doing so. This in itself causes a gap in knowledge, as it makes it difficult to understand whether the perspectives of participants in the current research is representative of the general population or not.

Clinical Implications and Future Research

It is clear from this review that very few of studies considered racial and ethnic equity in their research. This provides an issue for the generalisability and transferability to clinical practice of the research available, and it may also inadvertently reinforce stereotypes and prejudice when ethnicity and race is not managed in a thoughtful way. The above example of an over-representation of people who both have low income and are from a minoritized background in the studies that reported demographics, can strengthen stereotypes about poor or minoritized people having more ACEs. This is an issue if it is presented as facts without any consideration of root causes such as systemic racism and classism, and only two studies

in this review did briefly consider root causes (Flanagan et al. 2018; Kia-Keating et al., 2019).

Several recommendations for future research on routine ACE enquiry can be drawn from this review. Firstly, it is clear that more research in countries other than USA is needed, and it would particularly be recommended to include more qualitative research in an area that lends itself well to understanding people's experiences and perspectives. It would also be important for future research to be explicit in recording specific ACE tools they utilise, and research that compares experiences of different tools may be called for. Widening the settings in which this research is conducted, beyond the focus on child medical settings, might also be helpful for recruiting more men and elderly people as participants.

It is also clear that research in this area has a long way to go in terms of incorporating racial and ethnic equity principles. Future research ought to consider over-sampling people from minoritized backgrounds, but not without also considering potential biases when doing so, and spending time understanding root causes of any potential differences between different ethnic groups. It would also be beneficial for future research to follow guidelines for reporting on gender, and to make sure that their participants are able to self-identify their genders.

Strengths and Limitations

One limitation of the current review was that searches were restricted to research published in English. It is possible that including other languages would have remedied some of the knowledge gaps described in this review, for example the US-centric nature of the available research. The exclusion of studies not published in English is perhaps a particularly important limitation given the nature of this review. English-speaking countries are statistically likely to have more White people as participants in their research, which might have contributed to the lack of consideration for ethnic and racial equality.

Another potential limitation is that some papers were not found in the initial search and were instead found in the citation and reference list searches. This means it is possible that the initial search terms were not wide enough to capture all the relevant research. A wider search of multiple databases might have revealed more relevant research. However, it is likely that the thorough search of citations, reference lists and grey literature provided compensation for this.

Lastly, Daudt et al. (2013) have suggested that due to the lack of a risk of bias tool for quality appraisal of the included studies, scoping reviews provide less useful information for clinical practice or policy making. It is possible that as this review was not part of a wider research programme, but was a standalone review without a systematic review to follow up, there are some limitations to how its findings can be applied to practice. However, it can also be argued that this scoping review identified several knowledge gaps that can inform the methods and approaches of future research in the area. It can also help clinicians make informed decisions on whether there is enough evidence available to understand whether ACE enquiry would be helpful to their particular setting or service user group. Furthermore, while a formal risk of bias tool was not included, it is a strength of this review that the author created a checklist for racial and ethnic equity in order to evaluate the available research, which addressed the review question.

Conclusion

In conclusion, this scoping review has outlined several gaps in the research on routine enquiry of ACEs, and made recommendations for future research to fill these gaps. Routine enquiry of ACEs is still a relatively new area for research and practice, particularly outside of the USA, which explains some of the current lack of variety of settings, qualitative research and different ACE tools. The fact that it is a new area of research does not however explain the lack of demographic information provided, and the lack of racial and ethnic equity being

considered in most of the included studies. There are now many guidelines, recommendations and conversations about being conscious of ethnicity and race when conducting research, and the author hopes there will be more focus on racial and ethnic equity in ACE enquiry research going forward.

References

Adams, J., Hillier-Brown, F. C., Moore, H. J., Lake, A. A., Araujo-Soares, V., White, M., & Summerbell, C. (2016). Searching and synthesising 'grey literature' and 'grey information' in public health: critical reflections on three case studies. *Systematic Reviews*, *5*(1), 1-11. https://doi.org/10.1186/s13643-016-0337-y

American Psychological Association. (2019). *Bias-free language*. American Psychological Association. https://apastyle.apa.org/style-grammar-guidelines/bias-free-language.

Andrews, K., Parekh, J., & Peckoo, S. (2019). (working paper). *How to Embed a Racial and Ethnic Equity Perspective in Research Practical Guidance for the Research Process*. ChildTrends. https://www.childtrends.org/wp-content/uploads/2019/09/RacialEthnicEquityPerspective_ChildTrends_October2019.pdf

Arksey, H., & O'Malley, L. (2005). Scoping studies: Towards a methodological framework. International Journal of Social Research Methodology, 8(1), 19-32. https://doi.org/10.1080/1364557032000119616

Barrett, W. (2020, August 3). *Why I worry about the ACE-aware movement's impact*. Why I worry about the ACE-aware movement's impact. https://www.tes.com/news/why-i-worry-about-ace-aware-movements-impact.

Bright, M. A., Thompson, L., Esernio-Jenssen, D., Alford, S., & Shenkman, E. (2015). Primary care pediatricians' perceived prevalence and surveillance of adverse childhood experiences in low-income children. *Journal of health care for the poor and underserved, 26*(3), 686-700.

Bryant, C., & VanGraafeiland, B. (2020). Screening for Adverse Childhood Experiences
in Primary Care: A Quality Improvement Project. *Journal of Pediatric
Healthcare, 34*(2), 122-127. https://doi.org/10.1016/j.pedhc.2019.09.001

Burke Harris, N., & Renschler, T. (2015). *Center for Youth Wellness ACE-Questionnaire
(CYW ACE-Q Child, Teen, Teen SR).* Center for Youth Wellness.

Centers for Disease Control and Prevention (CDC). (2021). *Behavioral Risk Factor
Surveillance System Survey Questionnaire*. U.S. Department of Health and
Human Services, Centers for Disease Control and Prevention.

Chandler, G. E., Kalmakis, K. A., & Murtha, T. (2018). Screening Adults With Substance
Use Disorder for Adverse Childhood Experiences. *Journal of Addictions
Nursing, 29*(3), 172-178. https://doi.org/10.1097/JAN.0000000000000233

Chokshi, B., & Skjoldager, K. (2020). Adolescent Patient Perspectives on Addressing
Childhood Adversity in the Primary Care Setting. *Clinical Pediatrics, 59*(11),
1014-1018. https://doi.org/10.1177/0009922820928056

Concetta, P. (2018). Survivors voices, personal communication, in Sweeney, A. &
Taggart, D. (2018). (Mis)understanding trauma-informed approaches in mental
health. *Journal of Mental Health, 27*(5), 383-87.

Conn, A.-M., Szilagyi, M. A., Jee, S. H., Manly, J. T., Briggs, R., & Szilagyi, P. G.
(2018). Parental perspectives of screening for adverse childhood experiences in
pediatric primary care. *Families, Systems & Health: The Journal of Collaborative
Family HealthCare, 36*(1), 62-72. https://doi.org/10.1037/fsh0000311

Cronholm, P. F., Forke, C. M., Wade, R., Bair-Merritt, M. H., Davis, M., Harkins-
Schwarz, M., ... & Fein, J. A. (2015). Adverse childhood experiences: expanding the

concept of adversity. *American Journal of Preventive Medicine*, *49*(3), 354-361. https://doi.org/10.1016/j.amepre.2015.02.001

Daudt, H.M., van Mossel, C. & Scott, S.J. (2013). Enhancing the scoping study methodology: a large, inter-professional team's experience with Arksey and O'Malley's framework. *BMC Medical Research Methodology, 13*(1), 48. https://doi.org/10.1186/1471-2288-13-48.

Davis, R. E., Couper, M. P., Janz, N. K., Caldwell, C. H., & Resnicow, K. (2010). Interviewer effects in public health surveys. *Health Education Research*, *25*(1), 14-26. https://doi.org/10.1093/her/cyp046

Department of Health. (2005). *Research governance framework for health and social care.* UK government. *https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/139565/dh_4122427.pdf*

DiGangi, M. J., & Negriff, S. (2020). The Implementation of Screening for Adverse Childhood Experiences in Pediatric Primary Care. *Journal of Pediatrics, 222*, 174-174. https://doi.org/10.1016/j.jpeds.2020.03.057

Fallot, R., & Harris, M. (2006). *Trauma-Informed Services: a Self-Assessment and Planning Protocol.* Community Connections

Farrow, V. A., Bosch, J., Crawford, J. N., Snead, C., & Schulkin, J. (2018). Screening for history of childhood abuse: Beliefs, practice patterns, and barriers among obstetrician-gynecologists. *Women's Health Issues, 28*(6), 559-568.

Felitti, V. J. (2019). Health appraisal and the adverse childhood experiences study: national implications for health care, cost, and utilization. *The Permanente Journal*, *23*. https://doi.org/10.7812/TPP/18-026

Felitti, V. J., Anda, R. F., Nordenberg, D., & Williamson, D. F. (1998). Adverse

childhood experiences and health outcomes in adults: The Ace study. *Journal of*

Family and Consumer Sciences, *90*(3), 31.

Finkelhor, D. (2018). Screening for adverse childhood experiences (ACEs): Cautions and

suggestions. *Child Abuse & Neglect*, *85*, 174–179.

https://doi.org/10.1016/j.chiabu.2017.07.016

Flanagan, T., Alabaster, A., McCaw, B., Stoller, N., Watson, C., & Young-Wolff, K. C.

(2018). Feasibility and Acceptability of Screening for Adverse Childhood

Experiences in Prenatal Care. *Journal of Women's Health, 27*(7), 903-911.

https://doi.org/10.1089/jwh.2017.6649

Ford, K., Hughes, K., Hardcastle, K., Di Lemma, L. C., Davies, A. R., Edwards, S., &

Bellis, M. A. (2019). The evidence base for routine enquiry into adverse

childhood experiences: A scoping review. *Child Abuse & Neglect*, *91*, 131-146.

https://doi.org/10.1016/j.chiabu.2019.03.007

Gillespie, R., & Folger, A. T. (2017). Feasibility of assessing parental ACEs in pediatric

primary care: Implications for practice-based implementation. *Journal of Child &*

Adolescent Trauma, 10(3), 249-256.

Glowa, P. T., Olson, A. L., & Johnson, D. J. (2016). Screening for Adverse Childhood

Experiences in a Family Medicine Setting: A Feasibility Study. *The Journal of*

the American Board of Family Medicine, *29*(3), 303–307.

https://doi.org/10.3122/jabfm.2016.03.150310

Goldstein, E., Athale, N., Sciolla, A. F., & Catz, S. L. (2017). Patient Preferences for

Discussing Childhood Trauma in Primary Care. *The Permanente Journal*, *21*.

https://doi.org/10.7812/tpp/16-055

Hardcastle, K., & Bellis, M. A. (2019). *Asking about adverse childhood experiences (ACEs) in health visiting.* Public Health Wales. http://www.wales.nhs.uk/sitesplus/documents/888/Asking%20about%20ACEs%20in%20Health%20Visiting%20-%20Pilot%20Evaluation%20Report.pdf

Hardcastle, K., & Bellis, M. A. (2019). *Asking about adverse childhood experiences (ACEs) in General Practice Evaluation findings from a pilot study in Anglesey, North Wales.* Public Health Wales. https://www.wales.nhs.uk/sitesplus/documents/888/Asking%20about%20ACEs%20in%20General%20Practice.pdf

Homes, A., & Grandison, G. (2021). *Trauma-informed practice: toolkit*. Scottish Government. https://www.gov.scot/publications/trauma-informed-practice-toolkit-scotland.

Johnson, K., Woodward, A., Swenson, S., Weis, C., Gunderson, M., Deling, M., Cristiani, V., & Lynch, B. (2017). Parents' adverse childhood experiences and mental health screening using home visiting programs: A pilot study. *Public Health Nursing, 34*(6), 522-530. https://doi.org/10.1111/phn.12345

Kalmakis, K. A., Chandler, G. E., Roberts, S. J., & Leung, K. (2017). Nurse practitioner screening for childhood adversity among adult primary care patients: A mixed-method study. *Journal of the American Association of Nurse Practitioners, 29*(1), 35-45.

Kalmakis, K. A., Shafer, M. B., Chandler, G. E., Aponte, E. V., & Roberts, S. J. (2018). Screening for childhood adversity among adult primary care patients. *Journal of the American Association of Nurse Practitioners*, *30*(4), 193–200. https://doi.org/10.1097/jxx.0000000000000033

Kia-Keating, M., Barnett, M. L., Liu, S. R., Sims, G. M., & Ruth, A. B. (2019). Trauma-Responsive Care in a Pediatric Setting: Feasibility and Acceptability of Screening for Adverse Childhood Experiences. *American Journal of Community Psychology, 64*(3/4), 286-297. https://doi.org/10.1002/ajcp.12366

Larkin, W., & Cairns, P. (2020). Addressing adverse childhood experiences: implications for professional practice. *British Journal of General Practice*, *70*(693), 160–161. https://doi.org/10.3399/bjgp20x708929

Levac, D., Colquhoun, H., & O'Brien, K. K. (2010). Scoping studies: Advancing the methodology. *Implementation Science, 5*(1), 69. https://doi.org/10.1186/1748- 5908-5-69.

Mansfield, Y., Meehan, T., Forward, R., & Richardson-Clarke, F. (2017). Asking the question: Childhood sexual abuse in adults with mental illness. *Australian Social Work, 70*(3), 363-371.

Marryat, L., & Frank, J. (2019). Factors associated with adverse childhood experiences in Scottish children: a prospective cohort study. *BMJ Paediatrics Open*, *3*(1). https://doi.org/ 10.1136/bmjpo-2018-000340

Marsicek, S. M., Morrison, J. M., Manikonda, N., O'Halleran, M., Spoehr-Labutta, Z., & Brinn, M. (2019). Implementing Standardized Screening for Adverse Childhood Experiences in a Pediatric Resident Continuity Clinic. *Pediatric Quality & Safety*, *4*(2). https://doi.org/10.1097/pq9.0000000000000154

Maunder, R. G., Hunter, J. J., Tannenbaum, D. W., Le, T. L., & Lay, C. (2020). Physicians' knowledge and practices regarding screening adult patients for adverse childhood experiences: a survey. *BMC Health Services Research, 20*(1), 1-5. https://doi.org/10.1186/s12913-020-05124-6

McGregor, K., Julich, S., Glover, M., & Gautam, J. (2010). Health professionals'

    responses to disclosure of child sexual abuse history: Female child sexual abuse

    survivors' experiences. *Journal of Child Sexual Abuse*, *19*(3), 239–254.

    https://doi.org/10.1080/10538711003789015

Mejia, C. L., Telega, G., Wilson, S. L., & Nagorska, M. (2018). Screening for adverse

    childhood experiences within paediatric patients in Rzeszów, Poland. *Polish*

    Pediatry, 93(4), 306-311.

Mersky, J. P., Lee, C.-T. P., & Gilbert, R. M. (2019). Client and Provider Discomfort

    With an Adverse Childhood Experiences Survey. *American Journal of Preventive*

    Medicine, *57*(2). https://doi.org/10.1016/j.amepre.2019.02.026

Moher, D., Liberati, A., Tetzlaff, J., & Altman, D. G. (2009). Preferred reporting items for

    systematic reviews and meta-analyses: The PRISMA statement. *Annals of*

    Internal Medicine, 151(4), 264-269. https://doi.org/10.7326/0003-4819-151-4-

    200908180-00135

Munn, Z., Peters, M. D., Stern, C., Tufanaru, C., McArthur, A., & Aromataris, E. (2018).

    Systematic review or scoping review? Guidance for authors when choosing

    between a systematic or scoping review approach. *BMC Medical Research*

    Methodology, *18*(1), 1-7. https://doi.org/10.1186/s12874-018-0611-x

National Institutes of Health (1993). *National Institutes of Health Revitalization Act of*

    1993. Subtitle B--Clinical Research Equity Regarding Women and Minorities.

    US Department of Health and Human Services.

    https://orwh.od.nih.gov/sites/orwh/files/docs/NIH-Revitalization-Act-1993.pdf.

Pearce, J., Murray, C., & Larkin, W. (2019). Childhood adversity and trauma: experiences of professionals trained to routinely enquire about childhood adversity. *Heliyon*, *5*(7). https://doi.org/10.1016/j.heliyon.2019.e01900

Perez, C. C. (2019). *Invisible women: Exposing data bias in a world designed for men*. Random House.

Pérez-Stable, E. J. (2018, June 27). *Communicating the value of race and ethnicity in research*. National Institutes of Health. https://www.nih.gov/about-nih/what-we-do/science-health-public-trust/perspectives/science-health-public-trust/communicating-value-race-ethnicity-research.

Peters, M. D., Godfrey, C. M., Khalil, H., McInerney, P., Parker, D., & Soares, C. B. (2015). Guidance for conducting systematic scoping reviews. *JBI Evidence Implementation*, *13*(3), 141-146. https://doi.org/10.1097/XEB.0000000000000050

Popp, T. K., Geisthardt, C., & Bumpus, E. A. (2020). Pediatric Practitioners' Screening for Adverse Childhood Experiences: Current Practices and Future Directions. *Social Work in Public Health, 35*(1/2), 1-10. https://doi.org/10.1080/19371918.2020.1711839

Roberts, S. J., Reardon, K. M., & Rosenfield, S. (1999). Childhood sexual abuse: Surveying its impact on primary care. *AWHONN Lifelines / Association of Women's Health, Obstetric and Neonatal Nurses, 3*(1), 39– 45.

Selvaraj, K., Ruiz, M. J., Aschkenasy, J., Chang, J. D., Heard, A., Minier, M., Osta, A. D., Pavelack, M., Samelson, M., Schwartz, A., Scotellaro, M. A., Seo-Lee, A., Sonu, S., Stillerman, A., & Bayldon, B. W. (2019). Screening for Toxic Stress Risk Factors at Well-Child Visits: The Addressing Social Key Questions for Health

Study. *The Journal of Pediatrics*, *205*.

https://doi.org/10.1016/j.jpeds.2018.09.004

Smart, A., & Harrison, E. (2017). The under-representation of minority ethnic groups in

UK medical research. *Ethn Health, 22*(1):65-82.

https://doi.org/10.1080/13557858.2016.1182126

Stevens, K. (2021). Exploring Parent Perception of Adverse Childhood Experiences

Screening in Pediatric Primary Care: A Clinical Inquiry Project. [The Eleanor

Mann School of Nursing]. ScholarWorks@UARK

Tello, M. (2018, October 16). *Trauma-informed care: What it is, and why it's important*.

Harvard Health. https://www.health.harvard.edu/blog/trauma-informed-care-

what-it-is-and-why-its-important-2018101613562.

Thomas-Nawaz, D., Lindsay, S., Khan, Z., & Duxbury, K. (2015). *An Evaluation of

REACh: Routine enquiry into adversity in childhood.* Real Life Research.

https://warrenlarkinassociates.co.uk/wp-content/uploads/2019/01/july29-final-

full-evaluation-report-for-reach-1.pdf

Tink, W., Tink, J. C., Turin, T. C., & Kelly, M. (2017). Adverse Childhood Experiences.

Family Medicine, 49(1), 7-13.

UK Research and Innovation. (2021). *Our work on race*. UKRI. https://www.ukri.org/our-

work/supporting-healthy-research-and-innovation-culture/equality-diversity-and-

inclusion/our-work-on-race/.

US Census Bureau (2019). *QuickFacts United States.*

https://www.census.gov/quickfacts/fact/table/US/PST045219

Vitale, C., Fini, M., Spoletini, I., Lainscak, M., Seferovic, P., & Rosano, G. M. (2017). Under-representation of elderly and women in clinical trials. *International Journal of Cardiology*, *232*, 216-221. https://doi.org/10.1016/j.ijcard.2017.01.018

Walsh, G. (2020, August 3). The ACEs campaign: cause for worry or celebration? https://www.tes.com/news/aces-campaign-cause-worry-or-celebration

Weinreb, L., Savageau, J. A., Candib, L. M., Reed, G. W., Fletcher, K. E., & Hargraves, J. L. (2010). Screening for Childhood Trauma in Adult Primary Care Patients. *The Primary Care Companion to The Journal of Clinical Psychiatry*. https://doi.org/10.4088/pcc.10m00950blu

Section Two: Research Report

Black People's Experiences of Being Asked About Adverse Childhood Experiences:
A Qualitative Study

Abstract

Objectives

The objectives for this study were to explore the experiences of Black people of being asked about ACEs by mental health or counselling professionals and their perspectives on being asked about ACEs as part of routine enquiry with a commonly used ACE questionnaire. An additional aim was to understand their perspectives on how services should be asking about ACEs.

Design and Methods

This study used a qualitative methodology, with a critical realist reflexive thematic analysis approach. Ten people who identified as Black and had been asked about ACEs by a mental health professional or counsellor, were interviewed about their experiences and perspectives using semi-structured interviews.

Results

Four overarching themes, some with subthemes, were established: *Trust and safety as individual and systemic* (subthemes: *Trust in the system; Trust in the clinician; Racism; Keeping safe); It's the person, not the questions* (subthemes: *Being heard and understood; Similarity and difference); Engaged client, 'hard-to-reach' clinician?* and *People are not tick-boxes.*

Conclusions

The results highlight that people find it important and useful to be asked about ACEs, if it is done in an appropriate manner. Establishing trust and a therapeutic relationship is key to fostering this. Participants stated that the ACE questionnaire might miss important context,

and they relayed a preference for being asked about ACEs using more inclusive definitions of ACEs.

Practitioner Points

- Participants found trust in the system and the clinician, to be key when being asked about ACEs.

- It was seen as important that practitioners take the time to build a relationship before asking about ACEs.

- Participants found it important to be asked about ACEs, but reported several experiences of clinicians or services making it difficult to do so.

- Participants did not want to be asked about ACEs using a questionnaire, and they found it more helpful to use a wider definition of ACEs than that provided by a questionnaire.

Black People's Experiences of Being Asked About Adverse Childhood Experiences:
A Qualitative Study

Introduction

Adverse childhood experiences (ACEs) have been associated with several physical health problems such as heart disease and cancer, as well as increased likelihoods of obesity, hallucinations and depression (Brown et al., 2010; Chapman et al., 2004; Dong et al., 2004; Felitti et al., 1998; Whitfield et al., 2005). The concept of ACEs as a checklist of quantifiable data was first introduced through a US study. The ten ACEs compiled in this study were physical, emotional or sexual abuse; physical or emotional neglect; and family experiences of domestic abuse, substance abuse, mental illness, parental divorce, or a parent being in prison (Felitti et al., 1998). The checklist was created to identify the risk of various negative outcomes, so that preventative work could be conducted. Since then, asking people about ACEs has also become a proposed part of trauma-informed practice, which involves understanding people's past experiences in order to provide better health care (Homes & Grandison, 2021).

There has recently been growing interest in routine enquiry about ACEs in health care. A scoping review considered the evidence-base for routinely asking adults about ACEs. It found there was limited literature providing outcomes from ACE enquiry, and that few studies considered the feasibility and acceptability of routine enquiry (Ford et al., 2019). Only three studies considered how acceptable ACE enquiry was to service users, all of which concluded that their participants mostly found the experience acceptable (Conn et al., 2018; Flanagan et al., 2018; Goldstein et al., 2017). However, two of the studies relied on quantitative methods rather than in-depth qualitative explorations, and the qualitative study asked people of their perspectives on hypothetically being asked about ACEs, rather than their experiences of it (Conn et al., 2018).

More recently, in the UK, several health services across England, Scotland, Wales and Northern Ireland have introduced routine enquiry about ACEs, in an attempt to provide trauma-informed care (Asmussen et al., 2020). For example, Lancashire Care Foundation Trust has rolled out routine enquiry of ACEs across several services (Quigg et al., 2018), NHS Health Scotland recently made ACE enquiry a top priority and spent £1.3 million on an ACE hub and practitioner training (NHS Scotland, 2019), and Public Health Wales has recently supported several research projects on routine ACE enquiry (Hardcastle & Bellis, 2019).

A recent pilot study in Wales suggested mothers found ACE questionnaires delivered by health visitors to be acceptable and important (Hardcastle & Bellis, 2019). However, there was no further exploration beyond the Likert-scale responses. Furthermore, the sample in the study was 99% White British, which means it is not representative of the wider UK population. This point is highlighted by other studies suggesting that adult White British respondents were more likely to report ACEs than Indian or Pakistani people (Bellis et al., 2013). This could suggest that people with Indian or Pakistani heritage experience fewer ACEs, but it could also suggest that the ACE questionnaires are not sensitive to diversity, or that there are cultural reasons why people would not want to disclose trauma (Bellis et al., 2013).

It is important to explore this discrepancy and its potential causes, because people from minoritized backgrounds still experience higher unemployment, lower wages and worse accommodation than White people (Equality and Human Rights Commission, 2016). Black people (described by this government report as Black African, Black Caribbean and Black "other", and people with mixed Black and White heritage were not included as Black)*, as well as Pakistani and Bangladeshi people, are statistically more likely to live in the 10% most income-deprived areas in the UK (Ministry of Housing, Communities and Local

Government, 2020). When deprivation is the highest risk factor for difficult childhood experiences (Sidebotham et al., 2006), this highlights an oversight in existing research.

Black people in the UK are facing an added challenge, as they are most likely to live in the 10% of areas which are most deprived specifically in relation to crime and barriers to housing and services (Ministry of Housing, Communities and Local Government, 2020). In fact, 32% of Black people in the UK live in areas where barriers to housing and services are particularly high (Ministry of Housing, Communities and Local Government, 2020). This means that Black people in the UK live in areas where crime levels are higher, which is likely to increase experiences of ACEs, at the same time as they face structural barriers to accessing support.

Black children are also overrepresented in secure children's homes and young offender institutions and are more likely to be restrained in these institutions than White children (Bush, 2018). Reports from the UK show that Black people are ten times more likely than White people and three times more likely than Asian people, to be stopped and searched by police (Ministry of Justice, 2020). The Windrush Scandal saw British Black Caribbean people deported or placed in immigration detention, as well as losing employment, homes, benefits and access to health services (Tsangarides & Williams, 2019). It is possible that these examples of structural racism would lead to higher numbers of ACEs for Black children and adults, but no studies in England have so far found a significant relationship between ethnicity and childhood trauma (Bellis et al., 2014).

*Footnote: When referring to Black people, this paper will refer to people who have either self-identified as Black during recruitment, or people who other reports and research have referred to as Black. The researchers of this paper have referred to people with mixed heritage as Black, when the people in question have self-identified as Black. The researchers acknowledge that it is not always helpful to consider Black people as a homogenous group in research.

A recent book, "Addressing Adversity" published by the charity Young Minds (Bush, 2018), suggests a new definition of ACEs is required, to include traumas that Black people, and refugees and asylum seekers may be more likely to experience, such as imprisonment, the asylum process, hate crimes, discrimination, racism and institutionalisation. The current narrower definition of ACEs may be part of the explanation of why fewer minoritised people report ACEs. The Young Minds definition also encompasses additional traumas not captured by the original definition, such as deprivation, sexism and disablism.

It has also been suggested that Black communities may have a different understanding of mental health and traumatic experiences than that of the "Eurocentric mental health services" (Llewelyn & Murphy, 2014). In a qualitative research paper, Black men reported predominantly seeing mental health problems as an "illness" that needed to be treated with medication (Myrie & Gannon, 2013). This is perhaps not surprising, given that Black service users are less likely than White service users to be offered psychological or social support (Department of Health, 2003) and more likely to be prescribed psychotropic medication (The Sainsbury Centre for Mental Health, 2002). When considering this, mixed with the fact that Black people report experiencing overt racism when accessing services (Myrie & Gannon, 2013; Rabiee & Smith, 2014), it might be important to explore whether Black people feel comfortable disclosing ACEs to health professionals.

In addition to the experience of accessing services, it has been suggested that the traumatic experience of racism is cyclical, in the sense that common responses to distress in Black people have often been misinterpreted by authorities as aggressive, noncompliant or non-engaging (Carter et al., 2005). This could make it even more difficult for Black people to openly express their traumatic experiences, as they may feel disclosing traumatic experiences will not help them.

Most ACEs research so far has been conducted with assumptions of White, middle-class experiences, and have ignored traumas that occur on a community-level, such as being discriminated against or living in an unsafe neighbourhood (Cronholm et al., 2015). Cronholm et al. (2015) included a more ethnically and socio-economically diverse population in their ACEs research, and found that when the above-mentioned traumas, as well as experiencing bullying, living in foster care and witnessing violence, was added to the list of ACEs, 13.9% of people who had not reported ACEs on the original checklist, reported ACEs on the extended checklist. This supports the idea that the original ACEs checklist is too restrictive to capture the experiences of people from different ethnic and socio-economic backgrounds. * If the current definition of ACEs, or the context in which the ACEs enquiry is being done, is leading to people not feeling comfortable in disclosing ACEs, then this will be important to address.

The clinical value of the current research will be insight into whether routine ACE enquiry is acceptable and helpful to Black people. If it is, services can use ACE enquiry to help break intergenerational cycles of trauma (Tomison, 1996) and better implement trauma-informed care (Quigg et al., 2018). It will also be following the guidelines laid out by the Department of Health (2005), which highlights that the body of research evidence available should reflect the diversities of the population, including diversity of ethnicity and culture.

*Footnote: Since the start of the current study, two studies on routine enquiry of ACEs where a significant proportion of the participants were Black, has been conducted (Mersky et al., 2019; Selvaraj et al., 2019). They were American quantitative studies, and only one of the studies used the original ACE questionnaire by Felitti et al. (1998). They suggested ACE enquiry was generally acceptable to participants.

Aim and Objectives

This study aims to expand on the current studies available on ACE enquiry, by providing an in-depth qualitative exploration. Furthermore, as the researcher and supervisor identify as part of the White majority culture, in order to limit the extent to which ACEs research continued to be based on White people's understanding of the topic, it is important to ask the participants open-ended questions and space for them to provide their own reflections (Salway et al., 2011). For this reason, it is also important that a Lived Experience Consultant has been engaged.

The study wants to amplify the voices of Black people, who have largely been overlooked in ACEs research (Cronhold et al., 2015), and use their experiences of having been asked about ACEs by health professionals to provide perspectives on practice. The study also aims to hear participants experiences of filling out an adapted version of the most commonly used questionnaire for asking about ACEs which has been used as part of a UK government-funded pilot project (Quigg et al., 2018), as well as their perspectives on using the above-mentioned expanded definition of ACEs (Bush, 2018), in order to understand preferences regarding how to be asked about ACEs and which ACEs ought to be addressed.

The research objectives are:

- To explore the experiences of Black people of being asked about ACEs in mental health settings.
- To explore the perspectives of Black people on being asked about ACEs with a commonly used ACE questionnaire.
- To understand the perspectives of Black people on how services should be asking about ACEs.

Method

Design and Procedure

This study used a qualitative methodology, with a reflexive thematic analysis approach (Braun & Clarke, 2019). Using a reflexive thematic analysis approach allows for themes and patterns to be established from the data (Braun & Clarke, 2006; Braun & Clarke, 2019). Establishing patterns across participants was deemed to be the most helpful in terms of clinical relevance for services.

The study used semi-structured interviews to gather information (see appendix A for interview schedule). Half-way through the interview, participants were shown the ACE questionnaire (Quigg et al., 2018) and asked to share their answers if they feel comfortable to do so (see appendix B). This was to replicate the experience of routine ACE enquiry. The answers to the participants ACE questionnaires were not specifically recorded outside of the interview transcript, nor used in the analysis. This was because most participants expressed that they did not feel the answers to the questionnaire represented them or their experience, which meant that it did not appear relevant, nor respectful to the participants' experiences, to relay their ACEs scores in the research. The participants were also later shown the Young Minds definition of ACEs (Bush, 2018) as a comparison (see appendix C).

The interviewers aimed to create a setting where participants could feel safe, particularly as it was possible that the lead researcher could be seen to represent the long history of racist and harmful practice provided by majority White mental health professionals (Jackson, 2002). Participants were given the option of being interviewed by the lead researcher only, or by the lead researcher and the Lived Experience Consultant. This was to ensure that any participants that may feel uncomfortable speaking with a White researcher only, could still participate. Their preferences are included in Table 1.

The interviews were audio recorded and transcribed. Transcribing was done by the lead researcher. The shortest interview was 57 minutes and the longest interview was 103 minutes.

Expert by Experience Involvement

The study employed a Lived Experience Consultant, who also works as a Racial Equity Consultant and Trainer, Juliet McKenzie. She identifies as a racialised (Black) woman of Jamaican heritage. She consulted throughout the research process, co-conducted interviews, and had reflective conversations with the lead researcher (see appendix D for further information).

Participants

Participants were people over the age of 18 who identify as Black, and who had been asked about their own adverse childhood experiences in a mental health or counselling service in the UK. Whilst some current research is considering routine enquiry of ACEs in various physical health settings too, this is not yet widely implemented, whereas mental health and counselling services are more commonly asking their clients about childhood experiences. Therefore, participants with experiences from mental health and counselling services was sought. It was seen as important to invite participants who had been seen in counselling services as well as formal mental health services, as there are several well-established barriers to Black people accessing formal mental health support, so adding counselling services was thought to provide a wider range of participants.

Following the advice of Rubin and Rubin (2005) to gather rich and meaningful data, the study aimed to seek out participants who were experienced, knowledgeable and able to express their knowledge, people who had a variety of perspectives, and people who

represented a variety of demographics between them. Participants were therefore asked to complete a Qualtrics screening survey to assess this (see appendix E). People were excluded for interview if they were unable to speak English or unable take part in a video call.

The study aimed to recruit a minimum of 10 participants. This was based on the recommended project size for a doctoral level piece of research using a reflexive thematic analysis (Braun & Clarke, 2019). Thirteen people responded to the survey. Ten of them were interviewed, one person was not eligible because they had not been asked about adverse childhood experiences, and two people having filled out the survey, did not attend the interview.

Table 1. shows demographics and interview preference for each participant who was interviewed. Pseudonyms have been used, and some participants chose their own pseudonyms.

Table 1. *Participant demographics and interview preference*

Pseudonym	Age bracket	Gender	Ethnicity*	Interview preference
Grace	18-30	Female	Mixed Black and White heritage	Researcher only
Anaya	18-30	Female	Black African	Researcher only
June	31-50	Female	Black Caribbean	Both
Chantelle	18-30	Female	Black Jew	Both
Peter	31-50	Male	Black Caribbean	Researcher only
Samantha	51-70	Female	Black Caribbean	Both
O.	31-50	Female	Black Caribbean	Both
Denise	31-50	Female	Mixed Black and White heritage	Researcher only
Bonnie	31-50	Female	Black Caribbean	Researcher only
Janet	31-50	Female	Black Caribbean	Both

Each participant has defined their own ethnicity, and the researcher has reported this verbatim.

Recruitment Procedure

The sampling strategy was purposive sampling, as the researcher wanted to recruit people with particular characteristics and experiences to address the research question (Palinkas et al., 2015).

The participants were recruited through Twitter and other online channels. An advertising poster (see appendix F) was posted together with a link for the survey. An information sheet and consent form were added to the survey. Potential participants were asked to complete this before proceeding (see appendix G). The researcher contacted the eligible participants to invite them to video link interviews.

Ethical Approval

Ethical approval for the study was obtained from the University of Sheffield (see appendix H for further information on ethical approval and data security).

Analysis

As described, the analysis conducted was a reflexive thematic analysis (Braun & Clarke, 2019; Terry et al., 2017). The data was approached in a latent way, meaning concepts and assumptions underpinning the data was considered in the coding and theme development. The epistemological approach taken was critical realist (Willig, 2013). This approach assumes that data does not "mirror" reality, but needs to be interpreted for underlying structures to be understood, and it encourages considering context and mechanisms such as social or psychological factors in these interpretations. The researcher also acknowledges that their own experiences and assumptions will shape what data is gathered and how it is interpreted.

Furthermore, the approach taken was deductive and inductive, as the analysis focused on answering the specific research questions posed, but the researcher also wanted to allow for any unexpected ideas or experiences (Gale et al., 2013).

The analysis followed the six steps proposed by Braun & Clarke (2019). Firstly, the researcher familiarised themselves with the data by re-reading transcripts and making notes of initial observations in their reflexive diary (see below for description). The researcher then generated codes in Nvivo for any features of the data that could help answer the research question (see appendix I for coded transcript excerpt). The codes were then organised into broader patterns of meaning, which constituted the initial themes. The researcher used lists and reflexive diary entries rather than conceptual maps for this stage. The themes were then

reviewed, and they were checked against the dataset and changed when appropriate. The themes were then defined and named.

Quality Appraisal

To ensure interpretative validity, it was ensured that the conclusions from the data are backed up by evidence (Harper & Thompson, 2012). The researcher kept a log throughout the analysis of how the themes were chosen, and a list of corresponding codes were kept for each theme.

As the chosen method does not subscribe to the view that there is a universal truth to be discovered, the study is not aiming for objective or replicable results. Instead, it is aiming for reflexivity, so that others can confirm that the researchers have followed a rigorous process.

As part of this approach, member-checking was not incorporated, as member-checking would suggest there is a certain truth that can be "found", and this does not fit with reflexive thematic analysis (Braun & Clarke, 2019).

The lead researcher discussed the codes and initial themes with the other researchers, in order to sense-check and gather alternative insights into the meaning of the themes (Braun & Clarke, 2019).

The researcher expected that some codes will not fit the majority themes, and these were identified and mentioned in the analysis write-up.

The supervisor also audited the lead researcher's work throughout the process to ensure a high standard of rigour (see appendix J for audit questions).

Reflexivity

An audit trail in the form of a reflexive diary has been kept throughout the research process, which will allow other researchers to see the decision-making process, and therefore evaluate the quality of the analysis (Nowell et al., 2017). This diary included both notes on the practicalities of the research process, as well as personal reflections and insights (see appendix K for excerpt).

The researcher aimed for cultural humility throughout the process, which involves understanding other people's experiences within their cultural context, as well as working to understand how their own environment has shaped their assumptions, biases and values (Kumagai & Lypson, 2009).

To aid transparency and allow readers to understand the researcher's process of analysis, the researcher has included a statement about themselves. The lead researcher is a White woman who has lived in the UK for ten years. She considers herself to have had a relatively privileged upbringing. She acknowledges the importance of continued education about race and racism, and she has made a particular effort to educate herself on Black people's experiences through reading, discussion and reflection both before and during the writing of this paper. The researcher will often understand people's experiences through a social justice lens. This meant that the researcher would particularly notice when participants were talking about systemic issues, and this will likely have translated into the analysis and theme creation.

The researcher also acknowledges that a White person might not be able to fully understand the experiences of Black people, and she nonetheless hopes that she has managed to represent the views and experiences of the people who were interviewed.

The researcher recorded assumptions and biases in the reflexive diary, and on several occasions the researcher reviewed past conclusions when they noticed a new potential bias to ensure that this particular bias did not unduly affect their writing or analysis. An example of how the researcher has attempted to understand their own biases throughout the research process, is that the researcher initially sought to understand the experiences of people from BAME (Black and minority ethnicities) backgrounds as opposed to Black people's experiences only, but learned through reading and conversations with the Lived Experience Consultant, that the BAME term can be unhelpful when used to cluster all non-White ethnicities together and that it would be difficult to represent the experiences of such diverse populations in one research paper. The project was therefore changed to focus specifically on Black people's experiences.

Results

The analysis produced four themes, two of which also comprised of several subthemes (see Table 2 below). Some quotes have been edited to support clarity for the reader and missing data is represented by the use of '...'. Additional explanations of participant points are included within '[ ]'.

The themes and subthemes represent a selection of what the researcher deemed to be the most repeated and relevant parts of the interviews.

Table 2.

Themes and subthemes with pseudonyms of participants who contributed to each.

Themes	Subthemes	
Lack of trust and safety as individual and systemic	Distrust in the clinician	*Grace, June, Chantelle, Peter, Samantha, O., Denise, Bonnie, Janet.*
	Distrust in the system	*Grace, Chantelle, Peter, O., Denise, Bonnie.*
	Racism	*Grace, Anaya, June, Chantelle, Denise, Janet.*
	Keeping safe	*Grace, Anaya, June, Chantelle, Peter, Samantha, O., Denise, Bonnie, Janet.*
It's the person, not the questions	Being heard and understood	*Grace, Anaya, June, Chantelle, Peter, Samantha, O., Denise, Bonnie, Janet.*

	Similarity and difference	*Grace, Anaya, June, Chantelle, Peter, O., Denise, Bonnie, Janet.*
Engaged client, 'hard to reach' clinician?		*Grace, Anaya, June, Chantelle, Peter, Samantha, O., Denise, Bonnie, Janet.*
People are not tick-boxes		*Grace, Anaya, June, Chantelle, Peter, Samantha, O., Denise, Bonnie, Janet.*

Lack of trust and safety as individual and systemic

The concepts of trust and safety seemed to be a crucial part of understanding what needs to be considered when services are asking about adverse childhood experiences.

Distrust in the clinician. Firstly, having some level of trust in the person that is asking about ACEs, appeared to be an important factor in deciding whether the questions could be answered safely:

> *"Um I suppose when you meet somebody - you are going to share intimate information about myself with somebody, I am looking for all those signs, those nuances of whether this person is trustworthy or they have the emotional capacity to handle what I am coming with." (Samantha)*

For several participants, deciding whether a clinician could be trusted with their ACEs was related to the level of competence and expertise they felt was needed to hear people's traumas, and also to what the clinician's responses would be if there was trauma that needed addressing:

> *"Because I just, I see the GP as more about the physical body. They're not there for emotional support really are they. And what, and how they would fix that if, if I were to answer that question it would be about medicating more so…" (June)*

For some participants, the decision of whether to trust someone with the answers to ACE questions came down to the personality and approachability of the clinician. Questions about childhood trauma could be personal and vulnerable, and it seemed important that there is a positive connection with the person asking. Most participants said they would not trust their GP with answers to an ACE questionnaire:

> *"… it's about trust, I wouldn't trust them." (Denise)*

"I wouldn't share it with my GP. I just wouldn't fill that in with my GP, because I can't stand him." (Chantelle)

Distrust in the system. Several participants mentioned the importance of containment and feeling cared for when being asked about ACEs, and these factors might not only be important in an individual relationship, but also on a systems-level. It is possible that it might be difficult to trust a service when you feel you have to fight to get the support you need:

"I have done so much, and last year I was diagnosed with sensory processing disorder, and obviously I have had that since I was little and they have only just found out, so the last three or four years I have kind of been my own coordinator to get all these assessments done, because nobody else has done it or picked up on things, so yeah." (O.)

Participants talked about distrust in the medical profession in general:

"But yeah, there's just not enough trust full stop I think. I mean, I am not the spokesperson for Black people, but I have no trust or faith in the system…"

(Denise)

It was suggested that not feeling safe due to institutionalised racism needs to be considered, as it affects how willing and able people are to provide information to all services:

"…they have consistently shown me that they don't care about Black people…. You can't expect people who you have disregarded and left in the gutter for so long, to

then trust you with really personal information that can potentially be used against

them." (Denise)

The idea that information given through ACEs questions can be used against a person was repeated by a few participants. Some people were concerned that they could not trust services to use this information in ways that would help them. This idea came through particularly strongly from the male participant:

"Well, you just feel like it'll be used against you. You feel like, it'll lead to some kind

of like diagnosis or coercion, maybe a meds review (laughter). So it won't be

beneficial to reveal too much information." (Peter)

This tallies with the current situation for Black men in mental health institutions, where they are more likely to be seen as "aggressive" and more likely to be sectioned compared to people who are not Black (Care Quality Commission, 2010).

Racism. Several people gave examples of direct or indirect racism impacting on their access to and involvement in, health services. Black people have many good reasons not to trust institutions like the NHS, both due to historical abuses, but also due to current issues such as Black women being more likely to die in childbirth (ClearView Insights, 2020). Several examples of being treated differently than White peers in the health system was given:

"Um when all my friends who aren't Black, are able to tell me that they've like got a

scan or something for something they have gone to the GP once for, I have gone like

four time or five times, and even when I turn up for the scan for something, it's the

wrong part of my back, it's just like (pause). And my White male boyfriend will get

listened to at the doctor's really quickly, and it just leaves me to conclude, it just leads

me to that conclusion when I read the statistics, of being Black and female, and

medical bias and research bias." (Grace)

One of the reasons it is important to consider structural racism when asking about ACEs, is that it might influence how likely someone will be to trust the service with the information required when asked about ACEs:

"… I would be conscious of how could this information be used in a racist way… Racism constantly changes it's face and the way it impacts our community is constantly changing… I wouldn't even want to give you that information so that someone could make use of it in a way that was going to be harmful." (Denise)

In addition to the potential indirect effects on distrust in the system leading to people not wanting to disclose ACEs, some participants also discussed feeling that the questions they were asked and the care they were given, were informed by racial stereotypes. Sometimes this was experienced as clinicians not having enough cultural competence to understand the context of someone's childhood experiences, and sometimes it was through the clinician directing the conversation towards certain aspects of ACEs:

"I would often be like, … , can we talk about the things that are going on, and a lot of the times I'd get pried about my absent father…. who is Black as well, so I think there might have been a stereotype there somewhere, but yeah." (Grace)

Keeping safe. When it is difficult to trust the system or the individual asking about ACEs, it becomes particularly important to keep safe. Participants described considering whether a person or situation would be safe enough for them to disclose ACEs. Several

people talked about this being with someone or somewhere that feels comfortable, where there is enough time, and where appropriate responses are given. Some people described that the decision of how much to disclose was made partly based on assessing whether it was appropriate:

> *"...if somebody says, well tell me about what happened - I have to feel several things: is this an appropriate question, has this come from an appropriate person, do I feel safe to share this information with this person? So you can ask the question, but you are not necessarily going to get the answer that you're looking for, or the information that you are hoping for." (Samantha)*

The idea that people would not answer ACE questions if they did not feel comfortable in a situation, was repeated by several participants. Several people also described the importance of receiving a human and compassionate response when they disclosed difficult parts of their childhood, and some people would gauge reactions to disclosures to decide whether it would be safe to answer questions about ACEs:

> *"I think for me, it is about really being clear, you know, I'll mention one thing and see how the conversation goes, you know, see the expression on their face, how they react." (Peter)*

Sometimes people described having taken the chance to disclose something personal, but then realising it was not a safe space after all, and choosing not to divulge any more information:

> *"...made me feel like there were some things I couldn't talk about or that would be misunderstood. Because the things I had spoken about weren't as significant to me,*

they had been mishandled in my opinion, I didn't feel safe enough to explore any

deeper." (Bonnie)

Lastly, several participants talked about a fear of negative consequences for others, if they talked about their ACEs. Some people feared others would be upset if they knew, and some people were worried about the judgement of others:

"Just feeling judged, them being judged or me making them look bad, I really didn't

want that." (Janet)

It's the Person, not the Questions

Throughout the interviews, most people talked a lot about the importance of having a good relationship with the person asking the questions about adverse childhood experiences.

Being heard and understood. Several participants highlighted how building a relationship where it feels comfortable to discuss ACEs takes time and the clinician to be willing to understand the person who is being asked. Most participants described that they had at some point experienced positive therapeutic relationships where they had felt heard and understood when talking about ACEs:

"… it made me feel like someone was caring about me and where I was coming from

and wanted to kind of understand the full picture." (Peter)

Participants often remembered the feeling they got from the relationship with the clinician better than they remembered specific questions:

"I think rather than the questions, it was me developing trust with her, that's what

enabled me to speak about the experiences." (Samantha)

Several participants talked about the importance of the clinician asking about ACEs having a cultural awareness and understanding. For some people, it was easier to feel seen when they did not have to educate the clinician on their culture before answering questions, and for some people, there was also a sense of threat if the clinician did not have a cultural understanding:

"… I guess in Western culture, I guess because of the culture, British culture, there's lots of things that are seen as wrong in terms of upbringing practices that I knew was part of my culture, but that I didn't feel safe to explore with a therapist that didn't have the understanding." (Bonnie)

An aspect of being asked about ACEs that was mentioned repeatedly by many participants, was the importance of the clinician taking the time to see the individual and respect that sharing ACEs can feel like a big thing:

"It feels like I have given something precious of myself, that I feel should be handled delicately, and you know, if you give someone something precious to look at you expect them to have the same kind of endearment towards that thing, and look at it and handle it, not just look at it and hand it back, kind of thing or, take it and then go that's difficult, and hand it back." (June)

Similarity and difference. Several people commented on perceived similarity or difference with the person asking them about ACEs. Many people felt that having some level of similarity with the clinician was helping the therapeutic relationship:

"… we also had some similarities on how we understand religion, … and he said he identified with a lot of the stuff I was saying in terms of how I saw myself and how that impacted my life growing up… those things made me feel, okay he is not a Black guy, he is not from the Caribbean, but … he seems to have understood some aspects of me." (Janet)

The idea that the similarity with the clinician did not necessarily need to be ethnicity, was repeated by some participants. A couple of the participants highlighted instead the importance of seeing a clinician that identified as gay, as *"the dynamics of those [same-sex] relationships are very different to heterosexual relationships, and those nuances have to be appreciated very differently" (Bonnie).* Some people described having benefitted from seeing a Black clinician, and a few participants explained that they had initially thought that seeing a Black clinician would help the relationship, but then did not feel they were able to connect with them after all:

"I just don't want to be that stereotype saying oh, if my therapist was Black they would have understood more… [it] can make it easier for people to have therapy if they're the same culture, but it can also work the opposite as well." (June)

The idea that seeing a clinician with a similar ethnicity might not be beneficial, has been repeated in a qualitative study in America, where some Black participants stated they would prefer to see a Black therapist, and some Black people explained that they would feel the clinician was a part of the "elite" and therefore too far removed from their culture to be helpful (Thompson et al., 2004). Despite this, some participants explained that too much perceived difference could lead to a feeling of distance, which made it harder to feel comfortable in the relationship:

"The psychologist I saw, was White, middle class man, and although he was very

intelligent, … I did feel like he was out of sync." (June)

There was no consensus on which personal characteristics might make it easier to feel

connected to a clinician, but some participants mentioned that cultural awareness and open-

mindedness from the clinician could help mitigate most differences:

"Just asking me to clarify… or like what meaning did you assign to it." (Anaya)

Engaged client, 'hard-to-reach' clinician?

Black people are still under-represented in mental health services and are therefore

sometimes given the labels "hard to reach" or "disengaged" by practitioners (Ouro-Gnao,

2020). However, these assumptions are not supported by the data in this study:

Every participant in the study said that their childhood experiences were relevant to

who they were as adults. Several participants also described themselves as open and ready to

talk, and many participants described talking about ACEs in the right setting as a helpful

experience – which might all be indicators of being an "engaged client". There was a general

view that talking about ACEs is important:

"I mean, it's not about shying away from [talking about ACEs], because it is

significant and important and we need to talk about these things, so that people can

thrive and develop their potential." (Samantha)

Whilst some research talks about the stigma of getting mental health support and

talking about difficulties as something shameful (Myrie & Gannon, 2013), this was not

emphasised in this study, and instead there were a few examples of how family had been supportive:

"…my dad and family encouraged me [to speak with a professional], and said it is important to talk." (Denise)

Most participants did emphasise that it can be both "*nerve-wracking*" and "*exposing*" *(O.)* to talk about ACEs, even when they were motivated to do so. Participants particularly highlighted the importance of being in the right setting with an empathic and human clinician because the conversations about ACEs are difficult. Everyone in the study had talked to someone about ACEs, which supports the idea that they were engaged clients and willing to talk. However, most people stated that there would be situations where they would not answer questions about ACEs. This would not be attributable to "disengagement" or being "hard to reach", but to setting appropriate boundaries when they do not feel comfortable with the clinician or the setting. It was implied that the clinician might be the person that was "hard to reach" for the client. Clinicians were sometimes described as not able to cope with hearing ACEs:

"But they have no practical, or I would stretch to say in some cases human understanding, of how to talk to somebody who have had an abusive childhood. It's almost like they start shutting down themselves." (Chantelle)

And there were also descriptions of clinicians being too far removed from the clients to understand:

"…no disrespect, but if you are working and coming from a good family, a good upbringing, you go to work and yes you hear some bad stuff, but you go back to your life. Whereas the reality on the streets is very different." (Peter)

In some cases, the clinicians themselves admitted they were going to be "hard to reach", by stating outright that they did not understand the clients:

> *"... I think maybe because it didn't feel, and the therapist said as well, that he couldn't understand everything that I was trying to talk to him about." (Janet)*

People are not Tick-Boxes

When participants were shown the ACE questionnaire during the interview, most people initially said it felt *"fine" (Anaya)* or *"okay" (O.)* to provide the researcher with the answers to the questionnaire. However, when going into more detail, it became clear the participants had issues with the questionnaire:

> *"I wouldn't feel that's an appropriate way to touch such a sensitive topic…. fill this in, tick-boxes, I'm not so sure about that." (Samantha)*

Many participants found that the questionnaire was not clear, and that there were several questions that could be easily misunderstood. Several participants noted that using tick-boxes for ACEs could be seen as both bureaucratic and imprecise:

> *"... needing to feel like I need to fit into like this box, because I'd get treatment if I tick this box." (Grace)*

> *"It's not necessarily the amount of times [you experience trauma], it is the impact that it has on you - it could be just once, but it could scar you for a lifetime." (Samantha)*

Many participants also brought up the cultural practice of physically disciplining children, which would be counted as an ACE on the questionnaire. Participants were somewhat divided in whether they felt it was a traumatic experience or not to have been hit as children, but several participants mentioned that they would not continue the practice with their own children. However, participants were in agreement that the ACE questionnaire was not sensitive to this issue:

> *"… people from African and Caribbean backgrounds, parents discipline in a physical way… and I don't know how that can be communicated, or clearly within this questionnaire…I would feel that was a misrepresentation, like my answers are not accurate…" (Anaya)*

Most participants also felt that important context would be missed by the ACE questionnaire, which could lead to clinicians making the wrong conclusions:

> *"It is all about the context, it's all about knowing the how and the why I think. And I think that on the face of it, it can look really bad. Yeah, it leaves me apprehensive that people won't know the context, because it is much deeper." (Denise)*

Participants were also shown an expanded definition of ACEs for comparison, and all participants identified one or more ACEs that they had experienced in this definition, that was not covered by the questionnaire. Several participants described feeling that the expanded definition was *"more inclusive." (O.)*. However, one person noted that it might be burdensome to *"rack up more ACEs." (Bonnie)*. Most participants stated that they preferred the expanded definition, although two participants explained that they would prefer to be asked using a questionnaire - which supports the overarching idea, that there is no one-size-fits-all solution to asking about ACEs.

<center>**Discussion**</center>

This study aimed to understand the perspectives of Black people on what is important to consider when asking about ACEs, using a qualitative reflexive thematic analysis. Four overarching themes were established: *Lack of trust and safety as individual and systemic; It's the person, not the questions; Engaged client, 'hard-to-reach' clinician?* and *People are not tick-boxes.* The themes are discussed below to consider how the current study relates to and extends existing knowledge.

This study suggests that trust and safety are particularly important factors when people are asked to disclose ACEs. As this study interviewed only Black people, it cannot conclude whether people with other ethnicities would have highlighted the same need for trust and safety when talking about ACEs. An American study found that African Americans were less likely than White Americans to trust the health service, due to experiencing higher levels of racial discrimination (Armstrong et al., 2013). A recent UK report found that 60% of Black people believed their health is not as equally protected in the NHS as the health of White people, and this number was even higher for Black women, with 78% believing their health is not equally protected according to a report commissioned for the UK parliament (ClearView Insights, 2020). Given the fact that the NHS has not set any targets to end known disparities, such as Black women being five times more likely to die in childbirth than White women, these numbers are unsurprising (ClearView Insights, 2020). Considering this, it might be that trust and safety are more important to Black people when interacting with health services, because they might not have the benefit of a baseline level of trust in the system.

The findings of this study are also consistent with the literature on the impact of a good therapeutic relationship on positive outcomes in therapy (Lambert & Barley, 2001). It is

possible that clinicians see the ACE questionnaire as being less emotionally intense and more

likely to reduce the potential for adverse reactions than therapy, and therefore assume that it

does not require the same level of relationship-building, based on the participants' comments.

However, this study shows that disclosing ACEs can be difficult for several reasons, and that

people will not disclose unless they feel it is a reasonably comfortable situation in which to

do so. It therefore seems likely that the qualities that are needed to build a positive

therapeutic relationship, are also highly relevant when asking about ACEs.

Previous research supports the findings of the current study - that people do wish to

talk, but it is important to do this in a compassionate, open way. One US mixed-methods

study with 46% African American participants, suggested that participants found ACE

enquiry helpful and normalising (Chandler et al., 2018). This study did not however use the

ACE questionnaire (Felitti et al., 1998), but instead used an interview protocol that asked

people to talk about their childhood, and then followed this up with a compassionate response

and discussion. Another study on ACE enquiry saw participants talking about the importance

of clinicians being non-judgemental, building trust, and providing choice (Chokshi et al.,

2020), all of which was repeated by the participants in the current study.

The final theme of *People are not tick-boxes* diverges from the pattern of findings in

existing quantitative research. Hardcastle and Bellis (2019) found that 85% of participants

thought the questionnaire was acceptable, and 91% were very or somewhat comfortable with

filling out an ACE questionnaire in an American study (Flanagan et al., 2018). This is

different from the participants in this study who mostly did not prefer to be asked about

ACEs using a questionnaire. This difference might be explained by the qualitative approach

of the current study. Most participants stated that it was "fine" to be asked about ACEs with

the questionnaire initially but then went on to describe difficulties with the questionnaire and

situations in which they would be uncomfortable filling it out. The quantitative approaches used in previous research might not have captured these nuances in people's responses.

As far as the researcher is aware, the current study is also the first to present the participants with first, a commonly used ACE questionnaire and then, an alternative expanded definition. Participants in the current study were all generally in favour of being asked about ACEs, which corresponds with the other research presented. However, it is possible that the participants in the current study labelled the commonly used questionnaire as less helpful than participants in other research because they were shown alternatives and were provided with the space to discuss these and consider more encompassing ways of approaching routine ACE enquiry.

Strengths and Limitations

A potential strength of the study was the fact that interviews happened to be conducted in the aftermath of the Black Lives Matter protests. One of the participants suggested that this might have helped embolden Black people to speak more freely and have more hope that they will be heard, thereby allowing them to speak openly about both positive and negative experiences of systems.

Following on from this, a possible limitation of the research is that the lead researcher is White. There will inevitably have been blind spots and biases that influenced how the lead researcher approached the interviews and analysis. The lead researcher engaged in reflective practice and research to educate themselves, however, this is not comparable to lived experience.

It was a strength that a Lived Experience Consultant was employed, as they could use their empathic understanding to keep the focus on the most important parts of the research

and keep the questions grounded in real-life situations, as well as being crucial in reaching participants to recruit (Videmsek, 2017)

By allowing participants to choose whether they wished to be interview by the lead researcher alone or by both the lead researcher and the Lived Experience Consultant, it is possible that participants felt they had a safer space in which to speak, as it has been suggested that participants will feel more able to open up with someone who has lived experience (Ramon, 2000).

It is a potential limitation of the study that there were fewer participants who identified as being Black African or from mixed heritage. There were also more people in the 31-50 years old age bracket than others. Furthermore, the study was only able to recruit one male participant. Future research would benefit from recruiting a wider diversity of participants.

Many of the current participants had been asked about ACEs in therapeutic settings, as routine enquiry of ACEs is not yet widespread practice outside of therapeutic environments. Therefore, future research ought to conduct qualitative research with people who have been through the ACE enquiry process in other settings.

It could be considered a limitation that the participants were offered a monetary contribution following interviews, as it has been suggested that this practice can be coercive and therefore undermine scientific integrity (Macklin, 1989). However, others argue that this payment recognises the contribution participants made to the research (Zutlevics, 2016). The researcher concluded that in the current and historical context of Black people often not being paid appropriately for their work, it would be unethical to not provide payment for their crucial contributions.

Implications for Research and Practice, and Conclusions

One of the key findings from this study is that participants reported that it is important to be asked about ACEs when it is done in the right way and in the right setting. One part of ensuring it is done in the right way is the presence of a clinician who has the knowledge and resources to respond appropriately. This is important to consider for roll-out, perhaps particularly in non-therapeutic services. Other research has suggested that asking about ACEs has not led to a large increase in referrals or support (Hardcastle & Bellis, 2019). However, this might not be because it is not needed, but because clients do not feel there is an option for further support or because clients felt the clinician did not have enough expertise to address it. High quality staff training and ensuring there are satisfactory options for further support will also be crucial. Providing supervision for staff that ask about ACEs will also be important to support them in understanding their own reactions to clients' experiences. If they are given the time and space to consider their own reactions, they might be able to more easily respond in ways that help the client feel safe and heard.

Based on the responses from the participants in this study, alternatives to using the ACE questionnaire should be considered. Ideally, people ought to be given the choice of how and if they would like to talk about their ACEs. A truly trauma-informed approach understands that individual needs should be accommodated whenever possible (Homes & Grandison, 2021), and that this should be prioritised over the easier option of gathering data in the same way from every client.

When considering the themes, they appear to overlap to a large extent with trauma-informed practice principles – particularly those regarding safety, trust and choice (Homes & Grandison, 2021). It might therefore be beneficial for services to consider delivering routine ACE enquiry according to trauma informed principles, which might include allowing time for

a therapeutic relationship to build between the clinician and client before ACE questions are asked.

This study highlights that dismantling institutional racism and working to rebuild trust in the health system by providing equal levels of care to everyone should be considered a crucial part of routine ACE enquiry in trauma-informed practice (McIntosh, 2019). ACE enquiry cannot be seen as a standalone issue, and the whole system in which these questions are asked needs to be considered.

Lastly, whilst the current paper focused on Black people's experiences of being asked about ACEs, it is possible that the themes and recommendations would apply to a larger population. The lack of trust and safety for example, might also be experienced by people who have had traumatic childhoods and struggle with trusting people and feeling safe as a consequence, or those who have been let down by the benefits system or the asylum system and therefore find it hard to rely on public services.

Future qualitative research that considers the experiences of the above groups, is recommended. It would also be useful to understand the experiences of people from other minoritised groups. Qualitative research that aims to understand the experiences of people who have been asked about ACEs using questionnaires in a range of services, could help further inform practice. Future quantitative research could ask about acceptability of ACE questionnaires compared to other methods of asking about ACEs, rather than only asking about acceptability of questionnaires. It might also be important to capture people's reasons for not answering ACEs questions when feasibility studies are conducted.

References

Armstrong, K., Putt, M., Halbert, C. H., Grande, D., Schwartz, J. S., Liao, K., ... & Shea, J. A. (2013). Prior experiences of racial discrimination and racial differences in health care system distrust. *Medical Care*, *51*(2), 144. https://goi.org/10.1097/MLR.0b013e31827310a1

Asmussen, K., Fischer, F., Drayton, E., & McBride, T. (2020). *Adverse childhood experiences: What we know, what we don't know and what should happen next.* https://www.eif.org.uk/report/adverse-childhood-experiences-what-we-know-what-we-dont-know-and-what-should-happen-next

Bellis, M. A., Ashton, K., Hughes, K., Ford, K., Bishop, J., & Paranjothy, S. (2015). *Adverse Childhood Experiences and their impact on health-harming behaviours in the Welsh adult population.* Cardiff: Public Health Wales

Bellis, M. A., Hughes, K., Leckenby, N., Perkins, C., & Lowey, H. (2014). National household survey of adverse childhood experiences and their relationship with resilience to health-harming behaviors in England. *BMC Medicine*, *12*(1), 72. https://doi.org/10.1186/1741-7015-12-72

Bellis, M. A., Lowey, H., Leckenby, N., Hughes, K., & Harrison, D. (2013). Adverse childhood experiences: retrospective study to determine their impact on adult health behaviours and health outcomes in a UK population. *Journal of Public Health*, *36*(1), 81-91. https://doi.org/10.1093/pubmed/fdt038

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research In Psychology*, *3*(2), 77-101.

Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health*, *11*(4), 589-597. https://doi.org/10.1080/2159676X.2019.1628806

Brown, D. W., Anda, R. F., Felitti, V. J., Edwards, V. J., Malarcher, A. M., Croft, J. B., & Giles, W. H. (2010). Adverse childhood experiences are associated with the risk of lung cancer: a prospective cohort study. *BMC Public Health*, *10*(1), 1-12.

Bush, M. (2018). *Addressing Adversity: Prioritising adversity and trauma-informed care for children and young people in England.* The Young Minds Trust

Care Quality Commission (2010). *Count me in 2010.* https://www.cqc.org.uk/sites/default/files/documents/count_me_in_2010_final_tagged.pdf

Carter, R. T., Forsyth, J., Mazzula, S., & Williams, B. (2005). Racial discrimination and race-based traumatic stress. In R. T. Carter (Ed.) *Handbook of Racial–cultural Psychology and Counselling: training and practice.* (pp. 447-476). Wiley.

Chandler, G. E., Kalmakis, K. A., & Murtha, T. (2018). Screening Adults With Substance Use Disorder for Adverse Childhood Experiences. *Journal of Addictions Nursing, 29*(3), 172-178. https://doi.org/10.1097/JAN.0000000000000233

Chapman, D. P., Whitfield, C. L., Felitti, V. J., Dube, S. R., Edwards, V. J., & Anda, R. F. (2004). Adverse childhood experiences and the risk of depressive disorders in adulthood. *Journal of Affective Disorders*, *82*(2), 217-225.

Chokshi, B., & Skjoldager, K. (2020). Adolescent patient perspectives on addressing childhood adversity in the primary care setting. *Clinical Pediatrics, 59*(11), 1014-1018. https://doi.org/10.1177/0009922820928056

ClearView Insights (2020). *Failures to secure Black people's human rights.*

https://publications.parliament.uk/pa/jt5801/jtselect/jtrights/559/55906.htm

Coleman, D. (2006). Therapist—client five—factor personality similarity: A brief

report. *Bulletin of the Menninger Clinic, 70*, 232 -241.

https://doi.org/10.1521/bumc.2006.70.3.232

Conn, A. M., Szilagyi, M. A., Jee, S. H., Manly, J. T., Briggs, R., & Szilagyi, P. G. (2018).

Parental perspectives of screening for adverse childhood experiences in pediatric

primary care. *Families, Systems, & Health*, *36*(1), 62.

https://doi.org/10.1037/fsh0000311

Cronholm, P. F., Forke, C. M., Wade, R., Bair-Merritt, M. H., Davis, M., Harkins-Schwarz,

M., ... & Fein, J. A. (2015). Adverse childhood experiences: expanding the concept

of adversity. *American Journal of Preventive Medicine*, *49*(3), 354-361.

https://doi.org/10.1016/j.amepre.2015.02.001

Department of Health. (2003). *Fair access to care services – guidance on eligibility criteria*

for adult social care. UK government.

https://lx.iriss.org.uk/sites/default/files/resources/Fair%20access%20to%20care%20

services.pdf

Department of Health. (2005). *Research governance framework for health and social care.*

UK government.

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachm

ent_data/file/139565/dh_4122427.pdf

Dong, M., Giles, W. H., Felitti, V. J., Dube, S. R., Williams, J. E., Chapman, D. P., & Anda,

R. F. (2004). Insights into causal pathways for ischemic heart disease: adverse

childhood experiences study. *Circulation*, *110*(13), 1761-1766.

Equality and Human Rights Comission. (2016). *Healing a Divided Britain: the need for a comprehensive race equality strategy.* https://www.equalityhumanrights.com/sites/default/files/healing_a_divided_britain_-_the_ need_for_a_comprehensive_race_equality_strategy_final.pdf

Felitti, V. J., Anda, R. F., Nordenberg, D., & Williamson, D. F. (1998). Adverse childhood experiences and health outcomes in adults: The Ace study. *Journal of Family and Consumer Sciences*, *90*(3), 31.

Flanagan, T., Alabaster, A., McCaw, B., Stoller, N., Watson, C., & Young-Wolff, K. C. (2018). Feasibility and acceptability of screening for adverse childhood experiences in prenatal care. *Journal of Women's Health*, *27*(7), 903-911. https://doi.org/10.1089/jwh.2017.6649

Ford, K., Hughes, K., Hardcastle, K., Di Lemma, L. C., Davies, A. R., Edwards, S., & Bellis, M. A. (2019). The evidence base for routine enquiry into adverse childhood experiences: A scoping review. *Child Abuse & Neglect*, *91*, 131-146. https://doi.org/10.1016/j.chiabu.2019.03.007

Gale, N. K., Heath, G., Cameron, E., Rashid, S., & Redwood, S. (2013). Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Medical Research Methodology*, *13*(1), 117. https://doi.org/10.1186/1471-2288-13-117

Goldstein, E., Athale, N., Sciolla, A. F., & Catz, S. L. (2017). Patient preferences for discussing childhood trauma in primary care. *The Permanente Journal*, *21*. https://doi.org/10.7812/TPP/16-055

Green, J. J., & Thorogood, N. (2009). *Qualitative methods for health research*. Sage Publications.

Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An

experiment with data saturation and variability. *Field Methods*, *18*(1), 59-82.

https://doi.org/10.1177/1525822X05279903

Hardcastle, K., & Bellis, M. A. (2019). *Asking about adverse childhood experiences (ACEs)*

in General Practice Evaluation findings from a pilot study in Anglesey, North Wales.

Public Health Wales.

https://www.wales.nhs.uk/sitesplus/documents/888/Asking%20about%20ACEs%20in

%20General%20Practice.pdf

Hardcastle, K., & Bellis, M. A. (2019). *Asking about adverse childhood experiences (ACEs)*

in health visiting.

https://www.researchgate.net/profile/Katherine_Hardcastle/publication/330728758_

Asking_about_adverse_childhood_experiences_ACEs_in_health_visiting_Findings_

from_a_pilot_study/links/5c517d76a6fdccd6b5d389d7/Asking-about-adverse-

childhood-experiences-ACEs-in-health-visiting-Findings-from-a-pilot-study.pdf

Harper, D., & Thompson, A. R. (Eds.). (2012). *Qualitative research methods in mental health*

and psychotherapy: A guide for students and practitioners. John Wiley & Sons.

Homes, A., & Grandison, G. (2021). *Trauma-informed practice: toolkit*. Scottish

Government. https://www.gov.scot/publications/trauma-informed-practice-toolkit-

scotland

Jackson, V. (2002). In our own voices: African American stories of oppression, survival and

recovery in the mental health system. *University of Dayton Medical Journal.*

https://academic.udayton.edu/health/01status/mental01.htm:

Kumagai, A. K., & Lypson, M. L. (2009). Beyond cultural competence: Critical consciousness, social justice, and multicultural education. *Academic Medicine, 84*(6), 782–787.

Lambert, M. J., & Barley, D. E. (2001). Research summary on the therapeutic relationship and psychotherapy outcome. *Psychotherapy: Theory, Research, Practice, Training*, *38*(4), 357. https://doi.org/10.1037/0033-3204.38.4.357

Llewelyn, S., & Murphy, D. (Eds.). (2014). *What is Clinical Psychology?*. OUP

Macklin, R. (1989). The paradoxical case of payment as benefit to research subjects. *IRB: Ethics & Human Research*, *11*(6), 1-3. https://doi.org/10.2307/3564182

McIntosh, M. L. (2019). Compound Fractures: Healing the Intersectionality of Racism, Classism and Trauma in Schools with a Trauma-Informed Approach as Part of a Social Justice Framework. *Journal of Educational Leadership and Policy Studies*, *3*(1), n1.

Mensah, F., & Kiernan, K. (2010*).* 'Parents' mental health and children's cognitive and social development'. *Social Psychiatry and Psychiatric Epidemiology, 45*(11): 1023-35. https://doi.org/10.1007/s00127-009-0137-y

Ministry of Housing, Communities and Local Government. (2020). *People living in deprived neighbourhoods.* UK government. https://www.ethnicity-facts-figures.service.gov.uk/uk-population-by-ethnicity/demographics/people-living-in-deprived-neighbourhoods/latest

Ministry of Justice. (2020). *Stop and search.* UK government. https://www.ethnicity-facts-figures.service.gov.uk/crime-justice-and-the-law/policing/stop-and-search/latest

Myrie, C.V., & Gannon, K. N. (2013). "Should I really be here?" exploring the relationship between Black men's conceptions of wellbeing, subject positions and help-seeking behaviour. *Diversity and Equality in Health and Care, 10* (1)*,* 13-22.

NHS Scotland. (2019). *Adverse childhood experiences in context*. Scottish ACEs Hub

Nowell, L. S., Norris, J. M., White, D. E., & Moules, N. J. (2017). Thematic Analysis: Striving to Meet the Trustworthiness Criteria. *International Journal of Qualitative Methods*, *16* (1), 1-13. https://doi.org/10.1177/1609406917733847

Ouro-Gnao, I. (2020). *Mental Health Services: What is it about your outreach that makes it hard to reach our Black communities?* Mind. https://www.mind.org.uk/information-support/your-stories/mental-health-services-what-is-it-about-your-outreach-that-makes-it-hard-to-reach-our-black-communities/

Palinkas, L. A., Horwitz, S. M., Green, C. A., Wisdom, J. P., Duan, N., & Hoagwood, K. (2015). Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. *Administration and Policy in Mental Health and Mental Health Services Research*, *42*(5), 533-544. https://doi.org/10.1007/s10488-013-0528-y

Pistrang, N., & Barker, C. (2012). Varieties of qualitative research: A pragmatic approach to selecting methods. In H. Cooper, P. M. Camic, D. L. Long, A. T. Panter, D Rindskopf, & K. Sher (Eds), *APA handbook of research methods in psychology, Vol 2: Research designs: Quantitative, qualitative, neuropsychological, and biological* (pp. 5-18). American Psychological Association. https://doi.org/10.1037/13620-000

Quigg, Z., Wallis, S., & Butler, N. (2018). *Routine Enquiry about Adverse Childhood Experiences Implementation pack pilot evaluation (final report).*

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachm ent_data/file/712718/REACh-implementation-pack-pilot-evaluation-final-report.pdf

Ramon, S. (2000). Participative Mental Health Research: Users and Professional Researchers Working Together. *Mental Health Care, 3*, (7), 224–228.

Rabiee, F., & Smith, P. (2014). Understanding mental health and experience of accessing services in African and African Caribbean users and carers in Birmingham UK. *Diversity and Equality in Health and Care, 11,* 125-134. https://doi.org/10.1177/0022022115575737

Ritchie, J., Lewis, J., & Elam, G. (2003). *Designing and Selecting Samples*. Sage.

Salway, S., Barley, R., Allmark, P., Gerrish, K., Higginbottom, G., & Ellison, G. (2011). *Ethnic diversity and inequality: ethical and scientific rigour in social research.* Joseph Rowntree Foundation.

Sidebotham, P., Heron, J., & Team, A. S. (2006). Child maltreatment in the "children of the nineties": a cohort study of risk factors. *Child Abuse and Neglect 30*(5): 497-522. https://doi.org/10.1016/j.chiabu.2005.11.005

Terry, G., Hayfield, N., Clarke, V., & Braun, V. (2017). Thematic analysis. *The Sage Handbook of Qualitative Research in Psychology*, 17-37.

The Sainsbury Centre for Mental Health. (2002). *Breaking the circles of fear: A review of the relationship between mental health services and African and Caribbean communities.* Sainsbury Centre for Mental Health.

Thompson, V. L. S., Bazile, A., & Akbar, M. (2004). African Americans' perceptions of psychotherapy and psychotherapists. *Professional Psychology: Research and Practice*, *35*(1), 19.https://doi.org/10.1037/0735-7028.35.1.19

Tomison, A. M. (1996). *Intergenerational Transmission of Maltreatment.* National Child

> Protection Clearing House.

Tsangarides, N., & Williams, L. (2019). *Lessons not learned: The failures of asylum*

> *decision-making in the UK.* Freedom From Torture.

> https://www.freedomfromtorture.org/sites/default/files/2019-

> 09/FFT_LessonsNotLearned_Report_A4_FINAL_LOWRES_1.pdf

Videmšek, P. (2017). Expert by experience research as grounding for social work

> education. *Social Work Education*, *36*(2), 172-187.

> https://doi.org/10.1080/02615479.2017.1280013

Whitfield, C. L., Dube, S. R., Felitti, V. J., & Anda, R. F. (2005). Adverse childhood

> experiences and hallucinations. *Child Abuse & Neglect*, *29*(7), 797-810.

Willig, C. (2013). *Introducing qualitative research in psychology*. McGraw-Hill Education.

Zutlevics, T. L. (2016). Could providing financial incentives to research participants be

> ultimately self-defeating?. *Research Ethics*, *12*(3), 137-148.

> https://doi.org/10.1177/1747016115626756

Appendices

Appendix A

Proposed topic guide*

* These questions will be used as a guide and may slightly change dependent on the participant.

The researcher will remind participants that they can stop at any time, and that they may skip any questions they are not willing to answer. The participants will also be informed of the SHSC Safeguarding policy if they disclose anything that suggests they or anyone else is at serious risk of harm, or they disclose a serious crime.

The researcher will provide a reminder of the definition of ACEs written on the information sheet.

Please only share what feels comfortable right now. It is important to keep yourself safe.

As a little warm up to ease into it, please could you tell me a bit about yourself?

Can you tell me how you came to use the service where you were asked about ACEs?

Can you tell us what your experience of using the service was like?

Could you describe the context in which you were asked about ACEs? Who asked you? When were you asked? Were you given a reason for being asked about ACEs?

How were the questions presented? Verbally or with a questionnaire? (Can you remember any of the questions?)

How did the conversation make you feel?

Were there any part or parts of the conversation you found difficult?

How did you feel when you were asked these questions?

What did you gain from being asked these questions?

Were there any reasons you might have been reluctant to answer these questions?

In what way do you think it influenced the mental health professional/counsellor, when they heard your answers?

Did the questions you were asked, allow you to speak fully about your ACEs? Please elaborate.

Were the questions relevant to your experiences? How were they relevant?

Did you feel anything important was missed out in the conversation about your adverse childhood experiences?

Show participants the ACE questionnaire (in appendix B) and ask them to fill it out. Explain that this is a typically used questionnaire. Explain that they will be asked to show you the questionnaire. Say "here is a copy of a much-used questionnaire. Please could you fill this out, we will look at your answers together after you have filled it out."

Please can you tell me how it felt to fill out that questionnaire.

Were there any questions you found difficult to answer?

How does it feel to share the answers with me/us?

How would you feel if you were asked to share your answers with another health professional, such as your GP?

What did you think about being asked these questions by a health professional?

If a health professional used only this questionnaire assess your ACEs, do you feel anything important would be missed about your experiences? Tell us more.

Show participants Young Minds' definition of adverse childhood experiences (Bush, 2018) (in appendix C). Explain: This is a proposed expanded definition of adverse childhood experiences.

What are your thoughts about this longer list?

How do you feel when you see the expanded definition?

Are there any important childhood experiences you've had, that the questionnaire did not cover, but the longer list does cover? If you feel comfortable, can you give us a snapshot of those experiences? Please only share what feels comfortable right now. It is important to keep yourself safe.

Do you feel it would be helpful or unhelpful to be asked about a wider range of potential experiences?

Is there anything else you would like to tell me/us about how it felt being asked about your experiences?

Do you think that your childhood experiences are relevant to you as an adult? If so, in what way? If not, why not?

What should services be doing to support people who have had difficult childhood experiences?

Appendix B

Copy of ACE questionnaire

> ### Childhood experiences – About your life up to age 18 years
>
> *Before the age of 18 years (or up until now if you are currently under 18 years)...*
>
> 1. Did you live with anyone who was depressed, mentally ill or suicidal?
>   ☐ 1. Yes   ☐ 2. No
>
> 2. Did you live with anyone who was a problem drinker or alcoholic?
>   ☐ 1. Yes   ☐ 2. No
>
> 3. Did you live with anyone who used illegal street drugs or who abused prescription medications?
>   ☐ 1. Yes   ☐ 2. No
>
> 4. Do you live with anyone who served time or was sentenced to serve time in a prison or young offenders institution?
>   ☐ 1. Yes   ☐ 2. No
>
> 5. Were your parents separated or divorced?
>   ☐ 1. Yes   ☐ 2. No
>
> 6. How often did your parents or adults in your home ever slap, hit, kick, punch or beat each other up?
>   ☐ 1. Never   ☐ 2. Once or twice   ☐ 3. Many times
>
> 7. How often did a parent or any adult in the household ever hit, beat, kick or physically hurt you in any way?
>   ☐ 1. Never   ☐ 2. Once or twice   ☐ 3. Many times
>
> 8. How often did a parent or adult in your home ever swear at you, insult you, or put you down?
>   ☐ 1. Never   ☐ 2. Once or twice   ☐ 3. Many times
>
> 9. Did your parent(s) for long periods of time make you go without enough food or drink, clean clothes, or a clean and warm place to live?
>   ☐ 1. Never   ☐ 2. Once or twice   ☐ 3. Many times
>
> ---
>
> Section 2:
>
> *We would now like to ask you to answer some more questions about other specific experiences during the first 18 years of your life. Again, you do not have to complete this section if you do not want to and you do not have to answer every question. If you would prefer not to complete section 2, please hand the questionnaire back to your worker.*
>
> *Before the age of 18 years (or up until now if you are currently under 18 years)*
>
> 10. a) How often did anyone at least 5 years older than you (including adults) ever **touch you sexually?**
>   ☐ 1. Never   ☐ 2. Once or twice   ☐ 3. Many times
>
>   b) How often did anyone <u>less than 5 years older, the same age or younger than you</u> ever touch you sexually when you did not want to or felt unable to say no?
>   ☐ 1. Never   ☐ 2. Once or twice   ☐ 3. Many times
>
> 11. a) How often did anyone at least 5 years older than you (including adults) try to make you **touch them sexually?**
>   ☐ 1. Never   ☐ 2. Once or twice   ☐ 3. Many times
>
>   b) How often did anyone <u>less than 5 years older, the same age or younger than you</u> ever try to make you touch them sexually when you did not want to or felt unable to say no?
>   ☐ 1. Never   ☐ 2. Once or twice   ☐ 3. Many times
>
> Page 3 of 4

12. a) How often did anyone at least 5 years older than you (including adults) **force you to have any type of sex (oral, anal or vaginal)?**

☐ 1. Never   ☐ 2. Once or twice   ☐ 3. Many times

b) How often did anyone less than 5 years older, the same age or younger than you ever force you to have any type of sex (oral, anal or vaginal)?

☐ 1. Never   ☐ 2. Once or twice   ☐ 3. Many times

13. Have you ever been **asked to show or send images of a sexual nature**, OR been asked to **behave in a sexual way** in person or via social media (i.e. Facebook, Twitter, Instagram/ Snapchat, other)

☐ 1. Yes   ☐ 2. No

14. Have you ever done or were you ever forced or asked to do **anything sexual** (in person, online or via social media) **in exchange for money, drugs/alcohol, gifts, affection, protection/safety, accommodation, employment, status (popularity), or anything else OR because you felt threatened?**

☐ 1. Yes   ☐ 2. No

15. Is any of this sexual activity **still happening?**

☐ 1. Yes   ☐ 2. No

If Yes, who has been involved in the sexual activity? (choose all that apply)

☐ 1.Family member   ☐ 2. Non-Family member

16. Have you ever **told anyone** about any of this sexual activity?

☐ 1. Yes   ☐ 2. No

If Yes, did you receive any support?

☐ 1. Yes   ☐ 2. No

Resilience

17. While you were growing up, before the age of 18, was there an adult in your life who you could trust and talk to about any personal problems?

☐ 1. Never   ☐ 2. Once or twice   ☐ 3. Many times

Thank you for completing this health questionnaire. Please hand this form back to your worker.

If you would like to discuss anything on this form, please speak with your worker. Your worker will be able to talk with you about your responses on this form and discuss ways these experiences may have affected you. They can also discuss ways to support you, should you feel that you want any support.

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Appendix C

Copy of Young Minds definition of ACEs

Maltreatment
i.e. abuse or neglect

Violence & coercion
i.e. domestic abuse,
gang membership,
being a victim of crime

Adjustment
i.e. migration, asylum
or ending relationships

Prejudice
i.e. LGBT+ prejudice,
sexism, racism or disablism

**Household or
family adversity**
i.e. substances misuse,
intergenerational trauma
destitution, or deprivation

**Inhumane
treatment**
i.e. torture, forced
imprisonment or
institutionalisation

**Adult
responsibilities**
i.e. being a young
carer or involvement
in child labour

**Bereavement
& survivorship**
i.e. traumatic deaths,
surviving an illness
or accident

Appendix D

Further information on expert by experience

Juliet McKenzie is a Lived Experience Consultant who agreed to be a part of the research team. Juliet is also a qualified and experienced teacher of English and Drama, currently working as a Racial Equity Consultant and Trainer. After accessing mental health services, she developed an interest in the effect of language codes on the clinical outcomes of intercultural therapeutic alliances. This led her to co-produce and facilitate workshops focused on ethnicity and culture for trainee and qualified Clinical Psychologists. She is committed to improving access to, and provision of, psychological services for people from ethnic backgrounds different to that of the dominant group.

Juliet was on a casual worker contract with the University of Sheffield, and consulted on the research aims, the survey, the interview schedule and the recruitment process. Juliet co-conducted the interviews with the participants who chose to be interviewed by both the lead researcher and Juliet. The lead researcher had reflective conversations with Juliet throughout the process, which helped ensure the researcher noticed and addressed any biases and blind-spots.

Appendix E

Screening survey questions

We are inviting you to take part in a research project. We are interviewing Black people about their experiences of being asked about adverse childhood experiences in mental health services or counselling services. There are national plans to routinely ask people using health services about adverse childhood experiences..We know that Black people's experiences have not been prioritised in this type of research before, and we wish to help change that. We hope your contribution can provide advice on how services can best support Black people in the future.

Please note, we may not have the resources to interview everyone who fills out the online form. We will contact those who we will be able to interview. We are trying to select people who represent different ages, genders, and types of experiences.

You can decide whether or not you want to take part. Before you decide, it is important for you to understand why the research is being done and what will happen if you take part. Please take time to read the information on the following page carefully. Discuss it with others if you want to. Ask us by emailing if there is anything that is not clear or if you would like more information.

(Information sheet and consent form presented, see appendix G)

1. How old are you?
    a. Under 18
    b. 18-30
    c. 31-50
    d. 51-70
    e. 70+
2. Which gender do you identify as?
    a. Male
    b. Female
    c. If you do not identify as male or female, how do you choose to identify?
3. Please let us know your ethnicity
    a. Black Caribbean
    b. Black African
    c. Black African-Caribbean
    d. Black dual/multiple heritage
    e. Black and White mixed heritage
    f. How do you choose to identify?
4. Do you speak English, and understand written and verbal English?
    a. Yes
    b. No
5. Are you able to use Skype, Zoom, GoogleMeet or Microsoft Teams?
    a. Yes
    b. No
6. Have you accessed a mental health or counselling service in the UK, where you were asked about difficult childhood experiences?
    a. Yes
    b. No
7. Would you be willing to discuss your experience of being asked about difficult childhood experiences?
    a. Yes
    b. No
8. Tell us briefly in which context you were asked about difficult childhood experiences, and how much time you spent discussing this?
9. Tell us briefly how it felt to be asked about difficult childhood experiences.

10. Did you find it helpful or unhelpful to be asked about difficult childhood experiences?

- Scale of 1-5 of unhelpful to helpful

Please provide an email address we can contact you on to arrange a time for the interview.

Please note, if filling out this survey has brought up any difficult feelings or memories, you can contact the Samaritans any time during the day or night on 116 123.

Please click the button below to send your survey answers.

Appendix F

Social media advertisement

There are national plans to routinely ask people using health services about Adverse Childhood Experiences (ACEs). In research into asking about ACEs in the UK, very few Black people have been consulted. This study aims to find out how helpful current ways of asking about ACEs are in capturing Black people's experiences.

Black people's experiences of being asked about Adverse Childhood Experiences (ACEs)

We are looking for 12 people who:
- are over 18 years old
- identify as Black
- have been asked by a mental health professional or counsellor in the UK about difficult childhood experiences

What you would need to do:
- complete a 10-minute online screening survey
- speak to Eirill and Juliet for roughly one hour in a confidential video-call interview*

*Those who complete the one-hour interview will receive a £15 Amazon Voucher

For more information contact Eirill Hoyland Sodal (trainee clinical psychologist) on: ehsodal1@sheffield.ac.uk

This study has been approved by the University of Sheffield Research Ethics Committee

The University Of Sheffield.

Appendix G

Information sheet and consent form

Eirill Hoyland Sodal
Trainee Clinical Psychologist
Department of Psychology
University of Sheffield
Floor D, Cathedral Court
1 Vicar Lane
Sheffield
S1 2LT

Information Sheet

Black people's experiences of being asked about Adverse Childhood Experiences (ACEs)

We are inviting you to take part in a research project. You can decide whether or not you want to take part. Before you decide, it is important for you to understand why the research is being done and what will happen if you take part. Please take time to read the following information carefully. Discuss it with others if you want to. Ask us if there is anything that is not clear or if you would like more information.

What is the project's purpose?

The study wants to understand people's views on being asked about adverse childhood experiences. We are interviewing people from a variety of ethnic backgrounds. We want to find out if changes are needed to support people better in this process. We are interviewing people who identify as Black, as they have so far been under-represented in research, and we feel it is important that everyone's voices are heard.

Adverse childhood experiences mean difficult experiences that happened while you were a child. This can mean different things for different people, but some examples are suffering abuse, living with someone who did not look after you properly as a child, or your parents getting a divorce.

The study is part of the lead researcher's professional qualification as a clinical psychologist.

Why have I been chosen?

You have been chosen because you are over 18 years old, identify as Black, and have been asked about adverse childhood experiences by a counsellor or mental health professional. We hope that around 12 people will take part in the study.

Do I have to take part?

It is up to you to decide if you want to take part or not. If you decide to take part, you can keep this information sheet. We will also ask you to sign a consent form. You can decide that you

no longer want to take part any time before September 2020. You do not have to give a reason. If you want us to remove you from the research, please contact the lead researcher on ehsodal1@sheffield.ac.uk or on the number below.

What do I have to do?

You will be interviewed by us for roughly one hour.

We will ask you questions about how you felt about being asked about adverse childhood experiences. We will also ask you to fill out a questionnaire about your adverse childhood experiences. It is your choice whether you decide to answer all the questions or not.

What are the possible disadvantages of taking part?

This study has been given ethical approval from the University of Sheffield Research Ethics Committee. We will ask you to discuss your views on discussing adverse childhood experiences. It is possible that talking about these experiences might be upsetting to you. If you do feel upset, please let the interviewer know. We have allowed time for the researcher to check how you found the interview and support you if you feel burdened or distressed by your experience.

What are the possible benefits of taking part?

We will give you a £15 Amazon voucher for your time. We also hope that this work improves the support people are offered in the future.

Will my taking part in this project be kept confidential?

We will make all your information anonymous. All the information that we collect about you will be kept confidential. Only the research team can see the information. You will not be able to be identified in any reports or publications unless you tell us that you want to be identifiable. If you agree to us sharing the information you provide with other researchers (e.g. by making it available in a data archive) then your personal details will not be included unless you explicitly ask for this. If the researcher is concerned for your or others safety they will need to share information with relevant authorities.

What is the legal basis for processing my personal data?

Data protection legislation means we must tell you that the law we are following about your personal information is that 'processing is necessary for the performance of a task carried out in the public interest' (Article 6(1)(e)). You can find more information in the University's Privacy Notice: https://www.sheffield.ac.uk/govern/data-protection/privacy/general

What will happen to the data collected, and the results of the research project?

The results from this study will be analysed and written up as a thesis for the clinical psychology doctorate at the University of Sheffield. The researcher also wants to publish the results in a peer-reviewed journal. We will anonymise all the data, and no one will be identified. You may be identified if you specifically ask us to identify you and write down that you would like to be identified. When we write up the research, we may describe your age group, gender, ethnicity and experiences, but we will not include your name or any identifiable information.

We will store the written interviews securely on a university computer account. When the project is written and published, we will destroy the written interviews in line with University of Sheffield guidelines.

It is likely that other researchers at the university will want to use your data to answer future research questions. This will not happen unless you specifically tick the box in the consent form which asks about this.

Will I be recorded, and how will the recorded media be used?

We will only use the audio recordings of the interview to analyse it, and for quotes to be used in conference presentations and lectures. We will not use your interviews in any other way unless you give written permission. No one outside the project will be allowed access to the original recordings.

Who is organising and funding the research?

The University of Sheffield.

Who is the Data Controller?

The University of Sheffield will act as the Data Controller for this study. This means that the University of Sheffield is responsible for looking after your information and using it properly.

Who has ethically reviewed the project?

The University of Sheffield's Ethics Review Procedure has ethically approved this project, as administered by the Psychology department.

What if something goes wrong and I wish to complain about the research?

If you would like to make a complaint about this project, you should contact the lead researcher. If you feel that your complaint has not been dealt with well enough, you can contact the lead researcher's supervisor. If after this, you feel that your complaint has still not been dealt with well enough, you can contact. Prof Glenn Waller, Head of Department at g.waller@sheffield.ac.uk or Dr. Thomas Webb, chair of the Department Ethics Subcommittee on t.webb@sheffield.ac.uk .

If the complaint is about how your personal data has been handled, information about how to make a complaint can be found in the University's Privacy Notice: https://www.sheffield.ac.uk/govern/data-protection/privacy/general.

We will give you a copy of this information sheet, and a signed consent form to keep.

Thank you very much for taking the time to participate in this research project.

Contact details:

If you require further information, please contact the lead researcher.

Lead researcher	**Research supervisor**
Eirill Hoyland Sodal	Dr Vyv Huddy
ehsodal1@sheffield.ac.uk	v.huddy@sheffield.ac.uk
0114 2226650	0114 2226650

Eirill Hoyland Sodal
Trainee Clinical Psychologist
Department of Psychology
University of Sheffield
Floor D, Cathedral Court
1 Vicar Lane
Sheffield
S1 2LT
<div align="center">**Consent Form**</div>

<div align="center">**Black people's experiences of being asked about Adverse Childhood Experiences (ACEs)**</div>

Please tick the appropriate boxes	Yes	No
Taking Part in the Project		
I have read and understood the project information sheet dated 06/09/2019 or the project has been fully explained to me. (If you will answer No to this question please do not proceed with this consent form until you are fully aware of what your participation in the project will mean.)	☐	☐
I have been given the opportunity to ask questions about the project.	☐	☐
I agree to take part in the project. I understand that taking part in the project will include being interviewed and audio recorded.	☐	☐
I understand that my taking part is voluntary and that I can withdraw from the study at any time before September 2020; I do not have to give any reasons for why I no longer want to take part and there will be no adverse consequences if I choose to withdraw.	☐	☐
How my information will be used during and after the project		
I understand my personal details such as name, phone number, address and email address etc. will not be revealed to people outside the project.	☐	☐
I understand and agree that my words may be quoted in publications, reports, web pages, and other research outputs. I understand that I will not be named in these outputs unless I specifically request this.	☐	☐
I understand and agree that other authorised researchers will have access to this data only if they agree to preserve the confidentiality of the information as requested in this form.	☐	☐
I understand and agree that other authorised researchers may use my data in publications, reports, web pages, and other research outputs, only if they agree to preserve the confidentiality of the information as requested in this form.	☐	☐
I give permission for the anonymised interview transcript that I provide to be deposited in the University of Sheffield Research Department so it can be used for future research and learning	☐	☐
So that the information you provide can be used legally by the researchers		
I agree to assign the copyright I hold in any materials generated as part of this project to The University of Sheffield.	☐	☐

Name of participant   Signature   Date

Name of Researcher   Signature   Date

Eirill Hoyland Sodal

Project contact details for further information:

Lead researcher
Eirill Hoyland Sodal
ehsodal1@sheffield.ac.uk
0114 2226650

Research supervisor
Dr Vyv Huddy
v.huddy@sheffield.ac.uk
0114 2226650

Appendix H

Ethical approval form and further information on data security and ethical implications

Eirill Sodal
Registration number: 180156966
Psychology
Programme: Clinical Psychology Doctorate

Dear Eirill

PROJECT TITLE: Black peoples experiences of being asked about Adverse Childhood Experiences (ACEs)
APPLICATION: Reference Number 032061

On behalf of the University ethics reviewers who reviewed your project, I am pleased to inform you that on 20/07/2020 the above-named project was **approved** on ethics grounds, on the basis that you will adhere to the following documentation that you submitted for ethics review:

- University research ethics application form 032061 (form submission date: 13/07/2020); (expected project end date: 31/05/2021).
- Participant information sheet 1074309 version 3 (13/07/2020).
- Participant consent form 1074310 version 3 (13/07/2020).

If during the course of the project you need to deviate significantly from the above-approved documentation please inform me since written approval will be required.

Your responsibilities in delivering this research project are set out at the end of this letter.

Yours sincerely

Thomas Webb
Ethics Administrator
Psychology

Please note the following responsibilities of the researcher in delivering the research project:

- The project must abide by the University's Research Ethics Policy:
  https://www.sheffield.ac.uk/rs/ethicsandintegrity/ethicspolicy/approval-procedure
- The project must abide by the University's Good Research & Innovation Practices Policy:
  https://www.sheffield.ac.uk/polopoly_fs/1.671066!/file/GRIPPolicy.pdf
- The researcher must inform their supervisor (in the case of a student) or Ethics Administrator (in the case of a member of staff) of any significant changes to the project or the approved documentation.
- The researcher must comply with the requirements of the law and relevant guidelines relating to security and confidentiality of personal data.
- The researcher is responsible for effectively managing the data collected both during and after the end of the project in line with best practice, and any relevant legislative, regulatory or contractual requirements.

Data Security and Ethical Implications

All audio recordings and transcripts were stored on a University of Sheffield account, which could only be accessed by the lead researcher and the supervisor.

All participants were given an informed consent form to sign, which explains that they may withdraw from the study at any time, and that all data will be kept confidential and

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anonymous. Any identifying information was removed from transcripts. The participants were asked for informed consent that excerpts from their transcripts may be used in publication. At the beginning of each interview, the participant was reminded of confidentiality and safeguarding policies. The results of the study will be fed back to the participants who wish to see it.

A debrief form was shown to participants at the end of the interview, with information on who to contact if they needed further support after participating. The researchers also checked in with the participants during the interviews to ensure they were not too distressed by the questions.

Appendix I

Extract from coding

Transcript excerpt	Codes
C: So I feel like the two women projected a lot of stuff onto me when I talked about my experiences. Whereas I feel like with all the men, they just don't respond. There's just nothing. I feel like they're either looking bored, or they're completely dead behind the eyes or they do that thing where they don't want to to influence what you're saying so they're trying to be completely neutral but neutral is not real because, silence is not neutral position - if anything silence is more violent than saying the wrong thing. And I think especially because like throughout my life - so when I was a child like my uncles were abusive and would beat up my cousins in front of me. One of them used to beat up my auntie, that was quite common. And I had an abusive boyfriend myself, and then I was sexually assaulted by a man. So, and then they know this information when I tell them, and they're the sitting there as a man, being silent when I've told them all these awful experiences that I have had with men being violent and abusive since I was a child. And then they just sit there. I'm still to this point, I've met many, many professionals and I really don't understand what they want me to do when they just sit there.	Clinicians need to manage their own stuff
	Clinicians not responding to ACE disclosure
	Clinician giving unhelpful responses
	Male clinicians trying to appear unaffected as harmful
	Experiences of abusive men
	Clinicians not understanding context
	Male clinicians trying to appear unaffected as harmful
	Clinician not clarifying expectations

Appendix J

Audit questions

Data collection

1. Is there evidence that raw data was collected and is appropriate for the research aims?
    Yes/Partially/No

2. Has relevant demographic and background information been collected to contextualise the sample (e.g. gender, age, interview location/time)?

    Yes/Partially/No

3. Are there reflections/notes/summaries on the data collection process?
    Yes/Partially/No

Research/analysis process

4. Has the researcher engaged appropriately in supervision as part of the research process?
    Yes/Partially/No

5. Has the data been sufficiently coded? (e.g. is all the relevant data coded?)
    Yes/Partially/No

6. Has the data been systematically coded?
    Yes/Partially/No

7. Is it clear that the researcher has engaged in a process of refining and redefining the themes and subthemes and are these processes justified? (This may be evidenced by looking at different versions of the NVivo documents and notes, and changes to coding/themes should be justified).
    Yes/Partially/No

Cross-checks

8. Cross-checking randomly selected excerpts from the interviews against the corresponding coding and themes recorded on NVivo.
    Are these consistent?

    Yes/Partially/No

9. Vice-versa cross-checking randomly selected themes and subthemes from NVivo against the corresponding data.
    Are these consistent?

    Yes/Partially/No

Study write-up/results

10. Are quotes sufficient to provide evidence of the themes and subthemes?
    Yes/Partially/No

11. Does the results/write-up sufficiently address the aims of the study?
    Yes/Partially/No

Appendix K

Excerpt from reflexive diary

Post first interview:

Considered three extra questions to ask. Overall, felt like a useful conversation. I asked follow-up questions sometimes when race or racism was added to the conversation by the participant. Wondered how this was seen by the participant. Perhaps initially somewhat strange, but then she seemed more comfortable with it. Hard for me to keep a balance of wanting to communicate that I will believe you if you talk about racism, without also biasing things by stating my opinions. I don't want to cause any harm to participants by making them feel their views are not validated, so perhaps nodded along and provided more encouraging noises than I might have done otherwise. The priority was to keep the participant safe. Sometimes the participant would say 'It might be that...' etc regarding her experiences of racism, and then later clarify that she is quite sure of it really. Perhaps my whiteness got in the way of her stating it more firmly initially? Possible that internalised racism may have got in the way too.

While transcribing interview 8:

The only man we interviewed was talking a lot more about being hypervigilant to people's reactions and making sure he's keeping safe. He is also the only participant speaking specifically about psychosis. He points out that due to experiencing psychosis, he pays more attention to people in order to confirm what's in his head. It might be easy to interpret his hypervigilance and concern about keeping himself safe in a mental health service as part of paranoia related to psychosis. However, this would be ignoring the context of how Black men have been treated by society in general and mental health services in particular. It's important to acknowledge a context in which Black men objectively are less safe than other people in these services, and this fear of consequences if one 'reveals too much' or doesn't focus on

keeping oneself safe, must not be brushed off as merely a consequence of psychosis, but must be seen in the context of the real historic and ongoing injustice that Black men in particular suffer under mental health services. It would have been useful to see whether this feeling of threat, that seems different to how the women were talking about their experiences, was repeated by other men. The fact that despite a conscious and long-standing effort to recruit men in particular to this study, we could only get one participant (who works as an expert by experience and perhaps therefore is more comfortable in talking about his experiences) - that does say rather a lot.