Trauma Informed Care within Oncology?

Understanding the impact of childhood trauma on experiences of cancer and cancer services in adulthood.

Thesis submitted to the University of Nottingham for the degree of Doctorate in Clinical Psychology

August, 2025

Brooke Alexandra Rose Kesic, BSc (Hons.), MSc

20411111

Supervisors: Dr Anna Tickle, Dr Nima Moghaddam, Dr Michael Rennoldson, Dr Joanna Levene, Hannah Harris

School of Medicine, Mental Health and Clinical Neurosciences

University of Nottingham

Acknowledgements

I want to express my heartfelt gratitude to all the participants who contributed to this research. Your time, effort, and invaluable contributions have been crucial, and I am truly thankful to each one of you for helping to turn a research idea into a reality. Without your input, this study would not have been possible.

The unexpected life events that have been thrown my way have taught me valuable lessons and instilled resilience in me. These experiences have shaped me into the person I am today.

I am endlessly grateful to my parents, family, and close friends for their unwavering support and belief in me throughout my professional and academic journey. I look forward to spending much more time with all of you.

Thank you, Jeremy, for being such a wonderful presence in my life. Thank you for prioritising my office space when we moved house, the endless cups of tea and coffee and much-needed shoulder rubs. Your unwavering love, encouragement, and belief in me have been my driving force, every step of the way, even when I have felt like giving up (many times!). I appreciate you more than words can express.

I would like to convey my appreciation to my research supervisors, Dr Anna Tickle, Dr Nima Moghaddam, Dr Michael Rennoldson, Dr Joanna Levene, and Hannah Harris for their support and guidance. I am also grateful to Dr Hayley Cooper, Dr Adam Hill and Dr Rohan Naidoo for their support during what were undoubtedly challenging circumstances.

I am thankful for all my clinical supervisors who have played a significant role in my professional development and learning. Shannon, thank you for your support and our weekly jacket-potato tradition. Your encouragement and our cathartic rants gave me the confidence to continue.

Finally, to an incredible bunch of people thrown together in September 2021, my DClinPsy cohort. Special friendships have carried me through several ups and downs during training. I feel privileged to have trained alongside such a wonderful group of future Doctors of Clinical Psychology.

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Portfolio Abstract

Background: Cancer remains a significant health concern worldwide, despite advances in technology and treatment and can have a major impact on mental health. Studies have shown that past trauma can resurface in stressful environments. Trauma-informed care (TIC) is a growing area of research that seeks to understand how trauma affects individuals and to develop tools to support them. While trauma-informed approaches are being implemented in various clinical settings, their specific impact on individuals receiving adult cancer services in NHS England has not been thoroughly investigated. Most of the literature on this topic is international, with some recent developments in NHS Scotland and Wales.

Aims: In Aim 1a, the purpose of this study was to investigate whether there is a relationship between childhood trauma and: 1) the length of time it takes for individuals to seek help after first identifying cancer symptoms, 2) shame, 3) illness perceptions and 4) patient satisfaction with cancer services. Additionally, Aim 1b examined whether shame or illness perceptions mediates the relationship between childhood trauma and satisfaction with cancer services. Finally, Aim 2 explored patient's experiences of their cancer diagnosis and cancer services to identify whether satisfaction with cancer services in adulthood is influenced by childhood trauma.

Method: A mixed-method sequential explanatory design was implemented from a critical realism stance. The online survey was completed by 266 participants. Descriptive statistics, correlational and mediation analysis were conducted (quantitative data), and an inductive-deductive reflexive thematic analysis was implemented (qualitative data). Analysis integrated both the quantitative and qualitative data.

Results: In relation to Aim 1(a), findings indicate higher levels of childhood trauma are associated with lower levels of satisfaction with cancer services, mediated by an individual's illness perceptions of their cancer (Aim 1b). In the context of Aim 2, four themes were generated with *(subthemes):* 1) 'Connecting the dots': Resonance of childhood memories and current experiences. 2) 'Nobody ever told me': Powerlessness & cancer-related losses *(2a. Bodily Integrity. 2b. Identity Transition)*. 3) 'I just wanted everyone else around me to be okay': Distributed effects of cancer through the social network *(3a. Impact of diagnosis on the family. 3b. Accessing cancer* *support networks and connections with shared experiences)*. 4) ‘It’s down to bedside manner’: Patient satisfaction is shaped by relational care *(4a. Communication of diagnosis. 4b. Emotional Vs. Practical Support).* Patients only made connections back to their childhood trauma in Theme 1. The findings highlight that links back to ACEs were made only within a single theme, this highlights the potential importance of TIC in cancer services. Study limitations include the sample size not being generalisable to the wider cancer population or ethnically diverse, as White British people were slightly overrepresented in the sample.

Conclusions and Recommendations: While the findings do not definitively confirm the need for specific adjustments to cancer services, it remains important to consider the incorporation of TIC for the UK cancer population, which would require further empirical testing to validate its applicability.

Statement of Contribution

The systematic literature review was completed by Brooke Kesic, with supervision from Dr Anna Tickle and support from Dr Joanna Levene. Amendments were made based on feedback provided by Professor Thomas Schröder.

The small-scale research project was completed by Brooke Kesic, with support from Dr Emma Coyne, Anna Read, Greg Stretton, Bruno Mafrici and Dr David Dawson. The table below contains details of contributions to the main research study:

Domain	**Contributor(s)**
Research Protocol	Brooke Kesic, under the supervision of Dr Anna Tickle and Dr Nima Moghaddam, developed and wrote the research protocol for the current study. Supported by Hannah Harris. Sections of this are included in the final thesis write-up.
Thesis Project Design	Brooke Kesic, with supervision from Dr Anna Tickle, Dr Nima Moghaddam, Dr Michael Rennoldson, Dr Joanna Levene and supported by Hannah Harris.
Application for University Ethical Approval	Brooke Kesic, supervised by Dr Anna Tickle and Dr Nima Moghaddam
Literature Review	Brooke Kesic
Participant Recruitment	Brooke Kesic designed the recruitment process and recruited participants for the online survey, with supervision from Dr Anna Tickle and Dr Nima Moghaddam. Dr Anna Tickle, Dr Michael Rennoldson, Dr Joanna Levene and Hannah Harris

	supported recruitment advertisements via social media.
Data Collection	Brooke Kesic collected and scored all the data.
Quantitative Data Analysis	Brooke Kesic supervised by Dr Nima Moghaddam.
Qualitative Transcription	Brooke Kesic
Qualitative Data Analysis	Brooke Kesic with supervision from Dr Anna Tickle and support from Dr Michael Rennoldson and Dr Joanna Levene
Thesis Write-up	Brooke Kesic with supervision from Dr Anna Tickle and Dr Nima Moghaddam. Additional supervisory input from Dr Michael Rennoldson and Dr Joanna Levene.

JOURNAL PAPER

Trauma-Informed Care within Oncology? Understanding the impact of childhood trauma on experiences of cancer and cancer services in adulthood.

Short Title: *Trauma-Informed Care within Oncology?*

Brooke Kesic*[1], Dr Anna Tickle[2], Dr Nima Moghaddam[3], Dr Michael Rennoldson[4], Dr Joanna Levene[5], Hannah Harris[2]

[1]The University of Nottingham and Nottinghamshire Healthcare NHS Foundation Trust, UK

[2]The University of Nottingham, UK

[3]The University of Lincoln, UK

[4]Nottingham University Hospitals NHS Trust, UK

[5]Nottinghamshire Healthcare NHS Foundation Trust, UK

Journal: This paper has been prepared for submission to the British Journal of Health Psychology. Formatting guidance is available in Appendix A.

***Corresponding author information:** Brooke Kesic, Trent DClinPsy Programme, Division of Psychiatry & Applied Psychology, University of Nottingham, YANG Fujia Building, B Floor, Jubilee Campus, Wollaton Road, Nottingham, NG8 1BB, UK (**e**mail: msxbk9@exmail.nottingham.ac.uk)

Abstract

Objectives: This research aimed to explore whether Adverse Childhood Experiences (ACEs) influence individuals' experiences when accessing and engaging in cancer services as adults, including their satisfaction with cancer services, and whether cancer services are trauma-informed.

Design: An experimental study using a mixed-method sequential explanatory design. Stage one was an online quantitative survey that informed stage two, in which semi-structured interviews were completed after analysis of the survey data.

Methods: The online survey was completed by 266 participants. Descriptive statistics, correlation and mediation analysis was conducted (quantitative data), and an inductive-deductive reflexive thematic analysis was implemented (qualitative data). The deductive framework used was based on the Substance Abuse and Mental Health Services Administration (SAMHSA; 2014) trauma-informed care model (TIC), which addresses physical, relational and emotional challenges associated with trauma exposure (Sweeney et al., 2016). The overall study results integrated both the quantitative and qualitative data.

Results: Findings indicate a moderate negative correlation (*r* = -.40) between childhood trauma and patient satisfaction scores, suggesting that higher levels of childhood trauma are associated with lower levels of satisfaction with cancer services, mediated by an individual's illness perceptions of their cancer. The thematic analysis generated four themes relating to experiences of cancer care and how these are informed within personal and historical contexts: 1) *'Connecting the dots'*: Resonance of childhood memories and current experiences. 2) '*Nobody ever told me'*: Powerlessness & cancer-related losses. 3) '*I just wanted everyone else around me to be okay'*: Distributed effects of cancer through the social network. 4) *'It's down to bedside manner'*: Patient satisfaction is shaped by relational care. Patients only made connections back to their childhood trauma in Theme 1 and spoke about their cancer experiences more broadly.

Conclusions: The results offer preliminary insights into the potential importance of applying trauma-informed care to the cancer population. While the interview findings do not conclusively support this, it remains a significant clinical consideration that cancer services in the UK may benefit from adjustments to incorporate trauma-informed care for the UK cancer population.

Keywords: Adverse childhood experiences, cancer, childhood trauma, trauma-informed care, psychological distress

Data availability statement: Data available on request.

Acknowledgements: Thank you to every individual who offered valuable contributions to this research, without your input this study would not have been possible. Thank you to everyone who was involved in advertising this study for their contributions to recruitment. This study was completed as part of a Doctorate in Clinical Psychology, funded by Health Education England.

Introduction[1]

Cancer is a complex and increasingly prevalent disease that significantly impacts global health systems. In 2018, there were 18.1 million new cancer cases and 9.6 million cancer-related deaths worldwide (World Health Organisation, 2024). Projections for 2040 suggest that the number of new cancer cases will increase to 29.9 million annually (National Cancer Institute, 2024). In the United Kingdom (UK), cancer is the leading cause of death, accounting for over one in four deaths. In 2019, there were 387,820 cancer diagnoses (World Cancer Research Fund, 2023). Projections indicate that one in two people in the UK will be diagnosed with cancer during their lifetime (Cancer Research UK, 2022).

Receiving a cancer diagnosis is a multifaceted process that encompasses various emotional, physical, and social dimensions, including symptom identification, seeking medical help, diagnosis, treatment, and the possibility of remission or recurrence. These stages can deeply affect an individual’s mental health, particularly when combined with additional factors such as a person’s trauma history (Marshall et al.,2023). Despite significant advancements in cancer research and treatment, navigating cancer and cancer care remains a uniquely personal and challenging experience that affects individuals’ physiological, psychological, financial, and overall quality of life (Ramasubbu et al., 2020).

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[1] See Extended Introduction for further information.

The Role of Adverse Childhood Experiences (ACEs) in Cancer

Adverse Childhood Experiences (ACEs) refer to events during the first 18 years of life, such as abuse, neglect, and living in an unsafe environment, which can significantly impact an individual's development and well-being (Felitti et al., 1998). ACEs are interrelated (Dong et al., 2004) and associated with an increased risk of diseases and disease progression, including cancer (Brown et al., 2014). Moreover, ACEs can contribute to delayed healthcare seeking, especially for women and those avoiding routine health screenings (Farley, et al., 2002).

ACEs also affect interpersonal relationships (Poole et al., 2018) and may influence the relationship between patients and healthcare providers, particularly in settings where power imbalances exist (Kimberg & Wheeler, 2019). A lack of trust and a threatened sense of safety can negatively affect patients' experiences and engagement with healthcare services (Menschner & Maul, 2016), leading to poorer health outcomes (Mersky et al., 2013). ACEs may also increase the risk of re-traumatisation in adulthood, particularly in healthcare settings where patients may encounter triggers related to their past trauma (Marshall et al., 2023), such as power imbalances in the doctor-patient relationship (Kimberg & Wheeler, 2009).

Psychological Distress and Shame in Cancer Experiences

There is a significant unmet need for addressing the mental health effects of cancer (Fernando, 2020). Cancer patients often face emotional and psychological challenges, including adjusting to their diagnosis, managing relationship issues, and coping with treatment side effects (Hussain, Kingsley & Phil-Eboise, 2016). Common reactions to diagnosis include shock, denial, anxiety, and anger, with 13% of cancer patients clinically diagnosed with depression, and up to 20% self-reporting depressive symptoms (Pitman et al., 2018).

One of the most significant psychological challenges faced by cancer patients is the experience of shame. This may arise from societal stigma surrounding cancer, internalised beliefs of inadequacy, or feelings of self-blame and perceived defectiveness (Cancer Research UK, 2022). These experiences can significantly impact emotional wellbeing and influence help-seeking behaviours (Akin-Odanye & Husman, 2021).

ACEs can disrupt the development of healthy shame management, resulting in persistent shame that diminishes confidence and coping abilities (Rollins & Crandall, 2021). This enduring shame can lead to experiential avoidance, especially when confronting complex issues like cancer (Davis et al., 2023). Heightened internalised shame can negatively influence how individuals process their cancer diagnosis, exacerbating depressive symptoms and impairing treatment outcomes (Bigatti et al., 2012). For women who have experienced abuse, shame may be intensified, leading to feelings of self-blame for their cancer diagnosis and difficulty trusting healthcare providers (Clark et al., 2014). This internalised shame can affect coping strategies, well-being (Aydin-Sayilan & Demir-Dogan, 2020) and overall quality of life (Scharloo et al., 2005).

Understanding shame as a psychological factor is crucial for assessing how patients experience their cancer journey, including their diagnosis appraisal, self-efficacy (Broadbent et al., 2006), help-seeking behaviours (Tookey et al., 2018), and anticipated outcomes (Broadbent et al., 2006). The ‘Compass of Shame’ (Nathanson, 1992) illustrates how unacknowledged shame can impede healing, guiding four coping mechanisms: withdrawal, avoidance (through denial), attack and self-punishment behaviours (Nathanson, 1992). These mechanisms are particularly relevant in healthcare, where self-harm may serve as a form of self-punishment to manage shame (Garbutt et al., 2023).

Studies have explored the role of shame as a mediator between ACEs and mental health difficulties later in life (Dearing et al., 2005). For instance, Briere and Jordan (2009) found that individuals who experienced early trauma were more likely to internalise their shame, contributing to depression and post-traumatic stress symptoms in adulthood. This enduring shame is a significant variable in the path from childhood trauma to difficulties in coping with life stressors, including health-related challenges like cancer (Orth et al., 2006), underscoring the long-lasting impact of shame.

Impact of Illness Perceptions

Illness perceptions, much like shame, are associated with psychological distress and health behaviours (Petrie & Weinman, 2006). They play a critical role in shaping health-related behaviours, including treatment adherence (Hoekstra et al., 2022). In cancer care, an individual’s perception of their illness is influenced by factors such as cancer type, prognosis (Cockle & Ogden, 2021), and personal history, including ACEs (Marshall et al., 2023). McCorry et al. (2013) highlighted that illness perceptions at diagnosis predict psychological distress six months later. Negative illness perceptions can exacerbate fears of mortality and decrease life satisfaction (Bahçecioğlu Turan & Türkben Polat, 2024). Therefore, healthcare providers should be aware of how illness perceptions can impact cancer care (Petrie et al., 2007).

Satisfaction with cancer care can be influenced by factors such as disease-specific information, perceived control, and understanding of the illness, which can reduce negative illness perceptions (Husson et al., 2012). Additionally, satisfaction with healthcare can be shaped by doctor-patient interactions, with patient-centred communication and trust in the provider-patient relationship leading to better outcomes (Elkefi et al., 2024).

While research linking illness perceptions as a mediator between ACEs and healthcare satisfaction remains limited, studies emphasise the role of illness perceptions in managing chronic health conditions (Petrie & Weinman, 2006). ACEs can exacerbate these perceptions, leading to heightened anxiety, helplessness, and healthcare avoidance (Selwyn, 2020). The relationship between ACEs, illness perceptions, and healthcare satisfaction represents an emerging area of research in health psychology.

Delays in help-seeking behaviours

Delays in seeking medical attention for cancer symptoms can occur due to several factors including, the severity of symptoms, access to healthcare, personal beliefs, societal stigma, shame, and fear or denial surrounding cancer (Cotterill, 2023). Despite nearly six in ten people considering cancer their greatest health fear (NHS England, 2022), over half of UK adults do not consult their general practitioner within six months of noticing potential cancer symptoms (Smith, 2022). ACEs have also been identified as a predictor of lower trust in healthcare services, leading to reduced willingness to seek care and follow medical recommendations (Munoz et al., 2019).

The Role of Trauma-Informed Care (TIC) in Cancer Services

Trauma-Informed Care (TIC) is an approach that acknowledges the impact of trauma on individuals and aims to minimise re-traumatisation while offering comprehensive support (SAMHSA, 2014). TIC focuses on creating a safe, empowering environment to address patients' physical, psychological, and social needs (Sweeney et al., 2016). It is particularly beneficial for individuals with ACEs, as it fosters trust and mitigates the effects of trauma on healthcare behaviours (Gieseler et al., 2018). TIC has six core principles: 1) Safety, 2) Trustworthiness and Transparency, 3) Peer Support, 4) Collaboration and Mutuality, 5) Empowerment, Voice, and Choice, and 6) Cultural Issues (SAMHSA, 2014). These principles aim to create a supportive, strengths-based environment that reduces re-traumatisation and fosters trust between patients and healthcare providers (Cullen et al., 2022).

In cancer care, TIC could improve patient satisfaction and comprehensive support, crucial components for those undergoing treatment (Suija et al., 2013). Trust in the doctor-patient relationship is vital to patient satisfaction (Ferreira et al., 2023), while dissatisfaction often arises from unmet needs, poor communication, and lack of emotional support (Blodt et al., 2021). Implementing TIC in cancer services may improve patient engagement and outcomes, especially for individuals struggling to access care or build trust with clinicians (Gieseler et al., 2018). Though the effective implementation of TIC remains under-researched (Birnbaum, 2019), it holds potential to improve both patient and clinician experiences in cancer care.

The Need for a Comprehensive Understanding of Psychological Factors in Cancer Care

Understanding the psychological impact of trauma is crucial in cancer care for better patient coping (Lawson & Lawson, 2018). Addressing psychological factors like ACEs, shame, delayed help-seeking, and illness perceptions can affect how cancer impacts lives. By fostering trust and reducing power imbalances, these factors can enhance patient satisfaction, treatment engagement, and overall outcomes (De Nooijier, Lechner & De Vries, 2001; O'Magony & Hegarty, 2009).

Among these factors, shame is particularly relevant, given its potential role in how ACEs may influence current healthcare behaviours (Orth et al., 2006). Left unaddressed, the enduring effects of shame may elevate risks, leading to avoidance of cancer-related services and reduced engagement in treatment, resulting in poorer health outcomes (O'Magony & Hegarty, 2009). While it is essential to provide adequate and supportive care throughout the cancer journey, there is a dearth of empirical evidence regarding the psychological impact of ACEs on the cancer experience in adulthood. Understanding how ACEs influence health behaviours, particularly through shame and illness perceptions could inform care strategies to mitigate these impacts.

To bridge this research gap, two exploratory research questions are proposed:

1. (a) Does childhood trauma correlate with delays in seeking help for cancer symptoms, experiences of shame, illness perceptions, and patient satisfaction in oncology services? Additionally, (b) does shame mediate the relationship between childhood trauma and satisfaction with oncology services?

2. What are patients' experiences of their cancer diagnosis and cancer services (in adulthood) and does childhood trauma impact these?

By addressing these questions, healthcare providers can develop more effective and holistic care approaches to support the psychological well-being of cancer patients.

Materials & Methods

This study was granted ethical approval by the University of Nottingham's Research Ethics Committee (ref:3002)[2]. An Expert by Experience (EBE)[3] was involved in the development of the study.

Epistemological Stance[4]

Critical realism is the epistemological position adopted for this research. This position assumes that reality is constructed through individual observable contexts as we experience them (Pilgrim, 2019).

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[2] See the extended paper (Section 3) for further information on ethical approval and ethical considerations.
[3] See the extended paper (Section 2.2.1) for further information relating to experts by experience.
[4] See Extended Paper (Section 2.1) for further discussion on epistemological stance.

Study Design[5]

Given the scarcity of literature relating to TIC within oncology services in the UK, a mixed-methods sequential explanatory design (Ivankova, Creswell & Stick, 2006) was implemented. This approach is divided into two stages: stage one involves gathering widespread data via an online survey and analysing the data, followed by stage two, which conducts semi-structured interviews to explore a smaller sample of participant responses in detail.

Measures[6]

An online survey was created using validated measures of 1) ACEs, 2) shame, 3) illness perceptions, and 4) patient satisfaction with cancer services (Table 1). Demographic information[7] was collected to help contextualise the representativeness of the sample, including the length of time it took to seek medical help after first suspecting cancer symptoms.

An option to select ‘prefer not to say’ for every item was available due to the sensitive nature of the questions. An interview schedule was developed based on outcomes from the online survey analysis to explore themes identified in this research stage in more detail. The interview schedule was piloted with colleagues before implementation.

Semi-structured interviews[8]

Participants who had completed the survey and expressed their willingness to be contacted were invited to participate in an interview. The initial plan was to select participants using maximum variation to capture a wide range of experiences. Potential interview participants were contacted via email or telephone. However, 11 of the 20 responded consented and completed the interview. This final sample size of 11 participants aligns with Braun and Clarke’s (2019) recommendation for an adequate sample size to address a research question adequately. The interviews

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[5] See Extended Paper (Sections 2.2-2.3.1) for further discussion on design and methodology.

[6] See Extended Paper (Section 2.3) for further information on each measure implemented.

[7] See Extended Paper (Section 4.1.6.1) for further information relating to demographic information collated.

[8] See Extended Paper (Section 4.1.1-4.1.2) for further details on sampling.

were conducted after obtaining written informed consent (Appendix N). The interview schedule (Appendix O) explored experiences with cancer services, childhood trauma, and illness perceptions. Interviews lasted between 25 and 55 minutes (with an average of 40 minutes) and were recorded and transcribed via Microsoft Teams by the first author. Pseudonyms were used to protect confidentiality, and personally identifiable information was redacted. All participants had the opportunity to enter a prize draw for a £50 'Love2Shop' gift voucher as an incentive for their participation[9].

Analysis[10]

Online Survey: Preliminary analysis of the quantitative data involved data exploration, assumption checking, and the production of descriptive statistics using IBM's Statistical Package for the Social Sciences Programme (SPSS) Version 29. Data were omitted if participants failed to complete at least one of the measures.

Addressing Aim 1a, correlational analyses (Pearson's *r)* were carried out to identify relationships between 1) childhood trauma, 2) length of time to seek medical help, 3) shame, 4) illness perceptions and 5) patient satisfaction with cancer services. The magnitude of correlation coefficients was characterised as: .10 = 'small', .30 = 'moderate' and .50 = 'large'; with coefficients <.10 = 'negligible'. (Cohen, 1992).

To examine whether the relationship between ACEs and patient satisfaction with cancer services could be explained by shame experiences and illness perceptions (addressing Aim 1b), a mediation analysis was conducted using the PROCESS macro in SPSS (Hayes, 2022). Model 4 (parallel multiple mediation) was applied, with robust standard errors and 99% confidence intervals computed for all parameters based on 5,000 bootstrap samples (Hayes, 2022). In this model, ACEs (measured by the MAES) were specified as the independent variable, with shame experiences (EISS) and illness perceptions (IPQ) as parallel mediators, and satisfaction with cancer services (FAMCARE) as the outcome. Given the temporal sequence, ACEs, as childhood experiences, were assumed to precede adult experiences of shame, cancer-related perceptions, and satisfaction with cancer care.

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[9] See Extended Paper (Section 3.1.5) for additional information on participant reimbursement.

[10] See Extended Paper (Section 5) for further discussion on analysis.

Interviews: To explore Aim 2, data analysis followed Braun and Clarke's (2022) six phases of reflexive thematic analysis. Initially, inductive codes and themes were generated, followed by re-analysis using the SAMHSA's six TIC principles (SAMHSA, 1994) as the deductive framework (Table 2).

Table 1.

Validated measures used in the online survey.

Measure	Target Construct	Number of items	Example Items	Scoring	Reliability
Maltreatment and Abuse Exposure Scale (MAES; Teicher & Parigger, 2015)	Measures exposure to different types of maltreatment/abuse in childhood (defined as the first 18 years of life).	52	*'Hit you so hard that it left marks for more than a few minutes,'* *'Forced or threatened you to do things you did not want to do'.*	Items rated as 'yes' or 'no'. A total score was calculated by summing all items and ranges between 0 and 52. Provided a scaled cumulative ACE score. A higher score indicates greater exposure to maltreatment and abuse in childhood.	Good level of test-retest reliability of .98
The External and Internal Shame Scale (EISS; Ferreira et al., 2020).	A single measure of the global sense of shame.	8	*'I am unworthy as a person'.* *'Other people are judgemental and critical of me'.*	Items scored on a 5-point Likert scale ranging from 0 = 'never' to 4 = 'always' and totalled producing a single score. A higher score represents higher levels of shame.	Cronbach alpha of .89.
Brief Illness Perception Questionnaire (Brief IPQ; Broadbent et al., 2006).	Assesses an individual's cognitive and emotional representations of an illness.	8	*'How much control do you feel you have over your illness?'* *(0 = 'absolutely no control and 10 = extreme amount of control')*	8 items rated on a 0-10 Likert scale specific for each statement. Scores totalled for each item yielding a single score. Higher scores indicate a more threatening perception of the illness.	Cronbach alpha of .73
The FAMCARE-Patient Scale (FAMCARE-P13; Lo et al., 2009).	Measures levels of patient satisfaction with cancer services.	13	*'The way tests and treatments are performed'.* *'Information given about side effects.'*	Items rated on a 5-point Likert scale from 1 = 'very dissatisfied' to 5 = "very satisfied". Items are totalled, producing a single satisfaction score. Higher scores correspond with greater levels of satisfaction with the quality of their cancer care.	Reliability is high with Cronbach's alpha of .93.

Table 2.

Deductive Framework used: SAMHSA's (2014) TIC Principles.

TIC Principle *Does the data show evidence for or against…*	**TIC Principle Definitions**
1. Safety	Individuals feel physically and psychologically safe; the physical setting is safe, and interpersonal interactions promote a sense of safety.
2. Trustworthiness and Transparency	Decisions are conducted with transparency to build and maintain trust with clients, staff and others involved in the service.
3. Peer Support	Peer support and mutual self-help are key to establishing safety and hope, building trust, enhancing collaboration, and utilising stories and lived experiences to promote recovery.
4. Collaboration and Mutuality	Levelling of power differences between staff and clients. Demonstrating that healing happens in relationships and the meaningful sharing of power and decision-making.
5. Empowerment, Voice, and Choice	The ability of individuals, organisations and communities to heal and promote recovery from trauma. Foster empowerment for clients and staff alike. Clients are supported in shared decision-making choices and goal-setting to determine the plan of action needed to heal and move forward.
6. Cultural, Historical and Gender Issues	The organisation actively moves past cultural stereotypes and biases and incorporates policies, protocols and processes that are responsive to the racial, ethnic, and cultural needs of individuals, addressing historical trauma.

The lead researcher had personal experience of ACEs and family cancer, as well as training in clinical psychology. This could potentially affect interactions with participants during the interview and analysis processes due to some insight regarding certain processes and terminology discussed. However, the researcher engaged in regular supervision and utilised a reflective diary[11]. To ensure methodological quality, Clarke and Braun's (2022) 15-point checklist was used to self-assess the quality of the qualitative analysis (Appendix S). Additionally, the Good Reporting of A Mixed Methods Study (GRAMMS) (2008) checklist was used to self-monitor the quality of research and research reporting (Appendix T).

Results[12]

Participant Characteristics: Online Survey[13]

The online survey was completed by 266 participants (174 females, 88 males, and 1 person who preferred not to disclose their gender). Participant ages ranged from 21-83 years (*M* = 51 years). All participants had experienced at least one cancer diagnosis, with 92.9%(*n* = 247) having had a single diagnosis and 6.8% (*n* = 18) having had multiple cancer diagnoses.

Despite targeted recruitment efforts from cancer charities specialising in support for black and ethnic minority communities, these groups remain slightly underrepresented in the sample (*n* = 19, 7.1%), with the majority of participants identifying as White British (*n* = 247, 92.9%). However, although this demographic is slightly overrepresented in the sample, it is not substantially disproportionate to the UK population, where 81.7% of individuals identified as White in England and Wales (Office for National Statistics, 2021).

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[11] See Extended Paper (Section 5.12) for further information on quality monitoring and the researcher's epistemological position (Section 2.1).

[12] See Extended Paper (Section 6) for further discussion on results.

[13] See Extended Paper (Section 6.1.1) for extended stage one (survey) results.

Questionnaire Results[14]

The descriptive statistical outcomes, correlations, and internal consistency (Cronbach's alpha) coefficients are presented in Table 3.

The results of this study primarily applied to individuals with lower ACEs scores (as indicated by MAES scores), those who perceive their cancer diagnosis as more threatening (higher IPQ scores), and individuals with higher levels of patient satisfaction (FAMCARE scores). The sample appears to underrepresent individuals with lower ACEs scores and higher illness perception scores, suggesting that individuals with higher trauma scores, less severe illness perceptions, or lower satisfaction with cancer services may be underrepresented. For instance, the mean MAES score (13.2) falls towards the lower end of the ACEs scores and is one standard deviation below a clinical sample of adults who self-harm in a community sample (Garbutt et al., 2023). This indicates that the sample may not fully capture individuals with higher trauma scores or those who have not experienced ACEs to the same extent. Additionally, higher IPQ scores in the sample suggest that, on average, participants who view their cancer diagnosis as highly threatening, may limit the generalisability to individuals with more positive or neutral perceptions of their cancer.

In contrast, the mean patient satisfaction score (FAMCARE) indicates a relatively high level of satisfaction with cancer services, with the maximum possible score being 65. However, the range of scores reveals notable variability across the sample, suggesting that, while most participants reported satisfaction with their cancer care, there is considerable variation within the study sample. Comparatively, the sample's scores fall just below two standard deviations in a cancer population (Lo et al., 2009), implying that the experiences of cancer care in this sample are somewhat lower than those reported in Canadian populations with advanced cancer.

Addressing Aim 1a, correlation analysis identified statistically significant and positive associations between ACEs (MAES), levels of shame (EISS), and illness perceptions (IPQ). A statistically significant and negative relationship was found between ACEs and patient satisfaction (FAMCARE). There was a negligible, non-

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[14] See Extended Paper (Section 6.1.3) for extended stage two (interview) results.

significant relationship between the length of time it takes to seek help and childhood trauma (*r* = .03, *p* =.688).

Table 3.

Pearson correlations, descriptive statistics, and coefficients from the online survey (stage one).

Variables	1	2	3	4	5	Measure	Min.	Max.	*M*	SD	Range	*α*
Time (1)		.03	.03	.10	-.18**	Time	0.0	54.0	3.5	7.3	54.0	
N		229	228	228	229							
Childhood Trauma (2)			.21**	-.56**	-.40**	MAES	0.0	51.0	13.2	11.1	51.0	.95
N			265	265	265							
Illness Perceptions (3)				.33**	-.22**	IPQ	13.0	65.0	51.3	10.4	52.0	.58
N				265	265							
Shame (4)					-.24**	EISS	0.0	31.0	12.4	7.8	31.0	.92
N					265							
Patient Satisfaction (5)						FAMCARE	0.0	64.0	31.3	13.2	64.0	.94

Note. n = Number of participants. Min. = Minimum score. Max. = Maximum score. *M* = Mean score. SD = Standard Deviation. Time = Number of months to seek medical help after first suspecting cancer symptoms. E.g. 0 = sought help immediately. MAES = Maltreatment and Abuse Exposure Scale (Higher scores on the MAES represents more childhood trauma). IPQ = Brief Illness Perception Questionnaire (Higher scores represent more negative/threatening illness perceptions), EISS = External and Internal Shame Scale (Higher scores represent greater shame levels experienced), FAMCARE = Patient Satisfaction Scale. Higher scores on the FAMCARE represent greater levels of patient satisfaction. *α* = Cronbach's alpha (internal consistency in the present sample). **p* = <.05, ***p* = <.005.

Mediation Analysis

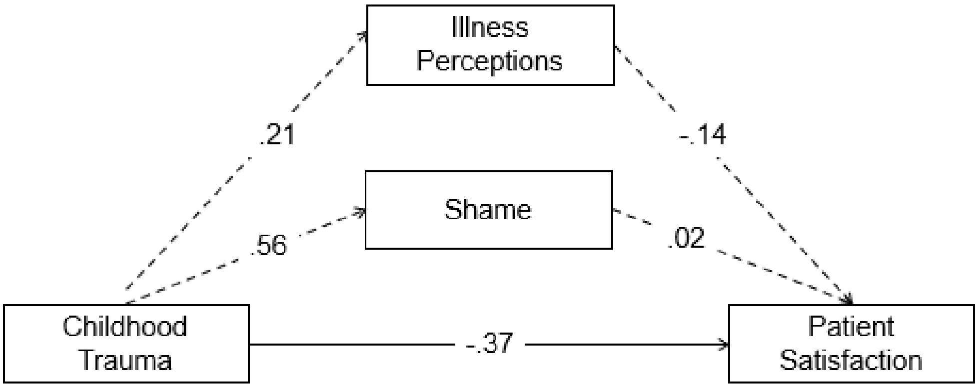
In relation to Aim 1b, a mediation analysis was conducted to determine whether the relationships between ACEs (measured by the MAES) and patient satisfaction (measured by the FAMCARE) outcomes were, to some extent, mediated by shame (measured by the EISS) and illness perceptions (measured by the IPQ).

The mediation model (Figure 1) illustrates a significant mediated effect between ACEs (MAES) and patient satisfaction with cancer care (FAMCARE). Based on the model and the logical sequence over the lifespan, ACEs precedes the development of both adult experiences of shame and illness perceptions related to a cancer diagnosis. However, the results show that a significant indirect effect on patient satisfaction with cancer care (FAMCARE) was only mediated through illness perceptions (IPQ), and not through shame (EISS).

The perception of cancer as a threat (as captured by the IPQ) was found to mediate the relationship between ACEs and patient satisfaction. Although shame did not significantly mediate the relationship between ACEs and patient satisfaction, the analysis indicates that patients’ views of their cancer diagnosis, particularly how threatening they perceive it to be, can substantially affect their satisfaction with cancer care. Thus, higher ACEs scores were associated with greater perceptions of cancer as a threat, which in turn decreased satisfaction with cancer care.

Figure 1.

Mediation Model of Childhood Trauma (ACEs), Shame, Illness Perceptions, and Patient Satisfaction in Cancer Care.



Direct effect = -.37, *p* <.001*

Total Indirect effect = -.22, 95%, CI [-.10, .06]
Indirect effect via IPQ = -.03, 95%, CI [-.06, -.01]*
Indirect effect via EISS = .01, 95%, CI [-.07, .91]

Note. * indicates a statistically significant relationship at $p < .05$.

Participant Characteristics: Interviews[15]

Eleven participants (8 female, and 3 male) took part in a semi-structured interview. The mean age of the interview sample was 61 years (*SD* = 16.01). All identified as White British and had accessed the NHS for their cancer care. Table 4 contains participants' pseudonyms and ages[16]. Table 5 provides the ranges of the online scores for the interview sample.

Table 4.

Participant Characteristics

Participant Pseudonym	Age
Ari	51
Bailey	55
Cameron	38
Danni	54
Eden	81
Izzy	69
Jack	73
Kathryn	76
Kendall	34
Nicole	76
Ray	69

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[15] See Extended Paper (Section 6.1.2 and 6.1.4) for extended stage two (interview) results, including additional demographic information.

[16] Please note: Randomly generated pseudonyms have been used for the interviewee names.

Table 5.

Online survey scores of the interview sample (stage two).

	Min.	**Max.**	***M***	**SD**
Time	0.0	13.0	2.90	3.93
MAES	2.0	27.0	10.36	7.28
FAMCARE	37.0	65.0	55.55	7.95
EISS	0.0	26.0	13.91	9.53
IPQ	5.0	57.0	30.27	14.73

Note. Min. = Minimum score. Max. = Maximum score. *M* = Mean score. SD = Standard Deviation. Time = Number of months to seek medical help after first suspecting cancer symptoms. E.g. 0 = sought help immediately. MAES = Maltreatment and Abuse Exposure Scale (Higher scores on the MAES represents more childhood trauma). IPQ = Brief Illness Perception Questionnaire (Higher scores represent more negative/threatening illness perceptions), EISS = External and Internal Shame Scale (Higher scores represent greater shame levels experienced), FAMCARE = Patient Satisfaction Scale. Higher scores on the FAMCARE represent greater levels of patient satisfaction.

Interview Findings[17]

In relation to Aim 2, four distinct but related overarching themes were constructed, three had subthemes as described below: 1) *'Connecting the dots'*: Resonance of childhood memories and current experiences; 2) *'Nobody ever told me'*: Powerlessness & cancer-related losses; 3) *'I just wanted everyone else around me to be okay'*: Distributed impact of cancer within the social network; and 4) '*It's all down to bedside manner'*: Satisfaction of cancer services shaped by relational care. A clear link between childhood trauma and experiences of cancer was identified by some participants in Theme 1. Themes 2-4 reflect the broader experiences of cancer, as participants did not make direct connections between ACEs and their cancer experiences.

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[17] See Extended Paper (Section 6.1.4) for extended stage two (interview) findings.

Theme 1: *’Connecting the dots’:* Resonance of childhood memories and current experiences.

This theme explores how ACEs, shapes individuals’ emotional and cognitive responses to cancer in adulthood. It emphasises the enduring influence and complexity of early trauma memories, even when not explicitly recognised as ‘trauma’.

For six participants, ACEs played a pivotal role in shaping their adult experiences of cancer, although only two explicitly described their childhood as ‘trauma’. Four people did not perceive their experiences as 'trauma', believing the term was 'too strong', yet they still identified a connection between feelings of inferiority, rejection, and invisibility in childhood and similar emotional patterns during their cancer experiences. For instance, Danni, who underwent a tumultuous childhood, reflected on how invalidating childhood relationships led to self-doubt, feelings of worthlessness, and delayed healthcare seeking, particularly when dealing with her cancer, “…I just always think that people are just gonna think I’m being mardy or stupid or whatever because that’s the message I had when I was growing up and certainly around this cancer…”

Similarly, Izzy, whole felt like a ‘nuisance’ and feared rejection or dismissal, spoke about supressing her emotional needs as a child. These emotions resurfaced during her cancer experience, reactivating her fear of being rejected or dismissed by healthcare professionals in cancer care, “The feeling seems to come back a similar feeling to the one you had as a kid. Please don’t leave or I’m going to be alone. With this, it comes back in an adult version...”

In response to questions about childhood memories, the majority revealed a family history of cancer, which influenced their outlook on life, health, and their diagnosis. The recollection of cancer within families had a significant impact on how participants viewed their own experiences. Overall, some participants recalled the impact of supporting family members through cancer, which influenced their perceptions of their own cancer experiences. For example, Nicole shared the emotional toll of supporting her partner through cancer while managing her own diagnosis. Whereas, Kendall, reflected on her father’s absence during her cancer treatment and used her family history of cancer to reframe her experience, understanding that her father's traumatic memories from his mother's cancer might have influenced his behaviours towards her, "…my grandma, she got diagnosed with myeloma…we had to turn her machine off… So him [dad] being in the ICU room was probably, Christ, so traumatic. Actually, I can see why he wasn't a regular visitor…"

Although the consideration of a family history of cancer was not originally anticipated to be included in inquiries regarding ACEs, the influence of a family cancer history emerged as a factor to consider in understanding people's emotional responses during their cancer experiences. Some, like Jack, suggested cancer services should incorporate questions about family cancer history to assess the potential emotional or traumatic impact. He argued that understanding such history could guide more trauma-informed empathic care, "…'Have you ever experienced cancer within your own immediate family?'…if they say 'yes', it might help to see what kind of experience they had and try and remove any trauma to the individual …that could be quite significant…"

This theme emphasises the importance of recognising how ACEs, even if not labelled as trauma, can be re-triggered during cancer care. The role of family history demonstrated how historical and familial context can influence cancer experiences and emotional responses. The inclusion and understanding of these components suggest that people would welcome recognition of this by clinicians to adapt care approaches, accordingly.

Theme 2: *'Nobody ever told me'*: Powerlessness and cancer-related losses.

The participants did not link their cancer experiences with past childhood trauma in relation to powerlessness and cancer-related losses. This theme explores the powerlessness felt during cancer experiences, particularly regarding a lack of control over diagnosis, treatment, and the resulting emotional and physical losses.

As Kendall describes, the imposition of a cancer identity feels akin to being trapped with no means of control or escape, "…you get on a rollercoaster, and you can't get off…everyone's like 'you're so brave'… you don't really have a choice...". Kendall's comparison of her cancer experience to a rollercoaster highlights the lack of agency and being unable to escape. Despite external praise for bravery, Kendall acknowledges that bravery during cancer treatment is not a conscious choice but a forced response, emphasising powerlessness in the face of psychologically distressing and uncontrollable circumstances.

A lack of control is echoed by many individuals, especially concerning medical decision-making. Izzy, for instance, recounts a powerful moment when her consultant dictated her treatment path without consultation, “I remember one consultant shouting for about an hour and a half…he said, ‘right I’m sending you straight away for a mastectomy. I don’t wanna hear any more talk’.” Izzy, is subjected to decision making by a consultant without room for discussion, further underlining the lack of control or choice in such situations. The description of 'shouting' implies a perceived aggressive assertion of power, leaving Izzy feeling powerless, without input or the possibility of negotiation.

The absence of patient involvement in medical decision-making, as described by Kendall and Izzy, undermines emotional safety and the lack of transparency in the communication between clinicians and patients, which can contribute to heightened psychological distress, if unaddressed.

Aim 1a, established that individuals with higher ACEs scores, viewed their cancer as more threatening. Ari, who experienced physical abuse as a child, voiced her overwhelming fear of cancer and the psychological toll it takes daily,“… you always fear scans…I get scanxiety…it is really awful waiting for results to know whether things are progressing or staying the same…” The phrase ‘scanxiety’ demonstrates experiences of powerlessness regarding health outcomes. The fear of scans and the wait for results highlight the vulnerability of not knowing what lies ahead, reinforcing a sense of helplessness and waiting for an outcome that is out of her hands, underscoring the importance of emotional support and recognising emotional distress as an integral part of patient care.

Subtheme 2a. Bodily Integrity

While bodily integrity might be expected to be related to childhood trauma, participants discussed it more broadly in the context of cancer, rather than linking it specifically to ACEs. This theme focuses on the broader experience of adjusting to life with cancer.

Cancer treatments often cause dramatic bodily changes, such as, the physical aftermath of surgery, hair loss, infertility and immunosuppression. These changes can trigger profound emotional responses, including anger, despair, anxiety, and sadness. The impact of treatment can be worsened by inadequate emotional support and communication. For example, Kathryn vividly described the emotional distress caused by the physical changes to her body following treatment, "…I've never seen anything as horrible… it was like the size of a tennis ball had been carved out of my leg…I looked at it and I thought what have they done to me?…" The sense of powerlessness in seeing something irreversible and invasive challenges her sense of bodily autonomy. Kathryn was left confronting a physical change which was compounded by a sense of inadequate emotional support and poor communication before her surgery, leaving her with a sense of powerlessness and the emotional reaction of questioning what had been 'done to' her.

This subtheme highlights that, similarly, to cancer itself, treatments or interventions are often endured without full control over the outcome. The loss of autonomy in decision-making processes and the inability to influence treatment outcomes can contribute to a profound sense of powerlessness.

Subtheme 2b. Identity Transition

Cancer patients often face the challenge of a forced identity shift in emotional, physical and identity-altering ways. For many, particularly those who have previously defined themselves by their career or hobbies, a cancer diagnosis and its physical consequences can lead to a profound sense of loss. Individuals are then forced to reconsider how they present themselves to the world and how they define their worth.

Bailey shared the difficulty in accepting changes to her body, which affected her self-image and ability to work, "Embarrassment certainly. I hide from the world because of it…it's difficult to tell people, isn't it? And it's difficult to find jobs because of it." While Bailey acknowledged a history of ACEs, she did not connect this to her desire to hide or her identity. The forced identity shift caused by cancer, especially when it impacts career or hobbies central to one's self-concept, can be destabilising. Cancer treatment forces an internal shift in identity, leading to individuals to reflect on who they are beyond the cancer diagnosis. Bailey's act of hiding suggests a loss of control also over how others perceive her, further exacerbating psychological distress.

The threat of mortality further complicates this significant identity shift. For example, Jack expressed fear of death and the impact it had on maintaining a stable sense of identity and the impact on his mental health,, "…I got actually quite scared…all I could think to say which was, 'Will I see my next birthday?'' (Jack). The constant awareness of one's mortality often forces individuals to reflect on their values, life experiences, and goals in a search for meaning, which can be particularly difficult for those who have been accustomed to being independent and in control. Jack's fear of death and his reflection on whether he will see his next birthday exemplifies helplessness in the face of cancer, taking away any sense of control over the future. Having to face mortality forces individuals to confront the reality that their life is at the mercy of an unpredictable disease.

As a healthcare professional, Ari's reflection on the shift in her identity is telling, "*… I was always on the one side treating people in the same situation. There I was suddenly teetering on the top of the fence and seeing the other side…"* (Ari). This shift illustrates the profound psychological impact of how a cancer diagnosis can shift the balance from a position of power (as a healthcare provider, in control of treatment and care) to one of vulnerability being the recipient of care. The metaphor of 'teetering on the top' highlights the emotional turmoil and dramatic shift in self-perception as life roles are altered, disrupting established ways of living, such as independence and control over one's life. The psychological impact of cancer forces Ari to confront her vulnerability, triggering an identity crisis and emotional turmoil.

This subtheme demonstrates how a cancer diagnosis strips individuals of control, both over their future and their bodies, creating a profound sense of vulnerability and uncertainty. As individuals additionally confront fears of mortality and navigate shifts in their identity, roles, self-perceptions, and sense of control are deeply affected, leading to feelings of helplessness and an additional intense struggle to redefine oneself in a new, unpredictable, and often terrifying reality.

Overall, Theme 2 examines the intersection of powerlessness and identity transition in cancer patients. The lack of empowerment, especially when medical decisions feel imposed, undermines patient agency and satisfaction. It highlights the importance of TIC principles, particularly, 'trustworthiness and transparency' and ‘empowerment, voice and choice’, suggesting that the application of TIC principles would be welcome to reduce distress and foster a more supportive, empowering environment.

Theme 3: *‘I just wanted everyone else around me to be okay’:* Distributed effects of cancer through the social network.

This theme highlights the distributed effects of cancer within social networks, illustrating how a cancer diagnosis affects not only the individual but also their family, friends and support systems. This theme is connected to identity (Theme 2) but focuses on the systemic changes and challenges that arise as one adjusts to living with cancer. Participants made no connection between their childhood trauma and cancer experiences in adulthood in Theme 3.

Subtheme 3a. Impact of diagnosis on the family

Family dynamics shift significantly when dealing with cancer, impacting established schedules and responsibilities. Many participants discussed relying on family and friends for emotional and practical support but also acknowledged the toll that their illness took on loved ones. Kendall, for example, felt like a burden, expressing, “I felt like it had ruined everybody’s lives around me…I just felt like I was like I was a bit of a problem...” This reflects the emotional burden individuals can feel, perceiving their diagnosis as disrupting the lives of those around them, leading to guilt and self-blame. Viewing oneself as a ‘burden’, shows how cancer not only affects physical health but also how it changes one’s role in the family. Families often need to adjust to provide care and emotional support, which can overwhelm both sides.

Acceptance of the diagnosis within the family was especially significant when there was a family history of cancer. Cameron found it difficult to disclose his diagnosis, saying, “…the most difficult thing for me was to communicate the diagnosis…to my parents specifically…we had many cases of cancer in our family, and you know that they would not take that well”. His concern highlights the emotional strain of having a family history of cancer, fearing that sharing his diagnosis would distress his parents. This reveals the psychological burden cancer has not only on the individual but also on their family, as it forces them to confront their fears and vulnerabilities.

However, not all participants felt supported. Danni, who felt dismissed by her family, particularly her sister, struggled with feelings of invalidation:

> …my sister who I'm very close to…'well it's only skin cancer; they've cut it out so what are ya worried about?'... that really does trigger in me that feeling of…'you just need to get just stop being stupid and get on with it' and that's the bit I struggle with…

This reaction made Danni feel her fears were being dismissed, leading to frustration and isolation. Different family responses to a cancer diagnosis can create emotional disconnection, especially when some family members fail to fully understand the emotional toll cancer takes.

This subtheme demonstrates how a cancer diagnosis affects both the individual and family dynamics. Feelings of being a burden or difficulty communicating the diagnosis illustrate the emotional toll that cancer has on the entire family unit. Conflicting reactions, from concern to minimisation or dismissiveness, can complicate support, leading to additional psychological distress as individuals confront cancer.

Subtheme 3b. Accessing cancer support networks and connections with shared experiences.

Becoming a member of the cancer community and seeking peer support networks is often a new and proactive process for those diagnosed. Half of the participants, including Nicole, welcomed this aspect of their identity, finding comfort in connecting with others through social media and organisations such as Maggie's and Macmillan. Nicole emphasised the value of shared experiences, stating, ''…that's the biggest support you can give anybody because you're meeting like-minded people…" This shows the importance of finding a community that understands and validates the emotional impact of cancer.

Others, like Eden, preferred to cope independently. Eden's reluctance to seek peer support stemmed from a long-standing tendency towards self-sufficiency, rooted in her past. She explained, "…I'm one of these people who just get on with things and try to do it myself without any outside assistance…" This mindset was shaped by her childhood experiences, where she lacked emotional support and was taught to be self-reliant. While this approach helped her cope, it also made it difficult to ask for help when needed.

Izzy showed ambivalence towards support networks, torn between wanting a sense of belonging and connection with others and wanting to maintain her privacy,"…I don't want to have to explain everything to everybody… all I really wanted was somebody to just put your arm around you and say, 'hey, come on, whatever happens, we'll be fine'." This highlights a desire to be offered comfort without the need for explanation. The need for a compassionate approach may be fulfilled through more intimate support networks, such as family, friends, or those who have shared experiences.

The diverse experiences in this subtheme highlight the importance of healthcare professionals signposting patients to peer support networks, as some individuals may require guidance and support in accessing these resources. For those who value shared experiences, such networks can provide crucial emotional support.

In summary, Theme 3 highlights the ripple effect cancer has on social networks, with participants navigating complex family dynamics and seeking support in various ways. Cancer reshapes personal identities, affects relationships, and influences support-seeking behaviours. This theme underscores the complexity of support networks, revealing different coping mechanisms and emotional needs while emphasising the importance of autonomy in choosing support systems. These findings align with the 'peer support' principle of TIC, though patients often seek support independently if healthcare providers fail to signpost to relevant services.

Theme 4: '*It's down to bedside manner*': Patient satisfaction is shaped by relational care.

The participants did not connect their ACEs with their current cancer care experiences. Theme 4, focusing on relational care, underscores the psychological needs of patients, playing a key role in building trust between clinicians and patients, which enhances satisfaction with cancer services.

Danni's account exemplifies the importance of the components contributing to relational care in patient satisfaction:

> …it's about that human touch…not being told about staging in a waiting room full of people, not having consultants with their back to you when they're telling you these things…and have that nurse in the room with you, with the appropriate information…
>
> (Danni)

Danni stresses how compassionate care, such as a nurse offering emotional support, makes a significant difference. The concept of a "human touch" emphasises that care should be personal and empathetic, rather than overly clinical and detached or impersonal. Simple gestures, such as the clinician's body language, can alleviate anxiety and help patients feel seen and valued, and not merely seen just as a diagnosis.

This subtheme recognises the necessity of privacy and dignity during medically sensitive discussions, such as cancer staging. Publicly disclosing such information can leave patients feeling exposed and powerless. Relational care emphasises personalising patient interactions and ensuring that sensitive information is shared privately and respectfully, making patients feel valued and protected, thus increasing satisfaction and supporting a trauma-sensitive approach to cancer care.

Subtheme 4a. Communication of diagnosis

The way a diagnosis is communicated greatly influences relational care relational care and patient satisfaction. For Izzy, receiving a cancer diagnosis over the phone, without consideration for her emotional state, undermined her trust in the healthcare system. She recalled:

> ...he phoned me up and said, 'By the way you've got secondary bone cancer.' Hang on a minute. I live by myself…you haven't said, 'Are you by yourself? Would you like to sit down? I would like you to come in and have a chat'... as he put the phone down he said, 'Mind you the x-ray wasn't that brilliant'.
>
> (Izzy)

Izzy's experience illustrates how a lack of empathy and emotional support when delivering a cancer diagnosis can worsen the emotional impact and erode trust in healthcare providers. A rushed, impersonal delivery of a diagnosis, without consideration for emotional state or privacy, heightens distress, reinforces feelings of being unheard, and negatively affects mental health, shaping perceptions of their care.

Similarly, Danni's experiences highlight the significance of non-verbal communication:

> …somebody's telling them in a really lovely, calm way, very close to them and looking at them in the eye. This guy had his back to me…that's where I get these images in my head that I'm not worth their time…I see it as being a reflection of my value…
>
> (Danni)

The consultant's body language, such as turning their back and avoiding eye contact conveyed disinterest and made Danni feel undervalued. This highlights how non-verbal cues can deeply affect a patient's emotional state, making people feel unseen or unimportant. Additionally, Danni's unmet expectations about how a cancer diagnosis should be communicated also stemmed from social media representations. Effective diagnosis communication involves not only words but tone, non-verbal cues, and consideration of the patient's emotional state. Poor communication, lacking empathy, can lead to feelings of powerlessness and erode trust, particularly for patients already feeling emotionally overwhelmed by their diagnosis and treatment.

This subtheme shows how poor relational care can affect how cancer patients perceive themselves and their illness, with negative perceptions (as identified in Aim 1) lowering satisfaction with cancer services. Patients' experiences are positively influenced by compassionate interactions that go beyond the clinical aspects of treatment, making them feel valued and more satisfied with their care. However, this would need to be empirically tested.

Subtheme 4b. Emotional Vs. Practical Support

The distinction of emotional and practical support in the context of cancer care highlights how both types of support play crucial roles in patients' experiences and addresses different needs. While some participants had access to the Psycho-Oncology service, this was inconsistent and dependent on the care team and hospital location. Ari noted, "… it's just how good your team or consultant is who may present you with it [Psycho-Oncology referral] as a choice..."

Emotional support, such as from cancer nurses, was a major source of reassurance for many. Danni, for instance, felt comforted by a nurse's promise to help her, alleviating her sense of powerlessness, "…'I'm gonna help you with that.' That was her statement…straight away it felt like, okay, I'm not having to fight through this on my own…" Danni's experience highlights the importance of validation, communicating a strong sense of partnership and empathy, and relieving individuals of the emotional burden of feeling alone in their cancer journey. The emphasis here is on how emotional availability and willingness to help can alleviate the additional stressors of cancer care.

Practical support, like transportation and financial advice, equipped participants to be better able to manage day-to-day challenges, enabling individuals to focus more on their health and wellbeing. Bailey received practical advice about benefits and transport, easing the burden of logistical concerns, "Maggie's were giving me lots of amazing advice about benefits and hospital transport and school transport because I couldn't even get my son to school."

Regrettably, Nicole's experience showed how gaps in emotional and practical support can lead to feelings of abandonment, "…Nobody contacted me at all. It was just, you know, get on, on your own…the stupid thing was they've got a new Hospice unit that'd just been opened, and nobody even mentioned it!" Nicole explained that her hospital's unit for individuals with non-terminal cancer diagnoses was still called the 'hospice', which was misleading and affected people accessing the unit.

Continuity of care, including support with logistics like travel and managing multiple hospital locations for appointments, was described as 'far worse than the actual treatment' (Jack). If unaddressed, practical barriers such as long travel distances or inconvenient appointment scheduling, can create significant stress, potentially overshadowing the treatment itself. Therefore, practical support, such as help with transportation, scheduling of appointments and accessibility, could be crucial for reducing stress and improving the overall experience of care.

This sub-theme focuses on the importance of both emotional and practical support in cancer care. Emotional support, like empathy from nurses, helps patients cope with the psychological challenges of cancer, while practical support, such as advice on financial benefits and transportation, can address logistical burdens. When both emotional and practical supports are coordinated and compassionate, patients feel empowered, valued, and less isolated during their treatment journey,

Overall, Theme 4 emphasises the importance of effective, compassionate communication and a collaborative approach to care, integrating both emotional and practical support in cancer care to meet patients' psychological and logistical needs. The variability in access to Psycho-Oncology services reveals gaps in psychological support; however, relational care that incorporates empathy, communication, and practical support can improve patient satisfaction and overall well-being, highlighting the need for compassionate, communicative healthcare that aligns with TIC principles.

Discussion[18]

At the time of writing, this study represents the first known exploratory research in the UK to examine the potential need for TIC in a cancer context, integrating a mixed-method research approach to capture a comprehensive view of the relationship between ACEs and cancer experiences in adulthood.

The primary aim of the study (Aim 1a) was to explore if there is a relationship between ACEs and 1) the length of time it takes to seek medical help after first identifying suspected cancer symptoms, 2) shame, 3) appraisals of cancer, and 4) patient satisfaction with oncology services in adulthood. Aim 2 sought to explore how ACEs might influence these factors at a deeper, psychological level, impacting experiences. The implementation of a hybrid methodology enhances the ability to capture dimensions of a phenomenon that might otherwise remain unexplored (Leahey, 2007), providing both statistical insights and rich qualitative data.

Findings in Context

This study contributes to the growing body of literature advocating for the integration of TIC frameworks in oncology settings to support cancer patients with the emotional and psychological trauma distress of a cancer diagnosis and

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[18] See Extended Paper (Section 7) for an extended discussion.

treatment. Individuals with ACEs often experience heightened distress, delayed help-seeking behaviours and challenges with treatment adherence. These findings align with the work of Sinko et al. (2023), who explored how trauma-related factors can influence treatment compliance and engagement, emphasising that trauma histories can exacerbate difficulties in navigating the cancer journey.

Furthermore, this study echoes the findings of Stillerman et al (2023), who highlighted the therapeutic benefits of TIC in improving emotional well-being and healthcare satisfaction among cancer patients. They argued that a TIC approach, which recognises the intersection of past trauma with current healthcare experiences, can enhance therapeutic relationships and lead to more personalised care. Building upon these findings, this study reinforces the need for oncology care providers to integrate TIC principles into their practice. Such an approach not only fosters a compassionate, patient-centred environment but also acknowledges that cancer itself can be experienced as a trauma, stemming from the uncertainty of diagnosis, invasive treatments and the threat of mortality (Simkhaev, 2024).

The quantitative findings (Aim 1) found that individuals with a history of ACEs may interpret their cancer diagnosis and treatment through the lens of past trauma, affecting their health perceptions and relationship with healthcare providers. This supports the notion that trauma survivors may be more attuned to the perceived threats, such as cancer (Foa et al., 2009), which can influence satisfaction with care. The negative correlation between ACEs and patient satisfaction aligns with existing literature linking ACEs to poorer health outcomes and difficulties accessing and navigating healthcare services (Sachs-Ericsson et al., 2016).

Interestingly, while prior research identifies shame as a significant mediator in health avoidance behaviours (Schnur et al., 2017), power dynamics and health outcomes of those with ACEs (Dolezal & Lyons, 2017), this study found that shame does not mediate the ACEs-healthcare outcomes relationship. Instead, the study demonstrates that ACEs influence not only health outcomes but also satisfaction with cancer services, with illness perceptions as a mediator (Aim 1b). These findings complement existing studies that recognise illness perceptions as a mediator in cancer-related distress (Lee et al., 2023). These findings suggest a need to further explore the psychological processes underlying illness perceptions and their impact on cancer care outcomes. It may also be beneficial to explore why shame was not identified as a mediator and whether there are certain conditions under which it does or does not mediate the relationship between ACEs and cancer care outcomes.

The qualitative findings of this study provided deeper insight into cancer care experiences, revealing how past trauma can influence current health struggles. The analysis highlights key concepts such as disempowerment, trust, and autonomy, highlighting the importance of enhancing patient agency and promoting transparency within cancer care. These findings align with the broader objective of Aim 2, which sought to uncover the psychological mechanisms underlying the associations between ACEs and cancer-related experiences, particularly in terms of patient satisfaction. As noted in Theme 1, the experiences described by participants suggest that cancer care can be intertwined with past trauma, even if individuals do not in the present moment make the connections. This reinforces trauma theory which posits that unresolved childhood trauma can influence present-day stress responses (Herman, 1992).

The lack of control over treatment decisions and the emotional burden patients face further emphasise the critical need for clear communication, supportive environments, and empathic interactions (core principles of TIC). These insights link to Aim 2, which aimed to explore how ACEs influence emotional and behavioural responses to cancer care and treatment, particularly in terms of patient satisfaction and the ability to navigate complex medical decisions.

Moreover, the study underscores the importance of effective healthcare-provider relationships in fostering trust and improving patient satisfaction (Williams et al., 2015), which are key components of TIC. The findings reinforce that TIC approaches, which address both the psychological and physical needs of patients, are crucial for improving patient outcomes. These insights support the integration of TIC principles as universally relevant in cancer care but also emphasise the need for further empirical testing of TIC principles in oncology settings, directly contributing to the understanding of how trauma impacts cancer care experiences in adulthood, as outlined in aim 2.

While most interviewees did not explicitly link ACEs with their cancer experiences, their responses reflected the presence or absence of TIC principles in cancer care more broadly. Certain aspects of cancer care, such as medical procedures and doctor-patient interactions, can evoke vulnerability and potentially re-traumatise individuals with ACE histories. These findings align with literature highlighting the importance of trust and security in patient satisfaction and health outcomes (Lown et al., 2011; Green et al., 2016). Although participants did not explicitly reference TIC principles, their experiences and needs inadvertently aligned with key aspects of TIC, such as control, communication, and emotional support. This suggests that even patients who do not associate their cancer experience with past trauma could benefit from TIC approaches, enhancing control, reducing anxiety, and improving care satisfaction.

Strengths & Limitations and Future Research[19]

This study provides valuable insights into the intersection of ACEs and cancer experiences. The hybrid methodology, combining quantitative and qualitative approaches, enhances the depth of the findings, offering a richer understanding of the psychological mechanisms linking childhood trauma and adult cancer experiences. This approach ensures both statistical and experiential aspects are considered.

The inductive-deductive reflexive thematic analysis ensured both emergent themes and pre-existing SAMHSA (2014) TIC framework informed the interpretation of the qualitative data. Adhering to mixed-methods quality standards, the study employed the Good Reporting of A Mixed Methods Study (GRAMMS) checklist (O’Cathain, Murphy & Nicholl, 2008), and a 15-point quality checklist (Clarke & Braun, 2022) to ensure rigor and credibility. Variability in participant quotes used, contributed to the rigour of the findings by providing a comprehensive representation of experiences, supporting the study’s validity, transferability, transparency, and robustness (Clarke & Braun, 2022).

In relation to Aim 1b, identifying illness perceptions as a mediator between ACEs and patient satisfaction with healthcare services is relatively niche. This studied identified illness perceptions as a mediator, offering insights into how early life experiences can influence health experiences in adulthood. This mirrors previous

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[19] See Extended Paper (Section 7.1) for further information on strengths and limitations.

literature which identifies that illness perceptions can influence patients' behaviours with accessing healthcare and mediate overall satisfaction with healthcare services (Petrie & Weinman, 2006).

However, several limitations must be acknowledged and addressed in future research. First, while the (quantitative) sample size is relatively large, it may not fully represent all cancer patients, particularly those with more severe forms of childhood trauma or complex health needs. Due to the limited use of these measures in existing research, it is also not possible to widely compare the results to normative populations as available information is sparse. Additionally, the cross-sectional nature of the study limits the ability to firmly establish causality.

Second, retrospective recall of childhood experiences introduces a potential bias, as participants' recollections may be influenced by memory distortions or inaccuracies, which could affect the study's generalisability (Raja, Rabinowitz & Gray, 2021). Although the focus of the research was on the after-effects of trauma in a cancer context in adulthood, rather than the precise nature of the trauma, recall bias remains a limitation.

Moreover, although participants were recruited from various parts of the UK, the geographical location of the cancer services accessed was not disclosed, which may limit the transferability of the findings to regions with different healthcare systems or cancer service provisions. Finally, as the study was not limited to a specific cancer site/type, the findings should be considered within the broader context of cancer. Future research could also develop interview questions that specifically explore trauma experiences and their links to current experiences to better understand how TIC is perceived across different populations.

Cultural implications are a fundamental aspect of TIC. However, another limitation of the study was the underrepresentation of ethnic diversity in the sample, with the majority of participants identifying as White British, despite efforts to recruit participants from ethnically diverse cancer organisations such as Cancer Black Care and B'Me Against Cancer. The lack of ethnic diversity is particularly important because individuals from ethnic minority backgrounds often face unique barriers in accessing healthcare services, which are experienced as an additional source of trauma (Hahmend et al., 2022), including institutional racism, inadequate care, dismissal of symptoms, and a lack of empowerment to voice concerns, leading to dissatisfaction with care and a loss of trust in healthcare services (Vaismoradi et al., 2021; Hahmed et al., 2022).

Given that individuals from ethnic minority backgrounds may experience distinct forms of trauma in healthcare contexts (Hahmed et al., 2022), and the literature indicates that individuals with minority sexualities and/or gender identities face health disparities in cancer care and more broadly when accessing healthcare (Radix & Maingi, 2008; Westwood et al., 2020), future research should aim to recruit more diverse participant samples to attempt to mitigate health inequalities and ensure that TIC is appropriately adapted to meet the needs of all patient populations. Additionally, the nuances of how trauma impacts the cancer journey should be explored by focusing on various cultural contexts to ensure equitable, trauma-sensitive care for all patients, regardless of ethnicity, gender identity, or sexual orientation.

Additionally, the interview sample included a higher proportion of older participants, and the relatively small sample size (compared to the data collected during the quantitative stage) limits the relevance of the findings to younger cancer patients. Consequently, the findings might be less relevant to younger cancer patients, who might have different experiences of ACEs and healthcare satisfaction with cancer care. This could have been reflective of the sample strategy; it would be interesting to ascertain if the recruitment platform naturally has a participant pool of an older mean age. It would usually be suggested to review previous research in similar areas to estimate the number of participants used in a thorough analysis. However, at the time of this research, this objective could not be achieved due to the limited available literature on the influence of ACEs on cancer care experiences in adulthood and the application of TIC in UK cancer settings.

During the quantitative stage of the research, ACEs were assessed in a broad sense, using a cumulative score. A useful area for future exploration would be to consider exploring the different subtypes in the MAES measure. Despite this, the sample also reflected a relatively low level of diverse childhood trauma, which may not adequately represent individuals with more prevalent or severe trauma experiences. This is a significant limitation, restricting the generalisability of the findings and highlights the challenges of conducting research with populations considered as ‘seldom heard’. Furthermore, one participant, who scored high on the childhood trauma measure, withdrew from the interview due to the emotional distress of their cancer diagnosis re-triggering historical trauma, highlighting the importance of considering the emotional impact of discussing trauma in cancer contexts, which should be carefully considered in future research.

Future research should explore the nuanced relationships between ACEs, illness perceptions, and patient outcomes, as well as the role of ACEs in specific cancer-related themes. Studies could also address potential sampling biases, clarify the role of ACEs’ in the qualitative component (Themes 2-4), and establish a trauma-informed approach to cancer care. Research could also investigate how ACEs shape illness beliefs and treatment perceptions, and how TIC approaches may influence healthcare satisfaction. Longitudinal studies may examine how illness perceptions evolve for individuals with ACE histories and impact ongoing healthcare experiences. Overall, the study suggests that TIC principles could enhance patients' sense of control, reduce anxiety, and improve the care experience for all, with cancer itself often perceived as a form of trauma (Simkhaev, 2024), even for those who do not identify with ACEs, highlighting the universal relevance of TIC principles in fostering a positive care experience.

Clinical Implications[20]

The findings of this study have significant implications for clinical practice. While most participants expressed general satisfaction with their care, the themes identified in the qualitative data highlight the emotional and relational dimensions of cancer care. Given the negative impact of ACEs on patient satisfaction, it is vital that cancer services in the UK adapt to meet these identified needs, which TIC approaches address by prioritising safety, trustworthiness and collaboration between healthcare providers and patients (SAMHSA, 2014).

Implementing TIC approaches in cancer care would recognise the importance of identifying early signs of distress, which are often present in cancer patients. Trauma can have a significant impact on both the physical and mental health of

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[20] See Extended Paper (Section 7.2) for further information on clinical implications and future research.

individuals, affecting their emotional well-being, coping mechanisms, and overall response to their cancer and recovery (Simkhaev, 2024). This study supports the notion that cancer itself can be experienced as a traumatic event, potentially exacerbating existing psychological vulnerabilities. By adopting TIC, healthcare providers can create a supportive environment that fosters empathy, respect, and sensitivity, helping patients process their experiences and reducing the likelihood of re-traumatisation.

This study's findings align with the NHS Long Term Plan for Cancer Care (NHS England, 2019) and the "major conditions strategy" in the UK (Department of Health & Social Care, 2023), which advocate for more personalised, patient-centred approaches to cancer care. These policies could benefit from incorporating TIC frameworks to address the psychological and emotional needs of cancer patients, particularly those with ACEs. By fostering an environment that promotes trust, safety, and empowerment, TIC can help mitigate the negative effects of trauma on cancer care experiences and improve overall patient satisfaction.

Recommendations for clinical practice include incorporating trauma-informed interventions that focus on altering illness perceptions. Clinicians should remain fully engaged with patients and communicate effectively by using simpler language while being attentive to non-verbal cues, in order to identify early signs of distress.

Based on the interview findings, introducing a 'trauma screening' within cancer services could help identify early signs of distress and ensure that care is tailored to patients' emotional needs. This could involve asking open questions such as, 'a cancer diagnosis can trigger reminders of distressing events from our childhood, has this happened to you?', or inquiring about a family history of cancer and how it may have influenced the individual's perceptions of their diagnosis. Simple questions like, 'how are you feeling?' could also encourage emotional expression. It is crucial to be mindful that some trauma responses (fight, flight, freeze, fawn, flop) can hinder an individual's ability to process information (Hayes et al., 2012). In the context of cancer, this could partially affect the ability to process information related to their diagnosis and treatment plans at that moment.

To understand trauma, we must have a full understanding of the individual, including all individual factors (SAMHSA, 2014). Providing TIC training to clinicians is significant. TIC training could help clinicians to recognise trauma responses and coping behaviours in patients struggling to regulate their emotions, while also adopting strategies to create a safe and supportive environment for patients. TIC training can also help clinicians address their own biases, manage trauma-related emotional responses, and engage with patients in a way that reduces the risk of burnout and vicarious traumatisation (De Hert, 2020). Additional training may be required for non-verbal communication to ensure all patients receive appropriate support. TIC can improve patient support and enhance treatment engagement, as patients are more likely to trust and engage with providers who demonstrate a trauma-sensitive approach (De Hert, 2020).

Finally, the implementation of TIC is complex and should be viewed as an ongoing, multifaceted process. This involves not only training clinicians but also developing systems and policies to support trauma-sensitive practices across healthcare.

Conclusion

This study reveals an association between ACEs and cancer experiences, with individuals who faced more childhood adversity often perceiving their cancer as more threatening and reporting lower satisfaction with cancer services. Ultimately, the preliminary evidence suggests that TIC could be a key intervention in improving care satisfaction and enhancing the emotional, psychological, and relational aspects of cancer care, regardless of whether patients explicitly recognise past trauma.

By adopting TIC principles, healthcare providers can better meet the complex needs of oncology patients, creating a more supportive and healing environment. This complexity points to the need for a nuanced approach to care, where healthcare providers are sensitive to how patients uniquely process trauma and illness. This study advocates for the integration TIC principles into oncology settings to create a compassionate, patient-centred environment that addresses both the physical and emotional needs of patients.

It is important to note, while the research supports the incorporation of TIC in cancer care, it does not establish a standardised framework for its application, as the study is exploratory in nature and lays the groundwork for future studies to explore how to better support this patient population. Future research should investigate the effectiveness of TIC in oncology and evaluate its impact on patient outcomes across diverse cultural and healthcare contexts while also addressing the study's limitations. Clinical recommendations include training healthcare providers in trauma-sensitive approaches, improving communication, and addressing power imbalances between healthcare professionals and patients. Implementing TIC could improve therapeutic relationships, reduce the risk of re-traumatisation, and foster a more compassionate approach to navigating life with, and beyond, cancer.

Statement of Contribution

'What is already known on this subject?'

- The application of TIC in cancer services is minimal within the UK.
- Trauma has been considered as a predisposing factor impacting engagement with cancer services.
- Attending cancer services could result in the risk of re-traumatisation and cause heightened psychological distress.

'What does this study add?'

- Association between ACEs and satisfaction with cancer services, mediated by illness perceptions.
- Trauma patterns can resurface in adult cancer care, potentially affecting access and utilisation of services.
- Underscores a need for TIC in cancer services, to foster an empathetic and comprehensive understanding of needs.

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EXTENDED PAPER

1. Extended Introduction

This section expands on the journal paper by providing further information on relevant literature, additional theory, and extended rationale to support the research.

1.1 Cancer

Cancer is defined as "a disease in which some of the body's cells grow uncontrollably and spread to other parts of the body" (NCI, 2023). Cancer can start almost anywhere, with more than 100 identified types. Cancer types are often named after the organ or tissues where the cancer forms (for example, lung cancer starts in the lung), or they might be described by the type of cell that formed the cancer (for example, squamous cell) (NCI, 2023). Brown et al. (2023) recently proposed a refined definition: cancer is "a disease of uncontrolled proliferation by transformed cells subject to evolution by natural selection," in an attempt to describe the many processes and transformations that cancer cells adopt, both specifically and more broadly over time.

Individuals across all types and stages of cancer diagnosis and treatment are reported to experience psychological distress, including difficulties adjusting to a range of issues, such as adjustment to diagnosis and treatment, relationship challenges, lifestyle changes, treatment side effects, and cancer remission rates (Hussain, Kingsley & Phil-Eboise, 2016). These factors can contribute to heightened levels of depression and anxiety, with up to 20% of individuals with cancer impacted by depression and 10% affected by anxiety (Pitman et al., 2018). Poor recognition and treatment of mental health difficulties are associated with reduced quality of life (Pitman et al., 2018). However, it is important to note that trauma responses to cancer can be considered normative, given the threat to life and well-being (Kazak & Noll, 2015).

1.2 Trauma

Derived from Ancient Greek roots, 'trauma' translates into 'wound' (Kolaitis & Olff, 2017). Today, 'trauma' is defined in several ways across the literature. Terr (1991) categorises trauma as 'Type 1' and 'Type 2'. 'Type 1' trauma refers to single-event traumas, such as an assault, life-threatening illness, witnessing a violent incident, or childbirth. 'Type 2' trauma, also known as repetitive or complex trauma, refers to interpersonal trauma experienced in a relationship and/or with an attachment figure during childhood. For this research, adverse childhood experiences (ACEs) or childhood trauma could fall under the category of ‘Type 2’ trauma, while a cancer diagnosis could be classified as ‘Type 1’ trauma.

Overall, trauma refers to an event, series of events, or sets of circumstances that are perceived as harmful and/or life-threatening (Office for Health Improvement & Disparities, 2022). Trauma can cause psychological distress, heightened hypervigilance to perceived threats, and a reduced sense of safety in the world. The psychological impact of trauma can have detrimental implications for an individual's physical, social, emotional, and spiritual well-being (Office for Health Improvement & Disparities, 2022).

A trauma-informed care (TIC) framework, developed by the Substance Abuse and Mental Health Services Administration (SAMHSA; 2014) conceptualises trauma through three components within a trauma-informed framework: the trauma event (external with long-lasting effects on well-being), how the event is experienced, and the trauma effects. SAMHSA (2014) suggests that traumatic events involve 'power over,' meaning there is often a power imbalance between one individual, group, or event over another (SAMHSA, 2014).

1.3 Adverse Childhood Experiences (ACEs)

In 1998, Felitti et al. published the first study on ACEs. Over two and a half decades later, ACEs are still cited in the literature as specific events that occur during childhood, which may impact the physical and emotional well-being of the child as well as their future in adulthood (Merrick et al., 2017). ACEs include abuse (physical, sexual, emotional), neglect, living in a house with domestic violence and/or substance misuse and/or criminal behaviour, or living with a caregiver who has mental health difficulties (Scott, 2020).

Measuring the prevalence of ACEs is incredibly challenging due to multiple variations in terminology and definitions of childhood adversity and trauma, as well as potential measurement biases. Often, prevalence statistics are not reported and do not account for the wider clinical picture of multiple or enduring trauma events. It is well documented that some crimes are likely to be underreported, such as hate crimes, and domestic and sexual violence (Elkin, 2021). In UK studies, it is reported that almost half of adults have experienced one ACE (Bellis et al., 2014) and 13% have experienced four or more ACEs retrospectively (Di Lemmie et al., 2019).

Research evidencing the relationship between ACEs and the development of physical and mental health illness has expanded and is well-documented. Individuals who experienced four or more ACEs were twice as likely to develop a chronic disease in adulthood (Ashton et al., 2016) and six times more likely to experience mental health difficulties (Di Lemmie et al., 2019). One study estimated the financial impact of ACEs on healthcare services in England and Wales, highlighting that the greatest ACE-related attributable costs to healthcare were mental health difficulties (£11.2 billion) and cancer (£7.9 billion) (Hughes et al., 2020).

A recent literature review (Hinnen et al., 2024) identified a continued association between ACEs and mental health difficulties in the cancer population, suggesting that ACEs may be a risk factor for anxiety, depression, fatigue and overall heightened emotional distress. However, the research did not identify whether specific ACEs were associated with particular impacts on cancer patients during specific phases (e.g. diagnosis, treatment, follow-up, or palliative) and treatment type (Hinnen et al., 2024). Additionally, it is important to note that not everyone facing these events will experience trauma-related adversity.

Emerging literature has recognised the effects of previous trauma history on mental health and the ability to access and engage in cancer services. Trauma has been considered a predisposing factor, occurring before a cancer diagnosis, but it can still result in decreased uptake of screenings, poorer engagement with cancer services and lower treatment compliance (Marshall et al., 2023). Attending cancer services frequently can increase the risk of re-traumatisation, with triggers related to past trauma (Marshall et al., 2023), further intensified by additional psychological distress caused by the threats of cancer (Ben-Ezra et al., 2011).

1.4 Shame

Linking trauma and cancer, as mentioned, there is evidence correlating trauma with poorer physical health (Ashton et al., 2016) and mental health (Di Lemmie et al., 2019). Shame is an emotion emerging within the trauma literature as one that can influence psychological distress, particularly in post-traumatic stress presentations (Taylor, 2015). There are multiple conceptualisations of shame, each with differing theoretical perspectives. Shame is a unique and complex response to an experience that is paired with self-conscious evaluation or beliefs that there must be something ‘wrong’ with oneself (Sedighimornani, 2018). Shame is included in the Diagnostic and Statistical Manual of Mental Health Fifth Edition (DSM-5), under post-traumatic stress disorder, categorised as a ‘persistent negative emotional state’ under the ‘negative changes in mood or thoughts that began or worsened after the traumatic event category’ (National Institute for Health and Care Excellence (NICE), 2023).

We experience shame when we become aware of the difference between our ideal self-image and our actual self-image. We attribute the negative event or experience inward, viewing ourselves negatively (Sedighimornani, 2018). Furthermore, shame can influence our behaviours and sense of identity, including judgments about our social desirability and acceptability (Matos & Pinto-Gouveia, 2009). For this research, shame is defined using Gilbert’s (2002) definition as a ‘multi-faceted experience’ that includes a ‘social or external cognitive component, emotional component, behavioural component, physiological component, and an internal self-evaluative component.’

Shame can arise in response to social threats to one’s identity and is a primary emotion where an individual feels helpless and out of control (Velotti et al., 2016). Experiencing shame might influence how an individual appraises events, influencing or increasing vulnerability and processing additional trauma, such as asking, ‘why me’ (SAMHSA, 2014). Additionally, cancer can evoke feelings of shame (Brennan et al., 2023), and research has established a connection between early experiences of shame and increased psychological distress (Farr, Ononaiye & Irons, 2021). Thus, understanding the complexity of shame is important when examining its interaction with an individual faced with cancer. Arguably, to manage experiences of shame, individuals may engage in behaviours to restore their threatened sense of self, either by engaging socially or withdrawing to avoid further damage to their self-image (De Hooge et al., 2018).

1.5 Barriers to medical help-seeking

Multiple factors can influence an individual's willingness and ability to seek medical help after suspecting cancer symptoms, with shame being one of these factors. Cotterill (2023) highlighted several barriers to cancer screening, including cancer stigma, behavioural stigma, and practical barriers. Research suggests that cancer stigma is particularly problematic among people from ethnic minority backgrounds (Martins et al., 2022). Certain cancer types are also noted to carry additional stigma, such as breast cancer and screenings relating to female "modesty" (Anderson de Cuevas et al., 2018), as well as misconceptions about perceived promiscuity in cervical cancer screenings (Chorley et al., 2017). In addition to stigma relating to cancer itself, health behaviours that heighten cancer risk, such as smoking, can also lead to inequalities and stigma, especially in cases like lung and head and neck cancers (Warner et al., 2022).

Furthermore, a trusting and positive doctor-patient relationship is associated with higher patient satisfaction (Blodt et al., 2021). As mentioned previously, SAMHSA (2014) suggests that the experience of trauma often involves a power imbalance. Therefore, it is important to consider how power dynamics might operate within healthcare settings, as it has been suggested that (re)traumatisation can occur due to these imbalances, particularly in the context of mental health (Sweeney & Taggart, 2018).

1.6 Illness Perceptions

There is an interconnected relationship between physical health and mental health. Individuals diagnosed with an illness or health threat may develop beliefs about their condition (Petrie, Jago & Devcich, 2007). These beliefs, known as illness perceptions, describe the cognitive processes through which the illness is interpreted or perceived (Rau & Williams, 2013). Illness perceptions are based on Leventhal’s (1980) Commonsense Representation of Illness Danger model, which outlines dynamic processes that explain how individuals perceive and interpret their illness both cognitively and emotionally, and how this influences their responses and behaviours. The model suggests that illness perceptions have five main components: identity (the label the individual uses to describe the illness), consequences (outcomes of the illness), cause of the illness, how long they believe the illness will last, and cure or control (the extent to which an individual believes they can control or recover from the illness) (Broadbent et al., 2006).

Scharloo et al. (2005) established a relationship between illness perceptions and quality of life in individuals with head and neck cancer. At the time of a cancer diagnosis, individuals often experience shock, denial, anxiety, anger, and/or depression (Pitman et al., 2018) and struggle with adjustment (Scharloo et al., 2005). Lazarus and Folkman's (1984) cognitive appraisal model reports that cognitive appraisals of stress are related to outcomes. Applying this model to a cancer-specific context, negative perceptions of illness such as self-blame or shame could help explain heightened distress and poorer cancer treatment outcomes (Bigatti, Steiner & Miller, 2012). Therefore, understanding how patients appraise their cancer diagnosis, could help inform how they adjust to their cancer diagnosis and treatment.

1.7 Trauma Informed Care (TIC)

1.7.1 Understanding and Defining TIC

TIC has its foundations in psychological theory, specifically attachment and trauma approaches. TIC considers the physical, relational, and emotional difficulties that are associated with trauma exposure (Sweeney et al., 2016) and can be broadly defined as an understanding of how trauma exposure affects clients from biological, psychological, and social perspectives (Oral, 2016). The following definition intertwines the physical, emotional, and psychological impact of trauma:

> 'Trauma is much more than a story about the past that explains why people are frightened, angry, or out of control. Trauma is re-experienced in the present, not as a story, but as profoundly disturbing physical sensations and emotions that may not be consciously associated with memories of past trauma…bodily reactions like a pounding heart, nausea, gut-wrenching sensations, and characteristic body movements that signify collapse, rigidity, or rage…The challenge in recovering from trauma is…establishing a sense of safety and the regulation of physiological arousal' (Bessel van der Kolk, 2014).

Originally developed by SAMHSA (2014), TIC acknowledges the impact of the biopsychosocial consequences of trauma and how trauma memories and responses can be reactivated in specific settings, affecting an individual's ability to feel safe and develop trusting relationships with healthcare professionals (SAMHSA, 2014). TIC aims to improve the quality of services by viewing individuals as 'whole'. For example, in a physical health setting, this means looking beyond diagnostic labels and understanding the individual's complete narrative, asking questions such as 'what has happened to you?' and ‘what do you need?' rather than 'what is wrong with you?' (SAMHSA, 2014).

TIC is a ‘trauma-informed programme, organisation or system’ based on four assumptions and six key principles. The four assumptions, known as the 'Four R's' are: (1) **R**ealise the widespread impact of trauma and understand potential paths to recovery; (2)**R**ecognise the signs and symptoms of trauma; (3)**R**espond by fully integrating knowledge about trauma into policies, procedures, and practices, and actively seeks to (4) prevent **R**e-traumatisation’ (SAMHSA, 2014). The six key principles of TIC are presented in Table 6.

Table 6.

SAMHSA's (2014) TIC Principles and definitions

TIC Principle	SAMHSA's Definition
1. Safety	Individuals feel physically and psychologically safe; the physical setting is safe, and interpersonal interactions promote a sense of safety.
2. Trustworthiness and Transparency	Decisions are conducted with transparency to build and maintain trust with clients, staff and others involved in the service.
3. Peer Support	Peer support and mutual self-help are key to establishing safety and hope, building trust, enhancing collaboration, and utilising stories and lived experiences to promote recovery.
4. Collaboration and Mutuality	Levelling of power differences between staff and clients. Demonstrating that healing happens in relationships and the meaningful sharing of power and decision-making.
5. Empowerment, Voice, and Choice	A belief in resilience, and in the ability of individuals, organisations and communities to heal and promote recovery from trauma. Foster empowerment for clients and staff alike. Clients are supported in shared decision-making choices and goal-setting to determine the plan of action needed to heal and move forward.
6. Cultural, Historical and Gender Issues	The organisation actively moves past cultural stereotypes and biases and incorporates policies, protocols and processes that are responsive to the racial, ethnic, and cultural needs of individuals, addressing historical trauma.

The Office for Health Improvement & Disparities (2022) provided an updated working definition of TIC, adapting SAMHSA's four R's from the original SAMHSA model. Table 7 contains the working definition of TIC (referred to as trauma-informed practice). The government also outlines the six principles of TIC: safety, trust, choice, collaboration, empowerment, and cultural consideration.

Table 7.

A working definition of TIC as defined by the Office for Health Improvement & Disparities.

TIC Principle	Meaning
Realise that trauma can affect individuals, groups, and communities	An approach to health and care interventions which is grounded in the understanding that trauma exposure can impact an individual's neurological, biological, psychological, and social development.
Recognise the signs, symptoms, and widespread impact of trauma	Aims to increase practitioners' awareness of how trauma can negatively impact individuals and communities, and their ability to feel safe or develop trusting relationships. Aiming to improve the accessibility and quality of services by creating culturally sensitive, safe services that people trust and want to use, empowering individuals about their health and wellbeing.
Prevent re-traumatisation	Seeks to avoid re-traumatisation (re-experiencing of thoughts, feelings or sensations experienced at the time of a traumatic event). Re-traumatisation is generally triggered by reminders of previous trauma which may or may not be potentially traumatic in themselves.

The inability to process trauma memories often results in those memories being stored as physiological reactions to stimuli that trigger the recall of the traumatic experience (van der Kolk, 1994). This contributes to the unpredictable manifestation of trauma symptoms in response to various stimuli. In physical healthcare settings, trauma responses can be triggered by intimate screenings and procedures, as well as non-invasive interventions such as the tightening of a blood pressure cuff or the weight of a lead-lined x-ray apron (Reeves, 2015). Healthcare professionals may not always recognise trauma responses. Thus, TIC uses knowledge about trauma to inform practices and help reduce re-traumatisation by fostering an environment in which individuals can feel safe, especially in settings where they might find it difficult to difficult to develop and maintain trusting relationships with clinicians (Gieseler et al., 2018).

Overall, TIC is defined as a set of organisational change processes to prevent (re)traumatisation across a range of services (Sweeney & Taggart, 2018). TIC promotes understanding and responsiveness to the impact of trauma, acknowledging the cultural and generational aspects of trauma histories and how interpersonal interactions, and the environment can trigger trauma responses. Reducing the potential for (re)traumatisation ensures that individuals can feel physically and psychologically safe enough to continue seeking care from healthcare services.

1.7.2 International TIC Research

TIC is a rapidly-growing area of research. For context, a Google Scholar search for ‘trauma informed’ returned 2,000,000 results (24.04.2024), and 118,000 results specifically for ‘trauma-informed’, with 3,300 articles added in the last year. Research related to ‘trauma-informed, cancer’ yielded 17,700 articles, with only 41 added in the last year. There is a vast range of research on TIC across a range of settings, with a large sample of research on TIC conducted in the United States (US).

A literature review of TIC and cancer care in Canada and the US found increasing interest in improving cancer outcomes (Davidson, Kennedy & Jackson, 2022). Additional studies highlight the importance of applying TIC to harder-to-reach populations, including those affected by racial health disparities (Dhawan & LeBlanc, 2021), homelessness (Kohler et al., 2021) and gender minorities (Sinko et al., 2023). For instance, Sinko et al. (2023) focused on improving cancer care for sexual and gender minority populations, providing recommendations for implementing TIC across the cancer continuum. Kohler et al. (2021) examined the application of TIC to support homeless women in accessing cervical cancer screenings.

Raja et al. (2015) developed a TIC pyramid, outlining specific suggestions for effective person-centred communication and care and emphasising the importance of understanding the effects of trauma (Raja et al., 2015). However, the literature remains limited, and gaps have been identified in the application of TIC, along with a lack of evidence-based outcomes (Davidson, Kennedy & Jackson, 2022).

1.7.3 UK TIC Research

Research on TIC in the UK appears to be significantly behind international efforts. Emsley (2022) completed a qualitative study of UK healthcare policies and professional perspectives of TIC, finding that the implementation of TIC in England is inconsistent, often lacking, high-level legislation or funding support, thus resulting in a limited UK evidence base.

In 2015, Public Health Wales found that nearly half of the Welsh population had experienced one ACE, and one in seven had experienced four or more ACEs, which were linked to poorer mental health outcomes. This data underscored the need to incorporate ACE considerations at the service development level (Ashton, Bellis, & Hughes, 2016). In response, a TIC framework, ‘Trauma-Informed Wales’, was co-produced with various stakeholders and supported by the Welsh Government. This framework focuses on a societal approach to understanding, preventing, and addressing the impacts of trauma and adversity (ACE Hub, 2022). An organisational toolkit was also developed to assist in embedding ACE Awareness and TIC practices (ACE Hub, 2022).

NHS Scotland developed a trauma-informed practice toolkit in 2021, which was later replaced by the ‘Roadmap for Creating Trauma-Informed and Responsive Change: Guidance for Organisations, Systems, and Workforces in Scotland’ (2023), supported by the National Trauma Transformation Programme. NHS England has highlighted the importance of TIC in healthcare settings, specifically linking trauma and mental health, in a strategy for supporting survivors of sexual assault and abuse (NHS England, 2018). However, despite government and NHS policy support in Scotland and Wales, there remains no NHS England framework or guidance on the effectiveness and acceptability of TIC in UK healthcare settings. It appears that the absence of a strategy in England has led to fragmented implementation compared to the coordinated efforts in Wales and Scotland (Emsley et al., 2022).

1.7.4 Limitations of TIC

TIC requires substantial time, resources, and evaluation (Huo et al., 2023). Implementing TIC in healthcare settings, necessitates a cultural paradigm shift and supportive leadership (Goldstein et al., 2024) at an organisational level (Huo et al., 2023), but this process faces resistance to organisational change (Goldstein et al., 2024). The limitations of TIC can be categorised into issues with its conceptualisation and operationalisation (Goldstein et al., 2024).

First, the definitions and frameworks for TIC vary significantly across the literature (Stillerman et al., 2023). TIC remains poorly defined, with multiple conflicting definitions (Bargeman et al., 2022) and inconsistencies in terminology (Goodman et al., 2016). Given this, it is challenging to establish a universally accepted conceptualisation of TIC, especially when the definition of trauma itself is still debated (Bargeman et al., 2022).

Second, there is limited empirical research on the operationalisation of TIC approaches (Birnbaum, 2019). Various components of TIC are operationalised and implemented in numerous ways (Champine et al., 2019), making it difficult to evaluate the effectiveness and outcomes (Birnbaum, 2019).

Third, political criticisms argue that SAMHSA’s TIC framework is ‘all-inclusive’ and attempts to ‘trivialise’ the clinical needs of individuals who might be vulnerable (Birnbaum, 2019). Tseris (2019) claimed that TIC is becoming decontextualised as it is increasingly implemented without sufficient attention to societal contexts.

Bargeman et al. (2020) highlighted ideological and infrastructural barriers to the implementation of TIC. Ideological barriers include opposition to TIC, perceptions of its ineffectiveness, and a lack of training and operationalisation. Infrastructural barriers include limited resources (such as funding) (Bargeman et al., 2020), a lack of physical and methodological capacity to evaluate TIC (Emsley et al., 2022), alongside clinicians’ time constraints and competing demands in time-pressured environments (Raja et al., 2021).

Although UK health policies endorse the idea of TIC, there is limited legislative strategy and funding due to the lack of evidence supporting its effectiveness (Emsley et al., 2022). However, this does not mean that this is an area of research not warranted. Despite these limitations, it is important to continue building knowledge on TIC frameworks and explore ways to operationalise and evaluate them. Goldstein et al. (2024) reported that successful TIC approaches could inform increased patient satisfaction and improved patient outcomes.

Specific applications of TIC in cancer care concerning the operationalisation and conceptualisation are not well reported, making it difficult for cancer services to recognise the value of TIC (Davidson, Kennedy & Jackson, 2022). TIC principles require adaptation for specific contexts (Huo et al., 2023). For example, Dhawan & LeBlanc (2021) provided a framework for applying TIC to hematologic cancer care, while Kohler et al (2021) explored TIC strategies for cervical cancer screenings. Furthermore, TIC can benefit both trauma survivors and the clinicians supporting them (Menschner & Maul, 2016) and can also support clinicians who have had experienced ACEs themselves (Lawson & Lawson, 2022).

1.8 Extended Rationale & Aims

ACEs affects health outcomes due to both biological (for example, heightened stress and inflammatory responses) and psychological factors (such as, anxiety, shame, depression, and negative views of oneself) (Hinnen et al., 2024). However, the specific prevalence of ACEs in an adult cancer population remains unknown due to limitations in reporting childhood trauma. Trauma has been considered as a predisposing factor for poorer engagement with cancer services, treatment compliance issues and risk of re-traumatisation (triggered by cancer-related fears (Marshall et al., 2023).

Individuals who have experienced ACEs may form a distinct oncology subpopulation at risk of these factors, in addition to facing additional psychological distress caused by the threats of cancer (Ben-Ezra et al., 2011). In the context of the NHS, services remain under strain. It could be hypothesised that delays in accessing support for suspected cancer symptoms might be partly attributed to individuals perceiving that their needs are ‘unimportant,’ leading to the avoidance of symptom exploration due to the pressures of the current healthcare system. These perceptions could re-trigger historical trauma patterns, reinforcing internalised experiences of being disregarded. If clinicians are unaware of the overlap between mental health and physical health, the likelihood of them assuming how an individual 'should' be engaging in their treatment journey could exacerbate trauma responses.

Recent literature reviews (Davidson, Kennedy & Jackson, 2022; De Groot et al., 2023), emphasise the need for exploring TIC in cancer services. Trauma can trigger shame, which in turn can affect engagement with healthcare services, influencing illness perceptions, psychological distress and care satisfaction. Furthermore, clinical environments can unintentionally cause re-traumatisation due to power imbalances.

Therefore, this exploratory study aims to investigate whether there is a relationship between childhood trauma with 1) the length of time it takes for individuals to seek help after first identifying cancer symptoms, 2) shame, 3) illness perceptions and 4) patient satisfaction with cancer services (Aim 1a). Additionally, the study aimed to examine if shame and illness perceptions mediate the relationship between childhood trauma and satisfaction with cancer services (Aim 1b). Furthermore, patient's experiences were explored to identify if satisfaction with cancer services in adulthood is impacted by childhood trauma (Aim 2). Without exploring the overlap between trauma and cancer experiences, services could incorrectly assume how individuals should access and engage in cancer services, potentially considering behaviours such as non-attendance to appointments as 'problematic,' or difficulties engaging in treatment as 'compliance' issues, rather than understanding behaviours via a trauma-informed lens.

It is hoped that the findings of the study may highlight potential areas for healthcare professionals to increase their recognition of trauma responses and how approaches can be adapted at both an individual clinician level and at a wider organisational level to help promote a holistic, person-centred approach that considers the importance of psychological wellbeing within a physical health context.

2. Extended Materials & Methods

2.1 Epistemological position

Research methods are underpinned by different philosophical assumptions of ontology, which is defined as what constitutes reality, and epistemology, which refers to the assumptions about how reality can be created and communicated (Al-Saadi, 2014). This study adopted the epistemological position of critical realism (CR), encompassing both quantitative and qualitative methodological approaches, as identified by the research aims of the study. CR adopts the stance that reality exists independently of our perceptions and is mediated by social contexts (Alele & Malau-Aduli, 2023) and mechanisms. Thus, research in healthcare settings focuses on exploring and understanding the complex interactions between social, psychological, and biological factors (Alele & Malau-Aduli, 2023).

Traditional epistemological positions, such as positivism, hold assumptions that reality is objective and that absolute knowledge can be sought via explanatory associations, which lead to prediction and control, predominantly through the application of quantitative methodological approaches (Park, Konge & Artino, 2019). On the other hand, interpretivists reject the idea of 'one reality' and emphasise that there are multiple realities which are socially constructed and subjective (Rehman & Alharthi, 2016). Therefore, research methodology in this paradigm focuses on exploring meanings and interpretations of events to form a comprehensive understanding (Rehman & Alharthi, 2016).

CR disputes both positivist and constructivist stances, arguing that reality consists of three levels: 1) the 'empirical' level, which consists of events as we experience them; 2) the 'actual' level, which consists of events that occur whether observed or not; and 3) the 'real' level, which comprises the causal mechanisms that produce the event itself (Lawani, 2020). CR explains events by exploring causal mechanisms (Rehman & Alharthi, 2016) and the effects of the social contexts (structures) in which people often operate (Stutchbury, 2021).

Physical health and illness are complex areas of study, and our understanding of them is constructed from what we observe and our attempts to interpret what we see happening (Alderson, 2021). CR can effectively identify and understand complex phenomena in healthcare settings, including whether change is required and how it can be generated (Koopmans & Schiller, 2022). CR approaches help answer questions about how and why things happen, as well as the influence of context within the complexities of healthcare (Sturgiss & Clark, 2020).

In this two-stage study, the CR approach allows for the collection of quantitative data in a cancer population, including ACEs, the length of time it takes to seek medical intervention after first suspecting cancer symptoms, shame, illness perceptions and satisfaction of cancer services. This data can be further interpreted through qualitative explanations of individuals' experiences, acknowledging 'multiple truths' through discourse. The application of qualitative methods supports explanations of existing mechanisms, while measuring underlying causal relationships and obtaining a better understanding of issues and testing the nature or strength of the mechanism can be achieved through the use of quantitative means (Lawani, 2020). Thus, the CR stance is well-suited to this research as this approach helps us understand how individual processes are affected by interactions with broader contexts, such as healthcare structures and can help explain both what we can and cannot observe (Alderson, 2021).

2.2 Study Design

2.2.1 Expert by Experience (EBE) Involvement

An important component of the study was the involvement of an Expert By Experience (EBE), who has lived experience of both childhood sexual abuse and cancer. The EBE involved in the research is a member of the Trent Doctorate in Clinical Psychology Service User and Advisory Care Panel (SUCAP). The EBE consented to provide consultancy on the project, using their lived experiences to inform decisions related to the materials used with participants, considering burdensomeness and language, and ensuring that the study was trauma-sensitive and not unintentionally distressing for participants. Language changes were made based on the EBE's feedback to ensure it was accessible to participants. Although the intention was to involve the EBE in the data analysis (interviews and theme development), unfortunately, they were not available at that time. However, they supported the development of the study design and data collection. Additionally, the researcher recruited two field supervisors who clinically work in cancer services within the NHS. The field supervisors attended research supervision meetings, supporting recruitment, analysis, and write-up.

2.2.2 Rationale for mixed methodology

Research in health psychology includes a range of methodological approaches. Two traditional methods are quantitative and qualitative approaches, with the mixed-methods approach now established as a third methodological paradigm (Teddlie & Tashakkori, 2011). This research implements a sequential explanatory design, which is the most appropriate choice for this study. This mixed-methods approach consists of two stages. Stage one enables the gathering of widespread data to identify potential relationships and patterns in the data. However, stage one does not allow for exploration of individual contexts and circumstances; therefore, stage two uses interviews to help explain the findings from stage one by focusing on participants' responses in rich detail, exploring patterns and divergences among individuals who have received a cancer diagnosis and their experiences of accessing and engaging with cancer services.

There are additional advantages to implementing this approach. A mixed-methods approach combines the strengths of quantitative research regarding data generalisability to large sample sizes with the rich detail of qualitative research. Second, this design allows the quantitative data to be contextualised with rich insights, offering a detailed exploration of the research questions. Third, if both sets of data converge, it strengthens the validity of the outcomes. Finally, it enables the collection and analysis of data from multiple perspectives, enhancing the validity and reliability of the research findings.

2.2.3 Measures

2.2.3.1 Online Survey

An online survey was developed using a university-approved online survey tool. As this was an exploratory study, the questionnaire was informed by psychological processes of trauma based on the literature. The questionnaire focused on eliciting data aligned with the research aims, which included: 1) a measurement of childhood trauma, 2) shame (a common emotional component after experiencing trauma), 3) illness perceptions (how someone views their cancer diagnosis), 4) patient satisfaction with cancer services, and 5) the length of time it takes to seek help. The construction of the survey was based on the following four validated measures:

1) Maltreatment and Abuse Exposure Scale (MAES; Teicher & Parigger, 2015): This questionnaire is a shortened version of the Maltreatment and Abuse Chronology of Exposure scale, which additionally requests participants to categorise their abuse chronologically (Teicher & Parigger, 2015). The MAES was selected to measure exposure to ten types of maltreatment in childhood. The addition of the chronology of each abuse type was deemed unnecessary for the aims of the study and would be additionally burdensome for participants in comparison to the MAES. One minor amendment made to the measure (approved by ethics) was to include individuals who had spent long periods in childhood with non-parental carers. Therefore, questions asking about the 'home/household' were changed to 'household/care home/boarding school' and ‘brother, sister, stepsiblings’ changed to ‘brother, sister, stepsiblings, other children you shared care homes/boarding schools with.’ Each section includes instructions exploring different types of abuse perpetrated by various individuals (for example, parents, siblings, stepparents, other adults in the household, and children the same age). Scores range from 0 to 52. However, this measure has some limitations in terms of simplicity, as only the total score was used (0-52). The MAES was selected as a quick baseline measure to identify the target population within the cancer service. The focus of the study is the impact of childhood trauma on other factors (see below).

2) The External and Internal Shame Scale (EISS; Ferreira et al., 2020): This scale is used to measure experiences of shame. Research indicates a connection between feelings of shame and stigma in cancer patients (Goyal et al., 2021). The EISS was chosen because shame is often a common emotional response to trauma, as indicated in the literature. The measure was kept short to minimise participant burden. Total scores on the EISS range from 0 to 32, yielding a single score. However, the measure can also be divided into 'internal' and 'external' shame experiences. It is important to note that the EISS was selected to assess overall levels of shame in the cancer population, rather than to explore shame experiences in detail.

3)Brief Illness Perception Questionnaire (IPQ-B; Broadbent et al., 2006): It is highlighted in the literature that negative illness perceptions are linked to poorer health-related quality of life outcomes (Jabbarian et al., 2021), while satisfaction with information provided in cancer services is associated with more positive illness perceptions (Iskandarsyah et al., 2013). The Brief Illness Perception Questionnaire (IPQ-B) is a shortened version of the original Illness Perception Questionnaire-Revised (IPQ-R) measure that assesses patients' illness beliefs. The IPQ-B was selected as a brief, single-item scale approach to assess individuals' cognitive and emotional representations of their cancer diagnosis on a continuous linear scale, producing a single score. A higher score represents a higher perceived threat of the illness. The IPQ-B was chosen for its brevity, which reduces participant burden (Broadbent et al., 2006). The validity of the IPQ-B was supported by its ability to distinguish between different illnesses, making it appropriate for assessing illness perceptions related to cancer (Basu & Poole, 2016). One minor amendment was made to the instructions, replacing the word 'illness' with 'cancer' to ensure the measure was relevant to the target population.

4) The FAMCARE-Patient Questionnaire (FAMCARE-P13; Lo et al., 2009): This questionnaire was developed to evaluate the quality of care in advanced cancer services. The total score ranges from 13 to 65, yielding a total satisfaction score. The FAMCARE-P13 was selected as a validated measure to identify overall levels of satisfaction with cancer care. The questions are not specific to a particular cancer type, making then broadly relevant for those who have experienced cancer.

Research supervision was utilised to discuss the creation of the online survey, taking into consideration a range of factors. Some free-text responses were provided, such as the length of time it took for someone to seek medical help after suspecting cancer symptoms. Free-text responses were enabled for the 'other' options, allowing participants to elaborate on their responses, ensuring that all experiences were captured.

3. Ethical Approval and Consideration

This research project adhered to the ethical guidelines outlined by the British Psychological Society for the Principles of Good Clinical Practice (2021) and the UK Policy Framework of Health and Social Care (Department of Health and Social Care, 2017).

This research was submitted for approval by the University of Nottingham’s (UoN) Research Ethics Committee on 13.02.2023. Based on reviewers' feedback on

17.03.2023 (Appendix B), revisions were completed and submitted on 20.04.2023 (Appendix C). Ethical approval was granted on 26.04.2023 (Appendix D).

An amendment was made and approved on 08.06.2023 (Appendix E), which modified the inclusion criteria to remove the 12-month cut-off period from their cancer diagnosis. This change aimed to broaden eligibility by allowing participants to reflect on diagnoses that may have occurred over a longer timeframe.

A second amendment was requested and submitted on 22.06.2023 due to the expiration of the University's data collection platform (Qualtrics) and migration to a new data collection platform (QuestionPro). Data already collected via Qualtrics was saved and stored securely. Permission was sought to add the new link (via QuestionPro) on the live Qualtrics questionnaire to redirect participants to the new platform. A request was also made to recruit participants via Prolific (https://www.prolific.com), a university-approved platform to ensure a sufficiently powered sample size. Participants are paid for their time to complete the questionnaire, with the cost covered by the research budget. These changes were approved on 11.07.2023 (Appendix F).

3.1 Confidentiality

Confidentiality, including its limitations, was explained in the participant information sheets (Appendix H, Appendix I, Appendix M). Before the interviews began, participants were reminded again about the importance of confidentiality. Only the primary researcher had access to identifiable data, such as consent forms. Data collected during stage two (signed consent form and email address) was stored on an encrypted memory stick in a password-protected document. Participants were assigned unique identifiers to link their data while allowing it to be removed if they chose to withdraw. During the analysis of the interview data, participants were given randomly generated pseudonyms, and the primary researcher transcribed the interviews, anonymising or omitting any identifiable information, such as names and locations, upon consent, for example, [Hospital Name] or [Consultant's name] appearing in the transcripts.

3.2 Information Management

Participants' privacy and informed consent were protected for all participants throughout the study in accordance with the Data Protection Act (UK Government, 2018). Data access was limited to the researchers and relevant regulatory authorities. Online survey data was held within the online survey tools (Qualtrics and QuestionPro). Computer-based/digital data was stored via password protection on the primary researcher's UoN OneDrive, and identifiable information was stored separately from interview transcripts. The primary researcher will retain all study-related documents and data following the UoN Code of Research Conduct and Research Ethics for at least seven years. If the primary researcher is unable to manage data protection, a second researcher will assume responsibility.

3.3 Informed Consent and Right to Withdraw

Participants volunteering for the first stage of the study (questionnaire) accessed the study through the QR code/web link on the recruitment poster (Appendix G). A participant information sheet for each stage of the research (Appendix H and Appendix M) provided information to help potential participants make an informed decision about whether to consent to taking part in the study. Contact details of the main researcher and supervisor were provided for participants to raise questions or concerns. Both information sheets emphasised voluntary participation. An additional information sheet was created for potential participants recruited via Prolific to state that participants would be paid for their time (Appendix I). Informed consent to participate in the study was given by completing a consent form and selecting the appropriate boxes on the questionnaire (Appendix J). For those opting to participate in an interview, informed consent was obtained after reading the participant information sheet (Appendix M). Signed consent was sent electronically to the lead researcher and signed by both the participant and researcher before the interview (Appendix N).

Following participation, participants received a debrief form (Appendix L, Appendix P), which reiterated the right to withdraw from the research without providing a reason. Participants had one week after completing the questionnaire to withdraw their data. After this period, participants were informed that it might not be possible to withdraw their responses, as the data would have been anonymised and integrated into the study. During stage one, no participants requested to withdraw their data from the study. Data was only used from individuals who gave informed consent and fully completed the questionnaire. During stage two, one participant withdrew their participation before providing signed consent, so the interview was not conducted. However, they did not wish to withdraw from the questionnaire.

3.4 Risk of Harm and Debriefing

While physical harm to participants completing this study was not anticipated, significant care was taken to minimise potential psychological harm due to the nature of sensitive topics such as childhood adversity and cancer experiences. All participant materials used (e.g. information sheets and the questionnaires used) were reviewed by the EBE (see Section 2.8) to avoid unintentionally causing distress. An additional response option of 'prefer not to say', was provided for each questionnaire item. The measures used in the questionnaire stage were carefully reviewed to consider potential re-traumatisation and participant burdensomeness. The information sheets (Appendix H, Appendix I, Appendix M) emphasised participants' right to withdraw from the study. During the interview stage, participants were offered a choice of modality (telephone or video call) and convenient time slots (including evenings and weekends). Participants were reminded that they could skip any question and had control over the amount of information shared.

Throughout the interviews, the researcher remained observant for signs of distress, monitoring both verbal and non-verbal cues, and prioritised participants' wellbeing. No participants became significantly distressed during the interviews; however, some became tearful when sharing past experiences or reflecting on the emotional impact of their cancer diagnosis and/or ACEs. Participants were given the option to pause the interview for a break and were asked if they wished to continue or move on to the next question. Participants were also given the opportunity to ask questions and were informed of the research aims. Debrief forms (Appendix L, Appendix P) included information on withdrawal rights, the anonymisation processes, and options to receive research results once the study has been finalised. Participants were signposted to support services if needed and were encouraged to engage in self-care activities following the completion of the interview.

3.5 Reimbursement of Participants

The ethical considerations surrounding participant incentives remain debated (Largent & Lynch, 2017). In health research, incentives are often a common practice, with three reportedly acceptable criteria: remuneration for out-of-pocket expenses, such as travel, compensation for participants' time, and incentives to encourage participation in research (Roa & Biller-Andorno, 2022). Rozynska (2022) emphasised the need for 'ethical anatomy' of payment for research participants, which must consider the following: individual rights must be respected with regard to making an autonomous choice about whether to engage, the risks and benefits of research must be articulated, and the remuneration must not be excessive, exploitative, or deceptive towards participants (Rozynska, 2022).

Researchers are ethically obliged to conduct all studies to the best of their ability and in accordance with the research protocol. This includes meeting pre-specified target sample size (Draper et al., 2009). In this study, participants were recruited via Prolific in an attempt to meet the pre-specified target sample size. Participants recruited via Prolific were compensated for their time after completing the questionnaire, based on Prolific's estimated time for completion. As an incentive, all participants were offered the chance to enter a prize draw to win a £50 Love2Shop gift voucher. This was optional, and not all participants chose to opt in. Two winners were randomly selected from the questionnaire stage, and two winners were randomly selected from the interview stage. Gift vouchers were sent electronically, as the preferred method of remuneration suggested by the UoN. Since gift vouchers do not count as taxable income, this would also not impact participants receiving financial income support.

4. Participants and Recruitment

4.1 Sampling Strategy & Sample Size: Online Survey

To obtain a large sample and maximise the representation of individuals diagnosed with cancer, an online survey was created to collect data (Appendix K). Online surveys allow for large sample sizes across wide geographical areas (Nayak & Narayan, 2019), which contributes to the cost-effectiveness of this data collection method. However, online surveys can present challenges regarding sampling and response rates (Nayak & Narayan, 2019).

The minimum target sample size required for stable estimates was 252 participants. This minimum target was necessary to ensure stable estimates of sample correlation coefficients that converge on population values (Schönbrodt & Perugini, 2013). The quantitative analyses addressing Aim 1 are correlational, specifically testing the association between childhood trauma and various treatment-seeking and engaging latencies. Ensuring the stability of estimated coefficients provides confidence in conclusions regarding the presence and directionality of correlations within the broader population. The study was powered to achieve a corridor of stability of ±.10 for any *r* coefficients ≥ .10, allowing for 80% confidence that the estimated coefficients will be within ±.10 of the true population value. This means that only fluctuations of small magnitude would be tolerated (Schönbrodt & Perugini, 2013). For example, if a correlation of 0.25 is observed between childhood trauma and treatment-seeking latencies, it can be confidently concluded that the 'true' correlation is likely of small-to-moderate magnitude (effect-size *r* between 0.15 and 0.35) in the broader population.

It is imperative to assess how the sample size correlates with the total number of individuals diagnosed with cancer in the UK, which stands at approximately 392,000 individuals annually (Macmillan, 2023). To capture a diverse range of experiences, the duration since cancer diagnosis was not a determining factor for inclusion. Therefore, it is not feasible to extrapolate the findings from the current sample to the entire cancer population, and this limitation should be considered when evaluating the applicability of the results. Moreover, the existing literature on the co-occurrence of cancer and childhood adversity is limited and assessing childhood adversity can be complex as it relies on individuals' self-identification of such experiences. Additionally, participants' specific locations were not recorded, making it impossible to ascertain whether the distribution of participants accessing cancer services varied across regions, limiting generalisability to cancer services nationwide.

4.2 Sampling Strategy & Sample Size: Interviews

To further examine the data obtained from the online survey, semi-structured interviews were conducted. The recruitment method used was purposive sampling, which is specifically chose to gain a deeper understanding of individuals’ cancer experiences and to provide a comprehensive understanding of the research question (Palinkas et al., 2019). The purpose, in this context, was to intentionally select participants who had relevant experiences or characteristics related to the research focus. Although the initial plan was to use maximum variation sampling, the final selection was based on individuals who had completed the survey and expressed a willingness to be contacted; these individuals were then invited for an interview. As a result, the number of participants was limited, and the lack of variation within the larger sample could affect its representativeness. All researchers involved were encouraged to share the recruitment advertisement via social media platforms and word of mouth to colleagues and others who met the criteria.

Qualitative researchers argue that there is no universally accepted measure for determining interview sample size, as it depends epistemological, methodological, and practical considerations (Vasileiou et al., 2018). It is suggested that the sample size should be large enough to gather detailed and comprehensive information but also manageable for data analysis (Vasileiou et al., 2018). The concept of data saturation, which originates from grounded theory, has been widely used to guide sample size decisions in qualitative research, interviews, (Vasileiou et al., 2018), but has faced criticism for lacking guidance before data collection and for its inconsistency with the theoretical foundations of reflexive thematic analysis (Braun & Clarke, 2022).

Fugard and Potts (2014) developed a quantitative tool for estimating appropriate sample sizes in thematic analysis, though this approach misunderstands thematic analysis as a uniform method (Braun & Clarke, 2016). Sim et al. (2018) argue that defining a sample size in advance is problematic when exploring phenomena where key themes cannot be anticipated. As a result, the concept of data saturation and sample size has been questioned as being overused and misunderstood (Tight, 2023). For this study, all participants who expressed interest in a follow-up interview were contacted. In the first stage, 117 participants from the online survey requested to be contacted for a follow-up interview. Out of these, 12 declined, 19 emails were undeliverable, and 66 participants did not respond. Ultimately, 20 participants responded to the initial interview invitation, and 11 of them consented to and completed the interview.

4.3 Inclusion Criteria

The inclusion criteria were kept broad to support a wide reach across the UK. Participants were required to meet the following criteria:

- Be over 18 years old.
- Have a previous or current cancer diagnosis.

- Be proficient in the English language.
- Reside in the United Kingdom.
- Have accessed cancer services in the United Kingdom.

4.4 Recruitment Procedure (online survey)

To maximise recruitment, the advertisement was shared across a range of social media platforms. Due to an unforeseen changeover of the online survey platform, the total number of participants who viewed the study advertisement is uncertain. However, the volume of participants that viewed the study (Table 8), was logged only from the primary researchers' social media accounts, though no personal demographic information was recorded. It is important to acknowledge that during the recruitment process, a large number of participants appeared to be duplicate responses. The secondary supervisor reviewed data cleaning, which involved removing duplicate responses, those who did not fully complete the survey, those who had accessed the study but did not proceed to complete any questions and the removal of those who did not consent to proceed with the study. Duplicate responses appeared to be less of an issue from participants who completed the questionnaire via the participant recruitment site (www.prolific.com).

The other researchers also shared the advertisement via their social media platforms. If participants had questions or concerns about the study, they were provided with the contact information of the lead researcher and supervisors. The advertisement was also emailed to several charity organisations to circulate via their social media platforms and/or newsletters. Details of the recruitment strategy are detailed in Table 8 and Table 9.

Table 8.

Online recruitment strategy for participants: online advertisements (July 2023-August 2023).

Recruitment Network	Additional Details
Facebook	Posted: Twice by the lead researcher. Received: Eight shares. Number of views: The number of views is unknown. Posted on several support blogs.
LinkedIn	Posted: Seven times. Re-shared: six times by members of the public. Number of views/impressions: x232
Twitter	Posted: Seven times by lead researcher. Re-shared: Five times by members of the public. Number of views: x946 views.

Cancer disparities, such as race/ethnicity, socio-economic status, and geographical location, can contribute to the unequal burden of cancer among different population groups (Arik et al., 2021). The unequal burden of cancer refers to the fact that certain groups experience higher rates of cancer incidence, poorer treatment outcomes and barriers to effective treatment compared to others (Arik et al., 2021). These disparities are influenced by various factors, such as racial and ethnic minorities, lower-income backgrounds, and rural communities, which are more likely to experience higher cancer incidence rates but have lower uptake of cancer services (Kale, 2023). In an attempt to reach these communities for recruitment, the research was promoted via word of mouth and advertised on additional social media pages, such as B'Me Against Cancer. The survey was advertised on a research recruitment site (Prolific.co) and was live for one month.

Table 9.

Online recruitment strategy for participants: charities contacted (May 2023 – August 2023).

Organisation contacted
Maggie’s
Cancer Research UK
Cancer Alliances (e.g. East Midlands, Northern, Lancashire & South Cumbria, Wakefield)
Genesis Care
Leukaemia Care
Self-Help
The Brain Tumour Charity Support Group
Cancer You Are Not Alone
Cancer Education UK
Cancer Care
Cancer 52
Cancer Black Care (CBC)
Sam’s Diamonds Cancer Support
Cancer Laryngectomee Trust
The Daisy Network
The Swallows

After seeing the advertisement on social media (Twitter), the Clinical Lead of the Northern Cancer Alliance contacted the researcher to request further information to support recruitment across the Northern UK region. A second member of the public also reached out to express their interest in the research, having previously supported a family member in authoring a paper highlighting the importance of childhood trauma in the aetiology of cancer (Harris, 2006).

4.5 Recruitment Procedure (Interviews)

The semi-structured interview schedule (Appendix O) was developed based on the data from stage one and discussions with the researchers. The interview questions were piloted with the EBE researcher and Trainee Clinical Psychologist colleagues. Since the interviews were semi-structured, the questions were not always asked in a linear order but were guided by the participant's narrative. This flexibility allowed for follow-up questions to be asked when appropriate. The interview began by discussing potential facilitators and barriers that influenced the individual's decision to seek medical help after suspecting cancer symptoms. The interview then moved on to explore the individual's experiences of accessing and engaging in cancer services. The questions were open-ended, allowing individuals to respond regardless of other factors, such as whether the diagnosis was historical or current, childhood adversity, or their satisfaction with cancer services.

The primary researcher collected and transcribed the interview data. To ensure the representativeness of participants' experiences and gather a range of responses, both telephone and video interviews via Microsoft Teams were conducted. Participants were given a choice of interview modality. Ten interviews were completed via Microsoft Teams, while one interview was conducted over the telephone due to internet connectivity issues. Direct quotes from the participant interviews, which represent the themes identified in the thematic analysis, are presented in the results section. The results were integrated into the interpretation and discussion phases.

4.6 Data Collection

4.6.1 Demographics

To aid the researchers in interpreting and contextualising the sample, additional demographic data specific to cancer were collected during the online survey and can be seen in Table 10. Additional demographics, such as participant age and assigned sex, were also collected provide further context for the data.

Table 10.

Health-specific demographic information collected.

Demographic Information	Response Options
Detection Route	Self-identified (self-checking) Results of a screening Incidental Other PNS
Cancer Type (e.g. location and prognosis)	Free-text box
Undergoing current treatment?	Yes No PNS
Healthcare Provider for treatment	NHS Private Both PNS
Other health conditions that require medical care?	Yes No PNS

Note. PNS = Prefer not to say.

In the analysis of interview data, cancer-specific demographics were considered essential for contextualising participants' experiences. These factors, including detection route, cancer type, stage, treatment status, healthcare provider, and co-existing health conditions, were thought to influence participants' emotional responses and overall healthcare experiences. For instance, differences in diagnosis routes, such as screening versus symptom-based detection, could elicit varied emotional reactions, such as relief or frustration, based on the timing and perceived urgency of care. Similarly, cancer stage and prognosis were expected to shape participants’ emotional well-being, with those undergoing active treatment potentially focusing on side effects, while those in remission might emphasise the emotional toll of living with cancer. Healthcare provider factors, including treatment at renowned cancer centres versus less-resourced settings, were anticipated to affect participants' satisfaction with care, communication, and available treatment options. Furthermore, participants managing co-existing conditions, such as diabetes or hypertension, could experience added complexity in their cancer care, potentially leading to feelings of being overwhelmed.

However, despite these relevant cancer-specific demographics being collected, the small number of participants in the interviews meant that these variables were ultimately not analysed in depth. Due to the limited sample size, it was not feasible to examine how these factors might interact or influence participants’ responses in a statistically meaningful way. Therefore, while these factors were recognised as potentially significant for providing a more nuanced understanding of participants’ cancer experiences, the analysis did not incorporate them in the final interpretation.

5. Data Analysis

Possible methodologies to answer the research questions were considered by the researcher and discussed during research supervision. Possible qualitative approaches, along with the rationale for using reflexive thematic analysis, are outlined below.

5.1 Choosing a Data Analysis Method: Survey Data

Data collated from the online survey were initially subjected to descriptive analysis based on the responses for each measure provided. Correlational analyses were completed to identify potential relationships between childhood adversity and the other variables, including the length of time it takes to seek medical help (after first suspecting cancer symptoms), illness perceptions, shame, and satisfaction of cancer care (Aim 1a). Any relationships identified between childhood trauma, and the other variables were then entered into a mediation analysis, which is considered a well-suited method to understand the relationship between variables and how one variable (mediator) can influence the relationship through other variables (Verma & Verma, 2023) (Aim 1b).

5.2 Choosing a Data Analysis Method: Interview Data

Qualitative methodologies to answer Aim 2 were considered by the researcher and discussed during supervision. Possible qualitative approaches and the rationale for using reflexive thematic analysis are outlined below.

5.2.1 Interpretative Phenomenological Analysis (IPA)

IPA is an inductive exploratory process that specifically focuses on how an individual makes sense of their unique experience and is informed by hermeneutics (Smith, Flowers & Larkin, 2009); recognising that observations are never truly 'pure,' thus observations must be inherently interpretative (Horrigan-Kelly et al., 2016). Phenomenology is the study of being and aims to identify the essence and reflect on the meanings of an individual's experience (Adams & Manen, 2010). The researcher is an integral part of the dynamic 'meaning-making' process, adopting a reflexive role, whereby the researcher makes sense of the participants making sense of their experiences (known as a double hermeneutic approach) (Peat, Rodriguez & Smith, 2019).

IPA was not considered for this study, as although participants all shared a common experience of having experienced a cancer diagnosis, the research aimed to explore other heterogeneous variables, including demographics and a range of experiences, such as, differing experience across multiple variables (e.g. ACEs, shame, and patient satisfaction). Therefore, the ideographic nature of IPA would be less suited to the analysis based on the mixed-methods approach and questions (Braun & Clarke, 2021).

5.2.2 Discourse Analysis (DA)

DA is embedded within social constructionist epistemology, where language is important and responsible for constructing social realities at three different levels (individual, social and cultural, and institutional) and managing social interactions (Mills et al., 2006). DA posits that there are no objective representations of reality; all accounts of reality are constructed via language, assuming no prior knowledge of linguistics (Gee, 2014). Therefore, language and context play an extremely important role within DA, as they influence multiple components. Language is a powerful force that shapes how we communicate, do things, and be things (social identities). There are multiple approaches to DA, including analysis of language content and structure

(Gee, 2014). While this might have been an interesting approach, this analysis adopts a differing epistemological position from that of the research and would have provided a narrow focus. It would not have addressed the research questions about the impact of childhood trauma on individuals accessing and engaging in cancer services and what their experiences look like.

5.2.3 Grounded Theory (GT)

GT is both the process and the product, an inductive approach that allows researchers to expand, develop, or challenge existing theoretical understanding of a phenomenon. GT starts with the data and then builds theory within the data (Khan, 2014). The research would typically continue data collection and analysis until data saturation is reached, meaning no new information to address the research question is identified (Guest et al., 2020). GT is an appropriate analysis when there is limited research in a particular area. More recently, a 'GT myth' was reported (Timonen et al., 2018) that challenges the rigid interpretation that GT must be entirely free of prior theoretical influences, emphasising instead the dynamic relationship between data and theory throughout the process, a pragmatic epistemological stance on GT. Most GT approaches discourage the researcher from engaging with existing literature before data analysis to encourage independence from the data (Glaser & Houlton, 2004). Therefore, GT was not considered to be an appropriate method of data analysis due to the mixed methods design of the research, as the interview stage of research was influenced by the analysis of the data obtained during stage one of the research (the questionnaire), rather than to develop a new theory about TIC in cancer services. Additionally, the researcher had already completed a literature review for the research proposal.

5.2.4 Reflexive Thematic Analysis (RTA)

RTA highlights the active role of the researcher and is bound by the researcher’s own beliefs, understanding, and meaning of the world. Therefore, critical reflection is ‘essential’ within RTA. Thematic Analysis (TA) is a flexible research approach concerning epistemology and methodology. The research adopts a systemic approach to analysis, generating initial codes and themes that represent patterns of meaning across the data (Braun & Clarke,2006).

The fluid application of RTA means that data can be analysed inductively or deductively. Inductive analysis is the ‘bottom-up’ approach, where themes are strongly linked to the data of the meanings and experiences of the participants (Willig, 2019). Deductive analysis is described as the ‘top-down’ approach that is theoretically driven and often offers a more detailed analysis based on the researcher’s theoretical interests (Willig, 2019). Finally, the integration of a hybrid inductive-deductive approach to mixed methods maps on well to theory-informed qualitative analysis (Proudfoot, 2023).

This research aimed to explore the experiences of the participant sample, and an RTA inductive-deductive approach was considered most appropriate. The inductive TA was important for the generation of codes from the data itself, meaning the data valued the participants' voices as much as possible (acknowledging researcher reflexivity). The deductive framework used was based on the six TIC principles of the Substance Abuse and Mental Health Services Administration (SAMHSA; 2014) TIC model (Table 11).

Table 11.

SAMHSA's (2014) TIC Principles and definitions

TIC Principle	SAMHSA's Definition
7. Safety	Individuals feel physically and psychologically safe; the physical setting is safe, and interpersonal interactions promote a sense of safety.
8. Trustworthiness and Transparency	Decisions are conducted with transparency to build and maintain trust with clients, staff and others involved in the service.
9. Peer Support	Peer support and mutual self-help are key to establishing safety and hope, building trust, enhancing collaboration, and utilising stories and lived experiences to promote recovery.
10. Collaboration and Mutuality	Levelling of power differences between staff and clients. Demonstrating that healing happens in relationships and the meaningful sharing of power and decision-making.
11. Empowerment, Voice, and Choice	A belief in resilience, and in the ability of individuals, organisations and communities to heal and promote recovery from trauma. Foster empowerment for clients and staff alike. Clients are supported in shared decision-making choices and goal-setting to determine the plan of action needed to heal and move forward.
12. Cultural, Historical and Gender Issues	The organisation actively moves past cultural stereotypes and biases and incorporates policies, protocols and processes that are responsive to the racial, ethnic, and cultural needs of individuals, addressing historical trauma.

5.3 Quality Monitoring

The topic of quality monitoring in mixed-methods research is a subject of debate (Fabregues & Molina-Azorin & Fetters, 2021), and as a result, the methods have been examined separately and throughout the entire study.

Regarding the quantitative method, face validity is commonly used as a measure of data quality (Allen, Robson & Iliescu, 2023). Face validity evaluates the clarity and extent to which the instrument measures the intended concept (Mohajan, 2017). The survey used in this study collected data that aligned with the research objectives and did not contradict the comprehensive interview data, which yielded similar findings. Therefore, it can be reasonably assumed that the measures have face validity.

Treharne and Riggs (2017) assert that transparency, triangulation, personal reflexivity, and end-user involvement are crucial aspects of quality in qualitative research. Quality monitoring has been addressed in the following ways:

Firstly, quality was ensured through ongoing research supervision and an audit trail that documented the researcher's decisions, as well as multiple drafts of theme development and stages of quantitative analysis. The progress of the study was recorded in supervision summaries and stored by the UoN's administration team for their records, with agreement from attendees that the notes accurately summarised the meetings.

Secondly, researcher reflexivity is essential for rigour (Johnson, Adkins & Chauvin, 2020). The lead researcher maintained a reflexive diary to remain aware of personal influences on the research. This involved ongoing reflections on ideas, decisions, and emotional responses[21] .

This study employed methodological triangulation by combining quantitative and qualitative data to explore the identified relationships more accurately (Ivankova, Creswell & Stick, 2006) and examine different aspects of the topic (Noble & Heale, 2019). The sequential explanatory method helped address the research questions,

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[21] See reflexivity below and Extended Paper (Section 8).

as the qualitative findings aligned with both the confirmations and divergences observed during the quantitative stage of the research.

Finally, regarding quality monitoring in qualitative analysis, Clarke and Braun's (2022) RTA checklist was used to self-monitor the analysis (Appendix S). Additionally, the Good Reporting of A Mixed Methods Study (GRAMMS) (2008) checklist was used for self-assessment to monitor the quality of the research reporting (Appendix T). This checklist was chosen because it provides reporting guidelines for mixed-method studies in healthcare research (O'Cathain, Murphy & Nicholl, 2008).

End-user involvement involves considering the population being researched and includes planning, design, and dissemination of the study. As mentioned earlier, this research involved an EBE. Further details regarding the dissemination of findings can be found below.

5.3.1 Reflexivity

Research is significantly influenced by the researchers and their perspectives on the subject matter (Holmes, 2020). The main researcher's interest in TIC and cancer services is rooted in various clinical encounters where individuals with a history of childhood adversity faced challenges in accessing and engaging with healthcare services. Through these experiences in different clinical settings, the lead researcher has observed the disempowerment of individuals in environments with established professional hierarchies, such as the relationship between doctor and patient.

The primary researcher has a strong interest in supporting individuals in mitigating the negative effects of childhood adversity, reducing trauma symptoms, and promoting post-traumatic growth. Personal experiences with cancer affecting family members have further fuelled a commitment to increasing EBE involvement in research and raising awareness of the psychological impact of trauma to bridge the gap between mental health and physical health in clinical settings. The focus of the interpretation has been on understanding the reasons behind difficulties and the experiences in clinical settings more broadly.

The researcher's values will shape the methodology and analysis approach, highlighting the importance of reflexivity to enhance the credibility of the research process, especially in ensuring quality research. For instance, the researcher made a conscious effort to seek clarification from participants even on familiar processes or terms to avoid assumptions. Keeping a reflective journal to document thoughts and experiences allowed for introspection on how values and beliefs could influence the research process, which was discussed during research supervision, particularly in the analysis phase. While two researchers lacked experience in oncology settings, this allowed for data-driven interpretations without bias from personal experience. In contrast, two additional supervisors with direct experience provided valuable insights for understanding the data in a broader clinical context. Lastly, one researcher with lived experiences of childhood trauma and cancer could offer interpretations based on both data and personal experiences.

5.3.2 Dissemination of Findings

To ensure that the results of this research are accessible to participants and can be utilised by professionals and researchers, they will be disseminated through various channels. The research findings will be condensed into a journal paper and submitted for publication in a peer-reviewed journal. Additionally, the results will be shared with individuals who expressed interest in the study findings. Researchers will be encouraged to share the findings on social media platforms, and field supervisors will be encouraged to disseminate the findings within relevant clinical settings. Furthermore, the research findings will be presented at conferences, and summaries will be shared with relevant charities.

6. Extended Results

6.1 Extended Participant Characteristics: Online Survey

Table 12.

Extended participant characteristics

Characteristics	Responses	*n*	*M*	SD
Age (years)	18-27	21	-	-
	28-37	38	-	-
	38-47	36	-	-
	48-57	66	-	-
	58-67	70	-	-
	68-77	25	-	-
	78-87	7	-	-
	PNS	3	-	-
	Total	**266**	**61.45**	**16.01**
Ethnicity	Asian/Asian British	9		
	Black/Black British	4		
	White	247		
	Mixed/multiple ethnic groups	4		
	PNS	2		
	Total	**266**		

Note. PNS = Prefer not to say. *n* = number of responses. *M* = mean. SD = Standard Deviation.

Table 13.

Extended cancer-specific participant characteristics.

Question	Responses	*n*	%
Detection Route	Self-identified (checks)	111	41.7
	Results of a screening	77	28.9
	Incidental	51	19.2
	Other	27	10.2
First cancer diagnosis?	Yes	247	92.9
	No	18	6.8
	PNS	1	0.4
Currently undergoing cancer treatment?	Yes	86	32.3
	No	177	66.5
	PNS	3	0.12
Which setting did you access and receive your cancer diagnosis and/or treatment?	NHS	220	82.7
	Private	22	8.3
	Both	24	9.0
Do you have any other health conditions that require medical care?	Yes	100	37.6
	No	154	57.9
	PNS	12	4.5

Note. PNS = Prefer not to say. *n* = number of responses. % = percentage of response for each item.

Table 14.

Extended cancer-specific characteristics: Cancer type/site.

	Responses	N	%
Cancer Type/Site	Breast	82	30.83
	Acute Myeloid Leukaemia	1	0.38
	Basal Cell	4	1.50
	Bladder	3	1.13
	Blood (unstated)	1	0.38
	Blood (Leukaemia)	5	1.88
	Blood (Lymphoma)	16	6.02
	Bone (Osteosarcoma)	1	0.38
	Brain	3	1.13
	Colorectal	2	0.75
	Cervical	27	10.15
	Endometrial	10	3.76
	Gastric	6	2.26
	Melanoma	4	1.50
	Ovarian	17	6.39
	Lung	9	3.38
	Pancreas	19	7.14
	Prostate	1	0.38
	Renal	24	9.02
	Liver	3	1.13
	Thyroid	1	0.38
	Oesophageal	1	0.38
	Skin (melanoma, squamous-cell	4	1.50
	carcinoma etc.)	11	4.14
	Synovial	1	0.38
	Testicular	6	2.26
	Thyroid	6	2.26
	Sinus	1	0.38

Although participants were encouraged to report the stage of their cancer, this data has not been reported here due to the wide range of responses, which are uniquely dependent on specific cancer type/site. The year participants were diagnosed with cancer ranged from 1987 to 2023 (*M* = 2015). However, 50.9% of participants received a diagnosis between 2018 and 2023 (*n* = 130), with 15.6% of participants (*n* = 40) receiving a diagnosis in 2022.

6.2 Extended Participant Characteristics: Interviews

To provide further context for the participants who were interviewed, extended characteristics have been provided. Table 15 represents participants' cancer type/site and cancer detection route. The year participants were diagnosed with cancer in the interview sample ranged from 2000 to 2022 (*M* = 2016).

Table 15.

Cancer type and detection route of those who were interviewed.

	Responses	***n***
Detection Route	Self-identified (checks)	7
	Incidental	2
	Cancer screening	1
	Other	1
	Total	**11**
Cancer Type	Breast	3
	Lung & CLL	1
	Melanoma	4
	Non-Hodgkin’s Lymphoma	2
	Testicular	1
	Total	**11**

Note. Other response = Attended A&E due to perceived allergic reaction. CLL = Chronic Lymphocytic Leukaemia. *n* = number of participants.

6.3 Extended Questionnaire Results

ACEs and Shame

Given the identified pathway between shame (as measured by the EISS) and cancer-related outcomes, as well as the small significance of shame in predicting these outcomes (Figure 1), it was pertinent to run a regression analysis to explore the negative correlation between shame and ACEs (as measured by the MAES). The analysis aimed to examine the strong direct effect of ACEs (MAES) and the overlap between the MAES and the EISS (Table 16).

Table 16.

Exploring the influence of EISS and MAES on FAMCARE scores.

Variable	Beta (β)	Standard Error	R²	*p value*
Model 1 (EISS → FAMCARE)			**.06**	
EISS	-.33	.08		<.001
Model 2 (MAES + EISS → FAMCARE)			**.16**	
EISS	-.05	.09		<.001
MAES	-.35	.06		<.001

Note. Shame scores (as measured by the EISS). MAES = ACEs scores. IPQ = Illness Perception scores. FAMCARE= Patient satisfaction scores. R² refers to the change in R2 between models, indicating the additional variance explained by adding variables to the model.

In Model 1 (Table 16), the EISS demonstrates a medium negative relationship with FAMCARE (-.33), explaining approximately 6% of the variance in FAMCARE. When MAES is added to the model (Model 2), the Beta for EISS decreases from -.033 to -.05, indicating that MAES accounts for a substantial portion of the variance previously attributed to EISS. This suggests that the inclusion of the MAES in the model could substantially weaken the unique contribution of EISS. The addition of MAES significantly increases the explanatory power of the model, as evidenced by R^2 increase from .06 to .16. The Beta for MAES is substantial and statistically significant (-.35), indicating that MAES is stronger and more influential predictor of

FAMCARE that EISS in Model 2. Although EISS remains statistically significant in Model 2, its impact on FAMCARE becomes minimal once the MAES is introduced. This finding is noteworthy because it indicates that MAES accounts for a significantly larger portion of the unique variance in the FAMCARE scores compared to the EISS. Consequently, the remaining variance in the EISS measure does not contribute additional explanatory power to the model.

Prior to conducting this research, it was hypothesised that the EISS, as a measure of shame, would encompass all elements captured by the MAES and potentially offer additional explanatory value. However, the mediation analysis revealed that the IPQ, not the EISS, serves as the independent factor mediating the relationship between ACEs and patient satisfaction with cancer services. This finding highlights the central role of the MAES in the model, while suggesting that, although shame may influence negative care experiences, it does not serve as a mediating variable.

While not directly pertinent to the research question regarding the primary variable of ACEs (MAES scores), it is worth noting that additional correlations were observed among variables that may impact future research.

Length of time to seek medical intervention.

Interestingly, a secondary post-hoc analysis further revealed that the only significant correlation with the length of time it takes to seek medical intervention was patient satisfaction, as measured by the FAMCARE (r = -.18, p = .007). This small negative correlation suggests that a shorter delay in seeking medical intervention is associated with higher satisfaction scores. While this finding does not directly address the research aims relating specifically to ACEs, it does highlight an important consideration: individuals who sought medical care more promptly appeared to report higher levels of satisfaction with their cancer care.

During the interviews, all participants mentioned factors that influenced their decision to seek medical help. Reasons for delaying medical intervention, or "putting it off for as long as possible", included busy family life and work commitments (Ari, Bailey), financial concerns related to self-employment (Izzy), fear of wasting the GP's time (Danni), apprehension about confirming the possibility of cancer (Ray), and the misinterpretation of symptoms as non-cancerous (Kendall). On the other hand, motivators for seeking medical assistance included the progression of symptoms (such as n enlarging lump, difficulties fitting into clothes, or unhealing symptoms) (Izzy, Kathryn, Jack, and Bailey), encouragement from their support networks (Danni, Kendall), GP advertisements promoting proactive symptom monitoring (Cameron), and prior experiences with cancer, whether through personal diagnosis (Nicole) or the loss of a loved one (Jack).

Testing of Covariates - Gender

A preliminary examination was conducted to explore whether the pathway from ACEs to patient satisfaction differed by gender, as literature suggests gender difference in ACEs may influence delays in seeking medical help, potentially impacting satisfaction with cancer care (Haahr-Pedersen et al., 2020). The analysis aimed to provide valuable context for future research on the broader set of connections, including potential links between delayed help-seeking and lower satisfaction with care. Additionally, the analysis also considered potential gender differences in shame and illness perceptions, the mediating factor.

Mean scores revealed small gender differences across all five measured variables: time to seek help, MAES, ISS, IPQ and FAMCAREs scores (Table 17). Specifically, females scored higher on the ACEs, shame (EISS), and illness perception (IPQ) measures, while males took slightly longer to seek treatment compared to females. These findings algin with existing literature suggesting that men may delay help-seeking more significant than women, including when faced with non-gender specific cancers (Fish et al., 2015).

A series of one-way ANOVAs were completed to examine gender differences across the five variables: Length of time to seek treatment (months), ACEs (MAES) , illness perceptions (IPQ), shame (EISS), and patient satisfaction (FAMCARE) outcomes (Table 17).

Table 17.

One-Way Analyses of Variance (ANOVA) results for gender differences in time to seek treatment, MAES, EISS, IPQ and FAMCARE scores.

Measure	Gender	Mean Score	Standard Deviation	Sum of Squares	df	Mean Square	F	*p* - value
Time	Male	3.73	7.80	28.08	1	28.08	0.69	0.41
	Female	2.98	5.61	9132.83	223	40.95		
MAES	Male	12.88	10.65	14.63	1	14.63	0.12	0.73
	Female	13.38	11.32	31926.20	259	123.27		
EISS	Male	11.06	7.56	218.94	1	218.94	3.66	0.06
	Female	12.99	7.82	15483.71	259	59.78		
IPQ	Male	27.32	13.73	2095.63	1	2095.63	12.36	<.001*
	Female	33.31	12.65	43914.24	259	169.55		
FAMCARE	Male	50	11.50	288.88	1	288.88	2.76	0.10
	Female	52.23	9.52	27098.21	259	104.63		

Note. Gender categories may represent binary gender differences. Time = Time to seek treatment (months). MAES = ACEs, EISS = Shame scores, IPQ = Illness perceptions scores, with higher scores indicating a greater perceived threat from the cancer. Higher scores represent the illness to be perceived as more threatening. FAMCARE = Patient satisfaction scores. Higher FAMCARE scores represents greater levels of satisfaction. df = degrees of freedom the number of independent pieces of information available to estimate a statistical parameter. F = The ratio of variances to determine if the group means are significantly different from each other.

The ANOVA results indicated that, while no statistically significant gender differences were detected in time to seek treatment, MAES, and FAMCARE scores (all *p*-values > .05), the EISS showed a near-significant difference between groups (F(1, 259) = 3.66, *p* = 0.057), indicating a trend toward a potential gender difference that may warrant further investigation.

Statistical significance was found in the IPQ, with females scoring higher than males (F(1,259) = 12.36, *p*=<.001), suggesting that females are more likely to interpret their cancer diagnosis as more threatening, which may lead to heightened emotional responses. These increased threat perceptions, if not met with adequate emotional support, may perpetuate and individual’s threat system, potentially affecting their satisfaction with services and care. The distinct ways in which ACEs are experienced and their subsequent impact on individuals suggest a need for gender-sensitive approaches in healthcare. Future research should address these identified disparities, examining how gender may shape influence cancer care experiences, including its influence on individual’s health behaviours, perceptions, and satisfaction with cancer care.

6.4 Extended Interview Findings

Theme 1 is the only theme in which participants made explicit connections back to childhood trauma. In Themes 2-4 participants connections back to trauma were not made by participants, who spoke about their cancer experiences more broadly.

6.4.1 Theme 1*: ’Connecting the dots’*: Resonance of childhood memories and current experiences.

The use of the term 'trauma' in both the questionnaire and interview to capture ACEs prompted a reassessment of life events for some participants. Four individuals did not associate their adversity with the term 'trauma,' for example, “Was what I went through really considered trauma?” (Ray). For those who did not label their experiences as 'trauma,' an alternative interpretation was described as, “something unfortunate that occurred in the past” (Kathryn).

The completion of the childhood trauma measure (MAES) activated memory processes of childhood events, overriding an individual's familiar defences and coping mechanism of compartmentalisation as evidenced by Ari, “…while I was doing it, I was quite emotional doing it because the questions made me ask myself about things that I’d kind of put away…”. This suggests that the questions prompted individuals to reflect on aspects of their past that had been previously suppressed or avoided. The experience of engaging with the questions appeared to re-open emotional memories, leading to a moment of self-reflection and emotional release. This highlighted the potential for introspection and emotional processing which could be triggered by revisiting difficult experiences, relating to trauma or other significant life events.

For some individuals, the interview was the trigger for recollecting past events, enabling them to establish correlations between their present circumstances and their personal history. In particular, some participants were prompted to recall specific memories upon recognising the connection between their current cancer diagnosis and their familial background of the disease. To illustrate, Kathryn initially struggled to comprehend why she found the provision of Macmillan cancer care resources distressing. However, during the interview, a discussion triggered a recollection, leading her to associate this memory with her current experiences and the symbolic significance of this in a medical context:

> I found it absolutely traumatic to go in there, not expecting it and to come out with a bag with Millan cancer care…I actually hid it under my jumper…Ah. It goes back to a to a memory of when my father died… you come out of the hospital with a brown paper bag with his watch and other personal effects…I think that's kind of triggered a memory that something happens, and you come out with a bag of stuff…'
>
> (Kathryn)

In this case, the hospital bag became a symbolic trigger, linking Kathryn's current cancer diagnosis to the trauma of losing her father. This illustrates how unresolved trauma can influence emotional responses to new stressors, such as receiving a life-threatening diagnosis. In terms of TIC, this experience highlights the importance of understanding the impact of past experiences on present emotions and responses. Clinicians should be aware that certain triggers, such as the way medical items or news are presented, could evoke past trauma in patients. By attuning to these emotional cues, healthcare providers can cultivate a more supportive and empathetic environment, thereby assisting patients in processing their experiences in a manner that feels both safe and validating.

Several individuals highlighted the links between their childhood memories and how these recollections shaped their perceptions and coping mechanisms throughout their lives, including their experiences with cancer. For example, Izzy, who was placed in foster care at a young age, described re-experiencing the feeling of being a "nuisance" during her cancer journey. This evoked a renewed sense of rejection, powerlessness, and neglect that she had encountered during her childhood:

> …you know people don’t really want you, you’re just an extra in life. So, when you get to cancer you feel that you’re in the same position where people don’t really want you. You’re just a nuisance and they’re trying to tick you off their list and get rid of you…they just want to do their protocol and you’re gone. A bit like being with a family that you know you’re the one extra, that they’re putting up with you but when you’re gone they feel they can have their family back again.
>
> (Izzy)

Izzy’s experience highlights how feelings of being a burden, rooted in childhood trauma, resurface during her cancer care. Her sense of being tolerated rather than wanted reflects early neglect and emotional unavailability. This trauma is triggered when she feels like a "checklist" item in the medical system, rather than receiving compassionate care.

These connections illustrate that the mechanisms between childhood and adulthood are also consistent in terms of coping strategies. Similar patterns of coping are re-enacted from childhood into adulthood, even when faced with different stressors. For instance, individuals may utilise compartmentalisation and avoidance as methods to cope with trauma both in childhood and when dealing with a cancer diagnosis, “…somebody that always puts everybody else first like me and withholds their emotion constantly because fear of people gonna leave and not want them. I think that’s what I see in me and in other people who have had cancer…” (Danni).

Danni's experience illustrates how the tendency to suppress emotions can serve as a coping mechanism, particularly in response to ACEs where a child may learn to hide their needs to avoid rejection or abandonment. When this pattern is carried into adulthood and during cancer treatment, individuals may fear that expressing their needs will result in further rejection or being seen as a burden. In the context of cancer, this behaviour can be intensified by the emotional toll of the disease, where individuals may feel their emotional and physical needs are secondary or that vulnerability could lead to judgment or isolation. TIC emphasises the importance of recognising and addressing these cognitive and emotional patterns, such as fears of abandonment, to help individuals regain a sense of empowerment and self-worth. This involves creating a safe space for patients to express their emotions, normalising their emotional responses, and ensuring their emotional needs are acknowledged and validated throughout their cancer journey.

Additionally, Ari struggled with a lack of control over her diagnosis during her cancer journey. As a child, she had learnt to internalise her difficulties and continued to suppress her emotions throughout her cancer journey, similar to how she felt as a child. This struggle of powerlessness caused her to feel disempowerment and a sense of anxiety and passivity during her cancer journey:

> …they never knew what happened to me because it wasn't an appropriate time for me to put my hand up and say actually, I had some issues…so you learn to keep quiet and get on…I think that's how I kind of how I am with ma treatment. Do. Have. Get on.
>
> (Ari)

Ari's pattern of "keeping quiet" and "getting on" suggests a learned behaviour that develops when a child's emotional needs are overlooked or dismissed, leading people to believe that expressing discomfort or asking for help is not appropriate or will be met with negative consequences. In the context of cancer treatment, this pattern can continue, with people feeling unable to express their struggles or needs. TIC would recognise these underlying fears and the individual's reluctance to speak up, aiming to create an environment where patients feel safe and supported in expressing their emotional and physical needs.

Danni's statement reveals a strong connection between her childhood experiences and their difficulty in expressing emotions, particularly anger, suppressing their own feelings, especially anger, to take care of others became a learned coping mechanism:

> …I see that there is a link between past experiences and not being able to express emotions, in particular anger …I have consistently withheld emotions from being a child er especially anger, um because there was a lot of anger in the household, and I was the one that had to look after everybody

> else... I think that's what I see in me and what I see in other people who have had cancer…
>
> (Danni)

The link Danni makes between their childhood emotional suppression, and their cancer experience suggests that these early experiences may have shaped their emotional responses to stress, illness, and the challenges of cancer. The inability to express anger could potentially contribute to internalised feelings of frustration or resentment, which may be harder to process and express, particularly when faced with a traumatic event like cancer. From a TIC perspective, Danni's experience highlights the importance of clinician's understanding how past experiences can affect present emotional expression and coping strategies.

Both the questionnaires and interviews prompted individuals to recall childhood memories, making connections between past trauma and their cancer diagnosis, including coping strategies. This suggests that a TIC approach in cancer settings would be beneficial in recognising how historical trauma can be re-triggered and potentially affect engagement and satisfaction with cancer services in adulthood.

Overall, Theme 1 suggests that by linking past trauma to current experiences, patients gain self-awareness, which can enhance their autonomy in managing cancer. The use of childhood coping mechanisms, such as compartmentalisation and avoidance, when trauma is re-triggered in adulthood, emphasises TIC's focus on understanding the impact of past trauma on present behaviour. However, as seen in some participants, TIC principles are not always fully integrated into cancer care but highlights the value of TIC principles in cancer care and the potential benefits of integrating TIC practices, such as trauma history screenings, to better support patients' emotional and psychological needs.

6.4.2 Theme 2: '*Nobody ever told me*': Powerlessness & cancer-related losses.

Shame and stigma are woven throughout this theme. An interesting link between people's perceived sense of control over their cancer and their perceptions of their childhood trauma was captured.

Some who did not identify their earlier childhood experiences as 'trauma' also did not identify their cancer as threatening, “…the cancer…I may be badly wrong in the long term, it’s not a big issue…you’re looking at it as it is and it’s all about surgical. Taking it out. End of story.” Ray’s response focuses instead on the physical, practical aspects of the diagnosis, possibly in an attempt to avoid or downplay the emotional or psychological challenges it might bring. This mindset can be a protective mechanism that distances the person from feelings of vulnerability, fear, or distress, which may feel overwhelming or unsafe to confront. It could reflect a potentially ingrained pattern of emotional avoidance, where focusing on the tangible, physical elements of the situation help maintain a sense of control or detachment. However, this would need to be explored further.

As shared by many, the emotional distress caused by a reduced sense of agency and feelings of powerlessness negatively impacted the cognitive and emotional adjustment to diagnosis. Due to the individual's body experiencing a constant source and sense of threat, a pattern of negative events or information can that compounds stress, often included difficulties with processing complex and vast amounts of medical information from attending multiple appointments, “There’s an awful lot of stuff thrown…it’s usually a lot of bad news, bad news, bad news...you just feel like you’re being hit all the time with something… (Ari)” The emotional toll of cancer, as captured by Ari, can evoke a sense of being under siege, as if there's no respite or space for relief. This could point to a feeling of powerlessness, as the person is unable to stop or control the flow of negative events or information, creating a situation where they may feel trapped or unable to escape from the emotional impact of their cancer..

6.4.2.1 Subtheme 2a. Bodily Integrity

Often beyond the individual’s control, changes in the physical body are among the most common side effects of cancer and its treatment, affecting all participants. Additionally, the psychological impact of the perceived inviolability of the human body was captured in the experiences of most participants, revealing the additional trauma individuals may face, not only from their diagnosis but also from ongoing side effects of medical interventions. For example, Eden relived the moment of her hair loss, “The worst thing ever…lots of people over the years they’ve all said the same, was losing my hair. Terrible… I remember it as if it was yesterday…I put my hand up…to wash my hair, it just came out in handfuls…”

Eden's statement highlights the profound emotional and psychological impact of hair loss during cancer treatment. The act of washing her hair symbolised a loss of control over both her body and the changes she was undergoing, reflecting significant distress that transcended physical discomfort and deeply affected her sense of identity and self-image. The enduring psychological impact of such experiences is evident, as Eden recalled the emotional effect of this event nearly two decades later. Hair loss, a visible marker of illness, often evokes vulnerability, a loss of control, and shifts in how one is perceived by others, representing a physical change closely tied to personal identity and appearance, which can be especially disconcerting during an already distressing time.

Bailey, like other participants, also recounted similar experiences, highlighting the profound influence that treatment had on every facet of her existence:

> I had no idea how the treatment was going to affect me, nobody ever told me that, you know, it would be very hard to function in your daily life which was hard because I lived on a farm on my own with a 6-year-old. In the middle of nowhere, with no transport.
>
> (Bailey)

A sense of shock, isolation, and powerlessness regarding the physical and emotional challenges that cancer treatment poses was similarly experienced by most participants. Bailey expresses a lack of preparedness, as no one had informed her of the significant difficulties that she would face in her daily life as a result of the treatment. Bailey’s circumstances highlight the physical and social isolation that individuals can face, intensifying the burden of managing both their own health and caregiving responsibility without adequate support.

One participant's detailed account of relapse demonstrated that it had the most profound impact on feelings of powerlessness, frequently resulting in anger:

> I was angry…I can take having cancer and stressing my parents, family and friends to hell, and my partner… Take the ability to have kids from

> me…I'm still on the planet you know…some people don't live, but then.. to just get it again...
>
> (Kendall)

As previously mentioned, the impact of cancer encompasses various side effects and losses, and in some cases, the additional burden of relapse. While there may be a certain level of acceptance or resilience in facing cancer and its treatment, Kendall's experience of relapse illustrates a profound sense of betrayal, highlighting the sense of powerless and the unpredictability of cancer after already enduring its physical and emotional effects. Kendall expresses anger at the emotional toll of her cancer, not only on herself but also on her loved ones, grappling with the internal conflict of being alive while experiencing multiple losses caused by the cancer treatment. Fertility a significant potential loss for cancer patients, can deeply affect one's sense of identity and future aspirations.

This sub-theme highlights both the physical and psychological ramifications of cancer and its treatment, particularly the alterations to the body that often lay beyond an individual's control. A shared experience among participants was the emotional distress associated with physical changes, which can persist long after treatment has concluded. Participants also expressed a sense of powerlessness, especially concerning the unpredictable and often severe side effects of cancer treatment. Consequently, it is crucial to recognise the profound impact physical changes can have on an individual's sense of self-worth and identity.

6.4.2.2 Subtheme 2b. Identity Transition

The physical changes caused by cancer treatment can be visible and impact how individuals perceive themselves as having cancer, affecting their sense of self, and increasing psychological distress.

As Kendall shared,, living with cancer can lead to depression and anxiety often fuelled by the persistent fear of death, "…I just can't get out of that headspace…something's telling me I'm not supposed to be on this planet…" Without compassionate support, such emotional distress can severely impact an individual's ability to maintain a stable and future-focused identity. The internal struggle, as experienced by Kendall, can disrupt one's sense of self, as individuals can often feel disconnected from their pre-cancer identity and unable to envision a future beyond their current physical and psychological suffering. These negative emotional states can impede the process of identity transition, potentially triggering a sense of not belonging or feeling disconnected from life.

Some participants noted that even after achieving remission, the identity of having had cancer persists, with external perceptions shaped by their cancer history continuing to influence their future healthcare experiences:

…I think they see an age; they see a previous diagnosis…it almost guides them to another diagnosis of similar instead of being open to, 'Well it could just be you had a strong drink last night and you're feeling a bit iffy.

(Izzy)

These external perceptions, rooted in past diagnoses, often reinforce the notion that a history of cancer defines one's health narrative permanently. The lingering impact of these perceptions, coupled with assumptions about age, can lead to preconceived notions regarding future health symptoms, even in the absence of cancer.

For others, the persistent cancer identity significantly influences the interpretation of future bodily changes. A common tendency to catastrophise, where new or unfamiliar symptoms are attributed to a prior cancer diagnosis, demonstrates how this identity continues to shape one's health perceptions and responses:

> …as parts of the body seem to be functioning differently, with age. So part is thinking hang on is that prostate, is that cancer inside the head…I've had these little bits start in a sense to catastrophise…there is something there, there isn't…I'm thinking a bit more that it could be…

(Ray)

The long-term impact of the cancer identity can lead individuals to interpret physiological changes through the lens of their cancer history, increasing heightened anxiety and uncertainty about future health. For instance, becoming more attuned to bodily changes and noticing symptoms more acutely with past cancer experiences shaping these perceptions, can amplify concerns. Ray's fears, likely stemming from normal age-related changes, reflect a deeper fear of the unknown and the lingering emotional effects of his cancer history. Thus, an individual's perceptions of ageing may influence the way they perceive future symptoms and possibly the likelihood of seeking healthcare in the future.

This sub-theme recognises the lasting effects of a cancer identity on an individual's physical and psychological well-being. The visible physical changes resulting from cancer treatment often disrupt one's sense of self and contribute to heightened psychological distress. Even after remission, the cancer identity persists, shaping how healthcare professionals and individuals perceive future symptoms. Furthermore, the natural ageing process complicates individual's perceptions of health, influencing how they interpret physical changes and health risks.

Overall, Theme 2 highlights the emotional distress and sense of powerlessness many cancer patients experience. Some struggle with overwhelming feelings of helplessness due to medical treatments, bad news and the loss of agency over their bodies. This emotional overwhelm and difficulty processing complex medical information when already in a state of psychological distress can hinder emotional adjustment and coping during cancer treatment.

6.4.3 Theme 3: *' I just wanted everyone else around me to be okay':* Distributed effects of cancer through the social network.

6.4.3.1 Subtheme 3a. Impact of diagnosis on the family

Trauma from cancer can affect not only the individual diagnosed but also their family members and many participants experienced this. Despite receiving support from their families, individuals often have to handle their family members' distress and adjustment to the diagnosis along with their own emotions. Kendall, for example, described her father's overwhelming sense of responsibility for her diagnosis, "…all he could think about is that how his genetics are responsible…there's no link…obviously they just worry that erm they'll have to bury me… It's just so fucking awful." A profound sense of emotional distress and guilt is likely linked to an individual's awareness of how their illness affects their loved ones and the emotional toll on those around them, which can contribute to feelings of burden and isolation and the uniquely great difficulty navigating these complex feelings.

This sub-theme highlights the complex emotional dynamics within families during cancer treatment, where individuals may prioritise caring for others' emotional needs at the expense of addressing their own. The theme illustrates a lack of TIC approaches, which emphasise a compassionate, non-judgmental environment that offers emotional support to challenge common emotional responses, such as anxiety and guilt, and to validate individuals' experiences, in an attempt to recognise and respond to the alleviation of the emotional burden associated with these concerns.

6.4.3.2 Subtheme 3b. Accessing cancer support networks and connections with shared experiences.

Participants accessed a range of support including emotional support, information about their diagnosis and treatment, practical support with finances and support to manage the physical side effects of cancer. Jack's account effectively represents the primary reasons most participants sought cancer support networks, as well as the compassionate, yet practical nature of support provided:

> … talk to qualified professional… pop in for a coffee…If you did have a little question …you just had to go along and say, 'Look, what the situations with regards to this?' They told me all about what entitlements I would have, ever was I financially in trouble…they told me everything. There wasn't a question unanswered as far as I was concerned.
>
> (Jack)

Jack's positive experience of support included his concerns being addressed comprehensively and the approachability of the care team. His comfort in asking questions and seeking clarification indicates a patient-centred environment where curiosity is welcomed. Additionally, his reference to financial support suggests a holistic approach to addressing both practical and emotional needs.

Individuals ambivalent about seeking support often experience conflicting feelings, desiring both distance for self-protection and care for emotional support. This ambivalence can often be rooted in childhood beliefs of being undeserving of care. Coping strategies may involve avoiding others, suppressing true desires, or, occasionally accepting compassion from others as demonstrated by Ari's experience, "I'd prefer to have a little bit more support and understanding and affection around me…it's a little bit like an armour I guess, it's keeping me okay but at some point you’re gonna get chips in it.” Ari’s expressed desire for emotional support and connection reveals feelings of isolation and a need for deeper emotional support to feel less vulnerable. The use of emotional defences to protect oneself from the emotional toll of cancer may serve as a protective mechanism. For example. Ari’s metaphor being like ‘armour’ illustrates that her coping mechanism offers her protection, but the acknowledgement of ‘chips’ reveals that even emotional resilience can have its limits.

This sub-theme evidences the significance of the ‘peer support’ TIC principle. Accessing support networks appeared to have provided participants with emotive and practical sources of support. Furthermore, it is important to consider how historical experiences shape individuals' coping strategies and could lead to some not seeking additional support despite struggling. Thus, evidence suggests that recognising an individual’s coping strategies and exploring components of support with them is important for quality of life.

Overall Theme 3, examines the broader impact of cancer, extending beyond the individual to affect their family and social network highlighting the diverse support sought by participants, including emotional and practical help. Support networks provided compassionate assistance, especially in managing cancer-related challenges, although some participants felt ambivalent about seeking support due to fears of vulnerability. This theme evidences the importance of peer support, a key TIC principle, where shared experiences in support networks can offer both emotional and practical benefits.

6.4.4 Theme 4: *‘It’s down to bedside manner’:* Patient satisfaction is shaped by relational care.

Ari and Eden shared different examples of what good quality care looked like which maps onto similar TIC principles, “…someone who’s got empathy and understanding of people…she picked up vibes from people. If you’ve got really good insight and understanding, communication skills and stuff like that.” (Ari). Eden stated, “…he [Consultant Oncologist] used to ring me when out of hours at night…he used to say are you alright, are you okay? I mean, what others would do that?.”

Both examples demonstrate the critical role of empathy in fostering positive relationships between patients and healthcare professionals. The ability of healthcare professionals to interpret patients' body language and sense their unspoken emotions, such as anxiety, fear, or confusion, reinforces the importance of empathic understanding in cancer care. This goes beyond addressing only the practical aspects of medical treatment, allowing professionals to connect with patients on a more personal level. Eden's example exemplifies empathy that appears to transcend routine medical care, aligning with the TIC principles of 'safety' and 'empowerment.' It emphasises the significance of relational care in the healing process, where a compassionate approach not only meets emotional needs but also fosters trust and a sense of safety in the clinician-patient relationship.

Effective communication should also include transparency about treatment procedures and processes, as well as normalising discussions about our emotions and validating patients' concerns:

> …I was asked to wait for my last infusion of chemotherapy in a waiting room so I would free the er the bed for incoming patients…I was quite weakened…I remember that I felt at the time like I was being let down…
>
> (Cameron)

Cameron's statement highlights emotional distress and neglect that can arise during vulnerable moments in cancer care, suggesting that both emotional and physical needs are not always prioritised. This failure to account for the physical and mental exhaustion of patients can come across as dismissive. The sense of being let down implies that individuals may have expected more compassionate care at a time of heightened vulnerability. This indicates a lack of TIC principles in cancer care. A TIC approach could reduce feelings of isolation and dismissal, fostering an environment that nurtures both the emotional wellbeing and physical needs of patients, ultimately upholding their dignity rather than contributing to a sense of dismissal or neglect.

Furthermore, as articulated by Jack, the establishment of psychological safety through high-quality relational care can mitigate the perceived threat of illness, enhancing patient satisfaction. Jack's experience highlights this dynamic, "his manner he actually wanted to know me. You know it's I know you've got cancer otherwise you wouldn't be sitting in front of me…do you have any concerns?...I felt totally safe." This demonstrates how a compassionate and attentive approach can reduce patients' anxiety and foster a sense of safety.

6.4.4.1 Subtheme 4a. Communication of diagnosis

Patient satisfaction appeared to be influenced by an associative memory relating to the manner of disclosure and influenced how relational care develops. This subtheme also considers those who have disagreed with their diagnosis and the way that their consultant communicated with them.

6.4.4.2 Subtheme 4b. Emotional Vs. Practical Support

Across most participants, practical support appeared to be more readily available within the treating team. In contrast, emotional support was often desired but tended to be contingent on the individual clinician or service. The current medical model of care was noted to be primarily focused on practical aspects, with less emphasis on addressing emotional needs.

Ray described his treatment as being like a 'shop, next one in, cut, scoop, go….' . His description reflects deeply transactional and impersonal experiences of care by comparing his treatment to a factory-like process, conveying a sense of being treated as just another case or object to be processed rather than a person with unique psychological and physical needs, with a lack of time or attention to the individual as patients were described as cycling through with little opportunity for personalised care or connection.

The feeling of being part of a mechanical process was also evident Danni's account, which resulted in her internal belief from childhood that her needs were not valid or unimportant compared to others:

> …having a better understanding of how it feels to think you're being told at that moment that you have cancer…there needs to be a little bit more empathy…it was literally like a conveyer belt…right, that one's out the way to bring the next one in. Just felt wrong…
>
> (Danni)

It was noted by the majority of participants that the emotional impact of receiving a life altering diagnosis was insufficiently acknowledged by healthcare professionals. The emotional experience of receiving a cancer diagnosis is both profound and complex, as demonstrated by Danni. However, for some individuals the manner in which their diagnosis was communicated appeared to dismiss the emotional impact, neglecting their emotional needs.

Challenges in maintaining continuity of care arise when patients are seen by different clinicians across various hospital locations. Some participants, such as Jack, expressed concerns within the cancer community are often not voiced due to fears of potential repercussion:

> …people won't kick back because they're terrified to upset the apple cart because they know they need that treatment, and they won't speak up. I know they don't. They won't complain on occasion for fear they could come back on them with regards to treatment and the way they're managed.
>
> (Jack)

Patients in cancer services often experience fear and powerlessness, which leads to reluctance in voicing concerns or dissatisfaction due to fears of negative consequences. The sensitive nature of treatment appears to make patients hesitant to express discontent, as they worry it may disrupt their care or their relationship with clinicians. Challenges in continuity of care and a lack of empowerment could result in suboptimal care, as patients might remain silent out of fear of losing access to treatment. These issues highlight the absence of TIC principles, which could contribute to continued increased vulnerability and emotional distress.

Overall, this final theme, highlights the disparity between practical and emotional support in cancer care, with practical support being readily accessible, while emotional support remains inconsistent and dependent on individual clinicians. Patients often described their experiences as mechanical and impersonal, particularly when receiving a cancer diagnosis, reflecting the medical model's predominant focus on physical treatment over emotional wellbeing. This theme suggests an absence of TIC principles in cancer care, highlighting a need for a more compassionate, person-centred approach which could mitigate emotional distress and foster greater patient empowerment.

6.4.5 Participants Perspectives on Enhancing Cancer Care

Finally, all participants provided suggestions for how services could be adapted to incorporate TIC principles. These included offering psychological support to help individuals adjust to a cancer diagnosis and treatment, establishing a ‘cancer link’ located at the GP to provide emotional support and advice when needed (as suggested by Danni), and addressing the impersonal nature of care by allowing patients the opportunity to express their feelings, in an attempt to tackle the current ‘sterile process’ (as emphasised by Bailey). Additionally, Ray and Jack proposed the inclusion of specific screening questions for clinicians, with Jack highlighting the importance of initiating conversations about mental well-being:

> …’Have you ever experienced cancer within your own immediate family previously?’...if they say yes, it might help to see what kind of experience they had and try and remove any trauma to the individual that they might have suffered as a result…that could be quite significant because it's all up here *taps head*…
>
> (Jack)

Drawing on her experiences with cancer care, Danni further emphasises the importance of training clinicians to adopt trauma-informed practices:

> I think if professionals were trained to pick up on some of those cues and they are quite easy to recognise. Then that would make them realise here in front of me is a person that is not possibly confident enough to tell me how she really feels., to ask for the things that she feels or be completely honest about what's going on because she fears that … I'm going to be dismissed or not believed…If they're gonna go into oncology that should be part of their understanding…you could help that person to feel more valued and therefore open up about some of the things that might be worrying them a bit more.
>
> (Danni)

Based on her experiences of cancer care, Danni emphasises the importance of training healthcare professionals, particularly in oncology to recognise non-verbal cues that might signal a patient’s discomfort, distress, or vulnerability in expressing their emotions. Danni suggests that many cancer patients lack the confidence to be open or honest about their feelings, fears or needs often due to a fear of being dismissed by healthcare providers. Her evidence advocates for the integration of TIC principles in oncology practice, ultimately fostering a more open and therapeutic patient-clinician relationship.

13. Extended Discussion

The current study was exploratory, using existing literature to inform the research aims. The aims were twofold: To identify if there is a relationship between ACEs and 1) the length of time it takes for someone to seek medical help from cancer services, 2) feelings of shame, 3) appraisals of cancer and 4) patient satisfaction within oncology services in adulthood (Aim 1a) and to determine whether shame mediates the relationship between ACEs and satisfaction with oncology services (Aim 1b). Second, the study aimed to provide an in-depth patient-driven exploration of individuals' experiences with their cancer diagnosis and oncology services in adulthood within the UK (Aim 2). A relationship was identified between ACEs and the following factors: 1) shame, 2) illness perceptions, and 3) patient satisfaction.

The application of TIC as a deductive framework incorporated multiple elements of psychological theories of trauma. These findings align with current literature demonstrating how traumatic events significantly impact individuals, as they may create feelings of loss of control and a heightened sense of mistrust due to the unpredictability of others, which is emphasised through these experiences (Li, 2022). Regardless of whether participants cognitively labelled their experiences as traumatic, they widely discussed their engagement with and satisfaction with cancer services. While most participants rated their satisfaction with cancer care highly, suggestions were still made on how to improve patient satisfaction levels.

TIC approaches are grounded in psychological theory and process, and the findings of this study appear consistent with the literature. Cognitive psychological models offer a useful framework for understanding how the experience of a cancer diagnosis in adulthood can reactivate childhood trauma memories and responses. The social-cognitive transition model of adjustment could be applied to participants ' expectations of cancer care; when these expectations are unmet, their disconfirmation can elevate stress and negative affect. Additionally, the ‘shattered assumptions’ theory (Janoff-Bulamn, 1992) provides insight into how experiences such as ACEs and cancer can disrupt an individual’s view of the world, revealing vulnerability and the loss of previously held beliefs of safety, just and predictability. This shift can lead to existential questions like ‘why me?,’ heightening the sense of vulnerability and awareness of mortality (Edmondson et al., 2011). Both of these cognitive theories align with the findings of this study, as evidenced in the interview data.

This study also builds on existing literature on powerlessness and identity experienced during cancer care. According to the literature, stigmatisation depends on whether an individual’s identity is threatened by the cancer diagnosis (Knapp, Marziliano & Moyer, 2014). It is, therefore, essential to consider additional contextual factors, such as cancer type, visibility, and the impact of cancer and its treatment on life goals (Knapp, Marziliano & Moyer, 2014). The visibility of cancer-related side effects, in particular, affects interpersonal relationships and psychological well-being (Knapp, Marziliano & Moyer, 2014). However, as noted in Theme 3, access to support networks and connections with individuals who share similar experiences can significantly aid in managing the visible side effects of cancer treatments. Additionally, a sense of stigma was present throughout all themes when accessing and engaging with medical providers. This connects with the importance of relational care, as participants reported that clinicians did not address the emotional impact of cancer on an individual’s life.

It would be valuable to explore whether the modality of the inquiries (interview or questionnaire) or, irrespective of modality, the subject matter itself triggered heightened emotional responses. Topics such as ACEs and the experience of a cancer diagnosis may evoke significant emotional weight, potentially eliciting more intense emotional reactions and more vivid recollections. Relational care emerged as a core factor influencing patient satisfaction with cancer services. These qualitative findings align with several items of the FAMCARE measure, particularly those related to communication and relationships with clinicians (Lo et al., 2009). Participants described several implications of cancer care and treatment, including developing a new ‘cancer identity,’ a sense of powerlessness and loss of autonomy, and the value of engaging with others who share similar experiences. These findings resonate with the broader literature on patient experiences with cancer and cancer care.

While this study did not explicitly link ACEs to cancer care experiences (apart from Theme 1), the TIC principles of safety, trustworthiness, collaboration, and empowerment remain relevant in shaping emotional and relational dynamics. The principle of safety highlights the loss of control cancer patients often experience due to medical interventions, which can cause distress. Regardless of trauma history, cancer patients can benefit from TIC approaches that promote agency. Many participants express powerlessness due to imposed medical decisions, emphasised the need for more collaborative, transparent decision-making processes that aligns with TIC's focus on patient voice. Peer support is essential for fostering trust and autonomy, enabling patients to choose emotional support to meet their needs. The lack of collaboration between healthcare providers and patients can often exacerbate emotional distress, underscoring the importance of TIC principles in improving patient care. Although not explicitly reference by participants, the application of TIC principles in cancer care may offer significant potential to improve patient experiences, satisfaction, and emotional well-being and should be empirically tested.

7.1 Strengths and Limitations

This research has highlighted the need for a TIC approach within an oncology population, regardless of whether individuals identify with a history of ACEs. The application of a mixed-methods approach is becoming more popular in health research (Wasati et al., 2022). The implementation of a hybrid/mixed methodology provides increased assistance in identifying unanticipated facets of a phenomenon that otherwise might not have been uncovered by a singular research method (Leahey, 2007). A mixed-methods approach enables the identification of prevalence/associations in a population, adding depth and breadth to a richer, deeper exploration (Wasti et al., 2022). Despite the strengths of a mixed-methods approach, it can often take longer to complete due to multiple stages of separate data collection and analysis (Wasti et al., 2022). For example, the interviews for this research could not be commenced until the data for the sample size had been collected and data analysed. The interviews facilitate a broader and patient-driven understanding of participants' experiences of cancer care.

During the qualitative stage (exploring Aim 2), applying a mixed inductive-deductive thematic analysis approach provided a contextual understanding of individual experiences, exploring nuances and similarities/differences between the participants, while the deductive approach followed a structured process. In summary, the use of both inductive and deductive approaches has allowed for a dynamic interplay between exploring the participant data and investigating the application of TIC values in cancer settings, using the SAMHSA framework as a guide. However, the breadth of the qualitative questions during the interview captured patient satisfaction more broadly rather than specifically focusing on those with higher MAES scores, highlighting a limitation of one methodology associated with the other.

The demographics of participants provided a range of views, with the age of participants ranging from 21-83 years old. However, the mean age was 51 years, so the views of those aged 18-50 are potentially underrepresented in this research. The date that individuals were diagnosed with cancer ranged from 1987-2022, with 50.9% of participants receiving a diagnosis between 2018-2023 (*n* = 130). Therefore, experiences of accessing and engaging in cancer services may have differed over time.

Another limitation of the current study is that 37.6% of participants reported having other health conditions that required medical care. Although this data was collected, it was not explored further. This could have provided further contextualisation of the results with regards to how an individual perceives their cancer and satisfaction with cancer services, as it could not be ruled out that more positive or negative experiences of other healthcare services may have shaped their views of satisfaction within cancer services. When considering the epistemological position taken, running further analyses on the additional demographics taken could have provided additional contexts in which the participants' experiences occurred.

It would be valuable to consider whether the modality of the inquiries (interview or questionnaire) or, irrespective of modality, the subject matter itself triggered heightened emotions. Consequently, topics such as ACEs and the experience of a cancer diagnosis may carry greater emotional weight, potentially eliciting a stronger emotional response and more vivid recollections.

Furthermore, this research examined at ACEs as a cumulative score in a broad sense, rather than focusing on individual categories. However, there may be important aspects within these categories that be explored in future research, such as the types of trauma or functions of trauma, which may serve as a useful area for further investigation.

Future research may wish to build on the current findings of this study and explore whether additional demographic factors influence patient satisfaction with cancer services. Although contextual demographic information was collected, additional analyses would be necessary to determine whether other contextual factors influence patients' experiences of cancer services. However, it is important to note that the location of the hospital accessed was not recorded. Further tests examining other contextual factors could be important, such as, exploring occupation, thought this would fall outside the scope of the current research question and could be better suited to a project focused on help-seeking attitudes and behaviours concerning accessing medical intervention once suspected cancer symptoms have been identified.

Finally, future research could specifically explore the link between ACEs and cancer experiences, as identified in Aim 1a, or explore the role of illness perceptions in more detail (Aim 1b). Rather than a cumulative MAES score, it might also be interesting to explore the pathway from trauma through illness perceptions to identify if some subtypes of ACEs are impacted more than others.

7.2 Clinical Implications and Future Directions

This research highlights several implications for clinical practice. The findings align with several TIC values, regardless of the patient’s experiences or satisfaction with cancer care. While only Theme 1 identified a connection between reactivation of ACEs and cancer experiences in adulthood, the quantitative data suggests that cancer diagnoses may trigger childhood memories, leading to recurring behaviours such as ambivalence toward peer support or decreased healthcare engagement. These behaviours may be exacerbated by a lack of psychological safety and feelings of powerlessness throughout the cancer journey, particularly during decision-making or when coping with treatment side effects.

Issues with continuity of care can significantly impact the development of a positive clinician-patient and affect overall satisfaction with care (Jeffers & Baker, 2016). Current pressures within the NHS are eroding positive doctor-patient relationships (Frayar, 2023), making it increasingly challenging for individuals to see the same clinician consistently (Fraser & Clarke, 2023). This trend reflects broader societal shifts, where individuals are often encouraged to engage in transactional interactions rather than cultivating long-term relationships (Oxtoby, 2021). Some participants reported that their experiences with accessing a GP influenced their help-seeking behaviours and perceptions of their cancer symptoms. Although this was not a specific theme in the research, barriers to seeking medical intervention, particularly through the GP, were found to align with the absence of the following TIC values, ‘safety,’ ‘trustworthiness and transparency’, ‘collaboration and mutuality’, ‘empowerment, voice and choice’, and age and cultural issues. These principles could serve as a helpful and practical guide for GPs, ensuring that these principles are reflected in their daily practice, as GPs often serve as the first point of contact for individuals with suspected cancer symptoms. However, this would require further exploration.

The majority of participants in the interviews expressed concerns about continuity of care, particularly related to the geographical locations of treatment. A recent study introduced the concept of "time toxicity", emphasising the significance of considering the amount of time spent coordinating treatment, such as travel and waiting times, versus the number of days spent in a home environment (Gupta, Eisenhauer & Booth, 2022). Research has shown that continuity of care is associated with positive treatment outcomes, better health outcomes, and overall patient satisfaction (Fan et al., 2005). Adopting this approach could mitigate some broader organisational issues mentioned and reduce re-traumatisation by aligning treatment strategies with individual patient goals.

Therefore, future directions for incorporating TIC in healthcare systems could include staff training to ensure that staff are trauma-informed and can recognise signs of trauma. It is also important to develop a more compassionate and holistic understanding of an individual's narrative within the medical model. This starts by reframing language, as what we say (and write) becomes part of an individual's narrative. Language can either stigmatise and blame or be used to develop compassion, empathy, and understanding. Language is used to apply and explore a sense of meaning, and a cancer diagnosis is no different. Regardless of whether an individual has a traumatic history, they may still search for meaning or comply with previous trauma patterns.

When considering the introduction of trauma screenings, organisations should address common barriers to asking about trauma, whether it is historical, recent, or current due to diagnoses. From this research, it was found that the majority of participants had connections to a family history of cancer. Instead of exploring the details, it would be beneficial to ask individuals about their emotions, how they are feeling, and if anything, difficult has come up for them. It is also important to inquire about their expectations or beliefs about the way their diagnosis is communicated, as these may be influenced by others' experiences with cancer, previous diagnoses, and the influence of social media and campaigns. Understanding trauma symptomology and presentation should be a pivotal aspect of cancer care, as individuals facing threat or trauma often experience shattered assumptions about themselves, others, and the world, leaving them in a state of psychological turmoil (Janoff-Bulman, 1992).

Therefore, clinicians should support the individual behind the medically diagnostic label and understand them as a whole person, including factors such as coping strategies and stress management. This understanding can help identify potential risk factors, such as avoidance or not attending appointments, and ensure that the most helpful interventions are offered. Based on the current literature on the application of TIC and the findings from this research, the following questions could be considered within cancer services and healthcare organisations as a starting point for implementing TIC approaches:

1. What aspects of our current practice already align with TIC?
2. What elements of our practice may inadvertently re-traumatise people using (and working in) our services? Which of these could be mitigated by changing our approach, whether through changes in clinical practice, processes, environmental factors and/or policies)?
3. What barriers exist internally and externally when attempting to create a TIC approach (These may include attitudes or defences against

TIC/trauma/psychological approaches, resistance to change or challenges)

7.3 Role of Clinical Psychology

The findings from this research are important to consider the application of TIC approaches within an oncology population. Clinical Psychologists play a crucial role in the application of TIC approaches within populations by addressing both the emotional and psychological needs of patients navigating cancer treatment. Consultation with Clinical Psychologists would be pivotal to developing service pathways to incorporate TIC approaches, considering the importance of the themes identified from this research, including adjustment to diagnosis, practical and emotional support, how to manage potential re-traumatisation and trauma responses.

Oncology patients may experience heightened anxiety, depression, or powerlessness. Clinical Psychologists can contribute to the psychological assessment and support of patients by assessing the psychological impact of both cancer and past trauma on patients. For example, helping cancer patients navigate feelings of stigma and shame, especially when it comes to visible side effects or perceived judgment within the healthcare system. They can support patients in reclaiming their sense of agency, fostering empowerment in cancer care, and addressing past trauma-related disempowerment. This approach can help ensure that a safe and empowering environment is created for both staff and patients. This can be done via the understanding and integration of psychological processes and evidence-based therapeutic modalities such as Compassion Focused Therapy (CFT). CFT could be useful to help support individuals adjust to their diagnosis, while learning to understand and balance the threat system when faced with a stressor, such as the re-activation of ACEs and adjusting to cancer diagnosis.

Clinical psychologists can educate both patients and healthcare clinicians about the impact of trauma on health outcomes. Clinical Psychologists are well-placed in the field and possess a specialist skillset from both a clinician/therapist stance and a researcher stance. This skill enables Clinical Psychologists to provide evidence-based training packages to support healthcare professionals with the element of TIC. For example, the development and facilitation of a training package to ensure that healthcare professionals can understand the importance of and learn skills to develop relational care and low-level psychologically informed interventions on how to identify and respond to trauma responses, e.g. poor engagement in treatment/appointments, freeze responses (including dissociative-type presentations) during appointments. Clinical Psychologists can also be developed in developing policies that prioritise psychological safety and ensuring that both patients and clinicians have access to appropriate support.

Additionally, Clinical Psychologists can utilise their research skills to evaluate TIC pathways. Clinical Psychologists can support healthcare professionals to understand and support their patients through a psychologically informed trauma lens, taking into consideration how an individual history of trauma and/or family history of cancer could influence their perceptions of their cancer diagnosis and how they perceive their satisfaction levels of care. This might support healthcare professionals to understand the psychological implications of the adjustment to cancer diagnosis and the treatment pathway and consider language use and how to respond to trauma. It is also important to consider how to develop a psychologically safe environment to reduce the potential for re-traumatisation, which might foster positive patient satisfaction and high-quality relational care. However, further research to determine what TIC would look like in a standardised manner by operationalising key components of TIC for a robust pathway would be vital for this field.

14. Critical Reflection

I would like to offer readers an opportunity to understand how I was drawn to this project and provide evidence of my reflective journey throughout this research process.

The initial concept for this project originated from my own personal and clinical experiences of psychological distress, childhood trauma, and the world of mental health systems. From as far back as I can remember, cancer has always been a part of my life. I have experienced multiple family bereavements at the hands of cancer. More recently, two immediate family members and a friend have successfully battled cancer. These experiences have allowed me to empathise with the frustrations and satisfactions of accessing cancer services.

My clinical experience of supporting individuals with trauma backgrounds has been both challenging and rewarding. I started as a healthcare assistant and then held multiple assistant psychologist roles in various clinical settings and presentations. Finally, I became a trainee clinical psychologist. In my clinical experiences of supporting people with trauma, what has always frustrated me is the unintentional re-traumatisation of services that are supposed to provide care and support. This frustration is particularly evident in certain settings such as forensic or inpatient mental health wards. Surprisingly, these frustrations even extended to a specialist trauma centre in the community.

After presenting initial ideas at the research panel, I noticed that my ideas were driven by a trauma-focused lens. I have always been interested in bridging the gap between mental health and physical health approaches within services. I believe that TIC approaches are an important piece of this puzzle that needs further development and understanding. In my clinical surroundings, I heard discussions about the development of trauma-informed services in inpatient wards, social care, and perinatal services. I noticed that certain NHS Trusts strongly advocate for the development and implementation of a TIC approach. Over the years, I attended various training sessions on responding to and supporting people who have experienced trauma. It was during these sessions that I quickly learned about the already established TIC approach within youth justice services.

I searched the literature and noticed a gap in understanding how to involve a patient's voice in research. I asked my primary supervisor, "How involved can SUCAP get?" It was important to me to have an EBE collaborate on the project. Initially, I was unsure of the specific direction to take. However, through research discussions and further literature searching, I observed that my two areas of passion (trauma and cancer care) were divided and appeared to be quite separate entities. I knew I wanted to explore TIC in cancer services, but the literature was so limited that I asked myself, "How can I truly know if this is an area of interest and need from the literature if it is so sparse?" I discussed this with my research supervisor, and we agreed that just because a topic lacks extensive literature does not mean it is not worthy of being researched.

Unfortunately, at the start of my research journey, a close family member was diagnosed with cancer. My world was turned upside down. I was geographically far from my parent's home, and my circumstances raised questions about my ability to carry out this research. Some questioned whether it would be wise to continue in this topic area. However, I did not hesitate. Being questioned ignited a determination within me to pursue this topic. Shortly after, in December 2021, a SUCAP[22] member observed my research presentation and approached me to offer support in constructing the concept and design of this research. This was an opportunity that I had only dreamed of and one that most researchers in my cohort did not have. I felt incredibly fortunate. From October 2022 to May 2023, I continued to navigate additional life circumstances that came my way, always with a fear in the background that these events would hinder the development of the project.

Since the beginning of this project, I wanted to recruit participants through the NHS. However, after receiving feedback from research panels and learning about the challenges of the ethical approval process, I quickly changed my approach. Initially, I was confused and naive about the ethics process. I could not understand why there were so many issues with it. I worried that my university's ethics process, might not accept the nature of my research. I also wondered if I would get more responses by recruiting through the NHS. My naivety about the complexity of the ethics process became clear when my initial ethics review took longer than the expected 21 working days and required follow-ups. This made me feel anxious and made me question the feasibility of the research. Despite having a detailed plan and research timeline, I encountered many obstacles along the way that I had not anticipated. I struggled with self-doubt and anxiety about my research skills and experience, particularly in this area.

Data collection was an emotional rollercoaster. I had concerns about recruiting a large sample size and whether people would be interested in participating, especially since I wasn't familiar with navigating social media platforms like Twitter. However, my anxieties eased when I received an unexpectedly high number of responses. I felt excited and motivated. This excitement was short-lived. Upon reviewing the collected data, I discovered many duplicate and incomplete

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[22] Service User and Carer Advisor Panel

responses. After removing incomplete responses and duplicates, I was left with a much smaller sample size than expected, which was discouraging. However, with support from my supervisor and colleagues, I learned that this was a common issue in online recruitment. However, the continued interest from others in the research rekindled my motivation. Despite the recruitment slowdown, I received an email from someone who had seen the study on Twitter and expressed interest in the research findings, having supported a family member publishing a paper before they died from cancer. This encouraged me to refocus on the importance of the research.

Looking back at my research experience, I realise how important it was to carefully consider various recruitment methods to reach a diverse and representative sample from what could be considered a ‘hard to reach’ population. It was initially challenging to recruit participants from different backgrounds, but building relationships with service staff and utilising platforms like Prolific helped me achieve my target sample size. Initially, I had concerns about paying participants for their time, but it was ultimately the right approach to ensure that the sample represented a diverse range of experiences. Closing the survey, I was pleased to see the level of interest in the research, but the lack of ethnic diversity in the sample prompted me to adapt my sampling strategy, with no effect, which was a disappointing component of this learning process.

After closing the survey, I was overwhelmed by the interest in the research, as 19 people responded to the invite. I realised I needed to apply maximum variation sampling to ensure diversity in the sample, including representation of ethnicity and a range of experiences and scores related to cancer satisfaction and childhood adversity. However, the sample lacked ethnic diversity and consisted mostly of white British female participants, so I had to change my sampling strategy to opportunistic.

Due to the limited number of individuals willing to be interviewed, I struggled to find diverse participants. It took a lot of time to secure interview slots, and some individuals withdrew due to personal reasons. I felt extremely anxious leading up to my first interview, worried about asking the right questions and managing potential distress from the participants. However, I sought feedback from my supervisors and colleagues, which helped ease my anxiety. Securing diverse participants for interviews proved challenging, and I encountered some unexpected hurdles such as scheduling difficulties and participant withdrawals. Seeking feedback from supervisors and colleagues helped alleviate my anxiety and improve the overall interview process.

During the interviews, I was acutely aware of the sensitive nature of the research and made sure to manage the sessions with great care and empathy. I was mindful of the sensitive nature of the research, carefully managing the interview sessions to ensure the participants' comfort and considering their preferences. I also used my judgment to assess the participants' distress and ability to continue. I allowed the participants to freely share their experiences, and I noticed improvements in my skills and confidence as the interviews progressed. Some moments triggered emotional responses in me, highlighting the real impact of the research on people's lives. Positive feedback from participants and the support of my peers were invaluable in building my confidence throughout the process.

The mixed-methods research design posed its own set of challenges, particularly in managing the workload and analysing the data effectively. I had to analyse the survey data before developing the interview schedule due to the mixed-methods research design. I discussed my personal beliefs with research supervision to focus on specific aspects of the data and watched tutorial videos and read statistical analysis books to overcome my anxiety. I managed the workload by breaking down my study days and felt pressure to analyse the quantitative data quickly due to falling behind schedule. I organised multiple copies of spreadsheets to prevent accidental data loss. I followed a linear approach, coding each transcript systematically. I checked the accuracy of the transcription immediately after each interview and revised it as needed. Looking back, I acknowledge that I should have started coding the data sooner after each interview. The sheer volume of transcriptions was overwhelming, and I felt lost and unsure of where to start. I sought guidance from research supervision to address my concerns and discussed my disappointment in the lack of representation of the sample size during the survey. I also reflected on my self-doubt and sought reassurance from colleagues and research supervisors that my feelings were natural, given the demands of the project.

As I look back on my research journey, I vividly recall the advice I received during research supervision about the significant challenge of setting the bar for finding something "completely new" in this field. Even though I aimed to avoid focusing solely on positive findings or what people wanted to hear, I found myself still yearning to discover something new and valuable. These thoughts were openly discussed during supervision meetings. Additionally, I tried to consider alternative perspectives, such as how an individual's occupation could influence their perceptions of their diagnosis and experiences. I also pondered whether my data would differ based on participants' childhood adversity scores or satisfaction levels. Initially, I questioned whether the fear of negative consequences would shape participants' perspectives on their cancer care. However, as I progressed through the interviews, individuals shared specific examples of their care, regardless of their perception. In an attempt to gain a different viewpoint, I reached out to the EBE to discuss the themes and gather feedback. Unfortunately, they were unable to provide consultancy at that time.

While writing up my findings, I realised that I felt an obligation to represent all interview participants equally. However, I found myself drawn to certain transcripts and pulled out more quotes from them. This initially left me disheartened, and I delved into uncovering the potential underlying reasons for this. I discovered that I was more familiar with certain transcripts and felt a particular connection with participants who had similar demographics and values as I did. As a result, I subconsciously prioritised transcribing and coding their transcripts before others. On the other hand, I found transcribing and coding interviews where participants talked about unrelated topics or struggled to provide specific examples and describe emotions to be more challenging. To ensure balance, I placed quotes from every participant into a table for each theme, aiming to attempt equal representation. However, it's important to note that there might be a bias, as in most research, participants who provide more detailed examples are quoted more often based on the saliency of their responses. Looking back, these reflections have provided invaluable insights into my research process and the nuances involved in ensuring balanced representation in qualitative analysis.

Overall, this entire process provided me with valuable insights and a deeper understanding of the complexities involved in conducting meaningful and impactful research. The support and guidance from my supervisors and colleagues were instrumental in overcoming doubts and addressing concerns throughout the entire research journey. It was a learning experience that taught me the value of seeking different perspectives and openly discussing my challenges during research supervision.

Although on multiple occasions I thought I had ‘bitten off more than I could chew’ with this project, I have managed to bring this project to a successful end after three years. This project provided unique insights into the need for TIC within oncology settings and offered a valuable contribution to the literature. Throughout this research, I faced multiple challenges, including personal life events, battling the infamous ‘imposter syndrome’ and the practical aspects of conducting research more broadly. Implementing a mixed-method approach, this project has demonstrated how two methods can complement each other. I hope that this research has shed light on essential aspects of TIC that play a role in creating safe and supportive environments, both physically and psychologically. As a result, I plan to carry on discussing the significance of TIC in various settings with current and future colleagues, contributing to future research and teaching efforts as necessary.

I would encourage anyone with an interest to continue the exploration of TIC within cancer services. Continued research in clinical settings will continue to raise awareness of the connection between mental health and physical health, these two topic areas are not separate entities, yet there still seems to be a divide between these areas in clinical settings. In my opinion, the benefits of further research in this area outweigh the challenges faced during this research. Additionally, this research has highlighted the invaluable contributions of Expert by Experience (EBE) and the importance of consistently incorporating EBE voices in research and services to enhance patients' experiences.

Finally, through the process of reflexivity, I learned to manage my well-being while juggling this research with academic and clinical demands. I have continued to develop an awareness of my position, assumptions, and biases, which would at times have been almost impossible to identify without reflective skills and learning how to manage biases. I hope my future clinical work will continue to be holistic, considering individuals as a whole, rather than focusing solely on their presenting difficulties, and taking into consideration wider societal systems that can influence someone's experiences. Completing this research project and a service evaluation has given me a 'taste' for continuing to build my confidence and skills, intending to pursue future research projects post-qualification.

To end this research journey, the therapist part of me is left thinking,

'*What will my participants think…'*

15. References

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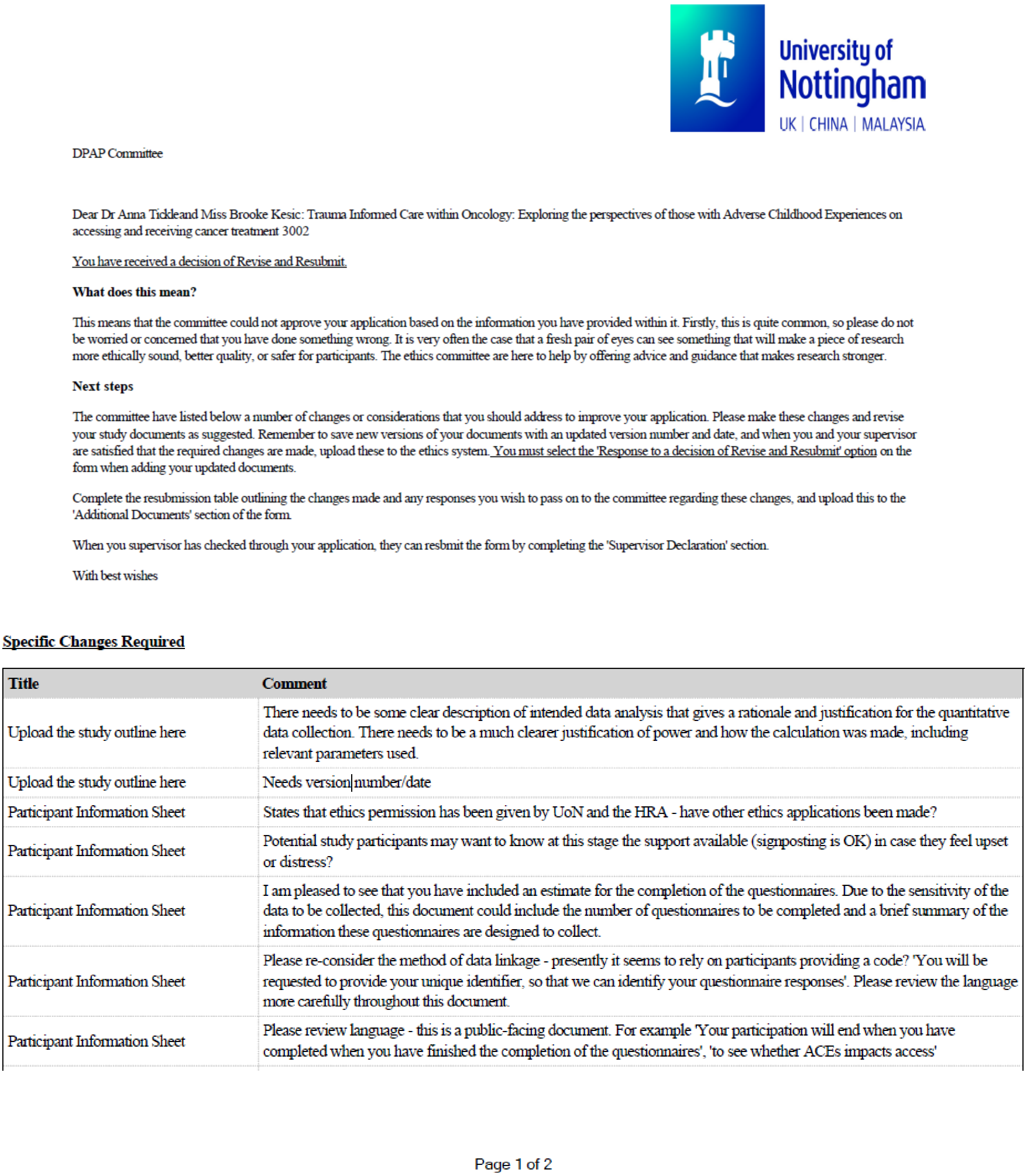
16. Appendices

Appendix A: Submission Guidelines

This journal paper has been written for publication in the British Journal of Health Psychology. Author guidelines were obtained from:

British Journal of Health Psychology: Author Guidelines (wiley.com)

Appendix B: University of Nottingham Revise & Submit Ethics



University of Nottingham
UK | CHINA | MALAYSIA

DPAP Committee

Dear Dr Anna Tickleand Miss Brooke Kesic: Trauma Informed Care within Oncology: Exploring the perspectives of those with Adverse Childhood Experiences on accessing and receiving cancer treatment 3002

You have received a decision of Revise and Resubmit.

What does this mean?

This means that the committee could not approve your application based on the information you have provided within it. Firstly, this is quite common, so please do not be worried or concerned that you have done something wrong. It is very often the case that a fresh pair of eyes can see something that will make a piece of research more ethically sound, better quality, or safer for participants. The ethics committee are here to help by offering advice and guidance that makes research stronger.

Next steps

The committee have listed below a number of changes or considerations that you should address to improve your application. Please make these changes and revise your study documents as suggested. Remember to save new versions of your documents with an updated version number and date, and when you and your supervisor are satisfied that the required changes are made, upload these to the ethics system. You must select the 'Response to a decision of Revise and Resubmit' option on the form when adding your updated documents.

Complete the resubmission table outlining the changes made and any responses you wish to pass on to the committee regarding these changes, and upload this to the 'Additional Documents' section of the form.

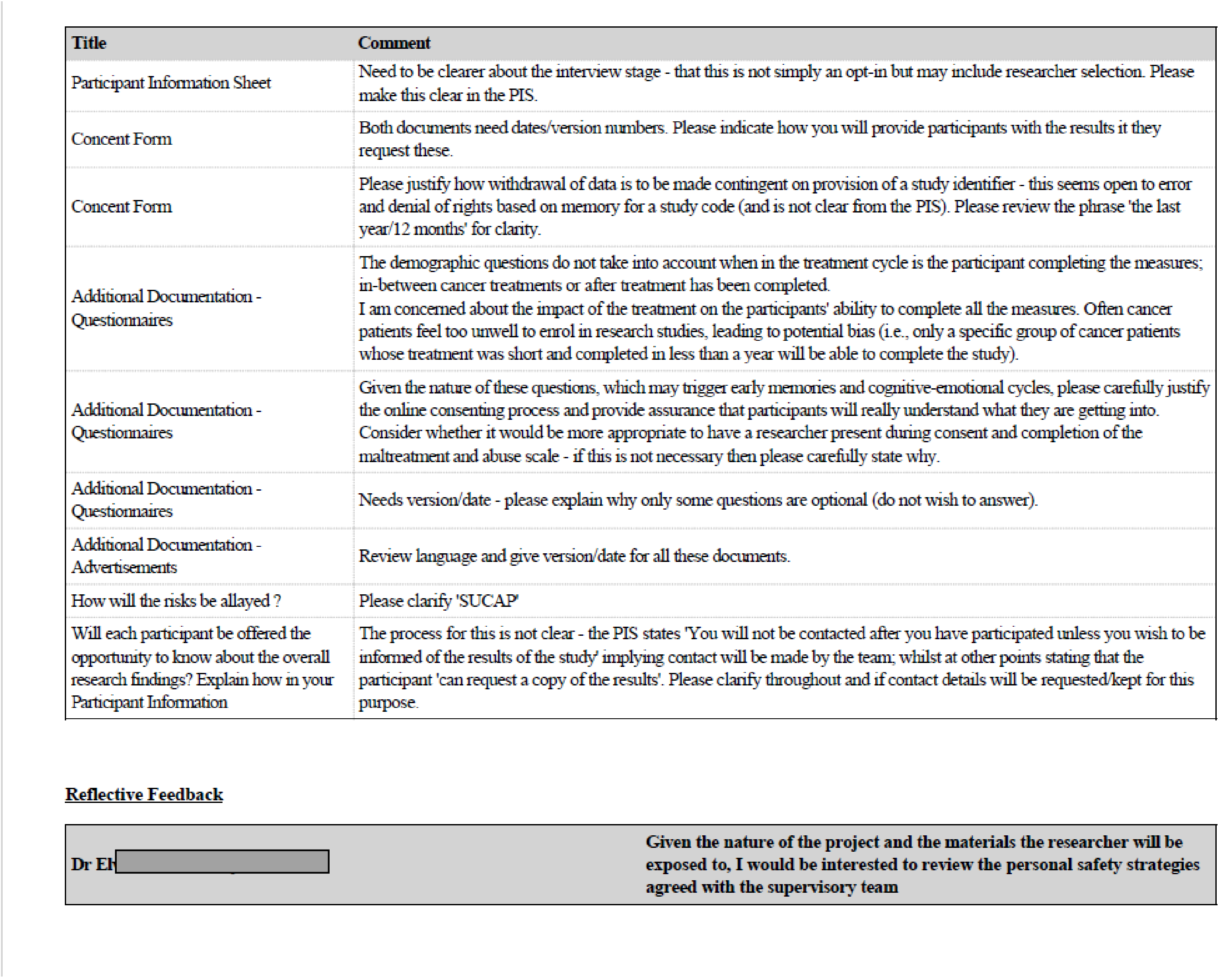
When you supervisor has checked through your application, they can resbmit the form by completing the 'Supervisor Declaration' section.

With best wishes

Specific Changes Required

Title	Comment
Upload the study outline here	There needs to be some clear description of intended data analysis that gives a rationale and justification for the quantitative data collection. There needs to be a much clearer justification of power and how the calculation was made, including relevant parameters used.
Upload the study outline here	Needs version number/date
Participant Information Sheet	States that ethics permission has been given by UoN and the HRA - have other ethics applications been made?
Participant Information Sheet	Potential study participants may want to know at this stage the support available (signposting is OK) in case they feel upset or distress?
Participant Information Sheet	I am pleased to see that you have included an estimate for the completion of the questionnaires. Due to the sensitivity of the data to be collected, this document could include the number of questionnaires to be completed and a brief summary of the information these questionnaires are designed to collect.
Participant Information Sheet	Please re-consider the method of data linkage - presently it seems to rely on participants providing a code? 'You will be requested to provide your unique identifier, so that we can identify your questionnaire responses'. Please review the language more carefully throughout this document.
Participant Information Sheet	Please review language - this is a public-facing document. For example 'Your participation will end when you have completed when you have finished the completion of the questionnaires', 'to see whether ACEs impacts access'

Page 1 of 2



Title	Comment
Participant Information Sheet	Need to be clearer about the interview stage - that this is not simply an opt-in but may include researcher selection. Please make this clear in the PIS.
Concent Form	Both documents need dates/version numbers. Please indicate how you will provide participants with the results it they request these.
Concent Form	Please justify how withdrawal of data is to be made contingent on provision of a study identifier - this seems open to error and denial of rights based on memory for a study code (and is not clear from the PIS). Please review the phrase 'the last year/12 months' for clarity.
Additional Documentation - Questionnaires	The demographic questions do not take into account when in the treatment cycle is the participant completing the measures; in-between cancer treatments or after treatment has been completed. I am concerned about the impact of the treatment on the participants' ability to complete all the measures. Often cancer patients feel too unwell to enrol in research studies, leading to potential bias (i.e., only a specific group of cancer patients whose treatment was short and completed in less than a year will be able to complete the study).
Additional Documentation - Questionnaires	Given the nature of these questions, which may trigger early memories and cognitive-emotional cycles, please carefully justify the online consenting process and provide assurance that participants will really understand what they are getting into. Consider whether it would be more appropriate to have a researcher present during consent and completion of the maltreatment and abuse scale - if this is not necessary then please carefully state why.
Additional Documentation - Questionnaires	Needs version/date - please explain why only some questions are optional (do not wish to answer).
Additional Documentation - Advertisements	Review language and give version/date for all these documents.
How will the risks be allayed ?	Please clarify 'SUCAP'
Will each participant be offered the opportunity to know about the overall research findings? Explain how in your Participant Information	The process for this is not clear - the PIS states 'You will not be contacted after you have participated unless you wish to be informed of the results of the study' implying contact will be made by the team; whilst at other points stating that the participant 'can request a copy of the results'. Please clarify throughout and if contact details will be requested/kept for this purpose.

Reflective Feedback

Dr E[redacted]	**Given the nature of the project and the materials the researcher will be exposed to, I would be interested to review the personal safety strategies agreed with the supervisory team**

Appendix C: University of Nottingham Ethics Amendments Table

Resubmission Table

STUDENT RESEARCH PROJECT ETHICS REVIEW

Division of Psychiatry & Applied Psychology, School of Medicine, University of Nottingham

Student name: Brooke Kesic
Supervisor name: Dr Anna Tickle
Project reference number: 3002
Project title: Trauma Informed Care within Oncology: Exploring the perspectives of those with Adverse Childhood Experiences on accessing and receiving cancer treatment.

Please ensure that the changes referred to below are clearly highlighted in yellow in updated versions of any documents. *Resubmitted documents with track changes are not acceptable and will be returned without review*.

Section/Document	Correction required	Previous text	New text
Upload the study outline here.	There needs to be some clear description of intended data		Updated in study outline: 'We aim to recruit a minimum sample-size of 252, to obtain stable estimates of sample correlation coefficients (converging

	analysis that gives a rationale and justification for the quantitative data collection. There needs to be a much clearer justification of power and how the calculation was made, including relevant parameters used.		on population values; Schönbrodt & Perugini, 2013). Our planned quantitative analyses (addressing research question 1) are correlational (e.g., testing the association between ACEs and treatment-seeking latencies) and ensuring the stability of estimated coefficients enables confidence in any conclusions that we draw about the likely presence and directionality of correlations in the broader population. Specifically, we are powering our study to achieve a corridor of stability of ±.10 for any *r* coefficients ≥ .10[1] (i.e., any associations of greater than negligible magnitude): enabling (80%) confidence that our estimated coefficients will be within ±.10 of the true population value (i.e., only fluctuations of small magnitude would be tolerated). For example, if we observe a correlation of 0.25 between ACEs and treatment-seeking latencies in our sample, we can be confident that the 'true' correlation is non-negligible and likely of small-to-moderate magnitude (effect-size *r* of between 0.15 and 0.35) in the broader population.'
Upload the study outline here	Needs version number/date	N/A	Document Version Number/Date added.

Participant Information Sheet	States that ethics permission has been given by UoN and the HRA - have other ethics applications been made?	This study has been reviewed and given favourable opinion by University of Nottingham Research Ethics Committee and the Health Research Authority.	Page 4 of the participant information sheet: 'This study has been reviewed and given favourable opinion by University of Nottingham Research Ethics Committee'. This change has been made and highlighted on both participant information sheets.
Participant Information Sheet	Potential study participants may want to know at this stage the support available (signposting is OK) in case they feel upset or distress?		Added signposting of 'NHS Mental Health Helpline for Urgent Help'. Please see page 2 of the participant information sheet, which now states the following: 'If at this stage you require emotional support, you can contact: Find an NHS talking therapies services - NHS (www.nhs.uk) If you require urgent mental health support, you can access it here: Get urgent help for mental health - NHS (www.nhs.uk)'

			Changes made to both PIS (Stage 1 & Stage 2) of the study.
Participant Information Sheet	I am pleased to see that you have included an estimate for the completion of the questionnaires. Due to the sensitivity of the data to be collected, this document could include the number of questionnaires to be completed and a brief summary of the information these questionnaires are designed to collect.		PIS (Stage 1), page 2: Changed to: ‘Approximately 12 people will be interviewed about their adverse childhood experiences and if this impacts experiences of cancer services today.’ PIS (Stage 2), page 2: Changed to: ‘ The interview will be about your adverse childhood experiences and if this impacts your experiences of cancer services today.’

Participant Information Sheet	Please re-consider the method of data linkage - presently it seems to rely on participants providing a code. 'You will be requested to provide your unique identifier, so that we can identify your questionnaire responses'. Please review the language more carefully throughout this document.		On the survey software (Qualtrics), the Participant ID formula has been changed from being assigned a random number to being asked to create their own unique ID number based on the following formula: 'Please enter your study ID number: This should be your house number (or first two letters of your house name), first initial of your first name & last letter of your surname. (e.g. if you lived at number 12 and your name was Jo Bloggs, your code would be 12JS OR if your name was Jo Bloggs and you lived at Flower View, your code would be FLJS)' If participants cannot remember their ID number, they can be prompted by the researcher reminding the participant of the formula (see above). This has also been changed on the PIS (pages 1 & 2) which now states: 'Before completing the online questionnaire, you created your own unique identifier. You will be requested to provide this prior to the interview…'

			‘… If you forget your identifier, the researcher can remind you of the code e.g. your house number, first initial of your first name and last letter of your surname’
Participant Information Sheet	Please review language - this is a public-facing document. For example, 'Your participation will end when you have completed when you have finished the completion of the questionnaires', 'to see whether ACEs impacts access'	‘…see if ACEs impacts experiences during adulthood of accessing cancer services and experiences of cancer services.’	Language reviewed. Please see both documents for changes which are highlighted in yellow. E.g.: ‘to see if ACEs impact adults accessing cancer services and experiences of cancer services today.’ – Page 1 PIS. ‘If you do not wish to be contacted to take part in a follow-up interview, your participation will end when you have finished the questionnaire, and you will not be contacted further. However, if you do wish to be contacted to take part in a follow-up interview, your participation will end when you have completed the interview... ’ – Page 3 of the PIS (Stage 1). ‘…see if adverse childhood experiences may impact on the length of time…’

		'Your participation will end when you have completed when you have finished the completion of the questionnaires', 'to see whether ACEs impacts access'	Page 2 of PIS (Stage 1): Added example question for adverse childhood experiences taken from the questionnaire to illustrate : 'Questions will also be asked about adverse childhood experiences for example, 'Sometimes parents, stepparents or other adults living in the house do hurtful things. If this happened during your childhood (first 18 years of your life), please check 'Yes'. If this did not happen in your childhood, please check 'No.' Question 1. Swore at you, called you names, said insulting things like your "fat", "ugly", "stupid", etc. more than a few times a year'
Participant Information Sheet	Need to be clearer about the interview	'…opt-in to be contacted to take	Page 2 of PIS (Stage 1) changed to : '…If you do not wish to be contacted to take part in a follow-up interview, your

	stage - that this is not simply an opt-in but may include researcher selection. Please make this clear in the PIS.	part in an interview…'	participation will end when you have finished the questionnaire, and you will not be contacted further. However, if you wish to be contacted to take part in a follow-up interview you will be asked to leave your preferred method of contact at the end of the survey. The researchers will select approximately 12 people from those who opt-in to be interviewed about their adverse childhood experiences and if this impacts experiences of cancer services today. Your contact details will be kept confidential and only be shared with the research team. Providing your contact details does not mean that you are in anyway obliged to take part in the follow-up interview and, you can still withdraw from the research at any time. If you are contacted by a researcher, they will provide you with more details on what would be involved and you will be given chance to ask questions If you are contacted to complete an interview, you participation will end when you have completed the interview…'
Consent Form	Both documents need dates/version numbers. Please indicate how you		Dates/Versions added to both documents.

	will provide participants with the results it they request these.		
Consent Form	Please justify how withdrawal of data is to be made contingent on provision of a study identifier - this seems open to error, and denial of rights based on memory for a study code (and is not clear from the PIS). Please review the phrase 'the last year/12 months' for clarity.	Do you wish to be contacted with a summary of the research findings? Do you understand that if you wish to withdraw and have your data destroyed, you have 1 week to do this by providing the research your	The statement has been removed from both consent forms. This is because participants can request a copy of the results. This is detailed in the PIS on page 3: ‘ If you wish to be informed of the results of the study, you can contact one of the researchers (see contact details below).’ Question changed to: ‘Do you understand that if you wish to withdraw and have your data destroyed, you have 1 week to do this by contacting the researcher. After this 1 week, your data may have already been used in analyses and can no longer be destroyed.’

		unique identifier? After this 1 week, your data may have already been used in analyses and can no longer be destroyed. I confirm that I have been diagnosed with cancer in the last year/12 months	Page 2 of Consent Form (Stage 1) changed to: I confirm that I have been diagnosed with cancer in the last 12 months.
Additional Documentation – Questionnaires	The demographic questions do not consider when in the treatment cycle is the participant completing the measures; in-between cancer		We had not included a question about where in the treatment cycle participants are because it was not relevant to the research question. Given the broad range of types and severity of cancer as well as huge variety in treatments asking where in the treatment cycle a participant is may not reflect their current sense of wellness. However, an additional item has been added in demographics to ask about treatment stage

	treatments or after treatment has been completed. I am concerned about the impact of the treatment on the participants' ability to complete all the measures. Often cancer patients feel too unwell to enrol in research studies, leading to potential bias (i.e., only a specific group of cancer patients whose treatment was short and completed in less than a year will be		to help characterise sample, structured as follows, with skip logic: “Are you currently undergoing treatment: yes/no Yes: What treatment: chemotherapy, radiotherapy, hormone, immune, surgery (within the last month)’ We will acknowledge in the limitations that there may have been some cancer patients who felt too unwell to complete the research and this may lead to potential bias. For ease, measures/questionnaire document has now been updated so all questions are in one document (rather than separate as uploaded previously). This is so it can be reviewed as it will be seen on the online software. New document is titled, ‘questionnaire including demographics_kesic_17.03.2023_version2’.

	able to complete the study).		
Additional Documentation – Questionnaires	Given the nature of these questions, which may trigger early memories and cognitive-emotional cycles, please carefully justify the online consenting process and provide assurance that participants will really understand what they are getting into. Consider whether it would be more appropriate to have a researcher		According to the UK Research and Innovation (UKRI) informed consent entails the following: - Giving sufficient and appropriate information about the research, to allow participants to make a meaningful choice whether or not to take part. - Ensuring there is no coercion so prospective participants can make an informed and free decision of their possible information. To address these points, the PIS is extremely comprehensive. Due to the information being provided online, participants are allowed as much time as they wish to consider their choices. Participants are also encouraged in the PIS to speak to others about the study and/or contact the researcher if they have any questions/concerns. Research cannot commence until the participant has indicated their consent and this has been recorded. Consent is not just the formal process of a form but also takes into consideration the fact that an individual can

	present during consent and completion of the maltreatment and abuse scale - if this is not necessary then please carefully state why.		withdraw at any point. This is emphasised in the PIS, consent and debrief forms. Given that the survey is online, participants can choose to exit the survey at any point (and return to it later if they wish to do so). Some research has suggested that there is not a substantial difference obtaining informed consent online compared to obtaining it via a paper/written format (Varnhagen et al., 2010). Being online, this study is anonymous, and participants can state that they do 'prefer not to say' to any question. It is made clear in the PIS that the research asks potentially triggering questions. There is a clear mechanism throughout the PIS that participants can contact either the research team or charity organisations and are encouraged to. These details are also reiterated in the debrief form. Advice has been sought during university research support panels regarding researcher presence during online completion of questionnaires. Literature suggests that participants have found participation in trauma research to be beneficial (Griffin et al., 2003, Jaffe at al., 2015,). It is less distressing than in person for some people to complete

			questionnaires of a sensitive nature compared to someone being present for completion, which could be more shaming. Researcher being present in person could also influence report-bias due to a potential fear of shame. With regards to the MAES/MACE: This scale has been used in self-report format for retrospective assessment of adverse childhood events via online platforms in previous research, e.g. https://doi.org/10.1371/journal.pone.0117423 <u>References:</u> • Griffin, M.G., Resick, P.A., Waldrop, A.E. & Mechanic, M.B (2003) Participation in Trauma Research: Is There Evidence of Harm?. *Journal of Traumatic Stress. 16*, 221–227.https://doi.org/10.1023/A:1023735821900 • Jaffe, A. E., DiLillo, D., Hoffman, L., Haikalis, M., & Dykstra, R. E. (2015). Does it hurt to ask? A meta-analysis of participant reactions to trauma research. *Clinical*

			Psychology Review, 40, 40-56. https://doi.org/10.1016/j.cpr.2015.05.004 - Teicher MH, Parigger A (2015). The 'Maltreatment and Abuse Chronology of Exposure' (MACE) Scale for the Retrospective Assessment of Abuse and Neglect During Development. *PLoS ONE 10*(2): e0117423. https://doi.org/10.1371/journal.pone.0117423 - Varnhagen, C. K., Gushta, M., Daniels, J., Peters, T. C., Parmar, N., Law, D., Hirsch, R., Sadler Takach, B., & Johnson, T. (2005). How Informed Is Online Informed Consent? *Ethics & Behavior, 15*(1), 37-48. https://doi.org/10.1207/s15327019eb1501_3
Additional Documentation - Questionnaires	Needs version/date - please explain why only some questions are optional (do not wish to answer).		Document version/date added. For ease, measures/questionnaire document has now been updated so all questions are in one document (rather than separate as uploaded previously). This is so it can be reviewed as it will be seen on the online software. New

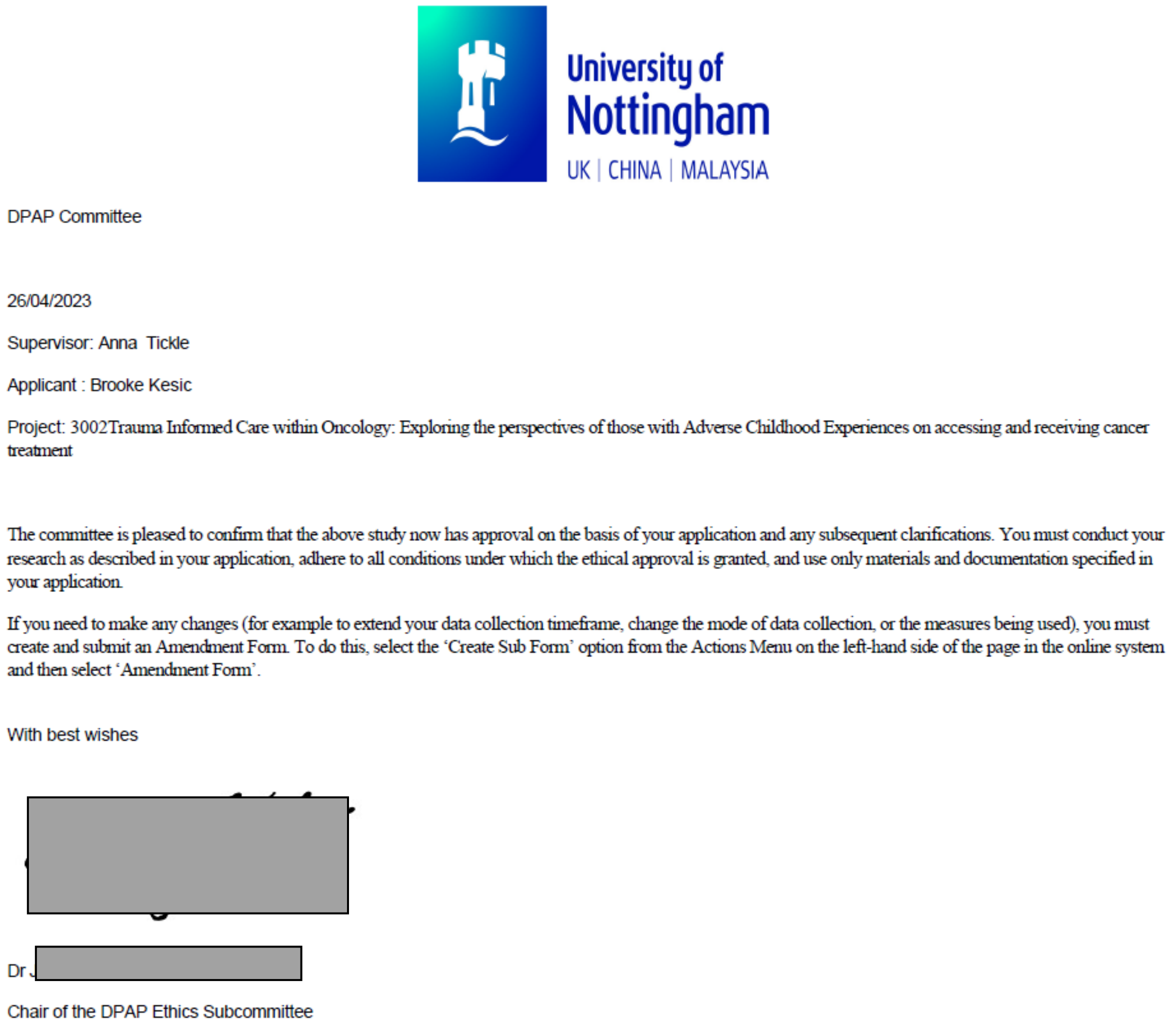
			document is titled, ‘questionnaire including demographics_kesic_17.03.2023_version2’ All questions have a ‘prefer not say option’ added to each question on the online survey format. Reason for this is recorded in the PIS and within ethics application - some participants may find the question too personal/distressing to answer. Added employment status options.
Additional Documentation – Advertisements	Review language and give version/date for all these documents.	‘HAVE YOU EXPERIENCED TRAUMA AND CANCER?’	Version/Date added. Amendments to language made e.g.: ‘HAVE YOU EXPERIENCED CHILDHOOD TRAUMA & A RECENT CANCER DIAGNOSIS’

		'…exploring if Adverse Childhood Experiences (ACEs) impacts your experiences in cancer services today.'	'…exploring if adverse childhood experiences may impact the length of time it takes to seek help from cancer services and your experiences in cancer services today.'
How will the risks be allayed?	Please clarify 'SUCAP'	…be reviewed by SUCAP…	…be reviewed by a member of the Trent Doctorate of Clinical Psychology Service User and Carer Panel (SUCAP)…
Will each participant be offered the opportunity to know about the overall research findings? Explain how in your Participant Information	The process for this is not clear - the PIS states 'You will not be contacted after you have participated unless you wish to be informed of the results of the study' implying contact will be made by the		All documents updated e.g. PIS, Consent forms to state that the participants can contact the researcher if they wish to be informed of the study results. Changes made have been highlighted and specifically referenced in other parts of this table.

	team; whilst at other points stating that the participant 'can request a copy of the results'. Please clarify throughout and if contact details will be requested/kept for this purpose.		
Reflective Feedback	Given the nature of the project and the materials the researcher will be exposed to, I would be interested to review the personal safety strategies agreed with the supervisory team	N/A	The Lead Researcher is a Trainee Clinical Psychologist, and the research team is made up of Clinical Psychologists who are used to managing distress. The Lead Researcher will utilise supervision regularly throughout the process. With regards to the expert by experience who is supporting the project, they are also provided regular support, particularly during data collection. We have also completed a risk management plan which has discussed strategies that can be implemented to manage any triggering information.

Additional Documentation – Debrief Sheets			Added additional support services which are now also listed in the PIS.

Appendix D: University of Nottingham Ethical Approval



DPAP Committee

26/04/2023

Supervisor: Anna Tickle

Applicant : Brooke Kesic

Project: 3002Trauma Informed Care within Oncology: Exploring the perspectives of those with Adverse Childhood Experiences on accessing and receiving cancer treatment

The committee is pleased to confirm that the above study now has approval on the basis of your application and any subsequent clarifications. You must conduct your research as described in your application, adhere to all conditions under which the ethical approval is granted, and use only materials and documentation specified in your application.

If you need to make any changes (for example to extend your data collection timeframe, change the mode of data collection, or the measures being used), you must create and submit an Amendment Form. To do this, select the 'Create Sub Form' option from the Actions Menu on the left-hand side of the page in the online system and then select 'Amendment Form'.

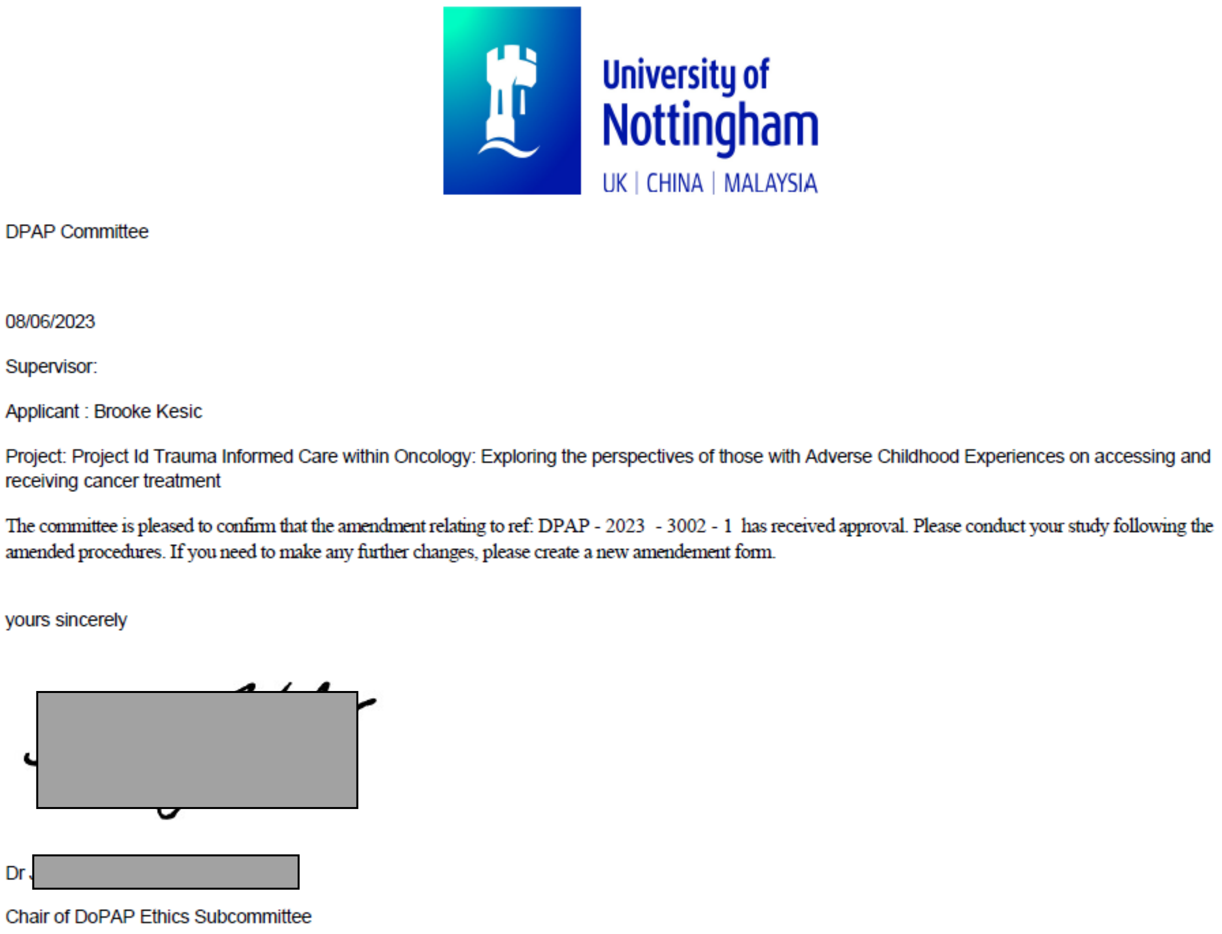
With best wishes

[redacted]

Dr [redacted]

Chair of the DPAP Ethics Subcommittee

Appendix E: University of Nottingham Ethical Approval of Study Amendments



University of
Nottingham
UK | CHINA | MALAYSIA

DPAP Committee

08/06/2023

Supervisor:

Applicant : Brooke Kesic

Project: Project Id Trauma Informed Care within Oncology: Exploring the perspectives of those with Adverse Childhood Experiences on accessing and receiving cancer treatment

The committee is pleased to confirm that the amendment relating to ref: DPAP - 2023 - 3002 - 1 has received approval. Please conduct your study following the amended procedures. If you need to make any further changes, please create a new amendement form.

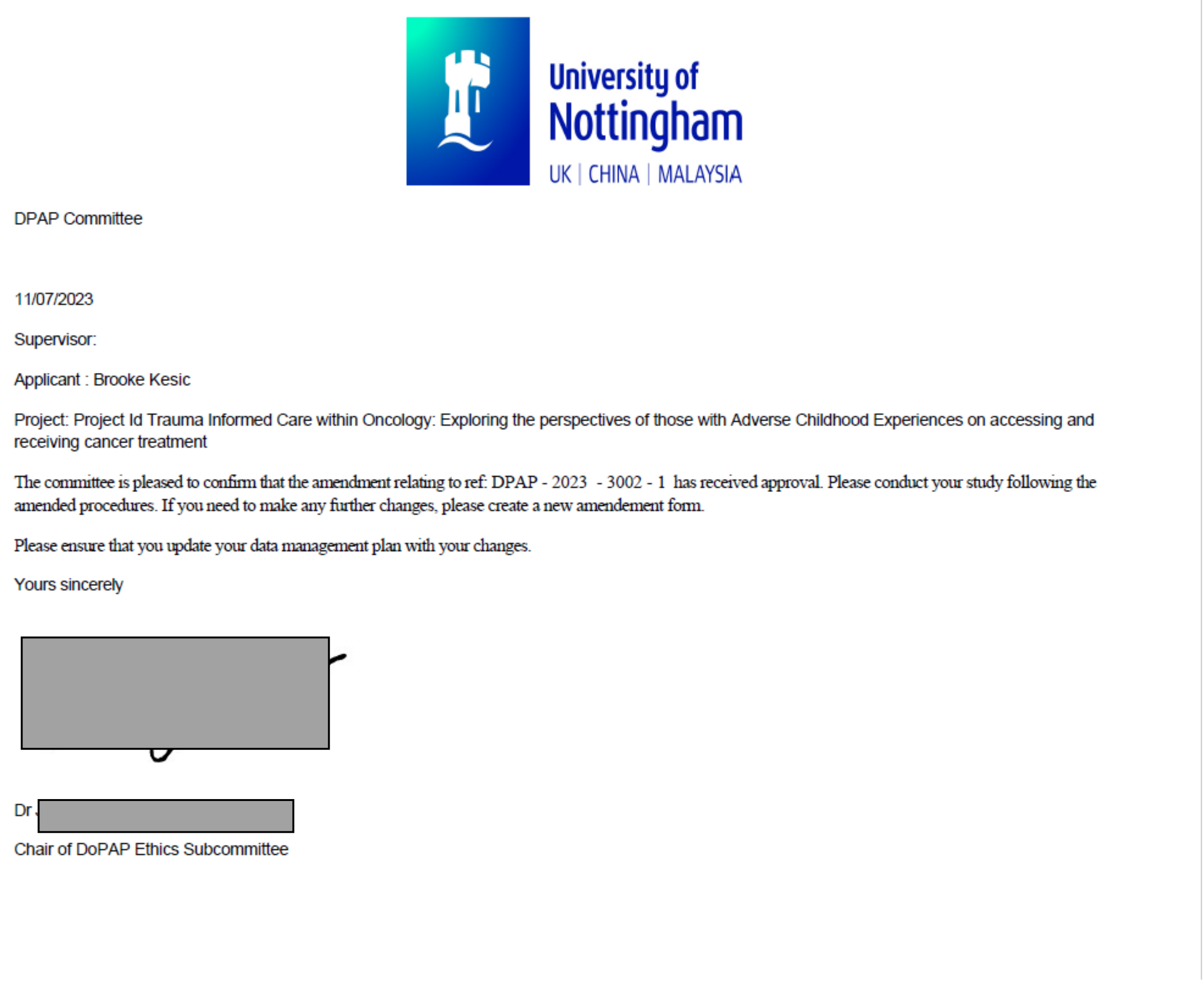
yours sincerely

[redacted]

Dr [redacted]

Chair of DoPAP Ethics Subcommittee

Appendix F: University of Nottingham Ethical Approval of Amendments (2)



University of Nottingham
UK | CHINA | MALAYSIA

DPAP Committee

11/07/2023

Supervisor:

Applicant : Brooke Kesic

Project: Project Id Trauma Informed Care within Oncology: Exploring the perspectives of those with Adverse Childhood Experiences on accessing and receiving cancer treatment

The committee is pleased to confirm that the amendment relating to ref: DPAP - 2023 - 3002 - 1 has received approval. Please conduct your study following the amended procedures. If you need to make any further changes, please create a new amendement form.

Please ensure that you update your data management plan with your changes.

Yours sincerely

[redacted]

Dr [redacted]

Chair of DoPAP Ethics Subcommittee

Appendix G: Study Recruitment Poster

HAVE YOU EXPERIENCED CHILDHOOD TRAUMA & A RECENT CANCER DIAGNOSIS?

WE NEED YOU!

Hi! I'm a Trainee Clinical Psychologist, looking for people to take part in an online questionnaire. The questionnaire will ask about childhood trauma to see if this impacts the length of time it takes for people to seek help from cancer services, as well as your experiences in cancer services today.

This research has been developed and supported by an expert by experience of both childhood sexual abuse and cancer. We hope that we are able to advance our understanding in this area, doing so can help us to identify how best to support people in a trauma-informed manner, to live well with, and beyond cancer.

CAN I TAKE PART?

We would like to hear from you if you are:

1. Aged 18 years or over **and**
2. Have received a cancer diagnosis in the last 12 months.

As a thank you for completing the questionnaire, you can be entered into a £50 prize draw. You will also have the option to be contacted to take part in a follow-up interview.

HOW?

Sign up/to find out more by clicking the following link below:

[insert online web-link of survey/QR code]

If you would like any further information, please contact Brooke Kesic (Lead Researcher at: brooke.kesic@nottingham.ac.uk.

This study has been approved by the University of Nottingham Research Ethics Committee. Ethics Reference: 3002.

Appendix H: Stage One (Online Survey): Participant Information Sheet

Participant Information Sheet

(Version 3.0: 08/06/2023)

Title of Study: Trauma Informed Care within Oncology: Exploring the perspectives of those with Adverse Childhood Experiences on accessing and receiving cancer treatment.
Lead Researcher: Brooke Kesic (Trainee Clinical Psychologist) brooke.kesic@nottingham.ac.uk
Name of Chief Investigator: Dr Anna Tickle (Clinical Psychologist) anna.tickle@nottingham.ac.uk
Local Researcher(s): Dr Nima Moghaddam, Dr Joanna Levene, Dr Mike Rennoldson, Hannah Harris

Ethics Reference Number: 3002

Thank you for showing an interest in this research project. My name is Brooke Kesic, and I am a Trainee Clinical Psychologist at the University of Nottingham. As part of my training, I would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. If you have any questions or concerns about this study, please do not hesitate to contact us (details above). Talk to others about the study if you wish. Ask us if there is anything that is not clear.

What is the purpose of the study?

This research project aims to explore the experiences of individuals who have experienced traumatic life events during childhood such as abuse, neglect, or an unsafe household environment, which are referred to as Adverse Childhood Experiences (ACEs). The aim of this study is to see if ACEs impact adults accessing cancer services and experiences of cancer services today. This study will ask those who have received a cancer diagnosis about the length of time it has taken to access cancer services (after first identifying suspected cancer symptoms), satisfaction of cancer services and perceptions of their cancer diagnosis, as well as understanding if ACEs impact experiences of cancer services. The study aims to gain a greater understanding of how to support this client group in a trauma-informed manner.

Why have I been invited?

You are being invited to take part because you have received a cancer diagnosis. We are inviting 252 participants like you, to take part in the completion of an online questionnaire, about your experiences of accessing cancer services and your treatment. Questions will also ask you about adverse childhood experiences that you may/may not have had.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part in the study, you will be given this information sheet to read online. You will be able to request an electronic copy of this form to keep. Once you have read the information about the study and what it involves, you will be asked to tick a box to state that you understand what is involved from you and that you consent to taking part in the research. You are free to withdraw from the research at any time and without giving a reason. This would not affect your legal rights.

What will happen if I want to take part?

You will be provided an online information leaflet about the study. If you wish to take part, you will be asked to provide informed consent. This will be done by ticking a box on the online form to state that you agree with what will be asked of you during the study and that you wish to take part. You will then have access to the online questionnaire to complete.

You will be asked to provide some information about yourself. For example, questions about your gender, age, and ethnicity. You will also be asked about your cancer diagnosis (site and stage) and when you were diagnosed. You will also be asked about the length of time it took for you to seek help from cancer services and whether you accessed private and/or NHS services. Questions will also be asked about adverse childhood experiences for example, 'Sometimes parents, stepparents or other adults living in the house do hurtful things. If this happened during your childhood (first 18 years of your life), please check 'Yes'. If this did not happen in your childhood, please check 'No.' Question 1. Swore at you, called you names, said insulting things like your "fat", "ugly", "stupid", etc. more than a few times a year' Due to the sensitive nature of the questions asked, you can report that you "prefer not to say" on any of the questions.

As the questionnaire is online, it can be completed on any internet-compatible device, during a time and in a location that is suitable for you. Completion of the questionnaire will take approximately 45 minutes. There is no time limit to complete each question. You will be able to leave the survey and re-enter to finish later if necessary. If you leave the link, you will only have 1 week from first accessing the questionnaire to finish your responses. When you have completed the questions, you will have the option to take part in an interview. If the researcher contacts you to take part in an interview, it will approximately be 60 minutes in length. It can be arranged to take place either face-to-face or via video/telephone call. A researcher will gather more information regarding the topics in the questionnaires including your experiences of accessing cancer services and/or treatment today. After completion of the interview, your participation in the study will be finished. If you do not wish to be contacted to take part in an interview, your participation in the study will end when you have completed the questionnaire.

Expenses and payments

Participation is voluntary and participants will not be paid to participate in the study. However, you will be offered the opportunity to enter a prize draw to win a £50 gift voucher. You will be contacted directly if you are the draw winner and will have 30 days to respond in order to claim your prize.

What are the possible disadvantages and risks of taking part?

Given the nature of the study, you will be answering questions which are sensitive in nature and may cause you distress. You are also being asked to answer such questions during a difficult time in your life, due to your cancer diagnosis. Questions will include you sharing information about potentially distressing aspects of your childhood, current experiences of cancer services and the potential impact that this might have on your current life. You do not have to share any information that you may find too uncomfortable to discuss. Once you have completed the study, you will be provided details of charity organisations and services that you can contact, if you find that your participation in the study has impacted you and you require support. If at this stage you require support, please see the end of this information sheet for a range of support services that you can contact.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get from this study may help to develop a greater understanding of how childhood traumas can impact experiences of oncology services in adulthood, which could contribute towards a more sensitive and trauma-informed approach to care in cancer services.

What happens when the research study stops?

If you do not wish to be contacted to take part in a follow-up interview, your participation will end when you have finished the questionnaire and you will not be contacted further. However, if you studies (unless you advise us that you do not wish to be contacted). This information will be kept separately from the research data collected and only those who need to will have access to it. All other data (research data) will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team given permission by the data custodian will have access to your personal data.

In accordance with the University of Nottingham's, the Government's, and our funders' policies we may share our research data with researchers in other Universities and organisations, including those in other countries, for research in health and social care. Sharing research data is important to allow peer scrutiny, re-use (and therefore avoiding duplication of research) and to understand the bigger picture in particular areas of research. Data sharing in this way is usually anonymised (so that you could not be identified) but if we need to share identifiable information we will seek your consent for this and ensure it is secure. You will be made aware then if the data is to be shared with countries whose data protection laws differ to those of the UK and how we will protect your confidentiality.

Although what you say to us is confidential, should you disclose anything to us which we feel puts you or anyone else at any risk, we may feel it necessary to report this to the appropriate persons.

What will happen if I don't want to carry on with the study?

Your participation is voluntary, and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you withdraw we will no longer collect any information about you or from you, but we will keep the information about you that we have already obtained as we are not allowed to tamper with study records and this information may have already been used in some analyses and may still be used in the final study analyses. To safeguard your rights, we will use the minimum personally identifiable information possible.

What will happen to the results of the research study?

The results of this study will be reported in the researcher's Doctoral thesis. It also will be prepared to be submitted to a peer-reviewed journal and presented at relevant conferences. Whilst direct quotes from the interviews might be include in the final write-up, your information will be anonymised, and you will not be identified. You can request a copy of the results of the study from the researcher. The contact details for the researcher are supplied at the end of this information sheet.

Who is organising and funding the research?

This research is being organised and funded by the University of Nottingham as part of the researcher's professional Doctorate in Clinical Psychology.

Who has reviewed the study?

All research in healthcare is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by University of Nottingham Research Ethics Committee.

Sources of support

If reading this information has made you think about your mental and/or physical health, please visit your local general practitioner (GP) or doctor or seek support from one of the sources below. If you are already in contact with a specialist service, you may wish to discuss any concerns or queries with them.

wish to be contacted to take part in a follow-up interview you will be asked to leave your preferred method of contact at the end of the survey. The researchers will select approximately 12 people from those who opt-in to be interviewed about their adverse childhood experiences and if this impacts experiences of cancer services today. Your contact details will be kept confidential and only be shared with the research team. Providing your contact details does not mean that you are in anyway obliged to take part in the follow-up interview and, you can still withdraw from the research at any time. If you are contacted by a researcher, they will provide you with more details on what would be involved and you will be given chance to ask questions If you are contacted to complete an interview, you participation will end when you have completed the interview and you will not be contacted after you have completed the interview. When recruitment has ceased, all participant data collected will be used to see if adverse childhood experiences may impact on the length of time it takes to seek help from cancer services and experiences in cancer services today. If you wish to be informed of the results of the study, you can contact one of the researchers.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. The researchers' contact details are given at the end of this information sheet. If this does not resolve your query, please write to the Administrator to the Division of Psychiatry & Applied Psychology's Research Ethics Sub-Committee rita.gohil@nottingam.ac.uk who will pass your query to the Chair of the Committee.

If you remain unhappy and wish to complain formally, you should then contact the Faculty of Medical and Health Sciences Ethics Committee Administrator, Faculty Hub, Medicine and Health Sciences, E41, E Floor, Medical School, Queen's Medical Centre Campus, Nottingham University Hospitals, Nottingham, NG7 2UH or via E-mail: FMHS-ResearchEthics@nottingham.ac.uk

Will my taking part in the study be kept confidential?

We will follow ethical and legal practice and all information about you will be handled in confidence.

If you join the study, we will use information collected from you during the course of the research. This information will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database at the University of Nottingham. Under UK Data Protection laws the University is the Data Controller (legally responsible for the data security) and the Chief Investigator of this study (named above) is the Data Custodian (manages access to the data). This means we are responsible for looking after your information and using it properly. Your rights to access, change or move your information are limited as we need to manage your information in specific ways to comply with certain laws and for the research to be reliable and accurate. To safeguard your rights we will use the minimum personally – identifiable information possible.

You can find out more about how we use your information and to read our privacy notice at:

https://www.nottingham.ac.uk/utilities/privacy.aspx

The data collected for the study will be looked at and stored by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people from regulatory organisations to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

Your contact information will be kept by the University of Nottingham for 1 year after the end of the study so that we are able to contact you about the findings of the study and possible follow-up

GP (General Practitioner): As a first port of call, you can visit your Doctor/GP for any health concerns you have. If you are not registered with a GP, you can use the online NHS Choices ' Find GP Services' tool to find your local practice: www.nhs.uk/Service-Search/GP/Location/Search/4

Macmillan: Offer a range of support services including diagnosis support, treatment, post treatment how to support others, worries and emotional concerns. You can also access local support including local cancer support groups run by volunteers and drop-in cancer information centres. You can access an online community for 24 hour support and ask an expert questions.
www.macmillan.org.uk
(Free) Helpline: 0808 808 00 00 (Open 8am-8pm every day)
Access an online chat (via the website)

Psychological Therapies: If you are looking for NHS-run psychological therapies (also called 'talking therapies' or 'IAPT'/'Improving Access to Psychological Therapies': this includes therapies such as counselling, psychotherapy and cognitive behavioural therapy_, you can look for your local psychological therapies online by using the online NHS Choices 'find psychological therapies' tool: Find an NHS talking therapies services - NHS (www.nhs.uk) - Please note services vary in whether you can directly refer yourself or if the service requires your GP to do so.

Mental Health Crisis: If you require **urgent** mental health support, you can access services to support you here: Get urgent help for mental health - NHS (www.nhs.uk).

NHS 111/NHS Direct: If you need medical help or advice fast, but it is not a life-threatening situation, you can call NHS 111 (England) by dialling 111 OR NHS Direct (in Wales) on 08454647

Listening & Emotional Support Services:

Maggie's: Charity providing free cancer support and information for those in the UK. Visit a centre (no appointment needed), call on: 0300 123 1801 or e-mail on: enquiries@maggies.org

Samaritans: Trained volunteers provide confidential and non-judgemental emotional support for individuals experiencing difficult feelings which could lead to suicide. They are there to listen to anything that is upsetting you, including intrusive thoughts and difficult thoughts of self-harm and/or suicide.
www.samritans.org
(Free) Helpline: 116 123 (24 hours a day, 365 days a year)

SANE: A UK charity supporting to improve the quality of life for individual's affected by mental illness. They provide emotional support and information for a range of mental health issues.
www.sane.org.uk
Helpline: 0300 304 7000 (open 4:30pm-10:30pm every day).

Switchboard: If you identify as gay, lesbian, bisexual or transgender, Switchboard is a confidential service and available to listen to any problems that you're having. They provide information, support and referral services. Phone operators all identify as LGBTQ+.
www.switchboard.lgbt
Helpline: 0300 300 0630 (10am-10pm every day)
1:1 webchat available (via their website)

SHOUT: Free, confidential 24/7 text messaging support service for anyone struggling to manage with a range of emotional difficulties. Text a trained Crisis Volunteer for support.
Text SHOUT to 85258.
Contact: https://giveusashout.org
Available in England, Scotland, Wales & Northern Ireland.

Appendix I: Stage One (Online Survey): Participant Information Sheet for recruitment via Prolific.co.uk

Participant Information Sheet
(Version 3.0: 08/06/2023)

Title of Study: Trauma Informed Care within Oncology: Exploring the perspectives of those with Adverse Childhood Experiences on accessing and receiving cancer treatment.
Lead Researcher: Brooke Kesic (Trainee Clinical Psychologist) brooke.kesic@nottingham.ac.uk
Name of Chief Investigator: Dr Anna Tickle (Clinical Psychologist) anna.tickle@nottingham.ac.uk
Local Researcher(s): Dr Nima Moghaddam, Dr Joanna Levene, Dr Mike Rennoldson, Hannah Harris

Ethics Reference Number: 3002

Thank you for showing an interest in this research project. My name is Brooke Kesic, and I am a Trainee Clinical Psychologist at the University of Nottingham. As part of my training, I would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. If you have any questions or concerns about this study, please do not hesitate to contact us (details above). Talk to others about the study if you wish. Ask us if there is anything that is not clear.

What is the purpose of the study?

This research project aims to explore the experiences of individuals who have experienced traumatic life events during childhood such as abuse, neglect, or an unsafe household environment, which are referred to as Adverse Childhood Experiences (ACEs). The aim of this study is to see if ACEs impact adults accessing cancer services and experiences of cancer services today. This study will ask those who have received a cancer diagnosis about the length of time it has taken to access cancer services (after first identifying suspected cancer symptoms), satisfaction of cancer services and perceptions of their cancer diagnosis, as well as understanding if ACEs impact experiences of cancer services. The study aims to gain a greater understanding of how to support this client group in a trauma-informed manner.

Why have I been invited?

You are being invited to take part because you have received a cancer diagnosis. We are inviting 252 participants like you, to take part in the completion of an online questionnaire, about your experiences of accessing cancer services and your treatment. Questions will also ask you about adverse childhood experiences that you may/may not have had.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part in the study, you will be given this information sheet to read online. You will be able to request an electronic copy of this form to keep. Once you have read the information about the study and what it involves, you will be asked to tick a box to state that you understand what is involved from you and that you consent to taking part in the research. You are free to withdraw from the research at any time and without giving a reason. This would not affect your legal rights.

What will happen if I want to take part?

You will be provided an online information leaflet about the study. If you wish to take part, you will be asked to provide informed consent. This will be done by ticking a box on the online form to state that you agree with what will be asked of you during the study and that you wish to take part. You will then have access to the online questionnaire to complete.

You will be asked to provide some information about yourself. For example, questions about your gender, age, and ethnicity. You will also be asked about your cancer diagnosis (site and stage) and when you were diagnosed. You will also be asked about the length of time it took for you to seek help from cancer services and whether you accessed private and/or NHS services. Questions will also be asked about adverse childhood experiences for example, 'Sometimes parents, stepparents or other adults living in the house do hurtful things. If this happened during your childhood (first 18 years of your life), please check 'Yes'. If this did not happen in your childhood, please check 'No.' Question 1. Swore at you, called you names, said insulting things like your "fat", "ugly", "stupid", etc. more than a few times a year' Due to the sensitive nature of the questions asked, you can report that you "prefer not to say" on any of the questions.

As the questionnaire is online, it can be completed on any internet-compatible device, during a time and in a location that is suitable for you. Completion of the questionnaire will take approximately 25-30 minutes. When you have completed the questions, you will have the option to take part in an interview. If the researcher contacts you to take part in an interview, it will approximately be up to 60 minutes maximum in length. It can be arranged to take place either face-to-face or via video/telephone call. A researcher will gather more information regarding the topics in the questionnaires including your experiences of accessing cancer services and/or treatment today. After completion of the interview, your participation in the study will be finished. If you do not wish to be contacted to take part in an interview, your participation in the study will end when you have completed the questionnaire.

Expenses and payments

You will be paid via Prolific once you have completed the study. You will be offered the opportunity to enter a prize draw to win a £50 gift voucher. You will be contacted directly if you are the draw winner and will have 30 days to respond in order to claim your prize.

What are the possible disadvantages and risks of taking part?

Given the nature of the study, you will be answering questions which are sensitive in nature and may cause you distress. You are also being asked to answer such questions during a difficult time in your life, due to your cancer diagnosis. Questions will include you sharing information about potentially distressing aspects of your childhood, current experiences of cancer services and the potential impact that this might have on your current life. You do not have to share any information that you may find too uncomfortable to discuss. Once you have completed the study, you will be provided details of charity organisations and services that you can contact, if you find that your participation in the study has impacted you and you require support. If at this stage you require support, please see the end of this information sheet for a range of support services that you can contact.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get from this study may help to develop a greater understanding of how childhood traumas can impact experiences of oncology services in adulthood, which could contribute towards a more sensitive and trauma-informed approach to care in cancer services.

What happens when the research study stops?

If you do not wish to be contacted to take part in a follow-up interview, your participation will end when you have finished the questionnaire and you will not be contacted further. However, if you wish to be contacted to take part in a follow-up interview you will be asked to leave your preferred method of contact at the end of the survey. The researchers will select approximately 12 people from those who opt-in to be interviewed about their adverse childhood experiences and if this impacts experiences of cancer services today. Your contact details will be kept confidential and only be shared with the research team. Providing your contact details does not mean that you are in anyway obliged to take part in the follow-up interview and, you can still withdraw from the research at any time. If you are contacted by a researcher, they will provide you with more details on what would be involved and you will be given chance to ask questions If you are contacted to complete an interview, you participation will end when you have completed the interview and you will not be contacted after you have completed the interview. When recruitment has ceased, all participant data collected will be used to see if adverse childhood experiences may impact on the length of time it takes to seek help from cancer services and experiences in cancer services today. If you wish to be informed of the results of the study, you can contact one of the researchers.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. The researchers' contact details are given at the end of this information sheet. If this does not resolve your query, please write to the Administrator to the Division of Psychiatry & Applied Psychology's Research Ethics Sub-Committee rita.gohil@nottingam.ac.uk who will pass your query to the Chair of the Committee.

If you remain unhappy and wish to complain formally, you should then contact the Faculty of Medical and Health Sciences Ethics Committee Administrator, Faculty Hub, Medicine and Health Sciences, E41, E Floor, Medical School, Queen's Medical Centre Campus, Nottingham University Hospitals, Nottingham, NG7 2UH or via E-mail: FMHS-ResearchEthics@nottingham.ac.uk

Will my taking part in the study be kept confidential?

We will follow ethical and legal practice and all information about you will be handled in confidence.

If you join the study, we will use information collected from you during the course of the research. This information will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database at the University of Nottingham. Under UK Data Protection laws the University is the Data Controller (legally responsible for the data security) and the Chief Investigator of this study (named above) is the Data Custodian (manages access to the data). This means we are responsible for looking after your information and using it properly. Your rights to access, change or move your information are limited as we need to manage your information in specific ways to comply with certain laws and for the research to be reliable and accurate. To safeguard your rights we will use the minimum personally – identifiable information possible.

You can find out more about how we use your information and to read our privacy notice at:

https://www.nottingham.ac.uk/utilities/privacy.aspx

The data collected for the study will be looked at and stored by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people from regulatory organisations to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

Your contact information will be kept by the University of Nottingham for 1 year after the end of the study so that we are able to contact you about the findings of the study and possible follow-up studies (unless you advise us that you do not wish to be contacted). This information will be kept separately from the research data collected and only those who need to will have access to it. All other data (research data) will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team given permission by the data custodian will have access to your personal data.

In accordance with the University of Nottingham's, the Government's, and our funders' policies we may share our research data with researchers in other Universities and organisations, including those in other countries, for research in health and social care. Sharing research data is important to allow peer scrutiny, re-use (and therefore avoiding duplication of research) and to understand the bigger picture in particular areas of research. Data sharing in this way is usually anonymised (so that you could not be identified) but if we need to share identifiable information we will seek your consent for this and ensure it is secure. You will be made aware then if the data is to be shared with countries whose data protection laws differ to those of the UK and how we will protect your confidentiality.

Although what you say to us is confidential, should you disclose anything to us which we feel puts you or anyone else at any risk, we may feel it necessary to report this to the appropriate persons.

What will happen if I don't want to carry on with the study?

Your participation is voluntary, and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you withdraw we will no longer collect any information about you or from you, but we will keep the information about you that we have already obtained as we are not allowed to tamper with study records and this information may have already been used in some analyses and may still be used in the final study analyses. To safeguard your rights, we will use the minimum personally identifiable information possible.

What will happen to the results of the research study?

The results of this study will be reported in the researcher's Doctoral thesis. It also will be prepared to be submitted to a peer-reviewed journal and presented at relevant conferences. Whilst direct quotes from the interviews might be include in the final write-up, your information will be anonymised, and you will not be identified. You can request a copy of the results of the study from the researcher. The contact details for the researcher are supplied at the end of this information sheet.

Who is organising and funding the research?

This research is being organised and funded by the University of Nottingham as part of the researcher's professional Doctorate in Clinical Psychology.

Who has reviewed the study?

All research in healthcare is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by University of Nottingham Research Ethics Committee.

Sources of support

If reading this information has made you think about your mental and/or physical health, please visit your local general practitioner (GP) or doctor or seek support from one of the sources below. If you are already in contact with a specialist service, you may wish to discuss any concerns or queries with them.

GP (General Practitioner): As a first port of call, you can visit your Doctor/GP for any health concerns you have. If you are not registered with a GP, you can use the online NHS Choices ' Find GP Services' tool to find your local practice: www.nhs.uk/Service-Search/GP/Location/Search/4

Macmillan: Offer a range of support services including diagnosis support, treatment, post treatment how to support others, worries and emotional concerns. You can also access local support including local cancer support groups run by volunteers and drop-in cancer information centres. You can access an online community for 24 hour support and ask an expert questions.
www.macmillan.org.uk
(Free) Helpline: 0808 808 00 00 (Open 8am-8pm every day)
Access an online chat (via the website)

Psychological Therapies: If you are looking for NHS-run psychological therapies (also called 'talking therapies' or 'IAPT'/'Improving Access to Psychological Therapies': this includes therapies such as counselling, psychotherapy and cognitive behavioural therapy_, you can look for your local psychological therapies online by using the online NHS Choices 'find psychological therapies' tool: Find an NHS talking therapies services - NHS (www.nhs.uk) - Please note services vary in whether you can directly refer yourself or if the service requires your GP to do so.

Mental Health Crisis: If you require **urgent** mental health support, you can access services to support you here: Get urgent help for mental health - NHS (www.nhs.uk).

NHS 111/NHS Direct: If you need medical help or advice fast, but it is not a life-threatening situation, you can call NHS 111 (England) by dialling 111 OR NHS Direct (in Wales) on 08454647

Listening & Emotional Support Services:

Maggie's: Charity providing free cancer support and information for those in the UK. Visit a centre (no appointment needed), call on: 0300 123 1801 or e-mail on: enquiries@maggies.org

Samaritans: Trained volunteers provide confidential and non-judgemental emotional support for individuals experiencing difficult feelings which could lead to suicide. They are there to listen to anything that is upsetting you, including intrusive thoughts and difficult thoughts of self-harm and/or suicide.
www.samritans.org
(Free) Helpline: 116 123 (24 hours a day, 365 days a year)

SANE: A UK charity supporting to improve the quality of life for individual's affected by mental illness. They provide emotional support and information for a range of mental health issues.
www.sane.org.uk
Helpline: 0300 304 7000 (open 4:30pm-10:30pm every day).

Switchboard: If you identify as gay, lesbian, bisexual or transgender, Switchboard is a confidential service and available to listen to any problems that you're having. They provide information, support and referral services. Phone operators all identify as LGBTQ+.
www.switchboard.lgbt
Helpline: 0300 300 0630 (10am-10pm every day)
1:1 webchat available (via their website)

SHOUT: Free, confidential 24/7 text messaging support service for anyone struggling to manage with a range of emotional difficulties. Text a trained Crisis Volunteer for support.
Text SHOUT to 85258.
Contact: https://giveusashout.org
Available in England, Scotland, Wales & Northern Ireland.

Appendix J: Stage One (Online Survey): Consent Form

Participant Consent

(Version 3.0: 08.06.2023)

STUDENT RESEARCH PROJECT ETHICS REVIEW

Division of Psychiatry & Applied Psychology

Project Title:	**Trauma Informed Care within Oncology: Exploring the perspectives of those with Adverse Childhood Experiences on accessing and receiving cancer treatment.**
Researcher:	**Brooke Kesic**
Supervisors:	**Dr Anna Tickle, Dr Nima Moghaddam, Dr Jo Levene, Dr Mike Rennoldson & Hannah Harris**
Ethics Reference:	*3002*

I confirm that I have read and understand the Participant Information Sheet for the above study.	☐Yes ☐No
Do you agree to take part in the online survey about Trauma Informed Care in Oncology?	☐Yes ☐No
Do you know how to contact the researcher if you have questions about this study?	☐Yes ☐No
Do you understand that your participation is voluntary, and you are free to withdraw from the study at any time, without giving a reason?	☐Yes ☐No

Do you understand that should you wish to withdraw from the study, then the information collected so far cannot be erased and that this information may still be used in the project analysis ☐Yes ☐No

☐Yes ☐No

Do you understand that should you wish to withdraw from the study, you have 1 week to do this by contacting the researcher. After this week-long period, your data may have already been used in analyses and can no longer be destroyed.

Do you give permission for your data from this study to be shared with authorised individuals from the University of Nottingham, the research group and regulatory authorities where it is relevant to taking part in this study, provided that your personal details will be kept confidential? ☐Yes ☐No

Do you understand that non-identifiable data from this study including quotations might be used in academic research reports or publications? ☐Yes ☐No

I confirm that I have been diagnosed with cancer ☐Yes ☐No

I confirm that I am aged 18 years old or over ☐Yes ☐No

By selecting ‘Yes’, I indicate that I understand what the study involves, and I agree to take part. I consent to take part in this research study. ☐Yes ☐No

Appendix K: Stage One: Online Survey

ACEs on accessing and receiving cancer treatment.

Start of Block: ID

Unique Study ID Number:
This should be your house number (or first two letters of your house name), first initial of your first name & last letter of your surname.

(e.g. If you lived at number 12 and your name was Jo Bloggs, your code would be: 12JS **OR** if your name was Jo Bloggs and you lived at Flower View, your code would be: FLJS).

Please write your unique ID number below and make a note of it for future reference.

____

End of Block: ID

Start of Block: Cancer

Q6 The first set of questions will ask you questions specifically about your cancer diagnosis and treatment (e.g., cancer site and stage).

Q7 What was the approximate date when you were diagnosed with cancer?

____

Q8 Is this your first cancer diagnosis?

○ Yes (1)

○ No (2)

Skip To: Q9 If Q8 = No

Skip To: Q10 If Q8 = Yes

Q9 How many previous cancer diagnoses have you received?

____

____

____

____

____

Q10 Which of the following detection routes best described your circumstances?

○ Self-identified (checks) (1)

○ Results of a cancer screening (2)

○ Incidental (3)

○ Other (please specify below) (4)

____

Q11 Looking back to when you first noticed signs or symptoms of cancer, how long did it take for you to seek medical help (e.g., in weeks, months, years)?

____

____

____

____

____

Q12 Please record your cancer type/site (e.g., breast, prostate, lung, colorectal)

____

____

____

____

Q13 Is there anything else you know about your cancer? (e.g., cancer stage?)

Q14 Are you currently undergoing cancer treatment?

○ Yes (1)

○ No (2)

Skip To: Q15 If Q14 = Yes

Skip To: Q16 If Q14 = No

Q15 What cancer treatment are you currently undergoing?

○ Chemotherapy (1)

○ Radiotherapy (2)

○ Hormone (3)

○ Immune (4)

○ Surgery *within the past month) (5)

○ Other (please specify) (6)

____

○ I prefer not to say (7)

Q16 Which setting did you access and receive your cancer diagnosis and/or treatment?

○ NHS (1)

○ Private Healthcare (2)

○ Both (3)

○ I do not wish to disclose (4)

Q17 Do you have any other health conditions that require medical care?

○ Yes (please specify below) (1)

____

○ No (2)

○ Prefer not to say (3)

End of Block: Cancer

Start of Block: Measures

Q18 The following questions explore different experiences you may have had as a child. Each section has its own instructions, but all responses are yes no, or prefer not to say. All questions ask you to focus on the first 18 years of your life.

Q19

Sometimes parents, stepparents or other adults living in the household/care home/boarding school do hurtful things. If this happened during your childhood (first 18 years of your life), please check 'Yes'. If this did not happen in your childhood, please check 'No.'

	Yes	No	Prefer not to say
Swore at you, called you names, said insulting things like your "fat", "ugly", "stupid", etc. more than a few times a year.	○	○	○

Said hurtful things that made you feel bad, embarrassed, or humiliated more than a few times a year.	○	○	○
	Yes	No	Prefer not to say
Acted in a way that made you afraid that you might be physically hurt.	○	○	○
Threatened to leave or abandon you.	○	○	○
Locked you in a closet, attic, basement, or garage.	○	○	○
Intentionally pushed, grabbed, shoved, slapped, pinched, punched, or kicked you.	○	○	○
Hit you so hard that it left marks for more than a few minutes.	○	○	○
Hit you so hard, or intentionally harmed you in some way, that you received or should have received medical attention.	○	○	○
Spanked you on your buttocks, arms, or legs.	○	○	○

Spanked you on your bare (unclothed) buttocks.	○	○	○
Spanked you with an object such as a strap, belt, brush, paddle, rod, etc.	○	○	○
Made inappropriate sexual comments or suggestions to you.	○	○	○
Touched or fondled your body in a sexual way.	○	○	○
Had you touch their body in a sexual way.	○	○	○

Q20 Sometimes parents, stepparents or other adults living in the household/care home/boarding school do hurtful things **to your siblings** *(brother, sister, step-siblings, other children you shared home/care homes/boarding schools with)*. If this happened during your childhood (first 18 years of your life), please check 'Yes'. If this did not happen in your childhood, please check 'No.'

Hit your sibling (step-sibling) so hard that it left marks for more than a few minutes.	○ Yes	○ No	○ Prefer not to say
Hit your sibling (step-sibling) so hard, or	○ Yes	○ No	○ Prefer not to say

intentionally harmed him/her in some way, that he/she received or should have received medical attention.			
Made inappropriate sexual comments or suggestions to your sibling (step-sibling).	○ Yes	○ No	○ Prefer not to say
Touched or fondled your sibling (step-sibling) in a sexual way.	○ Yes	○ No	○ Prefer not to say

Q21 Sometimes adults or older individuals **NOT** living in the household/care home/boarding school do hurtful things **to you**. If this happened during your childhood (first 18 years of your life), please check ‘Yes’. If this did not happen in your childhood, please check ‘No.’

Had you touch their body in a sexual way.	○ Yes	○ No
Actually had sexual intercourse (oral, anal, or vaginal) with you.	○ Yes	○ No

Q22 Sometimes intense arguments or physical fights occur between parents, stepparents, or other adults (boyfriends, girlfriends, grandparents) living in the household/ care home/boarding school. If this happened during your childhood (first 18 years of your life), please check ‘Yes’. If this did not happen in your childhood, please check ‘No.

Saw adults living in the household push, grab, slap or throw something at your mother (stepmother, grandmother).	○ Yes	○ No	○ Prefer not to say
Saw adults living in the household hit your mother (stepmother, grandmother) so hard that it left marks for more than a few minutes.	○ Yes	○ No	○ Prefer not to say
Saw adults living in the household hit your mother (stepmother, grandmother) so hard, or intentionally harm her in some way, that she received or should have received medical attention.	○ Yes	○ No	○ Prefer not to say
Saw adults living in the household push, grab, slap or throw something	○ Yes	○ No	○ Prefer not to say

at your father (stepfather, grandfather).			
Saw adults living in the household hit your father (stepfather, grandfather) so hard that it left marks for more than a few minutes.	○ Yes	○ No	○ Prefer not to say

Q23 Sometimes children your own age or older do hurtful things like bully or harass you. If this happened during your childhood (first 18 years of your life), please check ‘Yes’. If this did not happen in your childhood, please check ‘No.’

Swore at you, called you names, said insulting things like your “fat”, “ugly”, “stupid”, etc. more than a few times a year.	○ Yes	○ No	○ Prefer not to say
Said hurtful things that made you feel bad, embarrassed, or humiliated more than a few times a year.	○ Yes	○ No	○ Prefer not to say

Said things behind your back, posted derogatory messages about you, or spread rumors about you.	○ Yes	○ No	○ Prefer not to say
Intentionally excluded you from activities or groups.	○ Yes	○ No	○ Prefer not to say
Acted in a way that made you afraid that you might be physically hurt.	○ Yes	○ No	○ Prefer not to say
Threatened you in order to take your money or possessions.	○ Yes	○ No	○ Prefer not to say
Forced or threatened you to do things that you did not want to do.	○ Yes	○ No	○ Prefer not to say
Intentionally pushed, grabbed, shoved, slapped, pinched, punched, or kicked you.	○ Yes	○ No	○ Prefer not to say
Hit you so hard that it left marks for more than a few minutes.	○ Yes	○ No	○ Prefer not to say
Hit you so hard, or intentionally harmed you in some way, that you received or should have	○ Yes	○ No	○ Prefer not to say

received medical attention.			
Forced you to engage in sexual activity against your will.	○ Yes	○ No	○ Prefer not to say
Forced you to do things sexually that you did not want to do.	○ Yes	○ No	○ Prefer not to say

Q24 Please indicate if the following happened during your childhood (first 18 years of your life). If this happened during your childhood (first 18 years of your life), please check ‘Yes’. If this did not happen in your childhood, please check ‘No.’

You felt that your mother or other important maternal figure was present in the household but emotionally unavailable to you for a variety of reasons like drugs, alcohol, workaholic, having an affair, heedlessly pursuing their own goals.	○ Yes	○ No	○ Prefer not to say
You felt that your father or other important	○ Yes	○ No	○ Prefer not to say

paternal figure was present in the household but emotionally unavailable to you for a variety of reasons like drugs, alcohol, workaholic, having an affair, heedlessly pursuing their own goals.			
A parent or other important parental figure was very difficult to please.	○ Yes	○ No	○ Prefer not to say
A parent or other important parental figure did not have the time or interest to talk to you.	○ Yes	○ No	○ Prefer not to say
One or more individuals in your family made you feel loved.	○ Yes	○ No	○ Prefer not to say
One or more individuals in your family helped you feel important or special.	○ Yes	○ No	○ Prefer not to say
One or more individuals in your family were there to take you to the doctor or Emergency Room if the need ever	○ Yes	○ No	○ Prefer not to say

arose or would have if needed.	

Q25 Please indicate if the following statements were true about you and your family household/ care home during your childhood. If this happened during your childhood (first 18 years of your life), please check ‘Yes’. If this did not happen in your childhood, please check ‘No.’

You didn’t have enough to eat.	○ Yes	○ No	○ Prefer not to say
You had to wear dirty clothes	○ Yes	○ No	○ Prefer not to say
You felt that you had to shoulder adult responsibilities.	○ Yes	○ No	○ Prefer not to say
You felt that your family was under severe financial pressure.	○ Yes	○ No	○ Prefer not to say
One or more individuals kept important secrets or facts from you.	○ Yes	○ No	○ Prefer not to say
People in your family looked out for each other.	○ Yes	○ No	○ Prefer not to say

Your family was a source of strength and support.	○ Yes	○ No	○ Prefer not to say

Page Break

Q26 The next set of questions will ask you questions relating to your experiences of cancer services, as well as feelings that you might have experienced.

<u>Instructions:</u> For the following questions, please select the number that best corresponds to your **levels of satisfaction** experienced within **your accessed cancer service**:

How thoroughly the doctor assesses your symptoms.	○ Very Dissatisfied (1)	○ Dissatisfied (2)	○ Undecided (3)	○ Satisfied (4)	○ Very Satisfied (5)
Information given about how to manage pain.	○ Very Dissatisfied (1)	○ Dissatisfied (2)	○ Undecided (3)	○ Satisfied (4)	○ Very Satisfied (5)
The availability of nurses to answer your questions.	○ Very Dissatisfied (1)	○ Dissatisfied (2)	○ Undecided (3)	○ Satisfied (4)	○ Very Satisfied (5)

Information provided about your prognosis.	○ Very Dissatisfied (1)	○ Dissatisfied (2)	○ Undecided (3)	○ Satisfied (4)	○ Very Satisfied (5)
Speed with which symptoms are treated.	○ Very Dissatisfied (1)	○ Dissatisfied (2)	○ Undecided (3)	○ Satisfied (4)	○ Very Satisfied (5)
Information given about your tests.	○ Very Dissatisfied (1)	○ Dissatisfied (2)	○ Undecided (3)	○ Satisfied (4)	○ Very Satisfied (5)
The way tests and treatments are performed.	○ Very Dissatisfied (1)	○ Dissatisfied (2)	○ Undecided (3)	○ Satisfied (4)	○ Very Satisfied (5)
The availability of doctors to answer your questions.	○ Very Dissatisfied (1)	○ Dissatisfied (2)	○ Undecided (3)	○ Satisfied (4)	○ Very Satisfied (5)

Answers from health professionals.	○ Very Dissatisfied (1)	○ Dissatisfied (2)	○ Undecided (3)	○ Satisfied (4)	○ Very Satisfied (5)
Referrals to specialists.	○ Very Dissatisfied (1)	○ Dissatisfied (2)	○ Undecided (3)	○ Satisfied (4)	○ Very Satisfied (5)
The way tests and treatments are followed up by the doctor.	○ Very Dissatisfied (1)	○ Dissatisfied (2)	○ Undecided (3)	○ Satisfied (4)	○ Very Satisfied (5)
Information given about side effects.	○ Very Dissatisfied (1)	○ Dissatisfied (2)	○ Undecided (3)	○ Satisfied (4)	○ Very Satisfied (5)

The way the family is included in treatment and care decisions.	○ Very Dissatisfied (1)	○ Dissatisfied (2)	○ Undecided (3)	○ Satisfied (4)	○ Very Satisfied (5)

Page Break

Q27 Below are a series of statements about feelings people may usually have, but that might be experienced by each person in a different way.

Instructions: Please read each statement carefully and indicate on a scale of 0 (Never) to 4 (Always), how often you feel what is described in each item.

Other people see me as not	○ Never (1)	○ Sometimes (2)	○ About half the time (3)	○ Most of the time (4)	○ Always (5)

being up to their standards					
I am different and inferior to others	○ Never (1)	○ Sometimes (2)	○ About half the time (3)	○ Most of the time (4)	○ Always (5)
Other people don't understand me	○ Never (1)	○ Sometimes (2)	○ About half the time (3)	○ Most of the time (4)	○ Always (5)
I am isolated	○ Never (1)	○ Sometimes (2)	○ About half the time (3)	○ Most of the time (4)	○ Always (5)
Other people see me as uninteresting	○ Never (1)	○ Sometimes (2)	○ About half the time (3)	○ Most of the time (4)	○ Always (5)

I am unworthy as a person	○ Never (1)	○ Sometimes (2)	○ About half the time (3)	○ Most of the time (4)	○ Always (5)
Other people are judgmental	○ Never (1)	○ Sometimes (2)	○ About half the time (3)	○ Most of the time (4)	○ Always (5)
I am judgmental and critical of myself	○ Never (1)	○ Sometimes (2)	○ About half the time (3)	○ Most of the time (4)	○ Always (5)

Page Break

Q28 Instructions: For the following questions, please tick the number that best corresponds to **your views relating to your cancer:**

How much does your illness affect your life? (0 = no affect at all. 10 = severely affects my life) (1)	○ 0	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6	○ 7	○ 8	○ 9	○ 10
How long do you think your illness will continue? (0 = a very short time.	○ 0	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6	○ 7	○ 8	○ 9	○ 10

10 = forever) (2)											
How much control do you feel you have over your illness? (0 = absolutely no control. 10 = extreme amount of control) (3)	○ 0	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6	○ 7	○ 8	○ 9	○ 10
How much do you think your treatment can help your illness?	○ 0	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6	○ 7	○ 8	○ 9	○ 10

(0 = not at all. 10 = extremely helpful) (4)											
How much do you experience symptoms from your illness? (0 = no symptoms at all. 10 = many severe symptoms) (5)	○ 0	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6	○ 7	○ 8	○ 9	○ 10
How concerned are you	○ 0	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6	○ 7	○ 8	○ 9	○ 10

about your illness? (0 = not at all concerned. 10 = extremely concerned) (6)											
How well do you feel you understand your illness? (0 = don’t understand at all. 10 = understand very clearly) (7)	○ 0	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6	○ 7	○ 8	○ 9	○ 10
How much does your	○ 0	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6	○ 7	○ 8	○ 9	○ 10

illness affect you emotionally? (e.g., does it make you angry, scared, upset, or depressed?) (0 = not at all affected emotionally. 10 = extremely affected emotionally) (8)	

Start of Block: Demographics

Q29 Thank you for your time so far. You have almost finished the questionnaire. We would just like to ask a few more questions about you.

Q30 Which of the following describes your gender?

○ Male

○ Female

○ Non-binary

○ Prefer not to say

○ Other (please specify below)

____

Q31 What is your age? (Years)

____

Q32 Which of the following best describes your ethnicity?

○ Asian or Asian British

○ Mixed

○ Black or Black British

○ White

○ Chinese

○ Other ethnic group (please specify below)

____

○ I do not wish to disclose

Q33 How would you describe your relationship status?

- ○ Single
- ○ In a relationship
- ○ Married/civil partnership
- ○ Widowed
- ○ Divorced
- ○ Cohabiting
- ○ Other (please specify below)

____

- ○ I do not wish to disclose

Q34 How would you describe your sexual orientation?

- ○ Heterosexual/Straight
- ○ Homosexual
- ○ Bisexual
- ○ Pansexual
- ○ Other (please specify below)

____

- ○ I do not wish to disclose

Q35 What is your current employment status?

- ○ Unemployed
- ○ Self-employed
- ○ Part-time employee
- ○ Full-time employee
- ○ Retired
- ○ Prefer not to say
- ○ Other (please specify below)

____

Page Break

End of Block: Demographics

Start of Block: Interviews

Q36

Thank you for taking the time to complete this questionnaire.

As mentioned at the start of the survey, this study has been designed to help us to better understand the impact that childhood experiences may have on the length of time to seek help from cancer services and your experiences of cancer services. We aim to explore responses further in the next phase of the research, which will be an interview.

If you would be interested in taking part in the next phase of the research, please leave your preferred method of contact in the box provided (e.g. phone number, email etc.). Your contact details will be kept confidential and will only be shared with the research team. Providing your contact details at this stage does not mean that you are in anyway obliged to take part in further research phases, you can withdraw from the research at any time. If you are contacted by a researcher, they will provide you with more details on what would be involved and you will be given chance to ask questions and see if further participation would be in your best interest.

Based on the time taken to conduct further research, and the information that we are hoping to gather in this questionnaire, you may not be contacted to take part even if you leave your contact details. We would like to emphasise that we are very grateful to anyone who is willing to be contacted to take part in further research.

End of Block: Interviews

Start of Block: Block 9

Q37 **To thank you for your time, you have the opportunity to be entered into a prize draw to win a £50 gift voucher.**

If you do not wish to enter into the prize draw, please click on the next page to receive a debrief about the questionnaire including organisations you can contact for support.

If you do wish to be entered into the draw for an opportunity to win, please leave your e-mail below:

____

End of Block.

Appendix L: Stage One (Online Survey): Debrief

Participant Debrief Sheet

(Version 2.0 / 04/04/2023)

Title of Study: Trauma Informed Care within Oncology: Exploring the perspectives of those with Adverse Childhood Experiences on accessing and receiving cancer treatment.

Lead Researcher: Brooke Kesic (Trainee Clinical Psychologist)
brooke.kesic@nottingham.ac.uk

Name of Chief Investigator: Dr Anna Tickle (Clinical Psychologist)
anna.tickle@nottingham.ac.uk

Local Researcher(s): Dr Nima Moghaddam, Dr Joanna Levene, Dr Mike Rennoldson, Hannah Harris

Ethics Reference Number: 3002

I would like to thank you for taking part in our research study. The information you have shared with us is important in helping us to better understand the impact that adverse childhood experiences may have on the length of time to seek help from cancer servicers, your experiences of cancer services today and if they are trauma informed.

Questions and Withdrawing

If you have any further questions about the study, please feel free to contact the researcher. If you wish to withdraw your data, you can do so without providing a reason. Following your participation in the questionnaire, you will have 1 week to request that your data is destroyed by providing the researcher with your unique participant ID. Following this, it will not be possible to destroy the data as it may have already been used in analyses.

Further Participation

If you are interested with being contacted to participate in a follow-up interview, you will have provided us with your contact details on the previous page. If you are not interested in opting-in to be contacted for a follow-up interview, we thank you again for your time and interest in this study. If you find that any part of the study has caused you concerns, please see below information about organisations that can provide you with further support. Contact details have also been provided for the principal researcher.

Sources of support

If you find that any part of the study has caused you concerns, please feel free to contact the researcher or the researcher's supervisor. If participating in the study has affected you or made you think about your mental and/or physical health, please visit your local general practitioner (GP) or doctor or seek support from one of the sources below. If you are already in contact with a specialist service, you may wish to discuss any concerns or queries with them.

GP (General Practitioner): As a first port of call, you can visit your Doctor/GP for any health concerns you have. If you are not registered with a GP, you can use the online NHS Choices ' Find GP Services' tool to find your local practice: www.nhs.uk/Service-Search/GP/Location/Search/4

Macmillan: Offer a range of support services including diagnosis support, treatment, post treatment, how to support others, worries and emotional concerns. You can also access local support including local cancer support groups run by volunteers and drop-in cancer information centres. You can access an online community for 24-hour support and ask an expert questions.

www.macmillan.org.uk

(Free) Helpline: 0808 808 00 00 (Open 8am-8pm every day)

Access an online chat (via the website)

Psychological Therapies: If you are looking for NHS-run psychological therapies (also called ‘talking therapies’ or ‘IAPT’/’Improving Access to Psychological Therapies’: this includes therapies such as counselling, psychotherapy and cognitive behavioural therapy_, you can look for your local psychological therapies online by using the online NHS Choices ‘find psychological therapies’ tool: Find an NHS talking therapies services - NHS (www.nhs.uk) - Please note services vary in whether you can directly refer yourself or if the service requires your GP to do so.

Mental Health Crisis: If you require **urgent** mental health support, you can access services to support you here: Get urgent help for mental health - NHS (www.nhs.uk).

NHS 111/NHS Direct: If you need medical help or advice fast, but it is not a life-threatening situation, you can call NHS 111 (England) by dialling 111 OR NHS Direct (in Wales) on 08454647

Listening & Emotional Support Services:

Maggie’s: Charity providing free cancer support and information for those in the UK. Visit a centre (no appointment needed), call on: 0300 123 1801 or e-mail on: enquiries@maggies.org

Samaritans: Trained volunteers provide confidential and non-judgemental emotional support for individuals experiencing difficult feelings which could lead to suicide.

They are there to listen to anything that is upsetting you, including intrusive thoughts and difficult thoughts of self-harm and/or suicide.

www.samritans.org

(Free) Helpline: 116 123 (24 hours a day, 365 days a year)

SANE: A UK charity supporting to improve the quality of life for individual's affected by mental illness. They provide emotional support and information for a range of mental health issues.

www.sane.org.uk

Helpline: 0300 304 7000 (open 4:30pm-10:30pm every day).

Switchboard: If you identify as gay, lesbian, bisexual or transgender, Switchboard is a confidential service and available to listen to any problems that you're having. They provide information, support and referral services. Phone operators all identify as LGBTQ+.

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SHOUT: Free, confidential 24/7 text messaging support service for anyone struggling to manage with a range of emotional difficulties. Text a trained Crisis Volunteer for support.

Text SHOUT to 85258.

Contact: https://giveusashout.org

Available in England, Scotland, Wales & Northern Ireland.

Researcher Contact Details

Lead Researcher: Brooke Kesic (Trainee Clinical Psychologist)

E-mail: brooke.kesic@nottingham.ac.uk

Chief Investigator and Research Supervisor: Dr Anna Tickle (Clinical Psychologist, Associate Profession & Senior Research Tutor DClinPsy)

E-mail: Anna.Tickle@nottingham.ac.uk

Appendix M: Stage Two (Interviews): Participant Information Sheet

Participant Information Sheet

(Version 2.0: 03/04/2023)

Title of Study: Trauma Informed Care within Oncology: Exploring the perspectives of those with Adverse Childhood Experiences on accessing and receiving cancer treatment.

Lead Researcher: Brooke Kesic (Trainee Clinical Psychologist) brooke.kesic@nottingham.ac.uk

Name of Chief Investigator: Dr Anna Tickle (Clinical Psychologist) anna.tickle@nottingham.ac.uk

Local Researcher(s): Dr Nima Moghaddam, Dr Joanna Levene, Dr Mike Rennoldson, Hannah Harris

Ethics Reference Number: 3002

Thank you for showing a continued interest in this research project. Before you decide we would like you to understand why this research is being done and what it would involve for you. If you have any questions or concerns about this study, please do not hesitate to contact us (details above). Talk to others about the study if you wish. Ask us if there is anything that is not clear.

What is the purpose of the study?

This research project aims to explore the experiences of individuals who have experienced traumatic life events during childhood such as abuse, neglect, or an unsafe household environment, which are referred to as Adverse Childhood Experiences (ACEs). The aim of this study is to see if ACEs impact adults accessing cancer services and experiences of cancer services today. This part of the study will ask you questions about the length of time it has taken to access cancer services (after first identifying suspected cancer symptoms), satisfaction of cancer services and perceptions of your cancer diagnosis, as well as understanding if ACEs impact your experiences of cancer services. The study aims to gain a greater understanding of how to support this client group in a trauma-informed manner.

Why have I been invited?

We are inviting 12 participants like you who have received a cancer diagnosis in the last year and volunteered (after completion of the online questionnaire) to be contacted to take part in the interview stage of the research. The interview will be about your adverse childhood experiences and if this impacts your experiences of accessing and using cancer services today.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part in the study, you will be given this information sheet to keep (a copy will be made available electronically if you complete the interview via videocall/telephone). Once you have read the information about the study and what it involves, you will be asked to sign a consent from which states that you understand what is involved from you and that you consent to taking part in the research. You are free to withdraw from the research at any time and without giving a reason. This would not affect your legal rights.

What will happen if I want to take part?

You will be provided an information leaflet about the study. If you wish to take part, you will provide informed consent by a signed consent form. Before completing the online questionnaire, you created your own unique identifier. You will be requested to provide this prior to the interview. This is so we can link you to your questionnaire responses, so that you do not have to record your data twice. If you forget your identifier, the researcher can remind you of the code used to create your identifier e.g. your house number , first initial of your first name and last letter of your surname' . The interview will be via a video/telephone call, depending on your preference. The interview will approximately last for 60 minutes. A researcher will gather more information about the topics in the questionnaires. After completion of the interview, your participation in the study will be finished.

Expenses and payments

Participation is voluntary. You will not be paid to participate in the study. However, you will be offered the opportunity to enter a prize draw to win a £50 gift voucher. You will be contacted directly if you are the draw winner and will have 30 days to respond in order to claim your prize.

What are the possible disadvantages and risks of taking part?

Given the nature of the study, you will be answering questions which are sensitive in nature and may cause you distress. You are also being asked to answer such questions during a difficult time in your life, due to your cancer diagnosis. Questions will include you sharing information about potentially distressing aspects of your childhood, current experiences of cancer services and the potential impact that this might have on your current life. You do not have to share any information that you may find too uncomfortable to discuss.

You will be provided details of charity organisations and services that you can contact, if you find that your participation in the study has impacted you and you require support. This information will be provided to you on the Debrief Form once you have completed the study. If at this stage you require support, please see the end of this information sheet for a range of support services that you can contact.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get from this study may help to develop a greater understanding of how childhood traumas can impact experiences of oncology services in adulthood, which could contribute towards a more sensitive and trauma-informed approach to care in cancer services.

What happens when the research study stops?

Your participation will end when you have completed the interview. You will not be contacted after the interview. If you wish to be informed of the results of the study, you can contact one of the researchers. When recruitment has ceased, all participant data collected will be used to see if childhood experiences may impact on the length of time it takes to seek help from cancer services and experiences in cancer services today.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. The researchers' contact details are given at the end of this information sheet. If this does not resolve your query, please write to the Administrator to the Division of Psychiatry & Applied Psychology's Research Ethics Sub-Committee rita.gohil@nottingam.ac.uk who will pass your query to the Chair of the Committee.

If you remain unhappy and wish to complain formally, you should then contact the Faculty of Medical and Health Sciences Ethics Committee Administrator, Faculty Hub, Medicine and Health Sciences, E41, E Floor, Medical School, Queen's Medical Centre Campus, Nottingham University Hospitals, Nottingham, NG7 2UH or via E-mail: FMHS-ResearchEthics@nottingham.ac.uk

Will my taking part in the study be kept confidential?

We will follow ethical and legal practice and all information about you will be handled in confidence.

If you join the study, we will use information collected from you during the course of the research. This information will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database at the University of Nottingham. Under UK Data Protection laws the University is the Data Controller (legally responsible for the data security), and the Chief Investigator of this study (named above) is the Data Custodian (manages access to the data). This means we are responsible for looking after your information and using it properly. Your rights to access, change or move your information are limited as we need to manage your information in specific ways to comply with certain laws and for the research to be reliable and accurate. To safeguard your rights we will use the minimum personally – identifiable information possible.

You can find out more about how we use your information and to read our privacy notice at:

https://www.nottingham.ac.uk/utilities/privacy.aspx

The data collected for the study will be looked at and stored by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people from regulatory organisations to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant, and we will do our best to meet this duty.

Your contact information will be kept by the University of Nottingham for 1 year after the end of the study so that we are able to contact you about the findings of the study and possible follow-up studies (unless you advise us that you do not wish to be contacted). This information will be kept separately from the research data collected and only those who need to will have access to it. All other data (research data) will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team given permission by the data custodian will have access to your personal data.

In accordance with the University of Nottingham's, the Government's, and our funders' policies we may share our research data with researchers in other Universities and organisations, including those in other countries, for research in health and social care. Sharing research data is important to allow peer scrutiny, re-use (and therefore avoiding duplication of research) and to understand the bigger picture in particular areas of research. Data sharing in this way is usually anonymised (so that you could not be identified) but if we need to share identifiable information we will seek your consent for this and ensure it is secure. You will be made aware then if the data is to be shared with countries whose data protection laws differ to those of the UK and how we will protect your confidentiality.

Although what you say to us is confidential, should you disclose anything to us which we feel puts you or anyone else at any risk, we may feel it necessary to report this to the appropriate persons.

What will happen if I don't want to carry on with the study?

You have the right to withdraw from the study, without giving a reason as participation is voluntary. Your legal rights will not be affected. If you wish to withdraw your participation from the study, please contact us 1 week after completing the interview, as at this point, we will be able to extract the data you have provided.

However, 1 week after the completion of the interview, this will no longer be possible as the data you have provided may have been used for analyses. If this is the case, we will ensure to use the minimum of personally identifiable information, to safeguard your rights.

What will happen to the results of the research study?

The results of this study will be reported in the researcher's Doctoral thesis. It also will be prepared to be submitted to a peer-reviewed journal and presented at relevant conferences. Whilst direct quotes from the interviews might be include in the final write-up, your information will be anonymised, and you will not be identified. You can request a copy of the results of the study from the researcher. The contact details for the researcher are supplied at the end of this information sheet.

Who is organising and funding the research?

This research is being organised and funded by the University of Nottingham as part of the researcher's professional Doctorate in Clinical Psychology.

Who has reviewed the study?

All research in healthcare is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by University of Nottingham Research Ethics Committee.

Sources of support

If reading this information has made you think about your mental and/or physical health, please visit your local general practitioner (GP) or doctor or seek support from one of the sources below. If you are already in contact with a specialist service, you may wish to discuss any concerns or queries with them.

GP (General Practitioner): As a first port of call, you can visit your Doctor/GP for any health concerns you have. If you are not registered with a GP, you can use the online NHS Choices ' Find GP Services' tool to find your local practice: www.nhs.uk/Service-Search/GP/Location/Search/4

Macmillan: Offer a range of support services including diagnosis support, treatment, post treatment, how to support others, worries and emotional concerns. You can also access local support including local cancer support groups run by volunteers and drop-in cancer information centres. You can access an online community for 24-hour support and ask an expert questions.

www.macmillan.org.uk

(Free) Helpline: 0808 808 00 00 (Open 8am-8pm every day)

Access an online chat (via the website)

Psychological Therapies: If you are looking for NHS-run psychological therapies (also called ‘talking therapies’ or ‘IAPT’/’Improving Access to Psychological Therapies’: this includes therapies such as counselling, psychotherapy and cognitive behavioural therapy_, you can look for your local psychological therapies online by using the online NHS Choices ‘find psychological therapies’ tool: Find an NHS talking therapies services - NHS (www.nhs.uk) - Please note services vary in whether you can directly refer yourself or if the service requires your GP to do so.

Mental Health Crisis: If you require **urgent** mental health support, you can access services to support you here: Get urgent help for mental health - NHS (www.nhs.uk).

NHS 111/NHS Direct: If you need medical help or advice fast, but it is not a life-threatening situation, you can call NHS 111 (England) by dialling 111 OR NHS Direct (in Wales) on 08454647

Listening & Emotional Support Services:

Maggie’s: Charity providing free cancer support and information for those in the UK. Visit a centre (no appointment needed), call on: 0300 123 1801 or e-mail on: enquiries@maggies.org

Samaritans: Trained volunteers provide confidential and non-judgemental emotional support for individuals experiencing difficult feelings which could lead to suicide. They are there to listen to anything that is upsetting you, including intrusive thoughts and difficult thoughts of self-harm and/or suicide.

www.samritans.org (Free) Helpline: 116 123 (24 hours a day, 365 days a year)

SANE: A UK charity supporting to improve the quality of life for individual's affected by mental illness. They provide emotional support and information for a range of mental health issues.

www.sane.org.uk Helpline: 0300 304 7000 (open 4:30pm-10:30pm every day).

Switchboard: If you identify as gay, lesbian, bisexual or transgender, Switchboard is a confidential service and available to listen to any problems that you're having. They provide information, support and referral services. Phone operators all identify as LGBTQ+.

www.switchboard.lgbt

Helpline: 0300 300 0630 (10am-10pm every day)

1:1 webchat available (via their website)

SHOUT: Free, confidential 24/7 text messaging support service for anyone struggling to manage with a range of emotional difficulties. Text a trained Crisis Volunteer for support.

Text SHOUT to 85258.

Contact: https://giveusashout.org

Available in England, Scotland, Wales & Northern Ireland.

Appendix N: Stage Two (Interviews): Consent Form

Participant Consent

(Version 2.0: 17/03/2023)

STUDENT RESEARCH PROJECT ETHICS REVIEW

Division of Psychiatry & Applied Psychology

Project Title:	**Trauma Informed Care within Oncology: Exploring the perspectives of those with Adverse Childhood Experiences on accessing and receiving cancer treatment.**
Researcher:	**Brooke Kesic**
Supervisors:	**Dr Anna Tickle, Dr Nima Moghaddam, Dr Jo Levene, Dr Mike Rennoldson & Hannah Harris**
Ethics Reference:	*3002*

Participant Identifier *(assigned during the completion of the online questionnaire):*________

I confirm that I have read and understand the Participant Information Sheet for the above study	☐Yes ☐No
Do you agree to take part in an interview that will be recorded about your experiences of accessing and receiving cancer treatment?	☐Yes ☐No
Do you know how to contact the researcher if you have questions about this study?	☐Yes ☐No
Do you understand that participation is voluntary, and you are free to withdraw from the study at any time without giving a reason?	☐Yes ☐No

Do you understand that if you wish to withdraw and have your data destroyed, you have 1 week to do this by contacting the researcher. After this 1 week, your data may have already been used in analyses and can no longer be destroyed. ☐Yes ☐No

Do you give permission for your data from this study to be shared with authorised individuals from the University of Nottingham, the research group, and regulatory authorities where it is relevant to taking part in this study, provided that your personal details will be kept confidential? ☐Yes ☐No

Do you understand that non-identifiable data from this study including anonymous direct quotes from the interview will be used in academic research reports or publications? ☐Yes ☐No

Do you give permission for anonymous data collected in this study to be used by researchers in future studies? ☐Yes ☐No

Do you understand and agree to the limits of confidentiality as described in the participant information sheet? For example, the researcher may have to break confidentiality if there are concerns about risk and/or safety? ☐Yes ☐No

I confirm that I am 18 years old or over ☐Yes ☐No

Participant signature: Date:

Participant name:

Researcher Signature Date:

This consent form will be stored separately from any data to ensure data confidentiality

Appendix O: Stage Two (Interviews): Interview Schedule

Interview Schedule

1. What impacted the length of time it took for you to seek help from cancer services after noticing your cancer symptoms?
2. Do you think your history of adverse childhood experiences (if any) has impacted your experience(s) within cancer services?
3. Did you discuss your trauma history (if any) with your healthcare professional during your cancer assessment, diagnosis, or treatment? What was your experience of this?
4. If you did not discuss your trauma history (if any), what were the barriers to this?
5. If you experienced distress or periods of dissociation during cancer investigations or treatment, were you supported by the healthcare professionals involved?
   (Prompts: If yes, what helped/didn't. If no, what happened?)
6. How satisfied were/are you with your experiences with cancer services?
   (Prompts: Information & support received)
7. What was most/least helpful?
8. Would you access cancer services again if you had to? Why is that?
9. What do you think could be improved within cancer services to support people who have experienced trauma in their childhood?

Appendix P: Stage Two (Interviews): Debrief

Participant Debrief Sheet

(Version 2.0 / 04/04/2023)

Title of Study: Trauma Informed Care within Oncology: Exploring the perspectives of those with Adverse Childhood Experiences on accessing and receiving cancer treatment.

Lead Researcher: Brooke Kesic (Trainee Clinical Psychologist)
brooke.kesic@nottingham.ac.uk

Name of Chief Investigator: Dr Anna Tickle (Clinical Psychologist)
anna.tickle@nottingham.ac.uk

Local Researcher(s): Dr Nima Moghaddam, Dr Joanna Levene, Dr Mike Rennoldson, Hannah Harris

Ethics Reference Number: 3002

I would like to thank you for taking part in our research study. The information you have shared with us is important in helping us to better understand the impact that adverse childhood experiences may have on the length of time to seek help from cancer servicers, your experiences of cancer services today and if they are trauma informed.

Questions and Withdrawing

If you have any further questions about the study, please feel free to contact the researcher. If you wish to withdraw your data, you can do so without providing a reason. Following your participation in the interview, you will have 1 week to request that your data is withdrawn from the study by providing the researcher with your unique participant ID. Following this, it will not be possible to destroy the data as it may have already been used in analyses.

If you find that any part of the study has caused you concerns, please see below information about organisations that can provide you with further support. Contact details have also been provided for the principal researcher.

Sources of support

If you find that any part of the study has caused you concerns, please feel free to contact the researcher or the researcher's supervisor. If participating in the study has affected you or made you think about your mental and/or physical health, please visit your local general practitioner (GP) or doctor or seek support from one of the sources below. If you are already in contact with a specialist service, you may wish to discuss any concerns or queries with them.

GP (General Practitioner): As a first port of call, you can visit your Doctor/GP for any health concerns you have. If you are not registered with a GP, you can use the online NHS Choices ' Find GP Services' tool to find your local practice: www.nhs.uk/Service-Search/GP/Location/Search/4

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(Free) Helpline: 0808 808 00 00 (Open 8am-8pm every day)

Access an online chat (via the website)

Psychological Therapies: If you are looking for NHS-run psychological therapies (also called 'talking therapies' or 'IAPT'/'Improving Access to Psychological Therapies': this includes therapies such as counselling, psychotherapy and cognitive behavioural therapy_, you can look for your local psychological therapies online by using the online NHS Choices 'find psychological therapies' tool: Find an NHS talking therapies services - NHS (www.nhs.uk) - Please note services vary in whether you can directly refer yourself or if the service requires your GP to do so.

Mental Health Crisis: If you require **urgent** mental health support, you can access services to support you here: Get urgent help for mental health - NHS (www.nhs.uk).

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www.samritans.org

(Free) Helpline: 116 123 (24 hours a day, 365 days a year)

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Helpline: 0300 304 7000 (open 4:30pm-10:30pm every day).

Switchboard: If you identify as gay, lesbian, bisexual or transgender, Switchboard is a confidential service and available to listen to any problems that you're having. They provide information, support and referral services. Phone operators all identify as LGBTQ+.

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Helpline: 0300 300 0630 (10am-10pm every day)

1:1 webchat available (via their website)

SHOUT: Free, confidential 24/7 text messaging support service for anyone struggling to manage with a range of emotional difficulties. Text a trained Crisis Volunteer for support.

Text SHOUT to 85258.

Contact: https://giveusashout.org

Available in England, Scotland, Wales & Northern Ireland.

Researcher Contact Details

Lead Researcher: Brooke Kesic (Trainee Clinical Psychologist)

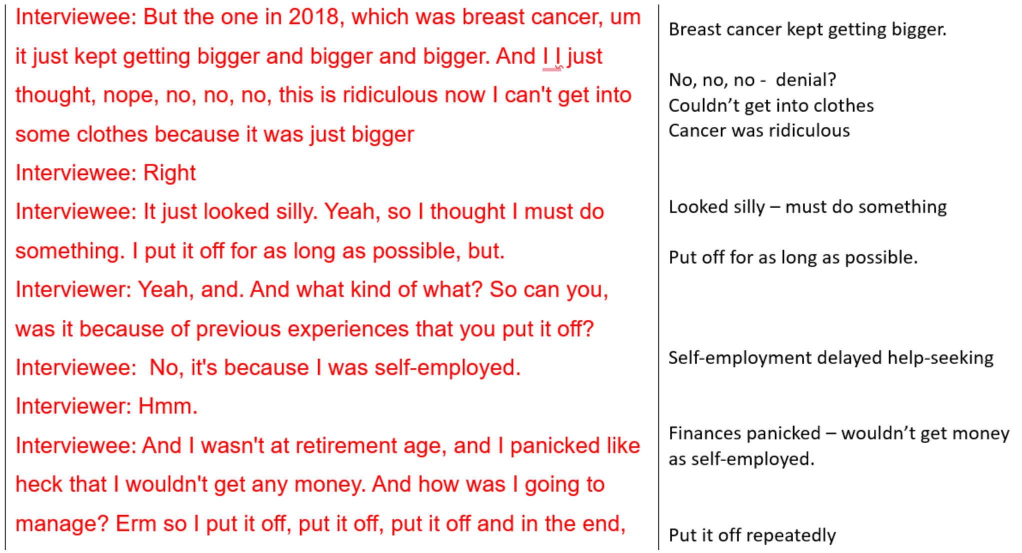
E-mail: brooke.kesic@nottingham.ac.uk

Chief Investigator and Research Supervisor: Dr Anna Tickle (Clinical Psychologist, Associate Professor & Senior Research Tutor DClinPsy)

E-mail: Anna.Tickle@nottingham.ac.uk

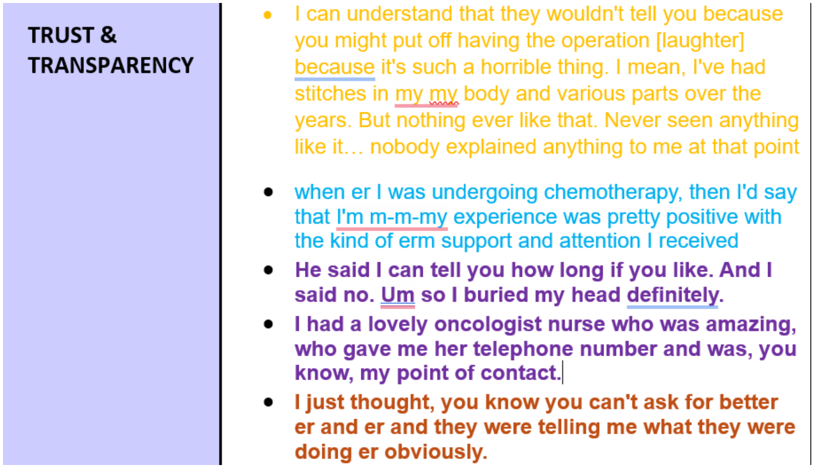
Appendix Q: Example of Coding

1.



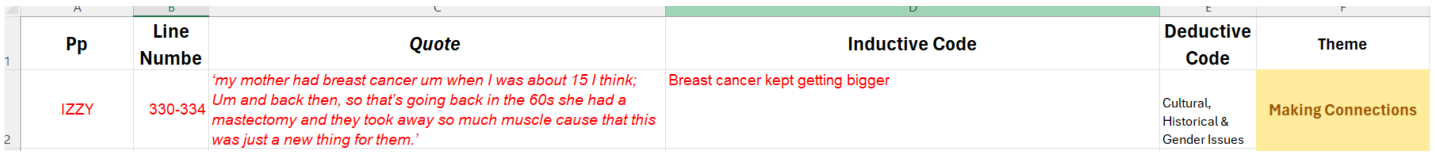
Interviewee: But the one in 2018, which was breast cancer, um it just kept getting bigger and bigger and bigger. And I I just thought, nope, no, no, no, this is ridiculous now I can't get into some clothes because it was just bigger	Breast cancer kept getting bigger. No, no, no - denial? Couldn't get into clothes Cancer was ridiculous
Interviewee: Right	
Interviewee: It just looked silly. Yeah, so I thought I must do something. I put it off for as long as possible, but.	Looked silly – must do something Put off for as long as possible.
Interviewer: Yeah, and. And what kind of what? So can you, was it because of previous experiences that you put it off?	
Interviewee: No, it's because I was self-employed.	Self-employment delayed help-seeking
Interviewer: Hmm.	
Interviewee: And I wasn't at retirement age, and I panicked like heck that I wouldn't get any money. And how was I going to manage? Erm so I put it off, put it off, put it off and in the end,	Finances panicked – wouldn't get money as self-employed. Put it off repeatedly

2.



TRUST & TRANSPARENCY	• I can understand that they wouldn't tell you because you might put off having the operation [laughter] because it's such a horrible thing. I mean, I've had stitches in my my body and various parts over the years. But nothing ever like that. Never seen anything like it… nobody explained anything to me at that point • when er I was undergoing chemotherapy, then I'd say that I'm m-m-my experience was pretty positive with the kind of erm support and attention I received • **He said I can tell you how long if you like. And I said no. Um so I buried my head definitely.** • **I had a lovely oncologist nurse who was amazing, who gave me her telephone number and was, you know, my point of contact.** • **I just thought, you know you can't ask for better er and er and they were telling me what they were doing er obviously.**

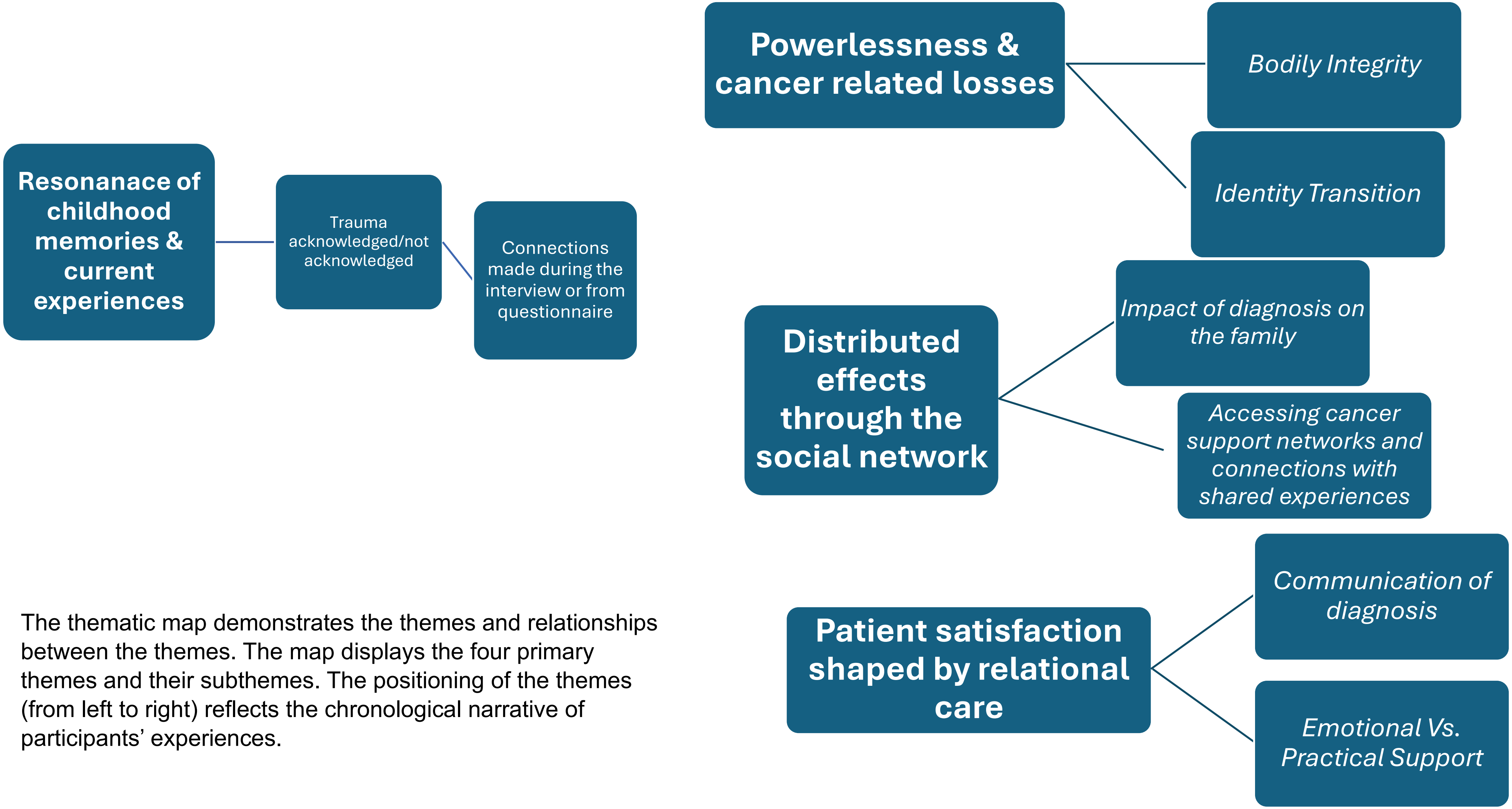
3.



Pp	Line Numbe	*Quote*	Inductive Code	Deductive Code	Theme
IZZY	330-334	*'my mother had breast cancer um when I was about 15 I think; Um and back then, so that's going back in the 60s she had a mastectomy and they took away so much muscle cause that this was just a new thing for them.'*	Breast cancer kept getting bigger	Cultural, Historical & Gender Issues	**Making Connections**

1. Each transcript was allocated a colour—an example of a transcript excerpt. The left column contains the transcript. The right-hand column contains coding.
2. Example of collated evidence for different participants after inductive coding.
3. The coding workbook was used after inductive and deductive coding rounds. The workbook contained the following steps as seen in the picture for every participant and code to keep all data together and organised:
    a. Participant Name
    b. Transcript line number
    c. Quote/Evidence
    d. Inductive Code
    e. Deductive Code
    f. Theme.

Appendix R: Thematic Map



The thematic map demonstrates the themes and relationships between the themes. The map displays the four primary themes and their subthemes. The positioning of the themes (from left to right) reflects the chronological narrative of participants’ experiences.

Appendix S: Checklist for Reflective Thematic Analysis (Clarke & Braun, 2022)

Process	No.	Criteria	Researcher Evidence
Transcription	1	Data has been transcribed to an appropriate level of detail. Transcripts have been checked against original recordings for 'accuracy'	Yes – The Data was transcribed verbatim by the researcher. The researcher listened and re-listened to each recording to ensure accuracy.
Coding and Theme Development	2	Each data item has been given thorough attention in the coding process	Yes – All data was coded through an iterative process of reading the transcript, coding, re-reading and re-coding, and making annotations as progressed.
	3	The coding process has been thorough and inclusive. Themes have not been developed from a few vivid examples.	Yes – Themes were developed using codes from all data from participant narratives.
	4	All relevant extracts for each theme have been collated	Yes – Extracts for each theme were collated from codes and stored in a Word Document.
	5	Candidate themes have been checked against coded data and with the original dataset	Yes – Candidate themes were checked against the original transcripts and codes.
	6	Themes are coherent, consistent and distinctive. Each theme is well-defined. Subthemes share the central organising concept of the theme.	Yes - Themes were discussed and revised by the researcher and during supervision to ensure consistency and coherence/ Concept for each theme was written up as a summary.
Analysis and Interpretation	7	Data have been analysed and interpreted, rather than summarised.	Yes – As evidenced in the write-up.
	8	Analysis and data match each other.	Yes – As evidenced in the write-up
	9	Analysis tells a well-organised and convincing story about the data and topic and addresses the research question.	Yes – The analysis addresses the research questions of exploring patients' experiences of their cancer and cancer diagnosis. Evidenced in the write-up.
	10	An appropriate balance between narrative and data extracts.	Yes – The researcher aimed for a balance between narrative and quotes. Evidenced in the write-up.
Overall	11	Enough time is allocated to complete all phases of analysis.	Yes – The research ensured extensive was allocated for the data analysis phase. Regular supervision attended to discuss progress and adherence to the research timeline.
Written Report	12	The specific approach and the particulars of the approach, including theoretical positions and assumptions are explicit.	Yes – A reflexive approach was implemented, and theoretical position and assumptions were evidenced in the write-up.
	13	There is a good fit between what was claimed and what was done (the described method and analysis are consistent).	Yes – As evidenced in the write-up.
	14	The language and concepts used are consistent with the ontological and epistemological positions of analysis.	Yes – As evidenced in the write-up
	15	The researcher is positioned as active in the research process.	Yes – The lead researcher acknowledged their position as an active agent throughout the research process. As noted in the write-up. Additionally, themes were reported as being 'generated' not as 'emerging' from the data.

Appendix T: Good Reporting of A Mixed Methods Study (GRAMMS) Checklist

(O’Cathain., Murphy & Nicholl, 2008).

GRAMMS Guidelines	Journal Paper	Extended Paper
	Section: Page	
Justification for a mixed methods approach to the research question.	Materials & Methods: p.13	Study Design: p.75.
Articulation of the design in terms of purpose, priority and sequence of methods.	Materials & Methods: p.13-15	Participants and Recruitment: p.81-82
Describe each method in terms of sampling, data collection and analysis.	Materials & Methods: p.13-18	Participants and Recruitment: p.81- 93
Delineate where and how integration occurs and who has participated in it.	Materials & Methods: p.13-15	Study Design: p.74-75
Describe any limitation of one method associated with the other.	Discussion: p.37	Extended Discussion: p.123
Described insights gained from mixing/integrating methods.	Discussion: p.37-40	Extended Discussion: p.123-124

POSTER

Trauma-Informed Care within Oncology?

Understanding the impact of childhood trauma on experiences of cancer and cancer services in adulthood.

UNIVERSITY OF LINCOLN

Brooke Kesic, Dr Anna Tickle, Dr Nima Moghaddam,
Dr Michael Rennoldson, Dr Joanna Levene & Hannah Harris

Trent Doctorate in Clinical Psychology

The University of Nottingham

Background

Although one in two individuals will receive a cancer diagnosis in their lifetime[1], the mental health effects of cancer remain an unmet need[2]. Trauma presentations can resurface in stressful environments. Trauma-informed care (TIC) is an approach to understanding how trauma affects individuals, by learning to identify signs of trauma and developing tools to effectively support an individual[3]. TIC literature is predominantly international based, with some recent developments in clinical settings in Scotland and Wales[4].

Aims

1. Does childhood trauma correlate with; a) the length of time to seek help from cancer services, b) feelings of shame, c) illness perceptions, and d) patient satisfaction levels within cancer services? Additionally, does shame mediate the relationship between childhood trauma and satisfaction with cancer care?
2. What are the patient's experiences of their cancer diagnosis and cancer services and does childhood trauma impact these?

Method

Data: 266 adults who had accessed cancer services completed an online questionnaire. Of these, 11 opted in to complete a follow-up semi-structured interview, informed by the survey outcomes. **Procedure:** Participants were recruited via social media and cancer charities. **Analysis:** Descriptive statistics, correlation and mediation analysis were conducted (survey data) and an inductive-deductive Reflexive Thematic Analysis[5] was implemented.

Results

Findings indicate a moderate negative correlation (r= - .40) between childhood trauma and patient satisfaction scores, suggesting that higher levels of childhood trauma are associated with lower levels of patient satisfaction, mediated by an individual's illness perceptions.

The following themes *(and subthemes)* were generated:

1. 'Connecting the dots': **Resonance of childhood memories and experiences.**
2. 'Nobody ever told me': **Powerlessness & cancer-related losses** *(2a. Bodily Integrity. 2b. Identity Transition).*
3. 'I just wanted everyone else around me to be okay': **Distributed effects of cancer through the social network.** *(3a. Impact of diagnosis on the family. 3b. Accessing cancer support networks and connections with shared experiences).*
4. 'It's down to bedside manner': **Patient satisfaction is shaped by relational care.** (*4a. Communication of diagnosis. 4b. Emotional Vs. Practical Support).*

Discussion

Findings indicate higher levels of childhood trauma are associated with lower levels of satisfaction with cancer services, mediated by an individual's illness perceptions of their cancer. Patients only made connections back to their childhood trauma in Theme 1. The findings highlight recommendations for implementing TIC in cancer services, although links back to ACEs were primarily identified by participants within a single theme, patients shared broader experiences of their cancer relevant to TIC principles.

Limitations: The sample lacked ethnic diversity as most participants identified as White British. Interview sample: smaller sample size, older average age of participants and lower scores on the childhood trauma measure compared to the survey stage.

Implications: TIC should be incorporated into oncology to improve patient satisfaction by addressing the psychological needs of individuals affected by ACEs and cancer-related trauma. Further empirical testing is needed to refine its implementation and validate the broader patient experiences shared in the study.

References. [1]Cancer Research UK. (2022).Cancer incidence statistics. https://www.cancerresearchuk.org/health-professional/cancer-statistics/incidence [2]Fernando, A. (2020). Mental Health and Cancer: Why It Is Time to Innovate and Integrate - A Call to Action. *Prostate Cancer, 6* (6) 1165-1167. [3]Substance Abuse and Mental Health Services Administration (SAMHSA). SAMHSA's Concept of Trauma and Guidance for a Trauma-Informed Approach. (2014). [4] Emsley, E., Smith, J., Martin, D., & Lewis, N. V. (2022). *Trauma-informed care in the UK: where are we? A qualitative study of health policies and professional perspectives.* Springer Science and Business Media LLC.

[5]Clarke, V., & Braun, V. (2022). Thematic analysis: a practical guide. *Thematic Analysis*, 1-100.