Implementing trauma-informed care: what is it like for experts by experience?

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ABSTRACT

Background: Trauma-Informed Care (TIC) is an approach to service delivery which recognises that many people have experiences of trauma and aims to embed this knowledge into the way services operate to minimise the chances of retraumatisation (Harris & Fallot, 2001). Including the perspective of Experts by Experience – people with lived experience of trauma and mental health services – is a key feature of how TIC is implemented (Sweeney et al., 2016). Within the UK, TIC is increasingly being adopted by healthcare services, although little is currently known about what it is like for Experts by Experience to undertake this work.

Aims: This study aims to explore what it is like for Experts by Experience to implement TIC within UK healthcare services.

Methods: Semi-structured interviews were carried out with 12 Experts by Experience who had been involved in implementing TIC within UK healthcare services. Interviews were analysed using Thematic Analysis.

Results: Two main themes were generated, 'Implementing TIC is distressing and traumatising' and 'Positive changes from implementing TIC', as well as five subthemes.

Conclusions: The themes generated from the interviews highlighted the way participants were invited to undertake TIC projects, paradoxically, was often done in a way which added to their distress. Although participants also highlighted the positive impact that implementing TIC can have on them and their relationships with colleagues, the results nonetheless raise questions as to whether it is ethical to invite Experts by Experience to implement TIC within the current service context. Various recommendations are made, including adopting a Human Rights Based Approach. Practical steps to reduce the chance of re-traumatisation of Experts by Experience are also provided.

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Glossary of terms

TIC - Trauma-Informed Care

UK – United Kingdom

PTSD - Post-traumatic stress disorder

C-PTSD – Complex Post-Traumatic Stress Disorder

BPD - Borderline personality disorder

DSM – The Diagnostic and Statistical Manual of Mental Disorders

APA – American Psychiatric Association

NHS - National Health Service

ACE – Adverse Childhood Experience

SAMHSA – Substance Abuse and Mental Health Service Administration

CR - Critical Realism

NTTP – National Trauma Training Programme

TA – Thematic Analysis

IPA – Interpretative Phenomenological Analysis

GT – Grounded Theory

BPS – British Psychological Society

UEL - University of East London

HRA – Health Research Authority

PIS – Participant Information Sheet

GDPR – General Data Protection Regulation

UN – United Nations

WHO – World Health Organisation

LGBTQI – Lesbian, Gay, Bisexual, Transgender, Queer/Questioning, Intersex

1. INTRODUCTION

1.1. Chapter overview

This chapter begins by describing my journey to the topic of this study. I provide a critical introduction to the topic of trauma, focusing on the historical, political and cultural factors that have shaped current definitions. A definition of trauma for the purposes of this study is then provided. I then offer an overview of Trauma-Informed Care and its application to mental health services in the United Kingdom (UK), before highlighting what is currently known about the experience of implementing this approach. The introduction then focuses on Experts by Experience and their role in implementing Trauma-Informed Care within UK mental health services. I will outline the current literature relating to the experience of Experts by Experience who have implemented Trauma-Informed Care. The chapter concludes with a rationale for this current study and the research aims.

1.2. Journey to the study

This study was developed and undertaken within a Clinical Psychology training programme based in a UK university. Despite having worked for over ten years in mental health teams prior to training, it was only while on this course that I was properly introduced to the history of the service user/survivor movement and mental health activism. Learning about the systematic oppression of people who are distressed and the struggles of this group to have a voice within mental health services was deeply uncomfortable but also had a powerful impact on me. This was further reinforced by the principles of critical psychology that my training has aimed to develop, exploring the ways in which the dominant culture, expressed through the work of psychologists, can undermine the ability of people to make their own meaning of their experiences. Reflecting on my previous roles, I began to see how power operated within these teams to keep service users silent. Complaints were

regularly met with scepticism and suspicion and often dismissed as part of the diagnosis the person had been assigned. Service user involvement was not included in any previous mental health training programmes I had undertaken and, in practice, was often viewed as an optional, special interest project amongst colleagues.

Training also introduced me to Trauma-Informed Care, both theoretically, in lectures, and in practice while on placement within various mental health teams. This approach shone a light on the potential for mental health services to re-traumatise people who use them, an acknowledgement which aligned with testimonies from the service user movement but which was rarely acknowledged within the teams I previously worked within. Again, reflecting on previous roles I had occupied, I regularly met service users who described their mental health within the context of traumatic experiences. However, these were often passed over in search of symptoms associated with the narrow diagnostic definition of Post-Traumatic Stress Disorder. By contrast, Trauma-Informed Care appeared to represent a broader and more nuanced understanding of traumatic experiences.

These two interests came together when I was invited to join a trauma-informed community of practice meeting. Within these meetings, various people, including those with lived experience of trauma and mental health services, met to update one another on their trauma-informed work and share experiences of implementing this approach. I found the meetings positive and motivating. Trauma-Informed Care, within these discussions, felt like a new way of working, which acknowledged the issues I was grappling with on training. I wondered about the people with lived experience within this group and what it was like for them to be involved and this became the starting point for my literature review.

1.3. Critical introduction to trauma

Trauma is a complex and multifaceted experience that has received significant attention and research in recent decades (Fernando, 2010; van der Kolk, 2014). While trauma is often viewed as a profoundly personal and individual phenomenon, it

is increasingly recognised as also being shaped by a variety of social, cultural, and political factors (Quosh & Gergen, 2008).

Since the late 17th century, the term 'trauma' has been used within medical science, typically to describe physical wounds from an external source, resulting in extensive shock or damage to the entire body system (Dalenberg et al., 2017). In the 20th century, the term was extended to refer not only to physical wounds but also to the psychological and emotional impact of catastrophic events (Figley et al., 2017), and the psychological experience of trauma was a central part of Freud's early psychoanalytic writings (1920; 1923). Within Western psychology, one important definition of trauma can be traced to the inclusion of post-traumatic stress disorder (PTSD) within early diagnostic manuals (American Psychiatric Association; APA, 1980). This was developed from observations of war veterans, beginning in World War 1 and descriptions of shell shock and continuing right up until the Vietnam War in the 1980s (Saigh & Bremner, 1999; van der Kolk, 2014). The current fifth edition of DSM (APA, 2013) subsumes criteria required for a PTSD diagnosis under the following headings: direct or indirect exposure to a distressing event; intrusive symptoms (e.g. nightmares, flashbacks); avoidance of distressing trauma-related stimuli (e.g. thoughts, feelings, places) negative alterations in cognition and mood; alterations in arousal and reactivity. Definitions of trauma PTSD have been expanded in subsequent editions of DSM. Diagnostic definitions of trauma have developed to include Type I, involving a single event, and Type II, or 'complex trauma, also referred to as complex-PTSD (C-PTSD), resulting from repeated exposure to extreme external events (Terr, 1991). DSM-5 (APA, 2015) also contains 'vicarious trauma', the first explicit statement that PTSD is possible even if the person has not personally experienced the threat or witnessed the event but instead was exposed to details, for example, as a professional.

Proponents of PTSD have also drawn on evidence from neuroscientific research to support it. Studies in this area have demonstrated the impact of traumatic events on the brain, including changes to the sensory systems, grey matter, neural architecture and neural circuits (Read, 2014). Biological explanations for PTSD have sought to

link it to individuals' genetics (Smoller, 2016) and focused on how the body's threat system, controlled by the amygdala, becomes primed to respond following a traumatic event (Pechtel & Pizzagalli, 2011). People who have experienced trauma are described as having a narrower 'window of tolerance', in which their threat system is constantly prepared for further trauma (Siegel, 1999; 2020). Psychological explanations for PTSD have also focused on internal processes, for example, exploring how traumatic memories are stored and the impact on the processing and integration of the memory (Brewin et al., 1996) or how individuals make sense of a traumatic event by filtering it through core beliefs about control, predictability, fairness, justice, luck and personal vulnerability (Foa et al., 1999). Other psychological theories focus on the individual's appraisal of the memories themselves and the extent to which these conflict with their pre-existing worldview (Beck, 1979; Ehlers & Clark, 2000). Developmental trauma theories have explored the impact of traumatic events on the relationship with primary caregivers and subsequent adaptive strategies developed to prevent harm (Bowlby, 1979; Crittenden, 2006). These theories have contributed to an understanding of some of the mechanisms underpinning trauma and PTSD and led to an influx of various trauma-specific therapies (Ehlers & Clark, 2000; Schauer et al., 2005; Shapiro, 1989).

As well as the individual, observable aspects of trauma, there is an increasing interest in how the experience is shaped by cultural, political, and societal factors (Archer, 2013; Quosh & Gergen, 2008). The majority of current PTSD and trauma research comes from Western societies, which are underpinned by several key values, including individualism and neoliberalism. Individualism is characterised by an independent view of the self, and actively pursuing one's wishes and needs is deemed important (Kwan et al., 2002). This ideology can shape how trauma survivors are expected to cope. Locating the problem within the individual and placing the responsibility on them to overcome their difficulties fails to consider the role of broader social and historical context (Barker et al., 2015). This individual view of trauma is compounded by the dominance of a Western medical model of distress. Critics of a medicalised PTSD construct of trauma suggest it frames it as an 'illness'

and uses scientific words to suggest permanence and solidity to the concepts which are unjustified (Boyle, 2011; Harper & Speed, 2014). Rather than viewing responses to traumatic events as natural human reactions, constructing them as PTSD risks pathologising the experience (Boyle & Johnstone, 2014). This may encourage individuals to internalise the problem and further aggravate trauma responses by encouraging victim-blaming narratives (Brown, 1995; 2013). Diagnoses such as PTSD also play a role in maintaining power structures. Psychiatry remains a dominant profession in many mental health settings, and by default, the main perspective becomes a medical one (Carey & Pilgrim, 2010). This clear hierarchy of power within services makes introducing an alternative explanation for distress challenging. Pharmaceutical companies profit enormously from a medicalised system for distress (Mazzucato et al., 2020) and maintain their grip on the mental health market in various ways, including non-funding of alternative treatments (Pilgrim, 2014), large-scale advertising campaigns (Main et al., 2004) and even sponsoring the definition of mental health problems (Read, 2008) in an apparent move to reconstruct distress for self-interest. For many people whose cultural identities are not of the Western mainstream, individual, medical constructs of trauma are imposed onto their experience to describe distress. This may conflict with cultural norms and undermine natural systems of responding to these events from within the community (Stamm & Friedman, 2000). Collectivist cultures may place greater emphasis on communal support and interdependence, which can provide a more supportive environment for trauma survivors (Triandis, 2001). In this way, psychology has been accused of being imperialist in its attitude towards other cultures and has colonised them, supplanting indigenous ways of thinking with Western ideas (Burr, 2015).

Actively shifting responsibility onto the individual for their difficulties has also been shaped by neoliberal ideology, a key feature of UK politics and the organisation of healthcare systems (Harper & Speed, 2012; Ramon, 2008). Neoliberalism is a political and economic ideology which emphasises individual responsibility and has seen the focus move away from social inequalities (Harvey, 2007). This ideology has encouraged a view of trauma in which the events become de-contextualised and de-

politicised and obscures systemic forms of oppression - such as racism, ageism, ableism, and sexism - which generally are overlooked within mainstream trauma psychology (Fernando, 2010). This is despite evidence that social inequalities, power and oppression play an important role in how trauma is constructed (Tseris, 2014; Quosh & Gergen, 2008). Hermen (1992) was among the first to criticise the diagnostic model of trauma as privileging the male experience of exceptional, violent events and thereby assuming that violence, oppression and harassment are not part of everyday experience. She pointed out that women experience everyday assaults on their integrity and personal safety, but these examples of pain tend to be overlooked in the male-orientated PTSD definition, which focuses on single events. Feminist critiques of the diagnosis of borderline personality disorder (BPD) (DSM-5) point out that it is applied predominantly to women and survivors of childhood sexual abuse, effectively pathologising and silencing their response to trauma and systematic oppression (Shaw & Proctor, 2005).

Intersectionality highlights the importance of considering all aspects of an individual's social identity, as these are experienced simultaneously rather than in isolation (Crenshaw, 1989). Looking at how oppression and trauma intersect with an individual's social identity has also been an important area of study. For example, a person who experiences trauma as a result of interpersonal violence may also face discrimination based on their race, gender, or sexual orientation, which can further impact their mental health and well-being (Josephson, 2002). Radical changes that address poverty, economic insecurity, poor housing, and systemic oppression are desperately required so that experiences of trauma are less prevalent. A recent World Health Organisation (WHO; 2022) report highlights the substantial evidence that social conditions that drive and sustain poor mental health are rooted in inequality (Pascoe & Richman, 2009; Pickett & Wilkinson, 2010) and urges greater attention be paid to the distribution of money, power and resources at global, national and local levels. This intersectional perspective underscores the importance of considering the complex interplay of social factors in shaping individual experiences of trauma. Those who hold privilege and social power may be more likely to have their experiences of trauma validated and supported. At the same time

marginalised individuals may face barriers to seeking help and accessing support (Kira et al., 2013). Traumatic events are often associated with experiences of powerlessness, victimisation, and loss of control, which social inequalities and injustices can exacerbate. For example, individuals who belong to marginalised groups such as women, minority ethnic groups, lesbian, gay, bisexual, transgender, queer/questioning, intersex (LGBTQI) individuals may be more vulnerable to experiencing trauma due to systemic discrimination and oppression (Hatch & Dohrenwend, 2007; Mohan et al., 2006). In the UK, however, there is evidence that people from minority ethnic groups are less likely to receive an assessment when compared with White British groups (Harwood et al., 2021). Of those who are assessed, minority ethnic groups were also found to be less likely to be offered talking therapy. This inequality also shapes the experiences of trauma by contributing to a 'cycle of fear' in which people from minority ethnic groups are less likely to come forward to support and more likely to receive restrictive and punitive treatments when they do (Bhui, 2001; Keating & Robertson, 2004).

Finally, the historical context in which trauma occurs is another important factor in understanding how it is constructed. Traumatic events such as war, genocide, and colonialism have long-lasting impacts on individuals and communities, shaping their collective memories and experiences of trauma (van der Kolk, 2014). For example, the legacy of colonialism and ongoing racism in the UK has had profound effects on the mental health and well-being of minority ethnic communities (Bansal et al., 2022; Chakraborty et al., 2010). The ongoing trauma of systemic racism and police violence has sparked movements such as Black Lives Matter, which seeks to address the root causes of trauma and advocate for social justice and racial equity (Cobb, 2017). Increasingly critical psychology definitions of trauma now call for attention to be paid to life-threatening processes and collective trauma such as colonialisation (Duran, 2007), traumatic effects of racism (Sue, 2003; Sue et al., 2007) and trans or intergenerational trauma (Milich & Moghneih, 2018). This highlights the interplay of historical trauma and contemporary social issues, demonstrating the enduring impact of past injustices on present-day experiences of trauma.

1.4. Definition of trauma

Although definitions of trauma are complex and contentious, for the purposes of this thesis, I will use the following definition put forward by the Substance Abuse and Mental Health Service Administration (SAMHSA; 2014), which is based on the three 'E's (p. 7):

'An 'event', series of events, or set of circumstances that is 'experienced' by an individual as physically or emotionally harmful or life-threatening and that has lasting adverse 'effects' on the individual's functioning and mental, social, emotional or spiritual wellbeing.'

This definition of trauma is commonly used within UK mental healthcare services and their approach to service delivery, including Trauma-Informed Care (Sweeney et al., 2016), an overview of which is provided later in this chapter. In this definition, trauma includes events and circumstances which may involve the actual or extreme threat of physical or psychological harm and may occur as a single occurrence or repeatedly over time. An individual's experience of these events or circumstances helps to determine whether it is a traumatic event, as a particular event may be experienced as traumatic for one person but not for another, depending on the meaning they attribute to it. SAMHSA acknowledge how traumatic events, by their very nature, set up a power differential where one entity (whether an individual, a group or an event) has more power over another. The individual's experience of these events or circumstances is shaped in the context of this powerlessness and linked to a range of factors, including the individual's cultural and religious beliefs, age, gender, race, sexuality and disability. According to SAMHSA, the effects of the event are perhaps the most critical aspect of trauma and may occur immediately afterwards or have a delayed onset. In some situations, the individual may not recognise the connection between traumatic events and their effects. Traumatic effects can include being in a constant state of arousal and high alert, experiencing flashbacks, feeling numb, and being worn down physically and emotionally.

Critics of SAMHSA's definition of trauma suggest it is so vague and all-inclusive as to trivialise severe mental health difficulties, diverting attention from the clinical needs of the most vulnerable and highly traumatised (Birnbaum, 2019). It is argued this definition of trauma also risks conflating the event with the experience of trauma, thereby mixing up the objective and subjective aspects, something which is noted by those with experience in implementing trauma-informed care (Krupnik, 2019). However, this broader definition of trauma may capture more of the nuance in the range of traumatic experiences and represent a departure from the tight conceptual brackets of trauma as defined by the PTSD diagnosis (APA, 2015). For the purposes of this study, a definition that is commonly used within Trauma-Informed Care projects was adopted to ensure a shared understanding of what is being referred to.

1.5. Trauma-Informed Care

Trauma-Informed Care (TIC) was first described by Harris and Fallot (2001) as a model for mental health service delivery, which recognises that high numbers of people who use these services are trauma survivors, and without awareness of this, services are at risk of re-traumatising – meaning to become traumatised again – and exacerbating their difficulties. In what they termed 'a vital paradigm shift' for mental health services (p. 3), TIC seeks to incorporate an understanding of trauma, including its consequences and the conditions that enhance recovery, into all aspects of service delivery and is distinct from trauma-specific services which provide therapies designed to treat PTSD.

Key to this approach is how trauma is understood. Traditional approaches to trauma tend to understand it as a single event, which is typically diagnosed as PTSD. However, in TIC, a more nuanced view of trauma is taken, which recognises it can be a defining and organising experience that can come to form the core of an individual's identity. A fundamental shift in TIC is moving from thinking 'What is wrong with you?' to considering 'What has happened to you?' with the emphasis on

understanding the whole individual and appreciating the context in which the person is living their life, rather than looking to label and pathologise a particular symptom. Services need to be aware of the dynamics that characterise abusive relationships and make sure those dynamics are not inadvertently replicated. Trauma-informed services are strengths-based and focus on identifying the capacities people have to use to survive, with the goal of returning a sense of control and autonomy to the person.

In traditional services, service users are seen as passive recipients, and the providers are assumed to possess superior knowledge. Within trauma-informed services, however, both parties are acknowledged for bringing valid sources of information and expertise to the relationship. These relationships are based on openness and genuine collaboration, meaning that service users choose where, how and when they will receive support. Crucially, they also have an active voice in the design and development of services, so their knowledge can be included. Harris and Fallot (2001) acknowledge that these changes might be challenging for some teams and that they require a commitment from the organisation. The service provider must be clear about what they can and cannot do. By eliminating ambiguity and vagueness, over time, services can take steps to establish trust with trauma survivors. They provide examples of how services might adopt these changes, such as universal screening practices, training and education for practitioners, hiring trauma champions who think 'trauma first' and reviewing policies and procedures.

TIC is informed by research from various fields, including neuroscience, psychology, and social science (Sweeney et al., 2018). It reflects the growing acknowledgement that individual, interpersonal, and collective trauma is a highly prevalent public health problem (Magruder et al., 2017). Current understandings of the prevalence of trauma were advanced by a major retrospective study of over 17,000 predominantly White middle-class Americans (Felitti et al., 1998). Researchers found that two-thirds of respondents reported having experienced what they defined as an 'Adverse Childhood Experience' (ACE), for example, physical or sexual abuse, physical or emotional neglect and family dysfunction. Although the study has received criticism

for the experiences that were absent (Anda et al., 2020), the results were nonetheless significant in that they revealed that traumatic experiences were far more common than expected, highlighting what has since been described as 'a hidden epidemic' (Van der Kolk, 2014. p. 172).

Similar results have since been reported in England, with a household survey revealing that nearly half of the adults interviewed had experienced at least one ACE (Bellis et al., 2014). Experiences of trauma and adversity also regularly occur in adult life (Benjet et al., 2016), and research which have adapted the ACE items to consider adult experiences of trauma have found that lifetime exposure rates are even higher than previously thought, with some estimates over 90% (Stumbo et al., 2015). It has been suggested that traumatic experiences are often lost in time and concealed by shame, secrecy and social taboo (Felitti et al., 2009). A lack of recognition of the experiences of trauma among mental health professionals is supported by research, which highlights that the majority of trauma survivors are not directly asked whether they have experienced childhood abuse or neglect (Read et al., 2018).

The ACE studies have been significant in highlighting that these types of childhood experiences are prevalent and influence an individual's physical, mental and emotional health as an adult (Felitti et al., 1998; Felitti, 2009). For example, higher numbers of ACEs are associated with higher rates of adult obesity, heart disease, cancer, stroke, diabetes, depressive symptoms, suicide attempts and drug addiction. The effects of traumatic experiences are also cumulative, meaning the more a person is exposed to the greater the impact on mental and physical health (Felitti et al., 1998; Shevlin et al., 2008). These findings support research which has consistently found that people using mental health services have experienced high rates of trauma in childhood or adulthood (Kessler et al., 2010) and are associated with a range of difficulties, including PTSD (Mauritz et al., 2013); psychosis (Read et al., 2005); substance misuse (Carliner et al., 2016); depression and suicidality (Felitti et al., 1998), as well as higher levels of prescribed medication (Read et al., 2001); and more frequent hospital admissions (Mullen et al., 1993).

TIC builds on this research by assuming that the majority of people who use mental health services are trauma survivors and aims to treat everyone in a way which is most likely to be growth-promoting and least likely to be re-traumatising (Elliot et al., 2005). Mental health professionals are often fearful of asking people about historical or current trauma due to concerns about causing distress or vicarious trauma (Read et al., 2007). However, this avoidance has the potential to silence a vital aspect of a trauma survivor's experience and deny them an opportunity to connect this with their current mental health. Within TIC services, people are sensitively asked about their traumatic experiences and supported to make sense of these in terms of their current difficulties (Harris & Fallot, 2001). Interestingly, many members of the public already believe that trauma plays a causal role in mental health difficulties (Read et al., 2013). Framing reactions to trauma as coping strategies can help challenge stigma (Johnstone & Boyle, 2018; Reis et al., 2019), and within TIC, practitioners are supported to understand the distress and fears that underlie certain 'challenging behaviours' as a means of expressing needs (Sweeney et al., 2018).

Social inequalities also compound the experience of trauma. Those who are more marginalised, for example, people experiencing socio-economic disadvantage, women, minority ethnic groups and the LGBTQI community, are disproportionately affected by violence and trauma (Hatch & Dohrenwend, 2007; Mohan et al., 2006). TIC aims to move beyond narrow definitions of trauma and acknowledge how forms of systemic oppression and their intersectionality shape the experiences of trauma survivors (Sweeney et al., 2018). By viewing trauma events and the experience more broadly, its relevance extends beyond traditional trauma-specific services and becomes applicable to many human services, for example, physical health, education and schools, forensics, housing and social care (Cole et al., 2013; Havig, 2008). Trauma-informed mental health services are also strengths-based in that they reframe complex behaviour in terms of its function in helping survival and as a response to situational or relational triggers (SAMHSA, 2014). Rather than understand trauma as solely producing psychopathology, it is more helpful in clinical practice to conceptualise the traumatic experience as a process that triggers a

transformation or metamorphosis that evokes both strengths and vulnerabilities (Rousseau & Measham, 2007).

Research indicates that experiencing trauma in childhood can have a significant effect on neurodevelopment, making threat responses more easily triggered, and compromising the ability of trauma survivors to soothe themselves (Read, 2014; Van der Kolk, 2014). Experiencing trauma can also have a huge and devastating impact on interpersonal relationships by undermining a sense of safety and trust in others (van der Kolk, 2005). For example, multiple studies have highlighted the impact that traumatic events have on the perceived level of trust in relationships (Bell et al., 2019; Doyle & Cicchetti, 2017; Gobin & Freyd, 2014) and make accessing suitable support more challenging. There is evidence that experiences of mental health services can re-create these experiences. The use of 'power over' relationships between staff and service users become common and replicates a sense of powerlessness experienced by trauma survivors (Sweeney & Taggart, 2018). In these organisations, the needs of the service users can become secondary to the needs of the staff, and restraint and coercion may become widely used even when less restrictive options are available. Other working practices, such as rigid hierarchies and lack of supervision, can dehumanise service users to the point that human rights violations occur (Morgan & Paterson, 2019). Other examples of retraumatisation within mental health services include coercion, body searches, forced medication, round-the-clock observations, exposure to violence, physical restraint, and seclusion (Frueh et al., 2005; McKenzie & Bhui, 2007; Robins et al., 2005). Feeling powerless and unsafe only increases trauma survivor's fear, aggression and associated defensive mechanisms. Healthcare practitioners can also feel unsafe and, in turn, respond with more restrictive, authoritarian measures. Trauma-informed organisations assume that everyone accessing support has had traumatic experiences and, as a result, may find it difficult to feel safe within services and to develop trusting relationships with service providers (SAMHSA, 2014). Consequently, services are structured, organised and delivered in ways that promote safety and aim to avoid re-traumatisation. Developing relationships built on trust,

empowerment, transparency, choice and control become the bedrock of TIC services (Sweeney et al., 2018).

As well as being re-traumatising for trauma survivors, mental health systems can also be traumatising for practitioners who work in them. Working with traumatised people can be highly distressing for practitioners (Sabin-Farrell & Turpin, 2003) and lead to vicarious trauma (Ham et al., 2022; Sodeke-Gregson et al., 2013). Many people working in healthcare roles have lived through trauma experiences that are similar to those of service users (Bloom, 2006; Dheensa et al., 2023) and witnessing their inhumane treatment can stir up their trauma histories. Working in these challenging environments can lead to compassion fatigue and burnout, limiting their ability to empathise and support others (Schauben & Frazier, 1995). Mental health systems may also inflict 'moral injury' on practitioners by requiring them to work in ways that conflict with personal and ethical codes of conduct, eroding away their sense of providing compassionate care (Litz et al., 2009). Within a TIC service, healing thus becomes just as relevant to staff as it is to service users, making the provision of staff training, supervision and support of utmost importance (SAMHSA, 2014).

1.6. Principles of Trauma-Informed Care

Harris and Fallot's (2001) original descriptions of TIC have since been developed by SAMHSA (2014), who define it using four key assumptions, referred to as the four 'R's, which are described below.

According to SAMHSA, within a trauma-informed approach, all people at all levels of the organisation have a basic *realisation* that experiences of trauma are pervasive amongst people who use services. A TIC organisation understands how trauma can affect families, groups, organisations, and communities as well as individuals. Within a TIC approach, people's experiences and behaviour are understood in the context of coping strategies designed to survive overwhelming circumstances.

TIC also *recognises* that the experience and effects of traumatic events go beyond the narrow definition of PTSD and its symptom list and is aware of the signs of trauma in people, families, practitioners and others involved in the system. Trauma screening and assessment assist in the recognition of trauma, along with training and supervision.

A trauma-informed service *responds* by integrating this knowledge about trauma into policies, procedures and practices. A service should consider how this knowledge about trauma can be applied by everyone, whether directly or indirectly. Applying this knowledge, for example, could include providing a physically and psychologically safe environment or incorporating the perspectives of people with lived experience through establishing service user participation groups.

Finally, TIC seeks to *resist re-traumatising* people who use services, as well as the people who work in them. Organisations can inadvertently create stressful or toxic environments that increase distress for people who use them and cause further harm (Cusack et al., 2018). Re-traumatisation – meaning to become traumatised again – often results from services responding to peoples' experiences of trauma in a way that not only fails to support them but replicates and reinforces this trauma (Bloom, 2006; Sweeney et al., 2018).

As TIC has developed, various interpretations of the fundamental principles have been put forward. Developed in the US, Elliot et al. (2005) put forward ten principles of Trauma-Informed Care adapted for services that support women. These draw on research which highlights how large numbers of women who experiencine difficulties with alcohol or drugs have also experienced domestic and sexual violence (El-Bassel et al. 2000) and strategies survivors develop for self-protection combined with symptoms of trauma make accessing support more challenging. Building on the work of Harris and Fallot (2001), this interpretation of the trauma-informed principles highlights how experiences of trauma for women are often not isolated, one-off events. Instead, they emphasise how experiences of violence and victimisation for women have a broad impact, affecting their identity, relationships, expectations of

themselves and others, and ability to regulate emotions. Their model aims to create a safe, respectful service environment that validates women's traumatic experiences. In doing so, they aim to maximise their choices and sense of control over the support they receive.

Also developed in the US, the Sanctuary Model (Bloom, 2006) is a blueprint for organisational change that aims to create a trauma-informed therapeutic community. The Sanctuary Model was initially developed for adult trauma survivors in short-term inpatient services, but has since been adapted for a variety of healthcare settings (Saunders et al., 2023). This model emphasises the parallel process between trauma symptoms experienced by people who use services and within the organisation. Organisations committed to working with traumatised individuals face enormous stress and unfavourable financial, regulatory, social and political environments, meaning that these systems are at risk of becoming 'reactive, change-resistant, hierarchical, coercive and punitive' (Bloom & Sreedhar, 2008. p. 13). This means they frequently replicate the very traumatic experiences that the people they are supposed to treat have endured. Instead, the Sanctuary Model focuses equally on the experience of people using services and the people and systems who provide support and provides steps to create a culture within services based on the principles of non-violence and democratic decision-making.

In the UK, most nuanced and helpful description of TIC comes from Sweeney et al. (2018). Their principles include an appreciation of 'invisible trauma', which recognises the role of community, social and historical traumas such as racism, poverty, sexism and homophobia. They also include 'survivor partnerships' as a crucial principle within the TIC framework. They describe how mutual and collaborative relationships with people with lived experience are critical to all aspects of the work. In addition, they also propose that services can be led and delivered by people with lived experience of trauma, going further than previous implementation guides on the level of involvement that this group should be afforded (see Appendix A).

For the purposes of this study, however, I have referred to the six principles of TIC described by SAMHSA (2014), which are most referenced within UK TIC projects (Bush, 2018; Saunders et al., 2023). These include:

- Safety: Central to trauma experiences are threats to the person's safety. It is
 essential, therefore, that people who use services need to feel physically and
 psychologically safe throughout the organisation. This means the physical
 setting is safe, and interactions promote a sense of safety, in a way that
 is defined by service users.
- Trustworthiness and transparency: Trauma-informed services make decisions
 transparently to all those involved, with the goal of building and maintaining
 trust. A focus on openness, transparency, and respect is essential, as many
 trauma survivors will have experienced manipulative relationships that include
 a lack of trust.
- 3. Peer support: Trauma-informed services aim to encourage supportive relationships and mutual self-help between trauma survivors. They utilise their stories and lived experiences to promote recovery and wellbeing.
- 4. Collaboration and mutuality: Instead of traditional hierarchies, TIC aims to address power differences between healthcare practitioners and trauma survivors through shared decision-making, transparency and authenticity. This is important as power imbalances can reinforce a sense of helplessness in trauma survivors.
- 5. Empowerment voice and choice: Trauma survivors often experience a lack of power and control in their lives. Instead, TIC aims to empower them, for example, by using strengths-based approaches that focus on ways of coping rather than symptoms, to support individuals to take control of their lives.

6. Cultural, historical, and gender issues: TIC aims to leverage the healing value of traditional cultural connections and offer access to gender-responsive services. It should recognise historical trauma and develop policies, protocols, and processes that are responsive to the racial, ethnic, and cultural needs of trauma survivors.

1.7. Implementing Trauma-Informed Care in the UK

Over the past twenty years, TIC has been widely adopted in US health systems and supported by national policy and funding infrastructure (Brinbaum, 2019). While TIC, in practice, looks different for each service aiming to introduce it, implementation in the US has typically focused on introducing changes focused on training the workforce, trauma screening, and service development (Melz, 2019). Most research focused on evaluating trauma-informed services has been preliminary and typically confined to acute and residential services (Saunders et al., 2023). Adopting a trauma-informed approach is linked to a reduction in seclusions and trauma symptoms, increased coping skills, improved physical health, increased treatment retention, and shortened inpatient stays (Azeem et al., 2018; Gatz et al., 2007). However, less is known about the impact of community-based services (Saunders et al., 2023). It is argued that most research on TIC remains theoretical (Raja, 2015) and that there remains little systematic research on the content or quality of trauma-informed training (Emsley et al., 2022).

While TIC was developed in the US, it is increasingly being adopted by UK mental health services and policymakers (Sweeney et al., 2016). It represents a key element of several National Health Service (NHS) and Public Health strategy documents, including the NHS's Long-Term Plan (2019) and Mental Health Implementation Plan (2019). Within the US, it is recognised that significant amounts of time and resources are required to make the necessary organisational and cultural changes. TIC has been supported by the emergence of a massive TIC training industry and funding for SAMHSA (Birnbuam, 2019). In the UK, however, public services remain under-resourced, and there remains concern about whether

implementing TIC in this context carries all the risk of harm associated with that system, but with the added gaslighting of framing it as trauma-informed harm (Saunders et al., 2023).

In recognition of the need for adequate resources to be allocated, Scotland has been leading the way in embracing TIC, with the Scottish Government (2018) adopting a unified national strategy to create a trauma-informed workforce and implementing a National Trauma Training Programme (NTTP; 2020). Further evidence of the widespread adoption of TIC comes from Scottish policy, which recommends that everyone should have a basic knowledge of the principles, even those without a remit, to work with people known to be affected by trauma (NHS Scotland, 2021). Similarly, a recent NHS (2024) commissioning framework for mental health inpatient services includes TIC as one of four fundamental principles, with 'all therapeutic interventions and activities' (p. 17) required to be trauma-informed.

'Implementation' is a term commonly used within TIC literature to refer to the process of putting the assumptions and principles into effect. Various implementation guides for TIC have been published, with some generic and relevant to all services (Harris & Fallot, 2001; NTTP, 2020; SAMHSA, 2014; Trauma Informed Oregon, 2018), some for specific services (Bloom & Sreedhar, 2008; Huckshorn, 2004) and one aimed at assessing and measuring the extent to which a service is currently trauma-informed (Thirkle et al., 2021; 2022). Thirkle et al. (2022) recommend that organisations seeking to implement TIC should interpret and operationalise the principles based on their own settings and needs. As it is a service-level intervention, all members of the organisation should be invited to be part of the change in order for it to be beneficial; it must not be imposed upon individuals but rather emerge from discussions between people who are employed and those who use the service. As TIC invites change across the entire service, it typically involves a range of different activities, for example, TIC training for teams, utilising tools to explore current practice and identify strategies for improvement, running workshops and stakeholder events, forming working groups to co-produce plans for trauma-informed service delivery and their implementations (Harris & Fallot, 2001; NTTP, 2020). Community of practice also

offer useful spaces for networking, shared learning and reflection on examples of good practice, such as those published by Bush (2018).

1.8. Experience of implementing Trauma-Informed Care in the UK

As TIC is increasingly becoming part of the fabric of UK mental health services, a small number of studies have explored what it is like for the people occupying a traditional professional role to implement this approach. The term 'staff' is often used to refer to this group in the literature and was originally included in this study's proposal and documents. However, as the study progressed, I felt increasingly uncomfortable about the hierarchy this term implies and the superior expertise of people who have received professional training (Stickley, 2006). Although some participants have used the term 'staff', this may be influenced by the wording of questions, and this study will use the term 'practitioner' or 'members of the wider team' to refer to this group instead.

Vaswani and Paul (2019) interviewed 200 prison practitioners who had adopted a trauma-informed approach and found it led to increased empathy towards service users. Instead of remaining detached from them, the new approach encouraged them to take a more humanising view of the service users, which in turn nurtured better relationships. Along similar lines, Stamatopoulou (2019) spoke to 20 practitioners working in an inpatient forensic unit about their experience of transitioning to a trauma-informed service model and found they were more curious about the stories of service users, which enabled them to look beyond simple diagnostic labels. Participants were able to reconnect with the values of empathy and compassion, which they had held close earlier in their careers. This supports claims that TIC has the potential to lead to a fundamental shift in how mental health services are organised and delivered (Sweeney & Taggart, 2018).

However, other studies have highlighted some considerable challenges whilst attempting to implement TIC. Sweeney et al. (2016) summarise the experience of several key practitioners working across NHS services to implement TIC and report

that amongst their colleagues, there remains strong resistance to the notion that trauma plays a causal role in mental health difficulties, with medical explanations such as genes, neurology and diagnosis seen as more important. Similar findings were reported by Clark (2021), who interviewed 15 mental health colleagues about their experience of advocating trauma-informed changes and found that it was often difficult to challenge the medical model. Harris and Fallot (2001), in their original description of TIC, highlight the need for 'commitment to change' (p. 5) and from within services and that they 'question the reasonableness of doing things in the usual way' (p. 20) before any actual changes are introduced. The idea that TIC represents a novel approach for certain members of the wider team is supported by Stamatopoulou (2019), who found that transitioning to TIC was experienced by mental health practitioners as a 'paradigm shiff' (p. 101) and those involved underwent a process of 'reconstructing their professional identity' (p. 82) which involved unlearning how they viewed service users and themselves as professionals.

The continual change and upheaval within UK public services could also make practitioners weary of new initiatives and become a barrier to TIC being implemented (Sweeney et al., 2016). Like this, Stamatopolou (2019) found a context of limited resources and high workloads for practitioners frequently left them emotionally drained while implementing TIC and raised concerns about how sustainable the work is for those involved. More recently, Emsley et al. (2022) interviewed 11 senior practitioners from across NHS, private and charity organisations about their experience of implementing TIC. They identified several barriers to the work, including an unsupportive organisational culture, low staff morale and resistance to new initiatives, all of which could leave TIC at risk of becoming a 'box-ticking' exercise (p. 9). Similarly to this, Sweeney et al. (2016) suggest that without a system-wide change within services, TIC is at high risk of co-optation, meaning that mainstream implementation could become tokenistic, fragmentary and divorced from the core principles.

Concerns about the emotional impact of implementing TIC were also raised by several studies. Clark (2010) reports that battling against systems to introduce TIC

was exhausting and could lead to 'burnout' (p. 67) for practitioners. The emotional intensity of implementing TIC was also noted by Vaswani and Paul (2019), who found this approach connected practitioners more strongly with the trauma of the young people and, in doing so, often stirred up their own experiences of trauma. Sweeney et al. (2016) also observed that TIC invites practitioners to acknowledge and bear witness to the trauma stories of service users. Without adequate support, however, they suggest the reality of peoples' suffering can become overwhelming and even traumatising for those involved. It is concerning that supervision was not available for many people undertaking this work (Sweeney et al., 2018; Vaswani & Paul, 2019) despite it being identified as essential within several implementation guides (SAMHSA, 2014; Sweeney et al., 2016). As resources for teams are stretched further and morale within health professions lower, engaging with new initiatives like TIC becomes more challenging.

These studies shed some light on what it is to implement TIC within the UK. However, most research so far has focused on the perspective of practitioners employed and working within services rather than people identified as having lived experience of trauma and mental health services.

1.9. Experts by Experience

Working in partnership with people with lived experience of healthcare services and/or who identify as a trauma survivor is a key element of how TIC is implemented (Harris & Fallot, 2001; SAMHSA, 2014). Practitioners and people with lived experience both bring valid sources of information and expertise, and specific guides are available to ensure this dynamic itself remains trauma-informed (Blanch et al., 2012). Various terms – 'people with lived experience', 'trauma survivors', 'peer support workers' – have been used to refer to people with direct experience of trauma and mental health services (Chassot & Mendes, 2015). Although all terms have their value, 'Experts by Experience' will be used in this project as I feel it promotes a relationship of equals with professionals, whereby one's expertise

has been accrued through training and the other through lived experiences (Toikko, 2016).

Historically, there have been limited opportunities for people who are labelled as 'mentally ill' to be heard within society (Pilgrim & Treacher, 1992). It is argued their experience and knowledge have been 'subjugated' (Foucault, 1980), with the medical model able to dismiss their voice as part of the diagnosis attributed by mental health practitioners and thus allowing certain power structures to remain unchallenged (Campbell, 2008). It was against this backdrop that the UK service user/survivor movement developed in the 1970s, with inspiration taken from the civil rights movement (Rogers & Pilgrim, 1991). A central value of the service user/survivor movement is that lived experiences are valued on par with professional expertise and no longer denigrated as flawed by mental illness (Campbell, 1985). Other key aims of the movement include promoting individual and collective rights, voicing their views about the psychiatric system, creating alternatives to mainstream mental healthcare services, and developing support groups or user-led services (Chassot & Mendes, 2015).

As a result of this action, within the UK, NHS services now have a statutory responsibility to work in partnership with people and communities to design, deliver and evaluate their services (NHS Constitution for England, 2013; NHS England, 2023), and Experts by Experience are increasingly employed by services to support them with this (Repper & Carter, 2011). 'Co-production' is a term commonly used to describe work undertaken by Experts by Experience and services that is done in equal partnership, a process of empowering citizens and providing opportunities for their active participation in service development and delivery (Carr, 2018). It is a model of service development which ostensibly aims to challenge the dominance of professionals in public sector organisations by putting people who use services at the heart of the planning and delivery of services (Boyle et al., 2006a; Boyle et al., 2006b).

Several co-production guides have been published with the aim of ensuring that the involvement of people with lived experience is meaningful (National Service User Network, 2015; Ocloo & Mathews, 2016; Slay & Stephens, 2013), however, the nature of how people are invited to participate in co-production remains contentious (Cowden & Singh, 2014). Arguably, co-production was originally conceived as a means for altering the distribution of power or who makes decisions (Beresford, 2003). This requires a culture shift within services where the traditional hierarchy between practitioners and people who use services should be flattened and control shared equally (Boyle & Harris, 2009). The level of participation that people who use services are afforded can be evaluated using tools such as Arnstein's (1969) Ladder of Participation, with each rung representing increasing levels of agency, control and power. This continuum of participatory power moves from nonparticipation to degrees of tokenism and degrees of citizen power at the upper levels. Increasingly, however, services have shifted towards a 'managerial/consumerist' model of coproduction, essentially a non-political technique, which aims to improve services by gathering information from people with lived experience, but a model in which power structures remain unchallenged (Beresford, 2002).

Whilst the topic is too large to do justice here, studies that have explored the experience of co-production for Experts by Experience within the UK reveal that it can often be complex and nuanced (Gillard et al., 2013). For example, a largescale review of the experience of peer support workers in the UK found that involvement in service development was associated with sense of empowerment, hope and improved self-esteem (Repper & Carter, 2011). Participating in co-production projects alongside other people with lived experience and allies can provide a sense of solidarity for Experts by Experience and connect them to a bigger purpose beyond themselves, helping to shield the next generation from the painful experiences they had experienced (Waddingham, 2021). It can promote a sense of independence and empowerment (Ochocka et al., 2006) and allow people to practice a new identity different from mental health patients (Mead et al., 2001). Co-production can also help reduce the stigma experienced by professionals and the wider community,

partly through mutual work and the eroding of boundaries between people who use services and practitioners (Slay & Stephens, 2013).

However, there is evidence that co-production can also come with considerable challenges for Experts by Experience. Peer support workers also report being frequently viewed as having lower status by their colleagues and differences in are not adequately addressed (Repper & Carter, 2011). Drawing on their lived experience may require they revisit the most raw and painful parts of their life, whether explicitly shared or not, and leaves Experts by Experience at risk of being pathologised and sidelined if they do decide to share this (Waddingham, 2021). Despite the guiding principles of co-production, Experts by Experience remain subjected to stigmatised attitudes by health professional colleagues in their roles and uncooperative ways of working, leaving them at risk of feeling disrespected and their unique expertise undervalued (Byrne et al., 2017). Certain 'appropriate' Experts by Experience tend to be handpicked, with middle-class, White service users well represented (Ocloo & Matthews, 2016), despite research highlighting how more marginalised groups, such as those from minority ethnic backgrounds, are overrepresented in the most restrictive and traumatising parts of UK mental health system (Bhui, 2001; Bhui & Bhugra, 2002). Whilst co-production is meant to be an equal partnership and involve the flattening of power structures, Experts by Experience who are invited to participate are often only involved at the surface level of decision-making and are frequently expected to work within existing structures (Tritter & McCallum, 2006). They report being manipulated and used to create a veneer of credibility for a project whilst having little access to meaningful decisionmaking (Waddingham, 2021).

Co-production shares many similarities with the TIC principle of working in partnership with Experts by Experience, and perhaps represents an opportunity for empowering relationships and equal partnership. However, the repeated issues of how Experts by Experience are invited to undertake co-production raises questions about what it is like for them to be involved in implementing TIC. This question seems particularly pressing given the challenges raised by practitioners involved in

implementing TIC and the fact that Experts by Experience will be required to draw upon experiences of trauma within this work. To better understand what it is like for Experts by Experience to implement TIC, a systematic review of the literature was completed, identifying three relevant studies.

1.10. Literature search

Between September 2023 and April 2024, an exhaustive literature search was conducted to develop an understanding of the research related to Experts by Experience and the implementation of TIC.

EBSCO, an international online database resource, was initially searched using narrow search parameters. The reference lists from retrieved papers were manually searched for other relevant papers, which were then cross-checked against the initial search results. If these papers were not found, additional search terms were considered, and the search parameters were broadened to ensure no relevant publications were missed. Gradually, an index of relevant search terms was built up.

The following databases were then searched: EBSCO, PubMed, CINAHL and PsychINFO. Searching multiple databases is advisable to include the maximum potentially suitable studies (Bramer et al., 2017). These databases were selected after being identified as having a relevant focus for healthcare interventions (Bartolucci & Hillegass, 2010) and were searched by other TIC studies (Saunders et al., 2023).

The following search terms were used:

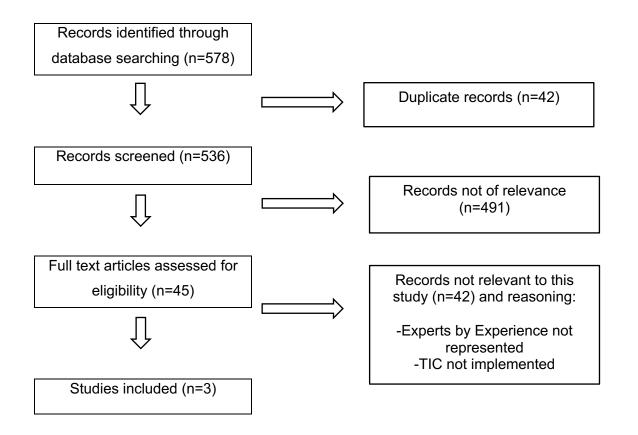
('expert by experience' OR 'lived experience' OR 'peer support' OR 'peer worker' OR 'peer advocate' OR 'survivor' AND 'trauma-informed care' OR 'trauma informed care' 'trauma-informed approach' OR 'trauma-informed approach' OR 'trauma-informed service' OR 'trauma-informed practice' OR 'trauma-informed practice' OR 'trauma-informed practice' OR 'trauma-informed practice' OR 'TIC' OR 'TIA' AND 'co-produce' OR 'co-production' OR '

design' OR 'participatory' OR 'partnership design' OR 'cocreation' OR 'co-creation' OR 'involvement' OR 'user led' OR 'user-led' OR 'peer led' OR 'peer facilitated')

The search yielded 578 results. The titles and abstracts of these results were read and filtered for relevance to the research aims. Where titles/abstracts did not provide sufficient information, full papers were accessed and checked. Only three publications specifically considered what implementing TIC is like for people with lived experience of mental health. The other 42 papers were retained and used as contextual information for the research. This process is summarised in Figure A.

The three papers of direct relevance are reviewed in detail below.

Figure A – *Literature search flow diagram*



1.11. Search results

Kahan, Lamanna, Rajakulendran, Noble & Stergiopoulos (2020)

Kahan et al. (2020) interviewed various stakeholders who had either been involved in development and facilitation of a group based on TIC principles within a Canadian homelessness team or had been recipients of the intervention. This included service providers, service users and three Experts by Experience. Semi-structured interviews were undertaken with participants and the data analysed using an inductive thematic analysis by three researchers. Their aims were to examine a range of perspectives on the intervention and whether it was implemented and experienced in accordance with the original goals.

Experts by Experience reported uncertainty in their role within the TIC project and that they were more passive than anticipated. Overall, participants also reported that the TIC group invited disclosures of personal trauma from people attending. These were experienced as distressing, and those facilitating the groups felt unsure of how best to respond, resulting in service users being asked to not share details of traumatic experiences as the group developed.

The researchers appear to have been separate from the TIC project, which supported participants in speaking more openly about their experiences and improving the validity of the findings. However, the findings are limited in what they can tell us about the overall experience of Experts by Experience involved in TIC work. Firstly, the data for all 19 participants were analysed together in this study, making it hard to understand the specific perspective of Experts by Experience. It also needs to be clarified the number of Experts by Experience involved in the development and facilitation of the TIC project and to what extent the three participants interviewed are representative of their experiences. Generalising the results is also limited, given the small sample size. Also, this study was undertaken in Canada, which makes generalising the findings to the UK difficult, as the two countries have vastly different healthcare systems (Cazzaniga, 2022).

McGeown, Potter, Stone, Swede, Cramer, Horwood, Carvalho, Connell, Feder & Farr (2023)

In the UK, McGeown et al. (2023) interviewed four Experts with Experience involved in the development of a primary healthcare intervention based on TIC that is aimed at improving access to primary care for people with a history of complex trauma. The research aimed to understand what it is like to co-produce a TIC project and ensure that relationships remain safe and collaborative. Four of the 29 women involved in the TIC project were interviewed, and the data was analysed against the SAMHSA (2014) trauma-informed principles.

Participants noted that having the support of other Experts by Experience within the group was 'healing' for them (p. 1905) but that hearing personal experiences of trauma from other Experts by Experience could be 're-triggering' (p. 1905) and counterproductive to the work. Existing hierarchies and unacknowledged power dynamics meant that some participants felt unable to disagree with ideas suggested by professionals and engaged in work they did not feel comfortable undertaking. Unacknowledged differences in power contributed to some Experts by Experience feeling let down and frustrated. Like Kahan et al. (2020), the group decided to focus less on experience-sharing and more on developing bespoke service improvements. However, the decision to feed this back took some separate discussions among the Experts by Experience. From their discussion with participants, the authors also reflected on how sharing details of their own lives could help reduce power differences and engender a sense of equality and community in the group. The blurring of roles, which is encouraged in co-production (Boyle et al., 2010), presented a dilemma, as from a trauma perspective, the authors feared a lack of consistency could destabilise and impair trust.

This study begins to highlight some of the complexities and nuances for Experts by Experience involved in implementing TIC in the UK and, along with Kahan (2020), also identified the challenges of how lived experience is used within this approach. Again, however, there are limitations to what these results can tell us about the overall experience of Experts by Experience involved in TIC projects. Four

Experts by Experience represents a small sample size, and their experiences come from within one TIC project, which makes generalising these findings beyond this project challenging. It is unclear to what extent these four participants are represent the overall 29 women who were involved in the project. It is possible that by self-selecting to participate, there is a positive bias in their experiences compared to the other women's. Participants were also interviewed about their experience by two researchers involved in the TIC project. This dual role may explain why uptake for the research was limited, as participants who experienced challenges within the work may be less likely to participate and share these concerns with the researchers. Those who do participate may also feel restricted in the types of experiences they can share, which raises questions as to whether the results of this research as more positive than the overall experience of the women involved.

Feedback from the four participants was also combined with interviews with five practitioners involved in the TIC project and reflective notes and observations from the various practitioners involved. This data was then analysed all together. The majority of data comes from participants who are not Experts by Experience, making it difficult to establish the findings that are specific to them. Analysing the data against the TIC principles helped link the findings to this overarching framework and offer suggestions for how these can be applied during the implementation process. However, by taking a top-down approach, the researchers may have overlooked emerging themes which do not fit with the established TIC framework and may have inadvertently narrowed the scope of the analysis (Braun & Clarke, 2022b).

Edelman (2023a)

Based on their involvement in TIC projects from within the UK, Edelman (2023a) shared several observations about the work. Although written from a practitioner's perspective, they highlight the potential negative impact this work can have on Experts by Experience. Edelman points out that TIC projects are often implemented in a way which fails to 'model the model' (p. 2), meaning undertaken in a way that itself is not trauma-informed. They felt practitioners could misinterpret the TIC mantra of 'What's happened to you?' (Harris & Fallot, 2001) as meaning they should

encourage detailed personal stories of trauma from Experts by Experience. While this may have the intention of being helpful, in reality, this risked re-traumatising those involved and reflected a common 'misconception' of TIC reported elsewhere (Sweeney & Taggart, 2018). Edelman also observed how discussions of trauma and other distressing topics often failed to provide adequate 'trigger warnings', highlighting potentially distressing material to those involved. They felt this risked invertedly reconnecting people with their lived experience and inducing a sense of shame if they did remove themselves or become triggered.

This study offers some helpful observations on the challenges of implementing TIC projects within the UK for Experts by Experience. It provides a more detailed description of how this work could add to the distress of people with lived experience. However, this is one mental health practitioner's perspective, and it is unclear what TIC projects the author has been involved with and the service context. Importantly, this article does not include the voices of any Experts by Experience directly involved in the work. Hypotheses are put forward about what it is like for them to be involved, but these ideas require further investigation.

These studies explore what it is like for Experts by Experience to implement TIC, highlighting potential challenges for them within the work. Taken together, they have similarities to research that has focused on the experience of practitioners involved in TIC projects, which highlighted how the work is often emotionally demanding, and difficulties introducing change meant specific projects were at risk of becoming tokenistic. At this stage, literature that has explored the experience of Experts by Experience remains limited in what it can tell us. The number of currently available studies is small, especially compared to studies focusing on practitioners' involvement in TIC. The experience of a small group of Experts by Experience in one TIC project is available. However, the validity of these results is somewhat limited, given that the researcher was also directly involved in the work and the perspectives of everyone involved, included practitioners, is included within the analysis.

1.12. The rationale for this study

TIC is a model for service delivery which recognises the high prevalence of trauma and aims to respond to the widespread effect these experiences can have by embedding this knowledge and avoiding the re-traumatisation of people who use services. Working in collaboration with people with lived experience and including their voices within the implementation of the TIC framework is a key part of the approach. A literature search identified three studies that explored what it is like to implement TIC from an Expert by Experience perspective. Of these, only one study, which is from the UK and includes the voices of people with lived experience, is available.

Our current knowledge of this area is limited and warrants more investigation. This study will adopt broad aims focused on how Experts by Experience describe their involvement in TIC projects and their relational and psychological experience of this work. This study will also speak with Experts by Experience from multiple projects across the UK and develop a broader picture of the general experience of this work. Previous studies have been undertaken by researchers who were also directly involved in the TIC project they are researching. However, this dynamic may inadvertently create a biased view of TIC projects by encouraging Experts by Experience with more positive experiences to participate and limiting the degree to which they can speak to challenges within the work, particularly regarding relationships between people with lived experience and members of the wider team. Instead, this study will be undertaken by a separate and independent researcher from the TIC projects.

1.13. Research aims

By exploring the experiences of Experts by Experience who have implemented Trauma-Informed Care in services, this research has several aims:

<u>Aim one</u>: Present the experiences and perceptions of Experts by Experience who have been involved in implementing Trauma-Informed Care.

<u>Aim two</u>: Explore the psychological experience of implementing Trauma-Informed Care for Experts by Experience.

<u>Aim three</u>: Explore the relational experience of implementing Trauma-Informed Care for Experts by Experience.

1.14. Research questions

The above research aims will be addressed by focusing on the following two research questions:

- 1. How do Experts by Experience describe their involvement with, and experience of, implementing Trauma-Informed Care?
- 2. How do Experts by Experience describe their psychological and relational experience of implementing Trauma-Informed Care?

2. METHODOLOGY

2.1. Chapter overview

This chapter will introduce the epistemological position I adopted for this study and provide a rationale for the methodology that was used. I will locate this study within the broader context in which it took place and locate myself as the researcher. I will then outline ethical considerations and the procedure for the study, including information about how it was designed, the participants, and the data collection process. Finally, I will describe how the data analysis was conducted.

2.2. Ontology and epistemology

Outlining the underlying assumptions about how we come to know what we know and the understanding of reality is an essential part of all research (Hathcote et al., 2019). Ontology asks the question, 'What is there to know?' and is concerned with what exists, the structure of reality and the nature of being, while epistemology asks the question, 'How can we know?' and is concerned about the limits of this knowledge (Willig & Rogers, 2017).

This research is undertaken from a critical realist (CR) position, which combines ontological 'realism', the belief in an independent reality, and epistemological 'relativism', the belief that there is no absolute truth (Pilgrim, 2014). CR collapses the traditional distinction between ontology and epistemology and posits that real processes underpin knowable and observable phenomena. CR can be useful in mental health research because it includes multiple domains of reality and is sometimes framed as a 'third way' between realist and relativist approaches, allowing for a 'double inclusiveness' (Bergin et al., 2008, p. 170). From a CR perspective, it is not possible to fully know 'reality' as the way we investigate or examine 'reality' is subjective and imperfect (Willig, 2019). CR also emphasises how the methods available to explore the world are imperfect and affected by many

things, including personal experiences and historical and cultural contexts (Harper, 2011).

This research assumes that trauma and TIC exist and will explore participant's experiences of these. In line with CR, it will explore both the observable (participant's experience of trauma and of implementing TIC) and the unobservable (what influences this). Within CR, reality is stratified into three levels (Fletcher, 2017). The empirical level refers to the realm of events as we experience them. At the actual level, there is no filter of human experience; instead events occur whether or not we experience or interpret them. Finally, at the real level, causal mechanisms and structures are viewed as acting to produce events. The primary goal of CR is to explain social events through reference to the effects they can have throughout these three layers of reality. A CR approach is suitable for the research aims in that it can provide depth and nuance to the analysis, helping identify aspects of the experience of Experts by Experience that are both observable and the unobservable processes which shape this. A CR position invites a perspective on trauma that acknowledges that the painful experience is real and observable while also allowing for an exploration of how the experience is shaped by other social factors such as history, culture, and politics. CR is primarily focused on understanding rather than merely describing social events and lends itself well to participant interviews as a research method, as used in this study (Vincent & O'Mahoney, 2018).

2.3. Rationale for methodology

2.3.1. Rationale for method of analysis

This study aims to explore what it is like for Experts by Experience to implement TIC by focusing on how they describe their overall experience, as well as their psychological and relational experience of this work.

A qualitative research method was selected to meet these study aims. Qualitative research aims to make sense of or interpret phenomena in terms of the meanings people bring to them (Denzin & Lincoln, 2008). A strength of qualitative research lies

in its capacity to explore participant's experience and their individual meaningmaking (Harper, 2011), which reflects the aims of this study. Qualitative research offers rich and compelling insights into the real worlds and experiences of people in a way which is completely different to, but also complimentary to, the knowledge we can obtain through quantitative methods (Braun & Clarke, 2014). Thematic Analysis (TA) is a qualitative method for developing, analysing and interpreting patterns across qualitative datasets (Braun & Clarke, 2006). It involves the systematic process of coding and developing themes and allows for an in-depth exploration of the factors and processes which give rise to a phenomenon. The end result of a thematic analysis should be to highlight the most salient constellations of meanings present in the data set, including affective, cognitive and symbolic dimensions (Joffe, 2011). TA can be conducted from different epistemological perspectives (Willig & Rogers, 2017) and is compatible with a CR position since it relies on the researcher's interpretation of participants' experiences and aims to identify general themes that could be seen to represent external reality whilst also not assuming one version of reality (Braun & Clarke, 2013).

TA is well suited to explore how a group of people makes meaning of the phenomena under study (Joffe, 2011). TA facilitates the gleaning of knowledge of the meaning of the phenomenon under study by the groups studied and provides the necessary groundwork for establishing valid models of human thinking, feeling and behaviour (Braun & Clarke, 2021a). It was felt to be well suited to understand how Experts by Experience describe their involvement in TIC projects and their psychological experience of this work. TA offers a functional qualitative approach for applied research and a toolkit for researchers who want to do robust and sophisticated analysis of qualitative data but present them in a way that is readily available to the public (Braun & Clarke, 2014). Finally, as a fairly inexperienced researcher, TA offers a relatively easy-to-learn qualitative approach without deep theoretical commitments.

TA was used to analyse the interview data in this study by following Clarke and Braun's (2021) recent guidelines, which identify the researcher's 'reflexivity' as a key

part of the process. Reflexivity is the process of critically evaluating how one's own experiences and beliefs relate to the research subject matter (Wilkinson, 1988). Practising reflexivity involves a disciplined practice of the researcher critically interrogating what we do, how and why we do it, and the impact of this on research (Clarke & Braun, 2021). Exercises, such as those described by Clarke & Braun (2021) and Shimmin et al. (2017), have supported reflexivity in this study, along with a reflexive diary (Appendix R). Reflexive TA, from a CR perspective, provides access to situated realities, not simple decontextualised truths. The goal is to provide a coherent and compelling interpretation of the data, anchored by the participant's accounts, that speaks to situated realities and the limits and constraints of the world participants exist within (Clarke & Braun, 2021).

While TA was considered the most appropriate method for this study, other qualitative methods were also considered. Interpretative Phenomenological Analysis (IPA) is a qualitative research methodology concerned with the detailed examination of personal lived experience. It is committed to examining the topic, as far as possible, in its own terms (Eatough & Smith, 2017). While this could be a helpful approach in meeting the research aims, IPA is not compatible with a CR position. The epistemological position which fits best with IPA is constructivism, which posits that we can only know reality through accessing others' subjective accounts of their experiences (Willig, 2017). TA is also recommended as an approach instead of IPA when there is a need for actionable outcomes with clear implications for practice and when the analytic interest is on how personal experiences are located within broader sociocultural contexts (Braun & Clarke, 2021a). Both points are relevant for this study, in which the context in which Experts by Experience are working is essential to consider, and there are potentially important clinical implications to be made.

Grounded Theory (GT) is a qualitative methodology that generates theories from the available data. It is another methodology commonly used to analyse qualitative data and is compatible with a CR stance (Willig, 2017). However, developing theories about the experience of Experts by Experience implementing TIC was felt to be premature due to the lack of previous research in this area (Braun & Clarke, 2021a).

2.3.2. Locating the research in the wider context

It is good practice when undertaking reflexive TA to locate the interpretation of data in the wider context (Clarke & Braun, 2021). This research was undertaken in the UK and focused on UK healthcare systems, which are underpinned by neoliberal ideologies and the medical model of distress as an 'illness' (Harper & Speed, 2014). The current political context of the UK is also relevant for this study. Several recent reports have highlighted systemic racism within public services (Casey, 2023; United Nations, 2023) and a hostile system in the UK aimed at deterring people from seeking asylum (Bulman, 2019). A period of austerity has also had a disproportionate impact on people living in poverty and people with mental health problems, increasing the burden of mental distress and marginalisation within the UK (Cummins, 2018). Social inequalities within the UK have been exacerbated over the past ten years (Marmot, 2020) and at the time of writing, the current government has indicated it intends to reduce support for people suffering from mental health difficulties (Rawlinson, 2024). In the past decade, the NHS, the main healthcare provider in the UK, has seen a rapid increase in the demand for mental health services while funding has simultaneously slowed down (Baker, 2024).

2.3.3. Locating the researcher

When undertaking reflexive TA, it is also good practice for the researcher to locate themselves and consider their social position, identifying where they occupy privilege and marginality (Clarke & Braun, 2021). This study will be shaped by my role as a trainee clinical psychologist. This professional role is also another position of power and privilege I hold in this study and needs to be located within the UK mental healthcare context, which has a long history of medicalising trauma (Boyle, 2011) and exerting 'power over' relationships with service users and Experts by Experience (Ocloo & Matthews, 2016).

Although I hope to be an ally to participants in this study and privilege their voices, acknowledging the history of the profession is important so this can be held in mind during the study. I was curious as to whether participants would view me as an

'insider' or 'outsider' status when conducting this research (Sherif, 2001) and what assumptions they might make about my own experiences of trauma. I decided against disclosing whether I identified as a trauma survivor or not to participants as I felt it would detract from the focus of the conversation.

Qualifying from this training programme is also dependent on undertaking and completing a thesis. I have felt tension during the development of this study as to whether it is ethical to ask participants to discuss their experiences and me to use this to receive a qualification. I considered alternative research methods, such as advocating for research led by people with lived experience (Brown & Ormerod, 2022), however, this was beyond the scope of this project. On reflection, I felt that although it is transactional, I hope this research privileges more marginalised voices and is not felt by them to be exploitative. As a White man, it is important to acknowledge the impact that these aspects of my identity have had on previous trauma research. Whiteness, the implicit assumption of the superiority of White people (Guess, 2006), it is argued, has encouraged an 'ontology of forgetting' where only certain experiences 'count' as being traumatic and others are effectively erased altogether (Pon, 2009). Similarly, Maleness, the privilege afforded to men in society, has also shaped definitions of trauma, silencing the experiences of gender-based violence within the definition of PTSD (Herman, 1992; 1998). This is particularly important to recognise as the oppressive impact of these processes is often dismissed or ignored (DiAngelo, 2022) and encourages a definition of trauma which is de-contextualised and de-politicised (Krupnik, 2019).

2.3.4. Rationale for data collection

Data was gathered using individual, semi-structured interviews to allow space for each participant's experience of implementing TIC and support meaning-making in their own way (Frith & Gleeson, 2011). This method is also consistent with a CR position, as it assumes that an external work exists independently from our construction but seeks to understand it by inviting multiple perspectives of the same reality (Khanna, 2019).

Focus groups were also considered as a method for data collection. While discussing their experience in groups can allow participants to build on one another's responses and generate ideas (Gibbs, 1997), it might also limit what they feel comfortable sharing (Liamputtong, 2011), and on reflection, this method was deemed less suitable.

2.4. Ethical considerations

Ethical approval for this study was sought and granted by the University of East London (UEL) and by NHS Health Research Authority (HRA), as the study intended to contact participants in their role as Experts by Experience within NHS mental health services. (See Appendix B, C, D & E). Ethical considerations were also informed by British Psychological Society (BPS) code of human research ethics (2021).

2.4.1. Informed consent

Informed consent was obtained from all participants, which was in line with BPS (2021) and UEL guidelines. Potential participants were first provided with a detailed Participant Information Sheet (PIS) (see Appendix F) before agreeing to participate in the research. This included information about the research's purposes, aims, and eligibility criteria, as well as outlining what participating would involve and the potential benefits and risks of doing so. The PIS also explained participants' right to withdraw, data management protocols, steps taken to preserve confidentiality, and how the findings were planned to be disseminated. Potential participants were advised to read through the PIS and then email me with any further questions. Consent was then obtained from each participant via an electronic consent form, a copy of which can be found in Appendix G. This form outlined the study and required participants to initial each of the 12 statements to confirm they consented to these and provide their signature.

Consent forms were emailed to each participant, and I was available by email or video call to answer any questions or concerns about the consent process. On the interview day, participants were again invited to ask any questions about the consent

process. All 12 interviews were undertaken over video. Shortly before the interview, each participant was also asked to confirm again that they were happy to consent to participate before proceeding. Participants were made aware that they could choose not to answer any of my research questions. It was explained to participants that they could ask to pause the interview and take a break at any point or request to postpone the interview for another time if they wanted. Participants were also reminded that they could choose to stop the interview at any point and did not need to provide an explanation. The interview schedule also included two 'checkpoints' where I asked if the participant was happy to continue or would like to pause or stop entirely.

Following the interview, participants were reminded that after the data collection, they had three weeks to state that they no longer wished for their data to be used. This information, along with information about how their data would be stored and support services, was also included in the participant debrief sheet. (See Appendix H).

2.4.2. Confidentiality and anonymity

Steps were taken throughout this study to maintain the confidentiality and anonymity of participants, in line with the BPS code of human research ethics (BPS, 2021) and UEL guidelines. All personal data collected as part of the research was held securely and processed in accordance with the UK General Data Protection Regulation (GDPR) and Data Protection Act (2018) to ensure participants were not identified in the data collected or in any write-up of the research.

Before the interviews, all contact with participants was done privately over email. Interviews were conducted over video using Microsoft Teams, and both participants and researcher agreed to speak from within a private, confidential space. The interviews were recorded via Microsoft Teams, and a transcription of the conversation was downloaded automatically onto my UEL Microsoft OneDrive account. Each interview recording and transcript were password-protected and saved using a pseudonym selected by the participants themselves to be used for the write-up.

I then removed all identifying participant information from the transcripts. Participant names were replaced with pseudonyms, and the names of other individuals were removed. Other potentially identifiable information, such as organisations or services, was either removed or, where appropriate, replaced with a meaningful description (e.g., Hackney \rightarrow London) so participants could not be identified via other details. After the transcripts had been anonymised, all interview recordings were deleted from Microsoft Teams, and only myself, the study supervisor and the examiners were provided with access to the anonymised transcripts. These steps to maintain participant confidentiality and anonymity were outlined to participants in the PIS. Space was provided ahead of interviews so that participants could ask any questions about the measures.

2.4.3. Data storage and management

A comprehensive Data Management Plan was completed in line with the Data Protection Act (2018) to cover all data generated by the research (Appendix I). This plan was approved separately by UEL and the NHS Health Research Authority. Completed participant consent forms were saved directly to my UEL Microsoft OneDrive account, and any local copies were deleted. Participant email addresses were retained to coordinate payment for participation and disseminate the research write-up. These were stored in a separate password-protected document on my UEL Microsoft OneDrive account.

Transcripts of interviews were downloaded directly from Microsoft Teams, password-protected, and saved to my UEL Microsoft OneDrive account. Any local copies of the transcript were deleted. Only I had access to the raw interview data, which was deleted after the transcripts had been anonymised. Anonymised transcripts will be retained for three years and held by the study supervisor, after which all the data will be deleted.

2.4.4. Wellbeing and risk management

A risk assessment was undertaken before the recruitment phase, a copy of which is included in Appendix J. This highlighted that inviting participants to reflect on their experiences of implementing TIC had the potential to be upsetting or distressing, and

the research, therefore, carried a minor risk to those participating. Steps to manage these risks were considered. Participants were provided with a PIS to ensure they were clearly informed of what taking part involved before being asked to provide written consent. Before the interview, participants were reminded that they could choose not to answer any of the interview questions and could end the interview at any point without providing an explanation.

The interview schedule included two break points to check that participants were happy to continue, and in the case of any emotional discomfort, I was available afterwards to offer support. All participants were provided with a list of generic and specific support services should they require additional emotional support following the interview. The risk assessment also identified a minor risk to me, highlighting how interviewing potentially distressed participants may also be upsetting. As a precaution, it was agreed that I could contact my supervisor for a debrief should any of the interviews have an emotional impact. Should the interviews have an emotional impact, they would consider whether more formal emotional support was required.

2.5. Interview schedule

I felt a rigid interview structure might feel formal and potentially intrusive for participants (Frith & Gleeson, 2011), so a semi-structured interview schedule was selected to allow for flexibility in the conversation and support participants to feel comfortable (Gill et al., 2008). A draft interview schedule was first created and comprised of ten separate questions based on the research aims. This draft was then refined through separate discussions between the research supervisor and me.

From these discussions, the number of questions was reduced to five, with optional follow-up questions if I felt it was appropriate to ask for more details. Each question was phrased using open language to encourage participants to speak freely about their experiences. (See Appendix K).

2.6. Data collection

2.6.1. Recruitment strategy

Determining the correct number of participants for a particular project that will provide a data set with sufficient depth, richness, and complexity can be challenging (Braun & Clarke, 2022). Rather than using statistical models to determine the required participant sample size, this study used the concept of 'information power' as a guide (Malteurd et al., 2016). 'Information power' refers to the amount of relevant information that a sample holds for the study; the more relevant information, the lower the number of participants required. The information power of the sample was determined during the interviews by considering various factors, including the aims of the study, the sample specificity, and the quality of dialogue. As the study has broad aims and the participants had experience implementing TIC from varied contexts, meaning there was variation in the specificity of their experiences, a larger sample was deemed suitable to provide sufficient information power. The quality of dialogue and the amount of relevant information within the sample were reviewed during the interview process. This was used then used to determine the overall information power and number of participants recruited.

Two separate recruitment strategies were used to generate a sample of people who had implemented TIC in varied contexts and ensure enough participants could be identified and recruited. The first recruitment strategy was done in conjunction with a local NHS Trust, which agreed to be a Participant Identification Centre in accordance with HRA guidelines. Recruitment was supported by a local collaborator who works as a clinical psychologist at the collaborating NHS Trust. I worked alongside them while on placement in their team during my clinical psychology training, and they expressed interest in the project. Their role was to use their network to identify other people within the NHS Trust who could support recruitment for the research. The local collaborator emailed several Expert by Experience leads within the Trust with details of the research, who, in turn, advertised the study to other Experts by Experience employed by the Trust. Through this process, I was also invited to attend one meeting and advertise the research directly to Experts by Experience. The

second recruitment strategy involved advertising the research with the National Service User Network (NSUN) via a newsletter to their members. Discussions were held with the organisation to ensure the research met their criteria, and a short description of the research was provided. A summary of the research and poster (see Appendix L) were then circulated in the NSUN June 2023 newsletter.

2.6.2. Participant inclusion and exclusion criteria

The PIS provided participants with detailed inclusion and exclusion criteria for the research, which was emailed to each person who expressed an interest. In this study, the role of 'Expert by Experience' was defined as someone who has direct experience of mental health services, either as a patient or as a carer or family member and invited to support service delivery by drawing on this lived experience (Toikko, 2016).

To be eligible, participants needed to have experience of implementing TIC while in the role of Expert by Experience. In this study, the SAMHSA (2014) definition of TIC was used, and the six principles of TIC were included in the PIS. Participants were required to be over 18 years old when they implemented TIC in order to be eligible, and it was only open to Experts by Experience who had been involved in TIC projects undertaken within UK healthcare services. As the principles of TIC are relevant and have been implemented within many service contexts, for example, mental health, drug and alcohol, homelessness, and forensics, participants with experience of implementing TIC in any mental healthcare service were eligible.

Participants who had experience of implementing TIC in NHS services and non-NHS services were also eligible. There was no exclusion based on the type of TIC project that Experts by Experience had been involved in implementing, and examples of the type of work were provided in the PIS.

Experts by Experience who do not speak English were eligible to participate.

People who were employed as mental health practitioners (e.g. mental health nurse, clinical psychologist, care co-ordinator), who also identify as trauma survivors, and who have experience of implementing TIC were not eligible.

2.6.3. Participant demographics

Participants were asked to provide some basic demographic information to reflect on the overall sample. This information was provided by 11 out of 12 participants.

Table 1: Summary of participants' demographics.

Participant	Age	Gender	Ethnicity
1	31	Male	Bengali
2	62	Female	Black African
3	40	Female	White British
4	26	Male	White British
5	38	Female	White European
6	51	Female	White Irish
7	х	x	х
8	25	Male	South Asian
9	52	Female	White British
10	42	Male	White British
11	57	Male	White British
12	38	Male	White British

Two participants were recruited via adverts within the local NHS Trust and 10 were recruited following advertisement with the NSUN bulletin. Although the participants who responded to the NSUN bulletin were not directly asked about where their TIC

projects took place, during the interviews it emerged they had experience implementing TIC not only in London but from across the UK.

Within the sample, participants had experience of implementing TIC in a range of different settings, including forensic services, mental health inpatient services, crisis services and drug and alcohol services. Participants also described having been involved in various types of TIC projects. These included developing and delivering TIC training and providing consultation to teams who were seeking to become trauma-informed, for example, by helping assess the extent to which certain physical environments were trauma-informed and how to undertake assessments in a trauma-informed manner. Participants also had experience evaluating the impact of services which had introduced trauma-informed changes. Some participants had experience being involved in multiple TIC projects that connected them to multiple teams, whereas others had only recently become involved in projects that were local to them.

2.7. Procedures

2.7.1. Interview procedures

Participants who self-identified were first emailed a copy of the PIS and encouraged to ask any further questions they had about the research. A copy of the Consent Form was then emailed to each participant to be completed before the interview and returned to me. Before the interview, participants were provided with an overview of the research aims and informed that the interview would be recorded to create a conversation transcription for the analysis.

Participants were given the option of being reimbursed with a £10 Amazon voucher for participating. They were reminded that they could refuse to answer any questions and withdraw from the research at any point without providing a reason. Finally, consent was then confirmed verbally before the interviews started. Participants were invited to select their pseudonyms and asked for basic demographic information (age, gender, ethnicity).

This information was requested to understand the characteristics of the sample better and provide a clearer idea of who the findings can be generalised to. Ethnicity, in particular, was important to record, given that people from ethnic minority groups tend to be underrepresented in research and Expert by Experience groups (Hussain-Gambles et al., 2004; Ocloo & Matthews, 2016). Without including details about the sample, the research risks assuming the stance 'absolutism', which assumes that the phenomena of interest are the same regardless (Hammer, 2011). This is important as research undertaken in the West tends to speak from a position of 'the norm' and reduces the reader's ability to evaluate aspects of the study (Braun & Clarke, 2021a) and risks the findings being overgeneralised and uncritically applied to those with differing cultural backgrounds (Tribe & Patel, 2007).

Interviews were semi-structured and comprised of five questions, with optional follow-up questions, informed by the research aims. Each interview started with the same question, and thereafter, there was flexibility in when each of the other four questions and follow-up questions were asked.

The interviews lasted between 30 – 45 minutes. Participants were asked at two break points if they were happy to continue before the interview resumed. At the end of each interview, the recording was turned off, and participants were provided with space immediately afterwards to debrief. Participants were reminded that they could contact me up to three weeks following the interview if they wished to have their data removed from the study. After the interview, participants were all emailed a debrief sheet and a voucher form to complete and return.

2.7.2. Transcription

Microsoft Teams automatically transcribed the interviews and saved them on my UEL Microsoft OneDrive. The transcripts were then reviewed while listening to the interview recording, and any words incorrectly transcribed were replaced with the correct phrase. All identifiable participant information was then removed, and potentially identifiable information was replaced with a meaningful description (e.g., Hackney \rightarrow London). This process also helped me become more familiar with the data.

2.8. Analysis

2.8.1. Thematic analysis

The process of TA involved six phases outlined by Clarke and Braun (2021): data familiarisation, data coding, initial theme generation, theme development and review, theme defining and write-up. These six phases were undertaken in a recursive way and involved movement back and forth between the different phases in a spirit of inquiry and interpretation (Terry et al., 2017).

2.8.2. Familiarising self with data

After the interviews, each transcript was checked for mistakes and anonymised, and during this process, initial ideas for codes and themes were noted down. I then spent time becoming familiar with the data and generating an initial list of ideas about what is in the data and what is interesting about it. I used both electronic and physical copies of the data and read over it in different locations, each of which bought a slightly different perspective.

In reflexive TA, data can be coded at a range of levels, from explicit or semantic to conceptual or implicit meaning. My initial observations and interpretations focused explicitly on what participants had shared and my immediate emotional reaction. At first, I felt a mixture of relief at having enough data for the project. However, this was quickly replaced with a sense of frustration at what was being shared.

As time went on, I focused on my interpretation of the implicit meanings by listening back to interview recordings while reading the transcript. Putting their words back alongside their tone of voice, facial expressions, and pauses in the conversation all helped to capture the nuances of what they were describing and opened up many new ideas for me. Most of the interviews were undertaken in a short space of time following the NSUN advert, and the tone of frustration from participants left me with the impression that this experience had gone unheard within TIC projects.

2.8.3. Generating initial codes

The next phase involved the production of initial codes from the data and organising

the data into meaningful groups. Codes identified a feature of the data that appeared interesting and referred to the essential segment or element of the raw data that can be assessed in a meaningful way (Braun & Clarke, 2006). This was done using the software NVivo, with sentences before and after the coded segments retained to keep the meaning of the text (Boyatzis, 1998), an example of which is included in Appendix M. The transcripts were re-read alongside the initial codes, and where there was overlap between codes, they were merged (Appendix N). Care was taken to ensure that important information represented by codes was not lost by re-reading transcripts and codes in context.

2.8.4. Theme construction

The next phase of analysis involved studying the data from the broader level of theme construction. Quotes for each code were printed and physically arranged into broad categories with loose theme definitions (Appendix O). The codes and corresponding text segments were reviewed together and studied for meaningful patterns and codes that may be inter-connected. This process was repeated several times to consider whether the codes could be conceptualised differently. Each data item was given equal attention, and themes were generated when a substantial number of participants contributed to them. Holding a CR position, I developed candidate themes which attended to the socially produced meaning and the lived experience of what participants described. Importantly, themes were not seen as naturally 'emerging' from the data; rather, they were subjectively extracted by me as the researcher and considered reflexively (Braun & Clarke, 2021b). An inductive, data-driven approach was taken, where themes were seen as context-driven and grounded in the data.

Following Braun and Clarke's (2022) suggestions on an inductive approach, the analytic process involved becoming immersed in the data and 'reading, reflecting, questioning, imagining, wondering, writing, retreating, returning' (Braun & Clarke, 2022, p.332). This process helped me to reflect on the unspoken meaning behind the words spoken by participants. It supported the aim of producing rich themes that could not have been anticipated before the analysis.

The intention was that they were not led by theory or preconceptions. However, it is impossible to enter a theoretical vacuum when doing TA. The lack of theoretical prescription inherent in TA is often misinterpreted as indicating that the method is atheoretical and that an inductive approach, in particular, is often used without the theoretical foundations being made clear (Braun & Clark, 2021a). Time in supervision helped to identify deductive influences and the lens through which I was approaching the data. For example, by adopting a CR approach, I assume that participants' words transparently communicated their individual experiences and that these are shaped by social, cultural, historical and political influences. Other deductive influences include narrative theory (White & Epston, 19990). Narrative approaches emphasise the link between power and broader dominant narratives in society, which shape the stories that are told about people and how they make sense of their experiences (White & Epston, 1990).

2.8.5. Reviewing themes

Once a set of candidate themes had been generated, these were refined. Thematic maps were useful as a way of identifying connections between themes (Appendix P). Some themes did not have sufficient data to support them, and others collapsed into each other, while other themes were broken down into separate items. This phase also involved reading all the collated extracts for each theme to check that they form a coherent pattern (Appendix Q). The validity of individual themes was also considered in relation to the data to check that they represent an accurate representation.

2.8.6. Defining and naming themes

Once a satisfactory thematic map of the data had been created, individual themes were then considered for their 'essence' and the distinct stories that they told about the data (Braun & Clarke, 2022). Care was taken to avoid paraphrasing the content of the data but to identify what is of interest about the themes and why.

2.8.7. Inter-rater reliability check

After the themes were named and defined, the research supervisor reviewed brief descriptions of these as part of an inter-rater reliability check. This check was not to

establish that the themes were unbiased or objective, as this would not be compatible with the CR position from which the study set out (Willig, 2017). Instead, the reliability check helped to establish whether the themes produced were seen as distinct and meaningful by someone independent.

2.8.8. Producing a report

Once I was satisfied with the set of themes, the next analysis phase involved creating a report of the findings. The report aims to communicate the complicated story of the data in a concise, coherent, logical, non-repetitive and interesting way. A summary of the data is outlined in the Analysis Chapter. This includes an overview of the themes and sub-themes and example data extracts for the reader to consider whether themes are reflective of the data.

3. ANALYSIS

3.1. Chapter overview

The two themes presented in this chapter have been developed through reflexive TA of the participant interviews. Each theme contains subthemes, and together, they aim to represent the essence of what participants shared (Braun & Clarke, 2022). These themes and subthemes will be used to address the research questions as follows:

- 1. How do Experts by Experience describe their involvement with, and experience of, implementing Trauma-Informed Care?
- 2. How do Experts by Experience describe their psychological and relational experience of implementing Trauma-Informed Care?

3.2. Thematic analysis

Details of the analytic process are provided in the Methods Chapter, and illustrative examples are included in Appendixes M, N, O, P & Q. Themes, subthemes and example quotes were shared with my supervisor. Following feedback and guidance from Clarke and Braun (2022b), these final themes and subthemes were created.

3.3. Final themes and subthemes

My analysis produced two themes and five subthemes, which can be seen below in Table 2.

Table 2: Summary of themes and subthemes.

Themes	Subthemes	
One: Implementing TIC is	One: Lived experiences are side-lined and silenced	
distressing and traumatising	Two: Connecting with traumatic experiences	
	Three: Frustration with the system	
Two: Positive changes from	Four: Using the distressing moments	
implementing TIC	Five: Improved relationships and positive team	
	culture	

The following descriptions aim to capture the defining features of each theme and subtheme according to what participants shared. I have attempted to 'tell a story' about the data in a way that aims to 'make sense' of what is going on, and that gives the audience a clear take-home message (Clarke & Braun, 2021). While I have presented each theme and subtheme as distinct, they overlap and interact, as I will endeavour to note throughout my analysis.

This section is supported by quotes from participants which include no identifiable information. I have made minor changes to participants' quotes to improve their readability, for example, by removing words that are repeated or shortening quotes without altering their meaning. Where quotes have been shortened, this has been made clear with (...), and where context is necessary for the reader to understand the quote, this has been included with [context]. A full list of quotes used within each subtheme is listed in Appendix S.

Theme one: Implementing TIC is distressing and traumatising

Participants frequently described their experience of certain TIC projects as being distressing and re-traumatising. Despite being invited to participate in TIC projects, they were often not meaningfully involved in the work, and their lived experiences

were excluded. Undertaking TIC projects also regularly connected participants with distressing memories. Paradoxically, this suggested that many TIC projects were themselves not trauma-informed, and the work itself potentially traumatising for participants.

Subtheme one: Lived experiences are side-lined and silenced

TIC invites teams to adopt a new way of working in which power is shared equally amongst those involved. Participants were invited to undertake TIC projects on the assumption that there would be space for their lived experiences to be shared and used to inform the changes that were implemented. Contrary to this, however, participants described various ways their voices were silenced and side-lined during TIC projects.

One clear example of this came from the level of power and decision-making participants were granted access to within TIC projects. Participants expected that they would occupy leadership positions within this work. Disappointingly, participants were only sometimes included from the beginning of projects or meaningfully involved in the work. Instead, they were required to work within existing hierarchies, and the work remained in the ultimate power of the service and practitioners.

Participants were also at risk of manipulation within TIC projects, simultaneously being asked to sign off on pieces of 'trauma-informed' work while also being excluded from meaningful decision-making. It felt as though participants could easily be manoeuvred in bystander positions despite this going against the fundamental principles of TIC. Contradictions like this in how participants experienced TIC highlight some of the clear challenges within work for Experts by Experience.

"I think another barrier can be the leadership aspect from a lived experience perspective. Although the model should be collaborative, it is often lead by clinical staff. There is still a hierarchy there, which goes against trauma, informed principles. And I think we've done a lot of work to try and reduce the hierarchy in our organisation, but it still exists."

Sarah

"That tick-box of 'yes, we have someone with lived experience', but signing off on some training when it's already been written is very different to have different voices in it from the beginning. Or having someone with lived experience co-facilitating it all the way through. So meaningful involvement of lived experience in Trauma-Informed Care is not ideal, as it isn't in many areas of the UK currently."

Sarah

Unaddressed power imbalances within TIC projects not only excluded participants but also had the potential to undermine their self-confidence. Being invited to provide deeply personal experiences within a TIC project only for these to be side-lined could understandably become confusing and frustrating for participants. The sense of disempowerment described by participants could quickly reconnect to other similar negative experiences, re-traumatising them further within the work.

"You are then working in a system that is saying there should not be power imbalances, but there are power imbalances. And you're in a lived experience role where you may not have great belief in yourself or self-worth. I think it has a big, negative personal impact."

Sarah

"And it's a challenge sometimes where you feel like, I know you agree with me, please don't leave me out on a limb here being the only person making this point."

Frankie

"And I came away feeling really demoralised. I am not your tick-box but also you have really brought down my confidence in in trauma-informed care, it was very demoralising. I've had enough shit. I don't need to. I found it extremely frustrating, demoralising and so unprofessional. Just so many things."

Tat

TIC is a framework for service delivery that requires teams' commitment to undergo meaningful change in how they view experiences of trauma. However, some participants' experience in this study made them feel that the work was tokenistic. Rather than being an opportunity to address widespread issues in how trauma is understood and responded to within services, participants felt that TIC was more focused on satisfying the service's aims and was somewhat performative. Approaching the work in this way risks exploiting participants and undermines their confidence in the approach itself. Participants were clear that when TIC was implemented in a tokenistic way, they felt it did more damage than good and risked re-traumatising them from being involved in the process. This view seemed to get to the heart of many of the issues raised by participants.

"I find it frustrating. Trauma-Informed Care is kind of becoming a tick-boxy thing. Lets rush it through. I'm aware, whether it's services or organisations, it's another great tick-box for them to say they're trauma-informed."

Tat

"When it's done badly I find it even more damaging. Now for me, you're better off not having trauma informed care than saying it's trauma informed and doing it's badly done. I think it can be so damaging, so damaging and very retraumatising."

Tat

Some participants were also concerned that these tokenistic changes were also being used to justify the diluting of specialist trauma services. There was a suspicion that the overall offering to people with more severe mental health difficulties would be reduced as a consequence of how TIC was implemented. Again, this reflected an eroding of confidence that participants had in TIC due to their involvement.

"I've witnessed some Trauma-Informed Care training on fight or flight' and that is just ticking a box...My concern is not having good services for post-traumatic stress disorder. Since Trauma-Informed Care some well-established services have been diluted."

Maria

Concerningly, participants also felt that colleagues were unprepared to hear what they had gone through and listen to their poor experiences with mental health services. TIC projects risked invalidating these experiences by failing to recognise the actual harm Experts by Experience have gone through and seeing these as understandable reactions. It also highlights a dilemma for participants: Should they modify their experiences for the benefit of other people involved or speak their mind and risk having their reactions pathologised and dismissed?

"If you are asking for this information from someone which comes from a close place, then it can't be sanitised. And sometimes you're going to hear stuff that's quite real and quite stark. Because that's the truth of people's experience. So sometimes for me that's been a challenge. Seeing spaces which maybe aren't prepared for that and don't really want it, was just awful."

Frankie

"I think sometimes it would be good if there was a greater understanding from staff and organisations. For example, knowing it is going to be normal for people to react in a way that's from a place of upset and real harm. That was lacking."

Frankie

Participants also reported silencing of more severe mental health difficulties. Members of the wider team provided less space for these experiences within TIC projects compared with other experiences, such as grief and bereavement. Perhaps underlying this was a lack of awareness of more severe mental health difficulties or an assumption that people having experienced psychosis, for example, would not also be part of a professional working group. It also highlights the type of lived experiences which members of the wider team preferred. However, the consequence was that those people with more marginalised voices risked being further excluded from having an input within service development.

"I'm just concerned. I thought to be a bit more discussion here about if somebody maybe experienced psychosis or dissociation... but there was pretty much nothing."

Tat

"Again it's just about being appropriate, it would be more appropriate for someone who is bereaved to be working as an Expert by Experience in a grief or bereavement or depression group. For me, I found it really demoralising because I thought it's kind of diminishing what I've experienced."

Tat

The homogenisation of lived experience was another subtle way that lived experience could become silenced within TIC projects. The title 'Expert by Experience' was perhaps interpreted by colleagues as implying that anyone could effectively come forward as a representative and speak on behalf of everyone, risking erasing the many differences among this group's lived experience.

"A lot of these roles are called like 'patient representative' but it's like, I'm not representative of anyone but me to be honest."

Frankie

"I couldn't be rolled out for everything. I don't have lived experience in everything. So I think it's success is also founded in involving people with relevant lived experience."

Sarah

The TIC framework may also influence the potential homogenising of experiences. By taking a broad definition of what represents trauma, there is a suggestion from participants that people with severe mental health problems were again overlooked, and their difficulties side-lined within TIC projects. Again, this highlights how lived experiences were shaped within the work, with some being amplified and others silenced.

"I feel serious mental health issues are diluted in the general population. It's become so diluted that someone who felt very lonely or a bit under the weather, they all go into a big pot, along with people with severe mental health problems are just pushed into a corner."

Maria

The medical model was another factor that shaped how participants' lived experience was constructed in TIC projects. Despite TIC being a psychosocial approach, members of the wider team remained wedded to medication as a primary treatment for trauma. They held the view that trauma was synonymous with PTSD. This may reflect TIC representing a new paradigm for certain practitioners and difficulties adjusting to a new approach. Nonetheless, not having this foundational TIC knowledge added to participants' frustrations. Reverting to biological explanations for trauma also somewhat undermined that their lived experience was relevant to the work.

"It just like medication, medication, medication. But they [staff] didn't really understand that trauma is not only helped with medication. There are many other ways which service users can be helped. I think a barrier is putting all the focus on medication."

Muleya

"I do find that when I'm talking to colleagues, there is utter confusion about why trauma needs to be treated as a separate entity as opposed to PTSD."

Robert

The potential for experiences within TIC projects to become homogenised was also identified as occurring through a lack of diversity within who is invited into an Expert by Experience role. A lack of diversity is reflected in the demographics of participants in this study and highlights how Whiteness and other forms of privilege operate to amplify certain experiences. Similar to this, participants noted a lack of attention to the intersections between trauma and culture, again suggesting that specific experiences were silenced within the work. Power could operate both from services, and Expert by Experience groups to exclude those with more marginalised voices from having a seat at the table.

"You need diversity in the group of Experts by Experience. This world of Experts by Experience, and I add to this, is very White and middle-class...I suppose is very straight, very cis. So I think for us to work better on these issues we need greater diversity within the Expert by Experience group...Are we closing it off to other people? Are we forming our own sort of hierarchy here, of well-connected people in this Expert by Experience world?"

Frankie

"And a big one I am sorry to say that people often forget in this country and are ignorant to it, is the cultural consideration. Empowering people is part of it, but cultural consideration is always forgotten about."

Robert

Participants were invited to participate in TIC projects because they had gone through extremely distressing and disempowering experiences. However, these results highlight how these very experiences were often replicated through being side-lined and silenced within the work.

Subtheme two: Connecting with traumatic experiences

Avoiding the re-traumatisation of people is one of the guiding assumptions of TIC. However, implementing TIC regularly reconnected participants with their own distressing experiences and symptoms associated with trauma. Alarmingly, some participants reported frequently experiencing flashbacks and periods of dissociation because of the work. Listening to participants during the interviews, it was clear that this was an upsetting and frustrating experience. Some participants, understandably, were reluctant to continue with the work and risk being exposed to further harm. Other participants appeared more resigned to this being inherent within the work and decided to continue nonetheless, often managing the reactions independently while the project continued around them. Some triggers for this were more obvious and explicit for participants, while for others, simply being involved in TIC projects meant they were implicitly brought closer to these experiences. It was unclear whether there was space to reflect and comment on the implementation process or the feelings stirred up within projects. At times, how participants were forced to manage these experiences felt like further examples of their lived experiences being silenced.

The potential to be re-traumatised by sensitive material was reported by several participants who were frustrated with colleagues who failed to give adequate warnings about what was being presented or discussed. Experts by Experience could unexpectedly be presented with material that reconnected with painful experiences and felt it demonstrated a lack of awareness about how the work might impact those involved. Reconnecting with painful experiences and the emotional burden of implementing TIC led some participants to question whether it was sustainable to continue. This overlapped with earlier comments about the lack of understanding amongst members of the wider team about the actual harm that Experts by Experience had suffered.

"You are living, breathing trauma every day. I go to work and it is difficult not to think back to traumatic experiences. I think there have been some training sessions that I've delivered where I might have dissociated through it because something has come up that's so relevant to me or just happens to be a day when I'm tired and can't deal with the content so much. I've been in meetings where I've flashbacks of past things."

Sarah

"What was even more disconcerting, there was no preamble. There was no warning 'this might be triggering'. I had no idea they were going to begin talking about abuse at that point...That could send somebody over the edge. Because it completely wobbled me and that was at a time when I was feeling really well."

Tat

"I think it can be so damaging, so damaging and very re-traumatising. I kind of made my own decision, thinking, right I don't want to do the next session because this is really, really triggering and really hard."

Tat

Similarly, participants also reported feeling overwhelmed by listening to the lived experiences of other people involved in TIC projects. Participants recognised that sharing lived experiences could be an important aspect of TIC. However, there was frustration with what other Experts by Experience decided to share and the lack of recognition of the impact this had on others. Participants looked to members of the wider team and those in senior positions to set boundaries and ensure the work remained manageable for those involved, but this was only sometimes provided. This spoke to the emotional intensity involved in certain TIC projects and perhaps a

misconception that the role of Expert by Experience was simply to recall their lived experience rather than using this constructively to inform changes.

"Earlier today I had to deliver some training with another Expert by Experience. She was oversharing about her personal life and, I don't want to blame anyone, but sometimes what other people are saying can, you know, be too much for us."

Taylor

"You cannot conduct this meeting, these kind of events, talking about really difficult subjects, when there are vulnerable people listening to it. And not thinking or caring about the effect you're causing other people. It is good to share about everyone's experience, but sorry, there was only so much I could hear. It was full on."

Maria

"I try to absorb and learn from other people, however I don't want other people throwing a stone on me, like we say in Italian. Every evening, I just log off and I don't want to hear about them anymore. Because if I start to care too much of what is happening around me, I couldn't cope. I already have enough challenges. I try to protect myself because sometimes it is too much."

Taylor

As well as having to contend with the impact of listening to the lived experiences of other Experts by Experience, on some occasions, certain practitioners also decided to share their own experiences of trauma. While members of the wider team may have good intentions in sharing their own experiences of trauma, this took attention away from the experiences of participants and risked silencing them further.

"It was so easy to get triggered by something else, it really affected me. There was one occasion when the mental health staff who had mental health problems, they were speaking about their trauma and it was hard to listen to. It was triggering. I was a bit shocked."

Maria

I actually think in a lived experience role, I've found staff can be more likely to talk to you about their trauma, more than they may talk to another clinical member of staff...But the emotional burden can be quite high at times. It can be a burden I guess, because you don't have any clinical training of what to do with it."

Sarah

One of the core TIC principles is to avoid the re-traumatisation of people who use services. Paradoxically, however, participants in this study highlighted how the work itself could reconnect them with traumatic memories and risked doing further harm. Coupled with the silencing and side-lining of their lived experiences meant that involvement in TIC carried a significant and complex emotional burden for participants.

Subtheme three: Frustration with the system

TIC is a service framework that requires change from across the system. However, participants highlighted several systemic issues that interfered with and obstructed the work, making implementing TIC more challenging for those involved. Participants frequently described a wider system that was rigid and resistant to change, which meant introducing meaningful change was difficult. In some instances, TIC projects were being undertaken despite the approach being at complete odds with the established culture within a service. In other teams, particular policies, such as risk management, were viewed as being of higher priority, limiting the extent to which

TIC change could be implemented. Participants often used a frustrated tone of voice to describe the systemic barriers they encountered. They appeared annoyed and let down at being invited to undertake this work without the necessary support from the wider system.

"It was a kind of clash of cultures. It was very interesting to what extent any kind of Trauma-Informed Care could be conceived or implemented within forensic setting, because it didn't fit at all with how services are operationalised. Or indeed how patients were conceptualised and treated. There was a head on clash. Between, you know decades of thinking and operations in secure forensic settings. So it's like, a bucket of water hitting a brick wall. The brick wall gets a bit wet, but it'll soon dry."

Elaine

"There are so many other things to do really. I don't want to say they are more essential, but more sort of like, you know, legal things or things focused on patient safety. So yeah, it's kind of other tasks getting in the way of focusing on trauma-informed care."

Chris

Teams also faced the challenge of attempting to implement TIC among several other priorities all at once, lurching from one change to the next. Members of the wider team needed help to give them the necessary time and attention. This competition for space meant that initiatives struggled to take root as services could not give them the time required. As a result, members of the wider team could be weary of new ideas and further changes, such as TIC. Rather than a collaborative relationship between those involved, this service context could become 'like a battle', leaving participants to push against an uncooperative system. This dynamic could create a feeling of further disempowerment for participants and compound their distressing, negative experience of TIC projects.

"You know the high-level NHS plans, they stick for a little bit until they're replaced by another concept. One is complex trauma and another is trauma informed. You feel like nothing kind of sticks and then you're onto the next thing."

Frankie

"It can feel like fighting one battle after another. So stepping into that space it can be like, gosh, why do I need to fight this battle again? Why does this need to be put at the centre again?

Frankie

Another systemic limitation and constraint cited by participants was the need for more resources to implement TIC effectively. In addition to a lack of time and competing demands, participants described how members of the wider team were often expected to implement these ideas on top of their busy workloads. TIC requires a commitment to change at all system levels for it to be effective. Passing responsibility onto a small number of already busy individuals only increased the chances of the work becoming tokenistic. Without adequate support, in terms of time and resources, the work could quickly become a burden and leave those involved feeling disheartened or exhausted.

"I think barriers can be, in healthcare, there's just so much change. Trauma informed care is another change and people are just tired of change."

Sarah

"I would say the main challenge has been time. Time being provided or allocated to it. Due to workload demands. Sometimes some staff have had to reschedule, or suddenly cancel. Some of the planned work on it has been delayed over and over."

Adam

There was also a suggestion that the systems themselves have become traumatised. Participants drew comparisons between experiences of trauma and the defensive way that systems responded to invitations to change. This perhaps explains some of the rigid policies and procedures that interfered with services' ability to implement new changes. Participants recognised how these systemic issues also affected members of the wider team and restricted the level of impact they could have. Nonetheless, it further highlighted the challenges participants faced in undertaking this work. Being met with defensiveness and resistance by the wider system only added to concerns that the work was tokenistic and risked further silencing participants' lived experiences. In this way, participants also felt frustration at the wider system for its role in making their involvement in TIC projects distressing and traumatising.

"I've realised that we work in systems and organisations that are traumatised themselves as a system, as an organisation. And organisations respond in a certain way or have policies and procedures due to this trauma."

Sarah

"There is a backdrop of scarcity of resources. Too little supply for too much demand. So I think that's a challenge. There's no easy solution to that...It's like everyone agrees and no one can do anything about it. And that's a challenge because there's a certain futility in that...And its difficult to know what to say back to that. Because people are genuinely saying we can only do what we can do. We're not superhuman."

Frankie

TIC is a service framework which invites change across the whole system. However, participants observed multiple factors, including conflicting team culture, competing priorities and a traumatised system, which made enacting TIC changes very difficult. Attempting to implement change in this context meant participants were frequently met with barriers and were at risk of becoming in a battle with a rigid and defensive system. Participants felt frustrated by the lack of support, a factor which only added to the risk of them becoming distressed and traumatised within TIC projects.

Theme two: Positive changes from implementing TIC

Participants also described how implementing TIC could positively impact them, albeit to a lesser extent. Being involved in this work enabled participants to use their traumatic experiences constructively, which could benefit current and future service users. When this was possible, it allowed some participants to develop a new perspective on their experiences of trauma. In addition, participants reported how involvement in TIC projects enabled them to feel more connected with members of the wider team and become part of a new trauma-informed team culture.

Subtheme four: Using the distressing moments

In contrast with previous examples where participants felt side-lined and silenced, they also felt members of the wider team amplified and saw the value in their lived experiences. Here, the work felt more closely aligned with the principles of TIC and

what participants had expected. Practitioners wanted to listen to and support participants in using their painful and traumatic experiences in a constructive way. There was an equal value placed on lived experience within these TIC projects and a recognition that all involved could learn from one another and lead to meaningful changes.

"Being there as part of the team, it has helped because we share our lived experience. And you know it changes their [colleague's] attitudes and the way they you know treat service users. And it's like 'ohh I never really knew that's what people go through'. It's like educating them. They're ignorant but open to learning. So they can improve their services to people who have gone through trauma."

Muleya

"...I find this is the best way to share your views and experience. And the reason why they [staff and services] have made these changes, because they hear about a difficulty and barriers faced by service users."

Hasan

When participants felt their experiences were incorporated into the TIC project, they felt more meaningfully involved. Instead of their involvement feeling tokenistic and their voices side-lined, participants were given power and a platform to feed into decision-making. The power of having their voices listened to was very powerful. The positive impact on certain participants was huge and described as empowering and life-changing. Participants could observe the changes they were contributing towards, bringing them closer to other service users who might benefit from the TIC work. They were no longer the patients or service users but experts with valuable knowledge to contribute.

"It gives me confidence, I get a lot of satisfaction from it. So when it is done well, it's been so empowering. I feel like I've got a lot to contribute because of my experience. I think it's really good because I've lived with this for such a long time and I'm quite a reflective person. Having a chance to share this, it's been life-changing for me in many ways."

Tat

"I've been doing this work for many years. And now I do it on a voluntary basis. But I will tell you, I have found it extremely, extremely rewarding...Because if Trauma-Informed Care is done in the correct manner, for me it is a win win situation. I feel it's helping me with my mental health in supporting and helping others from a professional perspective."

Robert

Some participants described how involvement in TIC projects enabled them to make sense of certain experiences differently. Working alongside members of the wider team helped them to put words to their experiences and supported them to see things from a different perspective. It was possible for Experts by Experience to identify alternative, preferred narratives about themselves, which were contrasted with the diagnostic labels they had previously been assigned. Support in the form of supervision also enabled participants to explore the impact of the work and facilitate new learning. When the work was done in this way, participants could take the distressing, disempowering moments from their lives and transform them into something new, positive and constructive.

"I've been able to use a lot of really crappy parts of my life when working with one particularly team who have just been phenonmenal. They give me faith back in the human race. They really listened to what I had to say."

Tat

"Actually it has helped me really make sense of some of my behaviours and understand where they were coming from. Despite having been through lots of services, a lot of therapy, I just hadn't made some of those links. So actually, at a personal level, just understanding trauma informed approaches has helped me move forward in my recovery. I'd gone through services for a long time with various diagnoses, trauma being one of them, but it was a bit of a light bulb moment of, actually the diagnosis doesn't have to be label."

Sarah

"I've experienced trauma personally and been involved in trying to improve the mental health services by talking to someone like you who is doing research, and it has really helped me verbalise things and see things from different perspectives."

Maria

"In my experience of delivering trauma informed care, it was so important that I had that support network and that I care for myself alongside it. And I think I was lucky in my job because we had quite a lot of support available within the team. We would have one to one supervision, team supervision, weekly staff meetings. And we also had access to a counsellor if we needed it."

Stephen

Subtheme five: Improved relationships and positive team culture

Again, contrasting with the earlier subthemes, participants described how their relationship with colleagues improved whilst implementing TIC. Encouragingly, there were examples of TIC projects in which the power dynamics changed, and members of the wider team could adopt more equal standing with participants. When this was possible, participants felt the relationships between those involved improved. Rather

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than being based on traditional service users and professionals, barriers were broken down, and richer relationships were developed.

"It starts to break down some of those barriers. Because you're on a topic that is common ground for many people... It feels like the divides are broken down rather than built up. I think it helps staff to be more involved in organisations...So I think it has changed my perception of other staff, clinical staff. And to a more positive healthy relationship I would say."

Sarah

An important part of what enabled the breaking down of barriers involved identifying members of the wider team who were prepared to use their power in a positive way. Trauma-informed allies shared similar values, and participants were able to work more strategically with them on projects. They could do this as a group rather than being a lone voice advocating for change. Although participants were critical of operating within existing power structures, they also appreciated how people in senior positions could positively use their power to amplify their voices. They created space to share lived experiences of trauma and were sensitive to ensure that this did not overwhelm other people present.

"Over time I think I've tried to develop the skills of planting seeds and developing allies. So who can you bring along on the journey? So when you're at decision points, you already have got three or four of you and one of them is clinical and one of them is a service manager. So stuff happens and changes because you're not a lone voice. And so I think the ally-ship, for want of a better word, and the use of power is so important."

Frankie

"I think one of the main things that helps is when it is done by people who have got integrity, who really care, who want to make change. But also aren't lived experience as a tick-box. You can smell it. It's kind of like the integrity of whoever involved."

Tat

"I experienced it where you've got somebody who is really skilled, really knowledgeable chairing. The person chairing has got that understanding that you're talking about trauma and mental health. The people around the table have got valued lived experiences...It's about a chair who has those skills to bring in people to it. For it to be held, for it to be safe, for it to be boundaried. And also, a recognition that you're talking about things that have messed people's lives or and are detrimental."

Tat

This new dynamic also enabled participants to better understand the challenges faced by the wider team and reflect on the impact of trauma within the systems they all worked within. In contrast to previous examples, when members of the wider team unexpectedly shared their lived experiences of trauma, this understanding seemed to come about more naturally through working together and witnessing the context of their work.

"I think, generally, it's led to kind of fuller, richer relationships with people that I work with. That's what I would say. I think it's helped to see people in three dimensions. Seeing their context... Most of this isn't personal or not caring. It is people not having space."

Frankie

"I now have a better understanding of why some staff behave in a certain way. And I have a much better understanding that staff have experienced their own trauma, which I didn't have a clue before, despite having been in services for a very long time."

Sarah

For certain teams, TIC extended well beyond isolated projects and became adopted in all aspects of their work. In contrast with previous examples of tokenism, TIC had become part of the team culture and was viewed as beneficial for service users and those working in the service, too. In these trauma-informed teams, participants described feeling better able to manage their mental health, highlighting the power and potential of TIC and suggesting it was possible to bring about a positive culture change within services using this framework.

"And that has built a very healthy team that has felt helpful for me. So I could come to work and say 'I'm having a bad day today. My mental health isn't great'. And that would be understood...So I think being a trauma-informed team or trying to operate in a trauma-informed way has allowed me to come to work as I am."

Sarah

"Trauma-Informed Care sort of becomes ingrained, you practice what you preach. So if we support each other and other individuals, that culture develops, it is natural. We practice Trauma-Informed Care amongst ourselves, and that's why we have strong, positive relationships develop within the team."

Stephen

Trauma is often relational and inflicted between people, but relationships also have the potential to provide people who have suffered trauma with a positive healing experience. Participants here identified certain aspects of the relationship that they found positive, particularly those who were prepared to reduce the power differences and get alongside them. These relationships appear possible within a team that is prepared to embrace a TIC approach.

4. DISCUSSION

4.1. Chapter overview

In this chapter, I will consider the results of this study and whether they answer the two research questions. I will then critically evaluate this study and consider how the results relate to the literature reviewed in the Introduction chapter. I will consider the clinical and research implications of its findings before concluding with a summary of the most important learnings from this research.

4.2. Summary of findings

The primary aim of the study was to capture and explore the views of Experts by Experience who had been involved in implementing TIC within UK mental health services. In the Analysis Chapter, I presented a qualitative evaluation of the data collected by presenting themes that were developed from twelve interviews. The Thematic Analysis produced two overarching themes and five subthemes in answering my research questions.

4.2.1. Research question one: How do Experts by Experience describe their involvement with, and experience of, implementing Trauma-Informed Care?

One of the main ways that participants in this study described their involvement with, and experience of, implementing TIC was distressing and re-traumatising. This adds to claims that how TIC is implemented frequently does not 'model the model' (Edelman, 2023a, p. 2). Underlying these distressing experiences was how power operated within TIC projects. Working in equal partnership with Experts by Experience is a key principle of TIC (Harris & Fallot, 2001; SAMHSA, 2014). Within the implementation, everyone involved should be viewed as having valid sources of information and expertise to contribute. However, participants in this study reported that, although they were present in projects, they lacked power, meaning their

experiences were often side-lined and silenced. This reflects previous research highlighting that service user involvement in healthcare most often occurs at the level of feedback and information giving and rarely reaches the higher levels of Arnstein's ladder of participation (Tritter & McCallum, 2006). The terms 'co-production', 'collaboration' and 'involvement' tend to be used interchangeably when referring to projects Experts by Experience work on, creating a vagueness which can disguise the nuance of how power operates within this work (Williams et al., 2020). Traumatic events are often associated with experiences of powerlessness, victimisation, and loss of control (SAMHSA, 2014). Participants risked having these experiences replicated and feeling re-traumatised within the work by being excluded from positions of power. Sweeney et al. (2018) describe the dangers of 'power over' (p. 177) relationships between service users and members of the wider team and their potential to be re-traumatising. The results of this study highlight how this dynamic can also operate within TIC projects, contrary to the principles. Perhaps underlying this is a lack of appreciation for experiential knowledge amongst partitioners. Other studies have identified a hierarchy of knowledge within service user involvement, and when lived experience is poorly understood, it becomes more likely to be devalued (Waddingham, 2021). It is suggested that we are living in an era of 'usercentred' services (Cromby et al., 2017) and putting people with lived experience at the centre of designing, delivering and implementing mental health services is included in the NHS Long-Term Plan (2019). However, these results add to research which raises questions about the capacity of mental health services to safely involve people with lived experience (Ocloo & Matthews, 2016). Perhaps underlying this is a hesitancy among mental health services to adopt a social justice approach when implementing TIC (Arnstein, 1969; Tritter, 2009). Models for co-production and service user participation as a means to social justice rely on structures of power relations being altered and practitioners being prepared to be actively challenging the systemic forms of oppression (Cruikshank, 1999; Sweeney et al., 2016). Based on the results of this study, some individual allies are willing to stand alongside Experts by Experience in this cause. However, others may be unwilling to acknowledge their own privilege and oppose groups that have more power.

Another feature of the experience of TIC projects from participants in this study was the subtle ways that their lived experience could be silenced within TIC projects. Experts by Experience felt they were viewed as a homogenous group, where anyone could be called upon as a lived experience representative. Critics of TIC suggest it can be so vague and all-inclusive that it trivialises severe mental health difficulties (Sommers & Satel, 2005). These claims have similarities to the concerns of participants in this study, who felt there was less space available for more severe mental health difficulties and that the overall support available to trauma survivors would become diluted. While TIC should include clear pathways to well-resourced trauma-specific services (Sweeney et al., 2016), it raises an important concern about how TIC could be used as a smokescreen for shifting resources away from those who are most vulnerable and severely unwell in order to cut costs (Jaffe, 2017). Edelman (2023a) suggests that this process may be caused by vague definitions of trauma with TIC projects, which conflate the event and the impact and lead people to assume that all experiences of trauma are similar. However, by viewing trauma as ubiquitous, they suggest colleagues may be more likely to assume that any trauma survivor will be able to provide relevant insights. Nonetheless, this highlights the danger that more acceptable voices and experiences are 'cherry-picked' by organisations (Martin, 2008), creating a narrower pool of ideas and potentially meaning that more marginalised voices are absent. This bias towards certain experiences may partly explain the lack of diversity within the Expert by Experience group identified by participants in this study. These findings are similar to other research, highlighting how UK Experts by Experience are more likely to be white and middle class and less likely to come from more marginalised groups (Ocloo & Matthews, 2016). The survivor movement is associated with a values-based way of approaching mental health, with a commitment to human rights, choice and creating space for marginalised voices (Chassot & Mendes, 2015). However, the results of this study highlight how these values can be undermined by who is granted access to TIC projects. Excluding marginalised people from TIC is also problematic as people from these groups are more likely to experience the added trauma of discrimination and oppression and are overrepresented in the most restrictive and potentially re-traumatising parts of the mental health system (Bhui, 2001; Keating &

Robertson, 2004). Not including their views in TIC projects limits the pool of ideas for improvement and risks further reinforcing health inequalities within services (Ocloo & Matthews, 2016). Any development of TIC must include a social justice component, as experiences of trauma are shaped by social, cultural, political and historical factors. While the framework of TIC may support services to identify some of the institutional and interpersonal factors which re-traumatise people who use services, critics of TIC argue that proponents of this approach have dropped some of their original focus on broader systematic oppression and societal injustices (McKenzie-Mohr et al., 2012).

Social, cultural and historical perspectives of trauma were reported as being absent from certain TIC projects by participants in this study, which adds to claims that this framework has moved away from addressing systemic oppression and social injustices. Acknowledging 'cultural, historical and gender issues' in relation to trauma is another key principle of TIC. This involves services recognising the role of 'invisible trauma', such as racism, poverty, colonialism, disability, homophobia and sexism and their intersectionality, and how these forms of oppression are experienced together (Sweeney et al., 2018, p. 323). However, participants in this study reported that nuanced discussions of these types of trauma were lacking, reflecting a wider trend of this principle being absent from TIC projects (Saunders et al., 2023) as well as some national implementation protocols (NHS Scotland, 2021). Sweeney et al. (2018) suggest that resistance to consider culturally diverse perspectives of trauma is linked to Western society's reluctance to acknowledge historical and cultural violence and their trauma legacies, meaning people often have little exposure to the notion of social, urban, historical and cultural trauma. The importance of overcoming this resistance is vital, as the people who use mental health services and the workforce are diverse in ethnicity, sex, gender, and class, and because trauma will present differently (Edelman, 2023b). There is a danger of Experts by Experience having to carry the additional burden of educating members of the wider team on historical and cultural violence, a process reported by participants within this study. If members of the wider team are unwilling to acknowledge the impact of institutional racism, there is also a danger of marginalised Experts by Experience having to raise issues such as racism and colonialism if they are involved in general activities, leaving them at risk of being further side-lined and positioned as problematic (Kalathi et al., 2011). This may contribute to a lack of diversity with Expert by Experience population reported by participants.

Frustration with the broader system was another meaningful way participants described their experience implementing TIC. Participants' descriptions of services that lacked the time and resources necessary to undertake TIC projects share many similarities with other research that has explored the experience of practitioners involved in this work. Emsley et al. (2022) reported several barriers, including inadequate funding, high-pressure working environments, low staff morale, resistance to new initiatives and a lack of organisational support. These barriers meant the responsibility was often left to passionate individuals to push for change. Similarly, Clark (2021) found that implementing TIC felt like 'a battle against the system' (p. 66) for certain practitioners. This left them at risk of 'emotional burnout' and feeling overstretched to the point where they questioned whether to continue the work (p. 77). TIC is a service framework which invites change across the system and represents a cultural shift within services (SAMHSA, 2014). However, participants observed this work being undertaken within systems under enormous stress. As identified within certain TIC models, the stressful context of many services makes them more likely to be change-resistant, hierarchical, coercive and punitive (Bloom & Sreedhar, 2008). This level of stress also increases the risk of coming to mean little more than treatment as usual, but simply repackaged as trauma-informed, and supports claims that England would benefit from a national TIC implementation plan (Emsley et al., 2022). Inviting Experts by Experience into this context risks causing more harm by placing them in opposition to systems which are actively resisting them while also carrying the added confusion of framing it as TIC (Saunders et al., 2023).

Participants in this study reported that services and members of the wider team often viewed trauma through the medical model lens and found adopting the TIC framework challenging. This may partly be due to TIC being delivered within multi-

disciplinary teams and to colleagues, such as psychiatrists, GPs and nurses, whose training is within a medical model. Like these results, Sweeney et al. (2016; 2018) observed a resistance to the notion that trauma plays a causal role in mental health difficulties among colleagues implementing TIC and that the medical model remains the dominant approach despite strong evidence for psychosocial factors being available (Read et al., 2005; Shevlin et al., 2007). The idea that TIC represents a novel approach for certain members of the wider team is supported by Stamatopoulou (2019), who found that mental health practitioners experienced transitioning to TIC as a 'paradigm shift' (p. 101). Similarly, in Clark's (2021) interviews of mental health colleagues' experience of implementing TIC, they found it was a struggle amongst the teams they worked with to view trauma from any lens other than that of the medical model. This supports the findings from this study, in which members of the wider team were reported to view trauma as an experience that required a diagnosis and treatment with medication. Sweeney et al. (2018) go on to suggest that undertaking TIC may challenge certain mental health practitioners' worldviews. Along these lines, Stamatopoulou (2019) found that forensic practitioners underwent a process of 'reconstructing their professional identity' (p. 82), which involved unlearning how they viewed service users and themselves as professionals. Perhaps the level of personal change that TIC invites members of the wider team to go through is not recognised or properly appreciated by services. Only one participant in this study reported that they received supervision while implementing TIC, and it suggests that more support is needed for everyone involved in this work to help reflect on the process.

While implementing TIC was often distressing and re-traumatising for participants in this study, they also highlighted important positive changes which resulted from the work. When participants were meaningfully involved in decision-making, and their lived experience led to tangible changes, it proved transformative. Involvement in TIC enabled them to use the incredibly harmful and distressing moments of their life for positive change. It may have also connected participants with something bigger than themselves, such as shielding the next generation from painful experiences and allowing them to feel aligned with the values of the survivor movement

(Waddingham, 2021). Implementing TIC also enabled other participants to develop different understandings of their experiences. In this way, it appeared to represent a strengths-based which supported participants to re-frame their symptoms as coping adaptations (Sweeney & Taggart, 2018). This supports the idea that experiences of trauma are much more than psychiatric symptoms and instead are a process that triggers a transformation or metamorphosis that evokes both strengths and vulnerabilities (Rousseau & Measham, 2007). The dominant discourses surrounding people who have experienced trauma and use mental health services tend to be problem-saturated (White & Epston, 1990) as well as pathologising and based on thin diagnostic labels (Busch & McNamara, 2020; Herman, 1992). Narrative approaches suggest that problems of living can occur when the stories told do not match their lived experience (Harper & Spellman, 2013), and the new personal meaning that participants report here may be explained by having access to new stories about themselves. Becoming involved in implementing TIC may allow Experts by Experience to identify the dominant discourses surrounding them and re-story their lives instead.

4.2.2. Research question two: How do Experts by Experience describe their psychological and relational experience of implementing Trauma-Informed Care? Power-over relationships between mental health practitioners and service users can inadvertently replicate a sense of powerlessness by disregarding a service user's experiences (Sweeney et al., 2018). In recognition of this, TIC aims to introduce a different dynamic based on trust, transparency, collaboration, respect and hope (SAMHSA, 2014; Sweeney & Taggart, 2018). However, several participants in this study described this harmful dynamic occurring within TIC projects and meant that Experts by Experience voice was silenced and side-lined. This has similarities to McGeown et al. (2023), who reported that existing hierarchies and unacknowledged power dynamics went unchallenged in a TIC project, which meant that Experts by Experience felt unable to disagree with ideas suggested and would go along with decisions they did not feel comfortable with. Implementing TIC as an Expert by Experience required participants to revisit painful and disempowering moments of their lives. However, the power dynamics also presented a challenge of how best to

share these with the wider team. These findings have similarities to previous research, which found that Experts by Experience are expected to share their lived experience with the correct amount of emotion and vulnerability and risk being pathologised or discredited if they overstep this invisible line (Waddingham, 2021). The danger of having lived experience of trauma pathologised for Experts by Experience involved in TIC seems particularly relevant given the reports in this study that certain teams remain wedded to a medical diagnostic model. Discrepancies between the principles of TIC and how it was implemented in practice left participants in this study feeling frustrated and confused. Simultaneously being told their views are central to a project whilst existing power structures remain in place has been described as 'crazymaking' for people with lived experience (Waddingham, 2021, p. 39) and is particularly problematic given the high proportion of people who use services have also experienced mistrusting or coercive relationships (Beck et al., 2011; Felitti et al., 1998; Felitti, 2009). Given the centrality of trust in working with people who have experienced trauma, transparency is crucial, and the rebranding of services as 'trauma-informed' needs to be accompanied by real systemic change (Sweeney & Taggart, 2018). By lacking the necessary 'commitment to change' identified by Harris and Fallot (2001, p. 5), services risk manoeuvring people with lived experience into a bystander role, where they witness the work being implemented in a way that contradicts their values. Mental health systems can inflict 'moral injury' on practitioners by requiring them to work in ways that conflict with personal and ethical codes of conduct (Litz et al., 2009). Undertaking TIC projects which are tokenistic may also risk inflicting the same harm on Experts by Experience.

Participants in this study also described feeling caught off guard by how distressing material was presented and discussed, unexpectedly connecting them with distressing experiences. Paradoxically, participants described feeling overwhelmed whilst trying to think about creating a safe, 'trauma-informed' environment for service users. Being blindsided by distressing material also undermined their capacity to engage in the work. Similarly, Edelman (2023a) observed that trigger warnings, used to highlight potentially triggering material, often come when people have settled in for

a session or immediately before a potentially triggering slide. This left people with little time to decide on how to respond and effectively out themselves if they do leave. How trauma was discussed might have taken participants out of their 'Window of Tolerance' (Siegel, 1999; 2020) and left them in the freeze response. This would have made it harder for them to advocate for themselves and potentially reinforce previous experiences of disempowerment.

This study also highlighted the potential to become re-traumatised by listening to the lived experiences of other Experts by Experience while implementing TIC, as reported in previous research (Kahan et al., 2020; McGeown et al., 2023). The repeated exposure to traumatic stories leaves people open to 'vicarious trauma' (McCann & Pearlman, 1990). Evidence suggests that people with histories of trauma are more susceptible to being vicariously traumatised (Chrestman, 1995; Pearlman & Mac Ian, 1995), again highlighting the potential for TIC to be additionally overwhelming for Experts by Experience. While the TIC mantra of 'What's happened to you?' rather than 'What's wrong with you?' (Harris & Fallot, 2001) can be depathologising, perhaps it also encourages practitioners to feel compelled to ask about trauma stories without considering whether this is safe, one of six misconceptions about TIC identified by Sweeney and Taggart (2018). Edelman (2023a) points out that encouraging lived experience within a group implicitly assumes that no one in the room will be re-traumatised and that personal trauma is somehow left at the door or already processed. This assumption can be further disempowering and re-traumatising for those involved, as well as inducing a sense of shame if people do become triggered. This process may also encourage an 'othering' of traumatic experiences, implying that anyone in a 'professional' space should not have their own personal trauma. This only adds to concerns that implementing TIC as an Expert by Experience risks silencing certain experiences.

This study also found that implementing TIC could positively impact the relationships between participants and members of the wider team. The results have similarities to research from the perspective of practitioners which also has found improved relationships between those involved in TIC projects. Stamatopoulou (2019) found

that implementing TIC allowed forensic practitioners to understand the life stories of service users better and develop an improved sense of connectedness. Clark (2021), reports that mental health practitioners were often inspired by people with lived experience of trauma and that this was a motivational factor for becoming and remaining involved. However, participants in this study were able to identify the actions from members of the wider team which support this change from the perspective of Experts by Experience, which was previously unknown. Identifying allies proved to be important for certain participants. These colleagues were able to set the tone by demonstrating their value of lived experience and setting boundaries amongst the group. Together, they could harness the power of their roles and strategically call for change when the time came. The importance of allies within service user involvement work has been identified elsewhere and appears to be associated with de-centring themselves and being prepared to use their power to create space for lived experience (Waddingham, 2021). The positive examples also provide some encouragement that TIC can be implemented in a way which does model the model and is healing for Experts by Experience. The results of this study reinforce the idea that relationships and context are both central to traumatisation but also offer a means to avoid it (NHS Scotland, 2018; van der Kolk, 2014). However, there is much to be done to extend this understanding, for example, not only by viewing TIC as between people but also within the systems level thinking, by acknowledging how broader structures may be traumatising (Edelman, 2023a; Edelman, 2023b).

4.3. Recommendations for future practice

4.3.1. Service level

How power operated within TIC projects was identified as an issue by participants within this study and meant that their lived experiences could be silenced and sidelined. While several co-production guides highlight the importance of reducing differences in power between those involved (National Service User Network, 2015; Ocloo & Mathews, 2016; Slay & Stephens, 2013), future TIC projects may benefit from also adopting a Human Rights Based Approach (Patel, 2019). This framework

would support restoring social justice within TIC, a process which was absent in certain projects, by helping services reflect on whether the FREDA principles (fairness, respect, equality, dignity and autonomy) are upheld (Curtice & Exworthy, 2010). This would also support the development of 'practitioner-activists' (Patel, 2019, p. 17) who uphold these principles within their work and aim to change the status quo, arguably a key element of TIC work which is not recognised within current guidelines. Arstein's ladder of participation (1969) should be referenced within TIC projects as a means of making it clear what type of involvement the project is aiming for and consulted regularly to assess if this is being achieved or not. This tools could also help identify 'managerial/consumerist' TIC projects and support them to view restoring social justice as a fundamental part of the work.

Guidelines on TIC recommend that services can be led and delivered by people with direct experience of trauma (SAMHSA, 2014; Sweeney et al., 2018), although this level of control and power was not reported to be the case by any participants in this study. One recommendation is for future TIC projects to be user-led, meaning that people who use a service also run the service and have the benefit of people making decisions having closer links to their community and a better understanding of their needs (Brown & Ormerod, 2020). Although this may represent a radical change for some services, it would nonetheless begin to address the harmful 'power over' relationships which are reported to operate within certain TIC projects.

This study highlighted the danger of lived experiences of trauma being homogenised within TIC projects and more marginalised voices being excluded. Linking TIC projects with broader social rights-based initiatives, such as education, forensic services, and employment, could build relationships with more marginalised groups and enable their voices to be included (Kalathil, 2008). In addition, services should consider building relationships with service user organisations like 'Catch-a-Fiya', which brings together people with lived experience from marginalised backgrounds to provide a network for information sharing and offer consultation on service development projects. This could be an alternative way to collaborate and ensure the voices of those most traumatised within services and least heard within them are

included. Including more marginalised Experts by Experience in generic service user involvement projects may risk the burden falling on these few voices to raise issues of systemic oppression and being perceived as having a 'chip on their shoulder' (Trivedi, 2009).

TIC projects that include Experts by Experience and members of the wider team need to acknowledge power differentials and consider the simultaneous interactions between social categories (e.g. race, gender, class, sexuality, disability), as well as the impact of systems of oppression (e.g. racism, colonialism, classism, sexism, ableism) (Kalathi et al., 2011). Failing to do this means these oppressive power structures will go unchallenged and continue to underpin the service context that Experts by Experience are introduced into. Given that this has the potential to silence the very experiences that made them eligible in the first place, it raises concerns about whether it is ethical to invite Experts by Experience into this context. To support them in exploring how power operates within TIC projects, services should include exercises which promote reflexivity and discursive reflection. Shimmin et al. (2017) provide a guide to service user involvement that encourages mental health practitioners to consider how power may operate within the project, both at a micro level in their relationships and at a macro level in society (see Appendix T).

For teams who decide to undertake a TIC project, the accusations of tokenism in this study may reflect the vagueness of SAMHSA's TIC principles and the difficulties of translating these into everyday practice (Hanson & Lang, 2016; Muskett, 2014). Instead, the principles described by Sweeney et al. (2018) provide more detailed and nuanced guidance, with the explicit instruction that services acknowledge forms of systemic oppression and their intersectionality. Services need to be clearer in how they define trauma and not conflate the event with the impact. They should focus their attention on understanding the unique consequences it has had on an individual and not allow experiences to become simplified and homogenised.

For those services unsure of the organisational process involved in becoming trauma-informed, resources such as the Trauma-Informed screening tool and

roadmap produced by Trauma-Informed Oregon (2018) could be used to map out the key steps. Trauma-Informed Oregon is a US organisation that offers consultation, training and resources to healthcare services that are seeking to become more trauma-informed. Their roadmap provides an overarching process for implementing TIC. It includes a helpful four-stage approach, with activities and exercises aimed at supporting teams to move from first becoming 'trauma aware', to 'trauma sensitive', then 'trauma responsive' and finally 'trauma informed'. Teams which are earlier in their journey to become trauma-informed could first address resistance by showing videos developed by the ACE interface and focus on becoming 'trauma sensitive' through activities which aim to establish foundational knowledge. Resources outlined by Sweeney et al. (2018, p. 330) could also help with this and reduce the burden for Experts by Experience to fight against the system. 'Understanding agency readiness' should also be assessed, including whether stable funding and the necessary resources (e.g. time for training, supervision) are available (Trauma-Informed Oregon, 2018, p. 6). This could be an opportunity to explore any resistance or suspicion within the team; however, undertaking this within services that are overwhelmed and have a risk-averse culture is likely to be challenging (Emsley et al., 2022).

This study also highlighted that practitioners are expected to implement TIC on top of their busy workloads and without the necessary resources. Large numbers of NHS practitioners report feeling burnt out due to their work (NHS England, 2023) and without adequate support, TIC puts them at further risk of becoming overwhelmed and traumatised too (Sodeke-Gregson et al., 2013). This adds to claims that a TIC in England should have a national implementation plan, similar to that in Scotland (Emsley et al., 2022). UK-wide Trauma-Informed Community of Action groups and local TIC working groups would also help to support the sharing of best practices and be one of the ways of responding to the systemic barriers identified here. Time and funding for specific TIC roles need to be set aside, as originally described by Harris and Fallot (2001). There are concerns that the availability of supervision has reduced within mental health teams (Sweeney et al., 2016), which might explain the examples of practitioners disclosing their own experiences of trauma to Experts by

Experience. Reinstating supervision and additional reflective spaces is needed to help explore the impact of their work and ensure practitioners' experiences do not become the focus of TIC work or further silence Experts by Experience.

4.3.2. Team relationships

People involved in TIC should consider how TIC principles are embedded in their interactions with Experts by Experience. As well as TIC resources, the 'See Think Act' guide (Royal College of Psychiatrists, 2015) focuses on the importance of ensuring safety through interactions based on 'relational security' and provides a helpful framework for how mental health practitioners can do this, for example, by maintaining clear boundaries and considering group dynamics. Members of the wider team should recognise that the TIC mantra of 'What has happened to you?' does not mean inviting trauma experience is always helpful. Practitioners need to strike a balance between allowing Experts by Experience sufficient space to express this and ensuring that others in the group are not overwhelmed and re-traumatised. Given the emotional burden and potential to become re-traumatised, it is important that Experts by Experience and practitioners involved are provided with the option of supervision. In addition, separate peer support sessions would allow people with lived experience to explore the team dynamics without the risk of challenging these in isolation and risk being pathologised. Supervision for Experts by Experience would also provide additional space to explore the impact of the work and develop new personal understanding, a positive consequence of involvement in TIC projects identified by participants in this study.

In addition, Edelman (2023a) provides some helpful, practical suggestions on how to safely implement TIC, for example, signposting where there is triggering material and using text shading to empower people to skip different content. For in-person events, trigger warnings could be provided in emails ahead of time, and stronger guidelines on how and when lived experience is shared could be agreed upon. Regular breaks allow everyone to step away, and explicit permission to raise concerns on behalf of others provides an opportunity for everyone in the room to take responsibility for keeping it safe and takes the onus off one individual. Services should also consider a

way of routinely evaluating to what extent they are 'modelling the model' of TIC and capturing the relational aspect of this rather than simply how many practitioners have received training. The Roots framework could be used in order to assess how well projects reflect the underlying principles and bring them into line with these, for example, by asking whether 'efforts made to communicate compassion through interactions' and 'staff can reflect, non-judgementally, on their own actions' (Thirkle et al., 2022, p. 29).

4.3.3. Experts by Experience

This research highlights the various dangers for Experts by Experience who are invited to participate in TIC projects within UK services, and the burden should not fall upon them to change. Nonetheless, this study's results have identified certain ideas and suggestions about implementing TIC that people with lived experience may wish to consider. Most importantly, Experts by Experience should be aware that there is a potential that the way they are invited to participate in this work will be retraumatising. Rather than working as isolated individuals, people with lived experience might consider joining service user groups and participating in TIC projects, which are undertaken in collaboration (Waddingham, 2021). Having other people effectively in their corner would hopefully provide a degree of protection from some of the dangerous processes identified here and more power to advocate for change if they do occur. Whilst Experts by Experience should perhaps approach invitations to implement TIC with caution, they should also be aware it represents an opportunity to use distressing aspects of their lives in a constructive, positive way. There is the chance to develop new understandings about their experiences and to contribute to a team culture within services, which reflects the TIC principles of mutuality, transparency, collaboration and empowerment.

4.4. Recommendations for future research

4.4.1. Co-production and user led research

In line with the principles of TIC, future research would benefit from being coproduced by Experts by Experience or entirely user-led. Involving people with lived experience meaningfully from the beginning would provide a different outlook on all aspects of study design, while occupying a dual role as Expert by Experience and researcher would reduce power differences between them and participants and potentially produce new perspectives on this topic. This would also be an opportunity to provide social justice to Experts by Experience by handing over power and decision-making within the research to people who use services. Co-produced or user-led research might also be more easily undertaken in conjunction with service user organisations representing more marginalised groups. This would be an important next step, given these voices were largely absent from this study. These groups also face additional forms of system oppression and discrimination, which require greater attention within TIC projects.

Based on the results of this study, co-produced or user-led research might be interested in exploring particular aspects of the experience of implementing TIC. For example, the process of using the distressing moments constructively within TIC projects and how this part of the work impacts Experts by Experience psychologically and emotionally. Given that TIC projects had the potential to silence certain lived experiences, future research could also evaluate the impact of tools that promote reflexivity and encourage discussions of the role of power, privilege, oppression, and discrimination in the work. For example, those provided by Shimmin et al. (2017) could be included within TIC projects and the impact those involved explored.

Understanding the experience of implementing TIC for Experts by Experience could also be supported through research based on quantitative methods, for example, by collecting participant responses to self-reported measures on measures on levels of stress, satisfaction, and empowerment following involvement in this work. Assessing the impact of involvement in TIC projects over time would also help to understand the longitudinal consequences.

4.4.2. Mental health practitioners and services

Given that this study highlighted the dangers of Experts by Experience being sidelined within TIC projects, future research could evaluate the impact of teams adopting a TIC approach based on the principles outlined by Sweeney et al. (2018) and in conjunction with a Human Rights Based Approach (Patel, 2019).

Participants in this study highlighted how implementing TIC was often hindered by systemic factors and a lack of support from the wider system. Research that explores the implementation of TIC at this level in more detail would be beneficial. Given that TIC requires a commitment to change from across the system, understanding the factors that facilitate the implementation of TIC and current barriers would help better understand what support should ideally be in place before inviting Experts by Experience to undertake this work.

This study also found that certain teams, particularly those more wedded to the medical model or where risk policies were prioritised, were more resistant to TIC. Future research could focus on evaluating the impact of interventions that aim to make these teams more 'trauma sensitive' and embed foundational knowledge, for example by using those outlined in Trauma Informed Oregon (2018, p. 4).

4.5. Critical evaluation

In the following section, I will critically evaluate this study in terms of its contribution, credibility and rigour, following Spencer and Ritchie's (2012) guidance which provides a helpful structure for evaluating qualitative research.

4.5.1. Contribution

Contribution refers to the 'value and relevance of research evidence', for example, to policy or practice (p. 229). Qualitative research involves providing an in-depth understanding of the way people talk about their experiences, which has relevance beyond the participants or context of the study (Denzin & Lincoln, 2008). Experts by Experience tend to be underrepresented in research (Repper & Carter, 2011), and by privileging their voices, this study makes a helpful contribution in this area. This has relevance to all people who wish to understand what it is like for people with

lived experience to undertake this work, especially those in positions of relative power, such as mental health practitioners. The results raise concerns about the repeated harm experienced by participants while implementing TIC and, therefore, also have relevance for policymakers who encourage the inclusion of Experts by Experience.

Until now, previous research in the UK has focused on the experiences of individual TIC projects and has been undertaken by researchers involved in the projects themselves (McGeown et al., 2023). This study is the first in the UK to explore the experiences of Experts by Experiences across multiple different TIC projects. Participants were recruited from across England, and certain individual participants were involved in numerous TIC projects in different areas. The range of work discussed by participants makes the results of this study more relevant and generalisable for other TIC projects going forward. The study was undertaken by a researcher who is separate and independent from the work. This may have encouraged Experts by Experience with more challenging experiences to participate in the study and provide a more accurate overall reflection of the work.

4.5.2. Credibility

Credibility refers to the 'believability' of findings but also how the researcher's conclusions are reached (p. 230). To support the credibility of this study, I have presented the evidence from which the conclusions were drawn, for example, by describing the process of categorising the data, considering not only the semantic surface-level explanations but also the unspoken latent meaning behind the words. Whilst TA cannot be described as accurate or objective, I have strived for 'stronger' themes which are compelling, thoughtful, rich, and nuanced (Braun & Clarke, 2021a, p. 8). I have tried to capture the process of how I interacted with the data to develop to reach my conclusions, giving the developing analysis some distance and taking a break from the process, as well as providing extracts in the form of participant quotes to show where these came from within the raw data.

4.5.3. Rigour

In qualitative research, rigour is seen as 'synonymous with methodological validity' (p. 231). The idea of consistency within qualitative research does not fit well given the approach uses flexible methods and relies on the researcher's own interaction with the data, however rigour is demonstrated in the careful documenting of decisions so to help the reader understand the logic behind my process and make it accountable (Lincoln & Guba, 1985).

I have increased the rigour of this study by presenting the reader with a transparent account of my relationship to, and process of analysing the data. In the Methods Chapter, I describe the analytic approach and reflexivity. In the Results Chapter, I have shared example quotes and their relationship to the themes. A complete list of quotes for each subtheme has been provided in Appendix S for the reader to consider. Inter-rater reliability checks with my supervisor also improved the rigour of this study. Candidate themes were discussed together, and identified themes were more representative of descriptive topics. More analysis was required to tell more compelling stories about the data. This process also allowed me to challenge several assumptions I have about the data and consider them differently.

4.6. Demographic data

The majority of participants (10) were recruited via an NSUN newsletter compared with those recruited from adverts from the local NHS Trust (2), despite being invited to speak directly with Experts by Experience within their NHS Trust meetings. On reflection, this may indicate that participants preferred speaking to someone separate from the service in which they are employed, and highlighting my link to the local NHS Trust may have invertedly been a barrier to participating.

The sample comprised six male and five female participants, representing a more diverse balance of genders than previous research exploring the experience of implementing TIC (McGeown et al., 2023). Participants' ages ranged from 25 to 62 years, with most aged between 40 and 62. It is difficult to know why fewer 'younger'

Experts by Experience decided to participate. Perhaps they are less likely to check the NSUN bulletin and more likely to engage in research advertised in other methods, such as via social media. It is possible, too, that being approached by a university student represented a degree of similarity with younger people which may have also restricted what they felt comfortable sharing. The age of participants might also reflect services reserving the role of Expert by Experience for those with greater perceived lived experience.

Eight participants identified as 'White' and six as 'White British', this reflects the general population of Experts by Experience, in which White, middle-class service users are well represented (Ocloo & Mathews, 2016). Service users from minority ethnic groups tend to be overrepresented in the most harmful and re-traumatising parts of the mental health system, experiences which could make them less likely to become involved as an Expert by Experience (Bhui, 2001; Keating & Robertson, 2004). Applications of TIC have been criticised for failing to acknowledge social trauma, such as racism and their intersections (Saunders et al., 2023; Sweeney et al., 2018), another factor which may explain why this group is underrepresented. Finally, as a White male researcher, I hold multiple levels of social privilege, which is likely to have influenced how participants viewed the study. Being presented with a poster containing my picture could have represented an embodiment of these harmful institutions and impacted those who were willing to participate.

4.7. Limitations

4.7.1. Sample limitations

This study was undertaken by a White researcher, and most participants were also White, which centres Whiteness and makes generalising the results to other groups difficult. This limits the impact of this study as racialised service users tend to be overrepresented in the most harmful and re-traumatising parts of the mental health system (Akther et al., 2019; Gajwani et al., 2016). Due to poor experiences fuelled by prejudice, the relationship between mental health services and racialised

communities can be fraught (Keating & Robertson, 2004), and a lack of trust can be a barrier to research participation (George et al., 2014).

This study recruited participants from one NHS Trust, and the NSUN, which meant the sample included people who had worked in a diverse range of services across the UK. However, participants also self-selected to take part in this study and it is therefore inherently biased in favour of people who have access to emotional, financial, time and other resources. All interviews took place over video, which excluded Experts by Experience who did not have access to the technology required to participate.

Non-English speakers face additional language barriers and poor outcomes with healthcare services (Pollard & Howard, 2021), and although this study was open to participants who did not speak English, the posters and advertisements were only made available in one language. On reflection, unless they were made aware of the study via word of mouth, it seems very unlikely this group would have been aware of this study. No additional funding was available for interpreters and hypothetically non-English speaking Expert by Experience had responded to the advert, unless they were able to organise an interpreter themselves, I am unsure whether it would have been possible for them to participate. This adds to a recursive process in which the most disenfranchised members of society tend to be excluded from research, and changes introduced as a result of research tend to favour those with the most resources. This systemic exclusion also alienates people with fewer resources, making them understandably less willing to participate and further exacerbating health inequalities (Lorenc et al., 2013). This is both a methodological concern due to sample bias and non-generalisability of findings and an ethical concern as this practice breaches the ethical principle of justice as the right to access health care and participate in research (Beauchamp & Childress, 2001).

4.7.2. 'Modelling the model'

The same problematic processes identified by participants involved in TIC projects were also at play in this study. Asking participants about their emotional experience

of implementing TIC risked connecting them with experiences of harm and disempowerment and replicating the same processes that have been criticised in this study. This project was also undertaken as part of a doctorate in clinical psychology and placed me in a position of power and privilege as the researcher in regard to the participants. The research has provided a voice for people who otherwise may not have been able to contribute, but it has also centred my own needs by enabling me to complete the training course.

This project did not involve any Experts by Experience, which also contradicts the TIC principles and reflects similar power hierarchies in research that are reported within the services in this study. The original intention was to identify someone with lived experience who could support the development of interview questions and dissemination; however, due to this being a doctoral thesis, there were limitations to the funding available. I already felt uncomfortable at only being able to offer a £10 voucher to participants, and asking someone to give up their time felt potentially exploitative, a criticism highlighted elsewhere by Experts by Experience (Waddingham, 2021). The lack of payment reflects another systemic barrier to meaningful involvement of people with lived experience.

To minimise the risk of harm, participants were provided with the list of interview questions in advance, and I offered the chance to de-brief at the end of each interview. Participants were given the opportunity to review and edit their transcript before analysis and were invited to select their pseudonyms, which I hoped provided some choice and a sense of empowerment within the project.

4.7.3. Epistemology

Taking a CR perspective for this study has meant I view participants' experience of TIC as real but that the tools for examining this are inherently limited and biased (Willig, 2013). Taking a critical approach to how I have used, analysed, and interpreted what participants shared has therefore been important. Due to the need to examine the biases with the tools used for analysis, critical realism can privilege the researcher's own interpretations over those of participants (Edwards et al.,

1995). In this study, I have sometimes struggled to strike a balance between presenting the realities of participants and capturing how this interacted with my own social context. I have attempted to describe my process of practicing reflexivity throughout this study and make this transparent, although capturing the nuance of this has been challenging.

4.8. Reflexive review

Reflexivity is an important part of conducting ethical research (Attia & Edge, 2017) and contributes to the credibility and reliability of research findings (Spencer & Ritchie, 2012). Embarking on this study, I felt it was important to use my privileged role as a trainee clinical psychologist to provide a platform for more marginalised voices. However, as time has gone on, I feel conflicted and uncertain as to whether this study has recreated some of the same side-lining and silencing identified by participants.

Many of the recommendations I have made within this study are also relevant to me. As a White man, the visible aspects of privilege I hold will have shaped the conversations with participants. I attempted to create a space that allowed participants to bring as much of their experience as they felt comfortable, for example, by naming and acknowledging different aspects of our identity and how they may influence our conversation at the beginning of the interview schedule. I have tried to be conscious throughout the study that Whiteness and Maleness do not silence certain experiences of participants. However, as the study has gone on, it has become clearer just how pervasive Whiteness is within research and more radical steps are needed beyond just practicing reflexivity in order to ensure the most marginalised voices are heard.

Similarly, although this project was undertaken as part of a university training programme that limited the amount of involvement of Experts by Experience, it would have been possible to consult with someone along the way. I decided against this, however, as I could not offer payment, and I feared the dynamic becoming

exploitative and tokenistic. However, in doing so, I missed the opportunity to address the power dynamics this study called for and failed to challenge the institution, which only allocates a minimal amount of funding for participants. Recognising my own part in the process of silencing described in this study has been uncomfortable and added to my sense of injustice for them. In early drafts of my thesis, I noticed myself taking a critical position to my mental health colleagues and perhaps pushing these negative feelings onto this anonymous 'other' group. However, as time has gone on and I have noticed my own limitations in this study, I have developed a different, more balanced, and understanding view towards them, recognising the complex contextual factors that make this work difficult.

Reflecting on the journey I have been on in undertaking this study, I feel I have developed a far better understanding of the present issues faced by people with lived experience and Experts by Experience within the current UK service context. I am more cautious about how TIC is implemented and the danger of this recreating the very harm that it is aiming to address within services. I have increasingly found myself informed by a human rights-based approach and social justice principles, and I am looking upward towards policymakers and political figures who have the power to make decisions that will address the underlying social conditions that sustain poor mental health.

4.9. Dissemination

It is important for me that the findings of this study are accessible to those who would most benefit from it. Following the submission of this thesis, I will consider suitable potential journals for publication. I will share the findings with the NHS Trust, which supported me in recruiting participants. I am currently on placement with another organisation that provides TIC training to all practitioners, and the findings will be shared with this team as well. A summary of the findings will also be shared with participants and I will be interested to discuss the findings with them, should they wish. My intention is also to share the results with the NSUN members via their email bulletin through which the study was originally advertised.

5. CONCLUSION

Trauma-Informed Care is an approach to service delivery which assumes that a large proportion of the population has experienced trauma and attempts to embed this knowledge into the way services operate to minimise the re-traumatisation of people who use them (Harris & Fallot, 2001). This involves the application of certain key principles, typically those outlined by SAMHSA (2014): safety, trustworthiness, peer support, collaboration, empowerment and cultural, historical and gender acknowledgements. In the UK, TIC is becoming increasingly popular and including the perspective of Experts by Experience - people with lived experience of trauma and mental health services - is a key element of how TIC is implemented (Sweeney et al., 2016). TIC strives to achieve mutual and collaborative relationships between Experts by Experience and other people involved in this work which reflect the principles of TIC.

This study sheds light on what it is like for Experts by Experience to implement TIC within UK mental health services. Paradoxically, this work was often undertaken in a way which itself was not trauma-informed. Participants reported that their lived experiences could be side-lined and silenced while implementing TIC, and the work frequently reconnected them with some deeply distressing and disempowering experiences. In certain TIC projects, existing power hierarchies remained in place, and participants were excluded from meaningful involvement, making many to feel the work was tokenistic. The contradiction between the TIC principles and the reality of their experience left participants feeling frustrated and confused. In addition, several systemic barriers to implementing TIC were identified, including a lack of resources and the challenge of undertaking this work alongside other competing initiatives. TIC requires a commitment to change from across the system. However, participants described the wider system working against them to implement these ideas, which reinforced a sense of frustration.

Despite these challenges, participants also described positive changes they observed from involvement in TIC projects. When participants were more meaningfully involved, the work allowed them to use the distressing and harmful parts of their lives constructively way and feel they were contributing to tangible changes. This opened up new possibilities in how participants made sense of their experiences. Relationships with members of the wider team could also improve during this work. Participants reported how barriers were broken down, and they could identify allies with shared values who could strategically work together to bring about change. TIC could result in a positive team culture, which enabled participants to feel more supported and manage the emotional nature of the work more comfortably.

Based on these results, several recommendations have been made. At a service delivery level, how participants describe the emotional impact of implementing TIC and the silencing of their experiences in this study raises concerns about whether it is ethical for Experts by Experience to be invited to participate in this service context. One solution is for services to implement TIC in conjunction with a social justice approach, which actively acknowledges and addresses power imbalances within the work. In addition to this, services should consider more user-led TIC projects, which put people who use services in the role of decision-makers. Steps also need to be taken to ensure more marginalised voices are not excluded from TIC projects, for example, by undertaking TIC projects in partnership with external service user organisations and routinely acknowledging how forms of systemic oppression and discrimination shape experiences of trauma. Finally, practical advice on how members of the wider team can undertake TIC in a way that minimises the chances of those involved being re-traumatising is put forward, including tips on how lived experience is shared and providing Experts by Experience with supervision spaces.

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7. APPENDICIES

Appendix A – Principles of Trauma-Informed Care (Sweeney et al., 2018)

Seeing through a trauma lens: Trauma-informed practices acknowledge and understand the high prevalence, common signs and widespread effects of trauma. There is an understanding of the ways in which trauma can influence emotions and therefore behaviour, leading the development of coping strategies that can seem excessive, dangerous and harmful without a comprehensive understanding of the multiple consequences of trauma.

Appreciation of invisible trauma and intersectionality: A broad-based understanding of trauma is adopted, involving an appreciation of community, social, cultural and historical traumas such as racism, poverty, colonialism, disability, homophobia and sexism and their intersectionality. Services understand the context and conditions of people's lives and are culturally and gender competent. To achieve this, staff remain open-minded and consider all perspectives.

Sensitive discussions about trauma: When service users are asked about trauma, this is done in respectful, sensitive, timely and appropriate ways, and the individual is offered a clear choice regarding whether or not to answer. There is an understanding of the potential re-traumatisation caused by describing traumatic events, and the potential damage caused by repeating one's story when nothing changes.

Additionally, survivors may not recognise that past events have had adverse, lasting effects on them, for instance because of definitions of trauma, the normalisation of traumatic events within families and communities or an ability to recall early experiences.

<u>Pathways to trauma-specific support</u>: When survivors are able to report a trauma history, and trauma-specific services are requested or desirable, these services are available, or facilitated through cross-agency coordination.

Preventing trauma in the mental health system: Trauma-informed practices understand that the fundamental operating principles of coercion and control in mental health services can lead to (re)traumatisation and vicarious trauma. Deliberate steps are taken to eliminate and/or mitigate potential sources of coercion and force, and accompanying triggers.

<u>Trustworthiness and transparency</u>: Trusting relationships are built between staff and service users through an emphasis on openness, transparency and respect. This is essential because many trauma survivors have experienced secrecy, betrayal and/or 'power over' relationships.

<u>Collaboration and mutuality</u>: Trauma-informed practices understand that there is a unilateral aspect to relationships in mental health case, with one person acting as a helper to a 'helpee'. These roles can replicate power imbalances and reinforce a sense of disability and helplessness in the helpee. Thus, relationships and interventions strive for collaboration through transparency, authenticity and an understanding of what both people see as helpful.

Empowerment, choice and control: Trauma-informed practices use strengths-based approaches that are empowering and support individuals to take control of their lives and service user. Such approaches are vital because many trauma survivors will have experienced an absolute lack of power and control. Adaptations to trauma are emphasised over symptoms, and resilience over pathology.

<u>Safety</u>: Central to trauma experiences are threats to the person's safety and often the integrity of their identity. Consequently, trauma-informed practices ensure that the staff member and the individual are emotionally and physically safe, both people defining what this means and negotiating it relationally. This extends to physical, psychological, emotional, social, gender and cultural safety, and it created through measures such as informed choice and cultural and gender competence.

<u>Survivor partnerships</u>: Trauma-informed practices strive to achieve mutual and collaborative relationships between staff and service users through partnership working. Additionally, services can be led and delivered by people with direct experience of trauma and mental health service use.

Appendix B - UEL ethics application



UNIVERSITY OF EAST LONDON School of Psychology

APPLICATION FOR RESEARCH ETHICS APPROVAL FOR RESEARCH INVOLVING HUMAN PARTICIPANTS (Updated October 2021)

FOR BSc RESEARCH; MSc/MA RESEARCH;

PROFESSIONAL DOCTORATE RESEARCH IN CLINICAL, COUNSELLING & EDUCATIONAL PSYCHOLOGY

	Section 1 – Guidance on Completing the Application Form				
	(please read carefully)				
1.1	Before completing this application, please familiarise yourself with:				
	 British Psychological Society's Code of Ethics and Conduct 				
	 UEL's Code of Practice for Research Ethics 				
	 UEL's Research Data Management Policy 				
	■ UEL's Data Backup Policy				
1.2	Email your supervisor the completed application and all attachments as ONE WORD DOCUMENT.				
	Your supervisor will look over your application and provide feedback.				
1.3	When your application demonstrates a sound ethical protocol, your supervisor will submit it for				
	review.				
1.4	Your supervisor will let you know the outcome of your application. Recruitment and data collection				
	must NOT commence until your ethics application has been approved, along with other approvals				
	that may be necessary (see section 7).				
1.5	Research in the NHS:				
	 If your research involves patients or service users of the NHS, their relatives or carers, as well 				
	as those in receipt of services provided under contract to the NHS, you will need to apply for				
	HRA approval/NHS permission (through IRAS). You DO NOT need to apply to the School of				
	Psychology for ethical clearance.				
	Useful websites:				
	https://www.myresearchproject.org.uk/Signin.aspx				
	https://www.hra.nhs.uk/approvals-amendments/what-approvals-do-i-need/hra-approval/				

- If recruitment involves NHS staff via the NHS, an application will need to be submitted to the HRA in order to obtain R&D approval. This is in addition to separate approval via the R&D department of the NHS Trust involved in the research. UEL ethical approval will also be required.
- HRA/R&D approval is not required for research when NHS employees are not recruited directly through NHS lines of communication (UEL ethical approval is required). This means that NHS staff can participate in research without HRA approval when a student recruits via their own social/professional networks or through a professional body such as the BPS, for example.
- The School strongly discourages BSc and MSc/MA students from designing research that requires HRA approval for research involving the NHS, as this can be a very demanding and lengthy process.
- 1.6 If you require Disclosure Barring Service (DBS) clearance (see section 6), please request a DBS clearance form from the Hub, complete it fully, and return it to applicantchecks@uel.ac.uk. Once the form has been approved, you will be registered with GBG Online Disclosures and a registration email will be sent to you. Guidance for completing the online form is provided on the GBG website: https://fadv.onlinedisclosures.co.uk/Authentication/Login

You may also find the following website to be a useful resource:

https://www.gov.uk/government/organisations/disclosure-and-barring-service

- 1.7 Checklist, the following attachments should be included if appropriate:
 - Study advertisement
 - Participant Information Sheet (PIS)
 - Participant Consent Form
 - Participant Debrief Sheet
 - Risk Assessment Form/Country-Specific Risk Assessment Form (see section 5)
 - Permission from an external organisation (see section 7)
 - Original and/or pre-existing questionnaire(s) and test(s) you intend to use
 - Interview guide for qualitative studies
 - Visual material(s) you intend showing participants

Section 2 – Your Details			
2.1	Your name:	Alex Turner	
2.2	Your supervisor's name:	Dr Hannah Eades	
2.3	Name(s) of additional UEL supervisors: Dr Matthew Jones-Chesters		
		n/a	
2.4	Title of your programme:	Professional Doctorate in Clinical Psychology	
2.5	2.5 UEL assignment submission date: 01/05/2024		

		n 3 – Project Details		
Please give as much detail as necessary for a reviewer to be able to fully understand the nature and purpose of your research.				
3.1	Study title: Please note - If your study requires registration, the title inserted here must be the same as that on PhD Manager	Implementing trauma-informed care: what is it like for experts by experience?		
3.2	Summary of study background and aims (using lay language):	Trauma-informed care (TIC) is an organisational change process which recognises that the experience of trauma is common among people who access services (mental health, drug & alcohol, homelessness charities) and is focused on preventing the re-traumatisation of people who use these services (Harris & Fallot, 2001). A trauma-informed service understands the impact of trauma and is responsive to individuals' respective needs by embedding this knowledge within the organisations policies, procedures, and practices (Substance Abuse and Mental Health Service Administration; SAMHSA, 2014). Collaboration between staff and people with lived experience of mental health challenges (frequently known as experts by experience) is one of the key		
		principles of TIC (Harris & Fallot, 2001; Sweeney & Taggart, 2018). In the UK, experts by experience and staff are increasingly working together to implement TIC by designing, delivering and evaluating trauma-informed services (Thirkle et al, 2022).		
		Research which has explored staff members' experience of implementing TIC suggests it is complicated. Some studies report that being involved in TIC changes had a positive impact on relationships		

(Chandler, 2008) and others reporting that TIC elicited

strong, difficult emotions (Sweeney et al, 2016).

However, no UK study has explored the

		implementation of TIC through the lens of experts by experience, a key part of the trauma-informed workforce. This study therefore aims to address this gap in the literature. This is particularly important as this experts by experience frequently occupy less powerful positions within services and tend to be overlooked in research (Repper & Carter, 2011). This study could have important implications for how services implement TIC.
		Experts by experience who have supported services to implement TIC will be invited to undertake a semistructured interview aimed at exploring their experience of this work. The results will be analysed via thematic analysis to identify reoccurring patterns and important themes.
3.3	Research question(s):	This study aims to understand what it is like for experts by experience to implement TIC within UK services.
		The study aims to address the following questions:
		1) How do experts by experience describe their involvement with and experience of implementing TIC?
		2) What is the emotional experience of implementing TIC for experts by experience?
		3) What are the perceived barriers and facilitators to implementing TIC?
		4) How does implementing TIC impact experts by experience relationship with staff and services?
3.4	Research design:	Qualitative Interviews
3.5	Participants:	The research aims to recruit between 8 – 12
	Include all relevant information including inclusion and exclusion	participants.
	criteria	This number is commonly selected within studies using
		thematic analysis to ensure there is sufficient data is
		available to identify reoccurring patterns and key
		themes. Research also highlights how participants

themes typically become saturated around this number (Guest el al, 2006).

Volunteer sampling will be used, meaning that participants will self-identify and volunteer. Snowball sampling may also be used to aid recruitment, whereby participants highlight the research to other eligible people who then also self-identify.

Inclusion Criteria:

Participants will be/have been, an expert by experience, in either a paid or voluntary capacity. Experts by experience are people with lived experience of mental health services, either as a service user, carer or family member.

Whilst in the role of expert by experience, participants will have also supported services to implement TIC changes. For example, developing or delivering TIC training for staff.

Participants do not need to also identify as a having direct experience of trauma or as a trauma survivor will be eligible.

Participants must be adults (over 18 years old).

TIC principles are relevant to various services (e.g. mental health, homelessness, drug & alcohol, homelessness, forensics, gambling) and experts by experience who have been involved in implementing TIC within any of these are eligible to participate.

Participants who do not speak English will also be considered, although the validity of analysing translated accounts may be limited (Van Nes et al., 2010).

Only people who have supported UK service are eligible.

Exclusion Criteria: Professionals who identify as trauma survivors and have experience of implementing TIC will not be included. Children (under 18 years old) are not eligible for this research. Individuals who are unable to understand the information sheet (with support) and cannot consent to participating will not be eligible. The research will be advertised with non-NHS service 3.6 **Recruitment strategy:** Provide as much detail as possible and user organisations, such as National Service User include a backup plan if relevant Network (NSUN) The research intends to be advertised to the members of these service user organisations, through a regular research newsletters which is emailed and made available online. A poster with details of the research and researcher's contact details will be provided as part of this. Interested participants will self-identify by contacting the researcher themselves by email. Further details about the research will be provided via a participant information sheet which will be sent via email. The researcher will be available to answer any further questions via email, phone or video. Participants will then be asked to complete a consent form and return this by email. If there are problems recruiting sufficient numbers of participants, additional advertisement of the research on social media (e.g. via twitter) will be considered.

The research aims to recruit between 8 - 12

		participants.
		This number was chosen to ensure there is sufficient data is available to identify reoccurring patterns and key themes (Guest el al, 2006).
		This research also has NHS Ethics approval (IRAS number 325470) in conjunction with an NHS Foundation Trust.
3.7	Measures, materials or equipment: Provide detailed information, e.g., for measures, include scoring instructions, psychometric properties, if freely available, permissions required, etc.	The interview will cover the following topics: - what TIC changes were you involved in? - emotional experience of TIC work? - any challenges or barriers? - how did it impact your relationships with professionals or services?
		Participants will be invited to provide basic demographic information; gender, age & ethnicity. The research requires the following equipment (which the researcher has access to): - a laptop - Microsoft Teams - Microsoft OneDrive.
3.8	Data collection: Provide information on how data will be collected from the point of consent to debrief	Semi-structured interviews will be conducted online via MicrosoftTeams. The information sheet and consent form will be sent to the participants prior to the interview.
		(See Appendix B for participant information sheet and Appendix C for consent form).
		The interviews will take place only if the participants give consent.
		I will conduct the semi-structured interview following the interview guide.

		At the end of the interview, I will revisit consent to use the interview data, debrief the participants verbally and also provide them with the debrief sheet.	
3.9	Will you be engaging in deception?	YES	NO ⊠
	If yes, what will participants be told about the nature of the research, and how/when will you inform them about its real nature?	_	rovide more information here
3.10	Will participants be reimbursed?	YES ⊠	NO
	If yes, please detail why it is necessary.	Offering reimbursement to participants is felt to be important in this research in order to recognise their tim and expertise.	
	How much will you offer? <u>Please note</u> - This must be in the form of vouchers, <u>not cash</u> .	£10 Amazon voucher will be	e offered to each participant.
3.11	Data analysis:	The data collected from participants in the interviews will be analysed using thematic analysis (Braun & Clark 2006). The data will be analysed for reoccurring patterns and	
important themes. These will be a specific codes which in turn will be data into relevant global and sub		will be used to arrange the	
		Thematic analysis is a flexible research tool whice allows for rich, detailed accounts to be collected participants (Howitt & Cramer, 2007) and is comwith a critical realist epistemological stance that research will be undertaken in.	

Section 4 – Confidentiality, Security and Data Retention

It is vital that data are handled carefully, particularly the details about participants. For information in this area, please see the UEL guidance on data protection, and also the UK government guide to data protection regulations.

	a Research Data Management Plan (RDMP) has been completed and reviewed, information from this ocument can be inserted here.			
4.1	Will the participants be anonymised at	YES	NO	
	source?		X	
	If yes, please provide details of how the data will be anonymised.			
4.2	Are participants' responses	YES	NO	
	anonymised or are an anonymised sample?	X		
	If yes, please provide details of how data will be anonymised (e.g., all identifying information will be removed	All identifying participant info during the transcription of in		
	during transcription, pseudonyms used, etc.).	Participant names and the na be changed to pseudonyms.	ames of other individuals will	
		Other identifiable information, such as geographical location will be replaced with a meaningful description (e.g. 'Hackney' to London') so that participants cannot be identified via other details. Only anonymised extracts of the interview transcripts will be included in research thesis write up. Participants will have the opportunity to select their own anonymous pseudonym to be used in transcripts and research thesis write up. cipant details Any personal data that is collected will be held securely and processed in accordance with the UKGDPR and the Data Protection Act 2018. Participants will not be identified by the data collected, on any material resulting from the data collected, or in any write-up of the research.		
4.3	How will you ensure participant details will be kept confidential?			
		Participants will be encourag interview in a confidential sp do the same.		
		Recordings of the interview a	and the interview transcripts	

will be stored on the researcher's OneDrive, whom only they have access to. Individual files will all be password protected. Each interview recording and interview transcript file will be named using a pseudonym. Transcriptions of the interviews will only be undertaken by the interviewer to protect the confidentiality of the participants. Participant names and the names of other individuals will be replaced with pseudonyms by the researcher during the transcription of interviews. The services that participants have implemented traumainformed care within will also be anonymised so that these are not identifiable. Other identifiable information, such as geographical location will be replaced with a meaningful description (e.g. 'Hackney' to London'). Only pseudonyms will be included in the research thesis write up. 4.4 The data will be stored on my UEL's password protected How will data be securely stored and backed up during the research? OneDrive account in a folder that is not synchronised on Please include details of how you will any devices. manage access, sharing and security Data will be sent to the supervisor as a backup during the research and stored on the supervisor's OneDrive account. Consent forms will be stored as password-protected files in a separate folder to other research data on UEL OneDrive. 4.5 Who will have access to the data and in I will have access to the raw data. My supervisor will have what form? access to the anonymised data. (e.g., raw data, anonymised data)

		Examiners may also have access to the anonymised if requested.		
		The intention is for anonymi be shared with a co-research experience of mental health data analysis. No raw data w researcher. The data will not be shared was a shared will not be shared will not be shared was a	ner (someone with lived services) to assist with the will be shared with the co-	
4.6	Which data are of long-term value and will be retained? (e.g., anonymised interview transcripts, anonymised databases)	The anonymised transcripts term value.	of interviews are of long-	
4.7	What is the long-term retention plan for this data?	Anonymised research data will be securely stored on my supervisor's UEL's password-protected OneDrive account for a maximum of 3 years, following which all data will be deleted. All identifiable information will be destroyed as soon as the allowed withdrawal period is over and transcripts have been created unless there has been an agreement with the participants to receive an update from the researcher on the outcomes of the research.		
4.8	Will anonymised data be made available for use in future research by other researchers?	YES	NO ⊠	
	If yes, have participants been informed of this?	YES	NO □	
4.9	Will personal contact details be retained to contact participants in the future for other research studies?	YES	NO ⊠	
	If yes, have participants been informed of this?	YES	NO □	

Section 5 – Risk Assessment

If you have serious concerns about the safety of a participant, or others, during the course of your research please speak with your supervisor as soon as possible. If there is any unexpected occurrence while you are

collecting your data (e.g., a participant or the researcher injures themselves), please report this to your supervisor as soon as possible. 5.1 Are there any potential physical or psychological risks to participants YES NO related to taking part? (e.g., potential adverse effects, pain, \boxtimes discomfort, emotional distress, intrusion, etc.) If yes, what are these, and how will The potential physical risks for participants in this they be minimised? research is very low. However, there are some potential psychological risks for the participants. Some potential risks include: There is a chance that in discussing their involvement in implementing TIC, participants may become emotional and distressed. The following steps will be taken to control for these risks: Participants will be provided with a detailed information sheet prior to interviews to support their decision in whether to participate or not. Example questions will be included in this. Participants will be able to take a break at any point during the interview and have the option of doing it over several meetings if this feels more manageable. If participants do become distressed during the interview, the interview will be paused, and reassurance offered by the researcher. They'll be reminded that they can pause and continue the interview another time. After the interview, a debrief will be offered to all participants, where they are invited to reflect on the experience of participating.

Debrief sheet will include services who could provide additional emotional support (e.g. Samaritans or Hub of

		Hope) if the interview touched on things that participants would like further help with.			gs that participants
		would like further help with.			
5.2	Are there any potential physical or	V-0			
	psychological risks to you as a researcher?	YES ⊠			NO ⊠
	If yes, what are these, and how will they be minimised?	There potential phy research are very lo	•	for the re	esearcher in this
		There are some por researcher, however	•	_	l risks for the
		The emotional impact of conducting an interview someone in distress.			
		The following steps will be		aken to co	ntrol for this:
		Should any of the indistressing, I will condense debrief and support	ontact my	•	
		I will consider paus distressing for me. how to proceed an support before dec	I will ask i d will con	my superv sider more	isor for advice on
5.3	If you answered yes to either 5.1 and/or 5.2, you will need to complete and include a General Risk Assessment (GRA) form (signed by your supervisor). Please confirm that you have attached a GRA form as an appendix:	YES ⊠ ATTACH FORM (signed)		ed)	
5.4	If necessary, have appropriate support services been identified in material provided to participants?	YES		o	N/A □
5.5	Does the research take place outside the UEL campus?	YES ⊠			NO
	If yes, where?	Online		I	
5.6	Does the research take place outside the UK?	YES			NO ⊠

	If yes, where?	Please state the country and other relevant details	
	If yes, in addition to the General Risk		
	Assessment form, a Country-Specific		
	Risk Assessment form must also be		
	completed and included (available in		
	the Ethics folder in the Psychology		
	Noticeboard).		
	Please confirm a Country-Specific Risk	YES	
	Assessment form has been attached		
	as an appendix.		
	<u>Please note</u> - A Country-Specific Risk		
	Assessment form is not needed if the		
	research is online only (e.g., Qualtrics		
	survey), regardless of the location of		
	the researcher or the participants.		
5.7	Additional guidance:		
	 For assistance in completing the 	e risk assessment, please use the AIG Travel Guard website	
	to ascertain risk levels. Click on	'sign in' and then 'register here' using policy # 0015865161.	
	Please also consult the Foreign	Office travel advice website for further guidance.	
	 For on campus students, once the 	he ethics application has been approved by a reviewer, all	
	risk assessments for research ak	proad must then be signed by the Director of Impact and	
	Innovation, Professor Ian Tucke	r (who may escalate it up to the Vice Chancellor).	
		conducting research abroad in the country where they	
		ent must also be carried out. To minimise risk, it is	
		its only conduct data collection online. If the project is	
		necessary for the risk assessment to be signed by the	
	Director of Impact and Innovation. However, if not deemed low risk, it must be signed by		
	·	vation (or potentially the Vice Chancellor).	
	_	dents are not explicitly prohibited from conducting	
	research abroad. However, it is	discouraged because of the inexperience of the students	
	and the time constraints they ha	ave to complete their degree.	

Section 6 – Disclosure and Barring Service (DBS) Clearance				
6.1	Does your research involve working with children (aged 16 or under) or vulnerable adults (*see below for definition)? If yes, you will require Disclosure Barring Service (DBS) or equivalent (for those residing in countries	YES	NO ⊠	

	outside of the UK) clearance to				
	conduct the research project				
* You are required to have DBS or equivalent clearance if your participant group involves:					
	(1) Children and young people who are 16 years of age or under, or				
	(2) 'Vulnerable' people aged 16 and over with particular psychiatric diagnoses, cognitive				
	difficulties, receiving domestic care, in nursing homes, in palliative care, living in institutions or sheltered accommodation, or involved in the criminal justice system, for example. Vulnerable				
	people are understood to be persons w	ho are not necessarily able to	freely consent to		
	participating in your research, or who m	nay find it difficult to withhold	consent. If in doubt about		
	the extent of the vulnerability of your ir	itended participant group, spe	ak with your supervisor.		
	Methods that maximise the understand	ing and ability of vulnerable po	eople to give consent should		
	be used whenever possible.				
6.2	Do you have DBS or equivalent (for				
	those residing in countries outside of	YES	NO		
	the UK) clearance to conduct the	X			
	research project?				
6.3	Is your DBS or equivalent (for those				
	residing in countries outside of the	YES	NO		
	UK) clearance valid for the duration	X			
	of the research project?				
6.4	If you have current DBS clearance,				
	please provide your DBS certificate	Certificate number: 0017390	61001		
	number:				
	If residing outside of the UK, please	Please provide details of the	type of clearance, including		
	detail the type of clearance and/or	any identification information	n such as a certificate		
	provide certificate number.	number			
6.5	Additional guidance:				
	 If participants are aged 16 or ur 	nder, you will need two separa	te information sheets,		
consent forms, and debrief forms (one for the participant, and one for their parent/guardian).			d one for their		
	 For younger participants, their information sheets, consent form, and debrief form need to 				
be written in age-appropriate language.					

Section 7 – Other Permissions			
7.1	Does the research involve other organisations (e.g., a school, charity,	YES	NO
	workplace, local authority, care	⊠	
	home, etc.)?		
	If yes, please provide their details.	PROVIDE ORGANISATION D	ETAILS
	If yes, written permission is needed		
	from such organisations (i.e., if they	Y	'ES

	are helping you with recruitment	
	and/or data collection, if you are	
	collecting data on their premises, or if	
	you are using any material owned by	
	the institution/organisation). Please	
	confirm that you have attached	
	written permission as an appendix.	
7.2	Additional guidance:	

- Before the research commences, once your ethics application has been approved, please ensure that you provide the organisation with a copy of the final, approved ethics application or approval letter. Please then prepare a version of the consent form for the organisation themselves to sign. You can adapt it by replacing words such as 'my' or 'l' with 'our organisation' or with the title of the organisation. This organisational consent form must be signed before the research can commence.
- If the organisation has their own ethics committee and review process, a SREC application and approval is still required. Ethics approval from SREC can be gained before approval from another research ethics committee is obtained. However, recruitment and data collection are NOT to commence until your research has been approved by the School and other ethics committee/s.

	Sectio	n 8 – Declarations
8.1	Declaration by student. I confirm that	
	I have discussed the ethics and	YES
	feasibility of this research proposal	
	with my supervisor:	
8.2	Student's name:	Alex Turner
	(Typed name acts as a signature)	Alex Turrier
8.3	Student's number:	
8.4	Date:	31/03/2023

Appendix C – UEL ethics approval letter



School of Psychology Ethics Committee

NOTICE OF ETHICS REVIEW DECISION LETTER

For research involving human participants

BSc/MSc/MA/Professional Doctorates in Clinical, Counselling and Educational Psychology

Reviewer: Please complete sections in blue | **Student:** Please complete/read sections in orange

Details	
Reviewer:	Dr Paula Corredor Lopez
Supervisor:	Dr Hannah Eades
Student:	Alex Turner
Course:	Professional Doctorate in Clinical Psychology
Title of proposed study:	Implementing trauma-informed care: what is it like for experts by experience?

Checklist			
(Optional)			
	YES	NO	N/A
Concerns regarding study aims (e.g., ethically/morally questionable, unsuitable topic area for level of study, etc.)		\boxtimes	
Detailed account of participants, including inclusion and exclusion criteria	\boxtimes		
Concerns regarding participants/target sample		□х	
Detailed account of recruitment strategy			
Concerns regarding recruitment strategy		□х	
All relevant study materials attached (e.g., freely available questionnaires, interview schedules, tests, etc.)	\boxtimes		

Study materials (e.g., questionnaires, tests, etc.) are appropriate for target sample	□х		
Clear and detailed outline of data collection	\boxtimes		
Data collection appropriate for target sample	□х		
If deception being used, rationale provided, and appropriate steps followed to communicate study aims at a later point			\boxtimes
If data collection is not anonymous, appropriate steps taken at later stages to ensure participant anonymity (e.g., data analysis, dissemination, etc.) – anonymisation, pseudonymisation	\boxtimes		
Concerns regarding data storage (e.g., location, type of data, etc.)		\boxtimes	
Concerns regarding data sharing (e.g., who will have access and how)		\boxtimes	
Concerns regarding data retention (e.g., unspecified length of time, unclear why data will be retained/who will have access/where stored)		\boxtimes	
If required, General Risk Assessment form attached	□х		
Any physical/psychological risks/burdens to participants have been sufficiently considered and appropriate attempts will be made to minimise	□х		
Any physical/psychological risks to the researcher have been sufficiently considered and appropriate attempts will be made to minimise	\boxtimes		
If required, Country-Specific Risk Assessment form attached			\boxtimes
If required, a DBS or equivalent certificate number/information provided	\boxtimes		
If required, permissions from recruiting organisations attached (e.g., school, charity organisation, etc.)	\boxtimes		
All relevant information included in the participant information sheet (PIS)	\boxtimes		
Information in the PIS is study specific	\boxtimes		
Language used in the PIS is appropriate for the target audience	\boxtimes		
All issues specific to the study are covered in the consent form	\boxtimes		
Language used in the consent form is appropriate for the target audience	\boxtimes		
All necessary information included in the participant debrief sheet	\boxtimes		
Language used in the debrief sheet is appropriate for the target audience	\boxtimes		
Study advertisement included	\boxtimes		
Content of study advertisement is appropriate (e.g., researcher's personal contact details are not shared, appropriate language/visual material used, etc.)	\boxtimes		

Decision options		
Ethics approval for the above-named research study has been granted from APPROVED the date of approval (see end of this notice), to the date it is submitted for		
AITROVED	assessment.	
	In this circumstance, the student must confirm with their supervisor that all	
APPROVED - BUT MINOR	minor amendments have been made before the research commences.	
AMENDMENTS ARE	Students are to do this by filling in the confirmation box at the end of this	
	form once all amendments have been attended to and emailing a copy of	

REQUIRED BEFORE THE	this decision notice to the supervisor. The supervisor will then forward the	
RESEARCH COMMENCES	student's confirmation to the School for its records.	
	Minor amendments guidance: typically involve clarifying/amending	
	information presented to participants (e.g., in the PIS, instructions), further	
	detailing of how data will be securely handled/stored, and/or ensuring	
	consistency in information presented across materials.	
	In this circumstance, a revised ethics application <u>must</u> be submitted and	
	approved before any research takes place. The revised application will be	
	reviewed by the same reviewer. If in doubt, students should ask their	
NOT APPROVED - MAJOR	supervisor for support in revising their ethics application.	
AMENDMENTS AND RE-		
SUBMISSION REQUIRED	Major amendments guidance: typically insufficient information has been	
SOBINISSION REQUIRED	provided, insufficient consideration given to several key aspects, there are	
	serious concerns regarding any aspect of the project, and/or serious	
	concerns in the candidate's ability to ethically, safely and sensitively	
	execute the study.	

Decision on the above-named proposed research study

Please indicate the decision:

APPROVED - MINOR AMENDMENTS ARE REQUIRED BEFORE THE RESEARCH COMMENCES

Minor amendments

Please clearly detail the amendments the student is required to make

- -State have NHS Ethics approval in UEL Ethics form
- -State you will anonymise the service names so these are not identifiable.

Major amendments

Please clearly detail the amendments the student is required to make

Assessment of risk to researcher			
Has an adequate risk assessment been offered in the application form?	YES ☑ If no, please request resubmission with	NO an adequate risk assessment.	
	the proposed research could expose the <u>researcher</u> to any kind of emotional, physical or he		
safety hazard, please rate the			
HIGH	Please do not approve a high-risk application. Travel to countries/provinces/areas deemed to be high risk should not be permitted and an application not be approved on this basis. If unsure, please refer to the Chair of Ethics.		
MEDIUM	Approve but include appropriate recommendations in the below box.		
LOW	Approve and if necessary, include any recommendations in the below box.		
Reviewer recommendations in relation to risk (if any):	All good.		

Reviewer's signature	
Reviewer: (Typed name to act as signature)	Dr Paula Corredor Lopez
Date:	02/06/2023
This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Ethics Committee	

RESEARCHER PLEASE NOTE

For the researcher and participants involved in the above-named study to be covered by UEL's Insurance, prior ethics approval from the School of Psychology (acting on behalf of the UEL Ethics Committee), and confirmation from students where minor amendments were required, must be obtained before any research takes place.

For a copy of UEL's Personal Accident & Travel Insurance Policy, please see the Ethics Folder in the Psychology Noticeboard.

Confirmation of minor amendments

(Student to complete)

I have noted and made all the required minor amendments, as stated above, before starting my research and collecting data

research and conecting data	
Student name:	Alex Turner
(Typed name to act as signature)	Alex Turner
Student number:	U2195636
Date:	09/06/2023

Please submit a copy of this decision letter to your supervisor with this box completed if minor amendments to your ethics application are required

Appendix D - UEL ethics approval letter

11th May 2023



Pioneering Futures Since 1898

Dear Alex,

Project Title:	Implementing trauma-informed care: what is it like for experts by experience?
Researcher(s):	Alex Turner
Principal Investigator:	Alex Turner

I am writing to confirm that the application for the aforementioned NHS research study reference **23/EM/0087**, IRAS project ID: **325470** has received ethical approval from the Ethics and Integrity Sub-Committee (EISC) and is sponsored by the University of East London.

The lapse date for ethical approval for this study is **11**th **May 2027**. If you require EISC approval beyond this date you must submit satisfactory evidence from the NHS confirming that your study has current NHS R&D ethical approval and provide a reason why EISC approval should be extended.

Please note as a condition of your sponsorship by the University of East London your research must be conducted in accordance with NHS regulations and any requirements specified as part of your NHS R&D ethical approval.

Please ensure you retain this approval letter, as in the future you may be asked to provide proof of ethical approval.

With the Committee's best wishes for the success of this project.

Yours sincerely,



Catherine Hitchens, Ethics, Integrity and Compliance Manager For and on behalf of

Professor Winston Morgan
Deputy Chair, Ethics and Integrity Sub-Committee (EISC)
Email: researchethics@uel.ac.uk

Appendix E – HRA ethics approval letter





Mr Alex Turner 61 Boscobel House Royal Oak Road London E8 1BU

Email: approvals@hra.nhs.uk

02 May 2023

Dear Mr Turner

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title: Implementing trauma-

informed care: what is it like

for

experts by experience?

IRAS project ID: 325470

Protocol number: N/A

REC reference: 23/EM/0087

Sponsor University of East London

I am pleased to confirm that <u>HRA and Health and Care Research Wales (HCRW) Approval</u> has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation.

The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "After Ethical Review – guidance for sponsors and investigators", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?

Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is 325470. Please quote this on all correspondence.

Yours sincerely, XXXXXXXXX Approvals Specialist

Email: approvals@hra.nhs.uk

List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	Version	Date
Copies of materials calling attention of potential participants to the research [Poster]	3	01 May 2023
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [UEL Professional Indemnity]		20 March 2023
Interview schedules or topic guides for participants [Interview Schedule]	2	25 April 2023
IRAS Application Form [IRAS_Form_28042023]		28 April 2023
Organisation Information Document [Organisation Information Document]	1	20 March 2023
Other [Email to Advertise Research]	1	25 April 2023
Other [Participant Debrief Sheet]	1	25 April 2023
Other [List of Actions and Responses 2]	1	01 May 2023
Participant consent form [Participant Consent Form]	2	25 April 2023
Participant information sheet (PIS) [Participant Information Sheet]	3	01 May 2023
Research protocol or project proposal [Research Protocol]	3	01 May 2023
Schedule of Events or SoECAT [Schedule of Events]	1	20 March 2023
Summary CV for Chief Investigator (CI) [Alex Turner CV]	2	21 April 2023
Summary CV for student [Alex Turner CV (version 2)]	2	21 April 2023
Summary CV for supervisor (student research) [Dr Hannah Eades CV]		20 March 2023

Appendix F – Participant information sheet





Alex Turner – Researcher University of East London

PARTICIPANT INFORMATION SHEET

IMPLEMENTING TRAUMA-INFORMED CARE: WHAT IS IT LIKE FOR EXPERTS BY EXPERIENCE?

Contact person: Alex Turner Email: <u>u2195636@uel.ac.uk</u>

IRAS: 325470 01.05.2023 Version Number: 3

You are being invited to participate in a research study. Before you decide whether to take part or not, please carefully read through the following information which outlines what your participation would involve. Feel free to talk with others about the study (e.g., friends, family, etc.) before making your decision. If anything is unclear or you have any questions, please do not hesitate to contact me on the above email.

Who am I?

My name is Alex Turner, a student from University of East London (UEL). I am studying for a Doctorate in Clinical Psychology.

What is the purpose of the research?

The aim of this study is to explore what it is like for experts by experience to implement traumainformed care.

Trauma-informed care (TIC) is an organisational change that recognises that the experience of trauma is common, and services need to think about how to avoid re-traumatising people (staff and service users) who use them.

People with direct experience of mental health services, either as a service user themselves or as a carer for someone else, are commonly known as experts by experience.

Experts by experience are increasingly employed by services to implement TIC ideas. For example, delivering training to staff on TIC, highlighting the links between trauma and mental health, embedding TIC in service design.

Research has explored professional's experience of implementing TIC has highlighted that it can be both helpful and challenging. This research aims to be different by focusing on how experts by experience find this work.

What are the aims?

This research aims to understand:

- How do experts by experience describe their involvement in TIC?
- What is the emotional experience of implementing TIC?
- What are the perceived barriers and facilitators to implementing TIC?
- How does implementing TIC impact their relationship with staff and services?

Who is eligible to take part?

You must be over 18 and been involved in implementing TIC as an expert by experience to be eligible. You do not need to identify as having personal experience of trauma or as a trauma survivor to be eligible.

Examples of TIC changes you may have been involved in:

- Involvement in any service development which foregrounds the role of trauma in peoples experience.
- Developing and delivering specific training on TIC for staff (e.g. as part of induction or one of session).
- Consulting on service policies and procedures, to ensure they are informed by TIC principles.
- Evaluating how trauma-informed services currently are (e.g. using ROOTS framework).

The principles of TIC are:



Why focus on experts by experience?

Experts by experience also tend to be overlooked in research and it is important to ensure their voices are heard and understood.

What will I be asked to do if I agree to take part?

If you agree to take part, you will be asked to undertake a 30 - 60 minutes semi-structured interview, over video on Microsoft Teams, about your experience of implementing TIC. Interviews will be like having an informal chat with the researcher. You will be able to take a comfort break at any point and stop the interview if you wish.

The interviews will be recorded. This is so that Microsoft Teams can automatically transcribe our conversation. I will then check the transcription for any minor errors in transcription and alterations made where appropriate. I will then anonymise the data by removing all identifiable information (your name, names of other people, specific places) and replacing them with pseudonyms. You will be able to select your own pseudonym for the study.

Once the recordings have been transcribed, they will immediately be deleted. The anonymised transcript of our conversation will then be included in the analysis. The entire anonymised transcript of our conversation will then be used to ensure your full account is included in the analysis.

Will I get paid for taking part?

A £10 Amazon voucher will be available for each participant as payment.

What are the benefits of taking part?

Participation in this study may offer a sense of empowerment and potentially provide a sense of purpose and self-awareness. It will also provide an opportunity to contribute to original research in this area

Can I change my mind?

YES. You can change your mind at any time during the interview, and up to **3 weeks afterwards**, and your data will not be used as part of the research. You can withdraw by contacting me (details below) or my supervisor Hannah Eades (details below). After 3 weeks data will not be able to be withdrawn and will be included in the study.

Are there any disadvantages to taking part?

The study is not designed to cause you any harm, discomfort or distress. However, there is a chance that talking about your experiences could be upsetting. You can take a break and opt out of answering any questions. I will be available immediately after each interview to provide a debrief and have sources of additional support, if required.

How will we use information about you?

We will need to use information from you for this research project.

This information will include your initials held by the researcher. People will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your initials. Your data will have a code number instead.

We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

What are your choices about how your information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.

We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

Where can you find out more about how your information is used?

You can find out more about how we use your information

- at <u>www.hra.nhs.uk/information-about-patients/</u>
- our leaflet available from chief researcher (Alex Turner)
- by asking one of the research team (details below)
- by sending an email to u2195636@uel.ac.uk

Generic Support Services

Samaritans:

If you feel you need someone to talk to, the Samaritans are available to call for free. 116 123

https://www.samaritans.org

Hub of Hope:

Hub of Hope is a mental health support database, bringing local, national, peer, community, charity, private and NHS mental health support services together in one place. https://www.hubofhope.co.uk

Focused Support Services

National Service Union Network:

A grassroots community group for people with lived experience of mental health distress. They offer various resources, including Online Peer Support. 020 7820 8982

https://www.nsun.org.uk/projects/peer-support

How will the information I provide be kept secure and confidential?

Nobody else will be informed that you have participated. Any names of individuals or teams or organisations which are mentioned will be changed to a pseudonym to keep them anonymous. All your data (recordings of interviews, consent form, demographic information, personal contact details) will be password protected and saved on my University One Drive which only I have access to.

Confidentiality may need to be broken should the researcher become aware of any serious risks to yourself or other people during the interview.

How long will my data be kept for?

The transcript will be kept for three years and there is a possibility it will be written up and published in a related journal in order to share the findings.

What will happen to the results of the research?

The research will be written up as a thesis and be publicly available on UEL's online Repository. Findings may also be disseminated through journal articles, conference presentations, talks, magazine articles, blogs. In all material produced, your identity will remain anonymous. Anonymised research data will be securely stored by Dr Hannah Eades for a maximum of 3 years. Once this time is over, all data will be deleted.

Who has reviewed the research?

My research has been approved by the School of Psychology Ethics Committee. This means that the Committee's evaluation of this ethics application has been guided by the standards of research ethics set by the British Psychological Society.

Who can I contact if I have any questions/concerns?

If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me:

Alex Turner u2195636@uel.ac.uk

If you have any questions or concerns about how the research has been conducted, please contact my research supervisor:

Dr Hannah Eades School of Psychology, University of East London, Water Lane, London E15 4LZ, Email: h.eades@uel.ac.uk

or

Chair of School Ethics Committee: Dr Trishna Patel, School of Psychology, University of East London, Water Lane, London E15 4LZ. (Email: t.patel@uel.ac.uk)

Thank you for taking the time to read this information sheet

Appendix G - Participant consent form



CONSENT TO PARTICIPATE IN A RESEARCH STUDY

Implementing trauma-informed care: what is it like for experts by experience?

Contact person: Alex Turner Email: u2195636@uel.ac.uk

IRAS: 325470 25.04.2023 Version Number: 2

	Please initial
I confirm that I have read the participant information sheet dated XX/XX/XXXX (version	
X) for the above study and that I have been given a copy to keep.	
I have had the opportunity to consider the information, ask questions and have	
had these answered satisfactorily.	
I understand that my participation in the study is voluntary and that I may withdraw at	
any time, without explanation or disadvantage.	
I understand that if I withdraw during the study, my data will not be used.	
I understand that I have 3 weeks from the date of the interview to withdraw my data	
from the study.	
I understand I will retain a copy of this consent form, and another copy will be retained	
by the researcher and stored securely for three years.	
I understand that the interview will be recorded using Microsoft Teams.	
I understand that my personal information and data, including audio/video recordings	
from the research will be securely stored and remain confidential. Only the research	
team will have access to this information, to which I give my permission.	
It has been explained to me what will happen to the data once the research has	
been completed.	
I understand that short, anonymised quotes from my interview may be used in material	
such as conference presentations, reports, articles in academic journals resulting from	
the study and that these will not personally identify me.	
I would like to receive a summary of the research findings once the study has been	
completed and am willing to provide contact details for this to be sent to.	
I agree to take part in the above study.	

Participant's Name (BLOCK CAPITALS)
Participant's Signature
Researcher's Name (BLOCK CAPITALS)
Researcher's Signature
Date

Appendix H – Participant debrief sheet



PARTICIPANT DEBRIEF SHEET

Implementing trauma-informed care: what is it like for experts by experience?

Contact person: Alex Turner Email: <u>u2195636@uel.ac.uk</u> IRAS: 325470 25.04.2023 Version Number: 1

Thank you for participating in my research. This document offers information that may be relevant now you have taken part.

How will my data be managed?

The University of East London is the Data Controller for the personal information processed as part of this research project. The University will ensure that the personal data it processes is held securely and processed in accordance with the GDPR and the Data Protection Act 2018. More detailed information is available in the Participant Information Sheet, which you received when you agreed to take part in the research.

If you change your mind, you can decide to withdraw from this study in the next **3 weeks afterwards**, and your data will not be used. You can withdraw by contacting me (details below) or my supervisor Hannah Eades (details below). After 3 weeks data will not be able to be withdrawn and will be included in the study.

What will happen to the results of the research?

The research will be written up as a thesis and will be publicly available on UEL's online Repository. Findings may also be disseminated through journal articles, conference presentations, talks, magazine articles, blogs. In all material produced, your identity will remain anonymous, in that, it will not be possible to identify you personally. Any names of individuals or teams or organisations you mention will be changed to keep it anonymous. Anonymised research data will be securely stored by Dr Hannah Eades for a maximum of 3 years, following which all data will be deleted.

What if I been adversely affected by taking part?

If you have been adversely affected in any ways from participating this this research, please do make the researcher aware. You may find the following resources/services helpful in relation to obtaining information and support:

Generic Support Services:

Samaritans:

If you feel you need someone to talk to, the Samaritans are available to call for free. 116 123

https://www.samaritans.org

Hub of Hope:

Hub of Hope is a mental health support database, bringing local, national, peer, community, charity, private and NHS mental health support services together in one place. https://www.hubofhope.co.uk

Specific Support Service:

National Service Union Network:

A grassroots community group for people with lived experience of mental health distress. They offer various resources, including Online Peer Support. 020 7820 8982

https://www.nsun.org.uk/projects/peer-support

Who can I contact if I have any questions/concerns?

If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.

Alex Turner u2195636@uel.ac.uk

If you have any questions or concerns about how the research has been conducted, please contact my research supervisor Dr Hannah Eades. School of Psychology, University of East London, Water Lane, London E15 4LZ.

Email: h.eades@uel.ac.uk

or

Chair of School Ethics Committee: Dr Trishna Patel, School of Psychology, University of East London, Water Lane, London E15 4LZ.

(Email: t.patel@uel.ac.uk)

Thank you for taking part in my study

Appendix I – Data management plan

UEL Data Management Plan



Completed plans must be sent to researchdata@uel.ac.uk for review

If you are bidding for funding from an external body, complete the Data Management Plan required by the funder (if specified).

Research data is defined as information or material captured or created during the course of research, and which underpins, tests, or validates the content of the final research output. The nature of it can vary greatly according to discipline. It is often empirical or statistical, but also includes material such as drafts, prototypes, and multimedia objects that underpin creative or 'non-traditional' outputs. Research data is often digital, but includes a wide range of paper-based and other physical objects.

Administrative Data	
PI/Researcher	Alex Turner
PI/Researcher ID (e.g. ORCiD)	0000-0002-7885-7237
PI/Researcher email	U2195636@uel.ac.uk
Research Title	Implementing trauma-informed care: what is it like for experts by experience?
Project ID	N/A
Research start date and duration	February 2023 – September 2024.

Research Description	This study seems to understand what it is like for experts by experience to implement trauma-informed care within UK mental health services. The study aims to address the following questions: 1. How do experts by experience describe their involvement with and experience of implementing TIC? 2. What values, hopes and ideas have experts by experience drawn on in being involved in implementing TIC? 3. What is the emotional experience of implementing trauma-informed care? 4. What are the perceived barriers and facilitators to implementing trauma-informed care? 5. How does implementing trauma-informed care impact their relationship with staff and services? The project will aim to recruit twelve participants in total, through purposive sampling, to participate in semi-structured interviews. The interviews will last approximately one hour and will conducted remotely, via video programming software (MS Teams). People who have occupied the role of experts by experience, paid or voluntary, and within this role have implemented trauma-informed care will be recruited. Several service user organisations – National Service User Network – have confirmed they will advertise the study on their bulletin to support with recruitment.	
Funder	N/A - part of professional doctorate.	
Grant Reference Number (Post-award)	N/A	
Date of first version (of DMP)	05/01/2023	
Date of last update (of DMP)		
Related Policies	UEL Research Data Management Policy UEL Data Backup Policy UEL Statement on Research Integrity UEL Statement on Research Ethics The Dara Protection Act	

	7
Does this research follow on from previous research? If so, provide details	N/A
Data Collection	
	Between eight and twelve, recordings (.mp4 file) will be generated from Microsoft teams and stored separately. Each of these will last approximately 60 minutes and estimated to be approximately 400 MB.
	Transcripts of the data will then be created from the interview and all the names and identifiable information will be given pseudonyms so participants can be re-identified if they wish to withdraw within the 3-week deadline.
	Between eight and twelve transcripts of the recordings will be stored as a word file (.docx format) which will be password protected. Estimated each file will be approximately 350 KB.
	The list of identifiers (pseudonyms) will be stored separately (.docx format) on the UEL one drive. Estimated this file will be 10 KB.
	The data will be exported to NVivo in a word file format (.docx format) and analysed as appropriate.
What data will you collect or create?	Thematic analysis will be used to analyse the data and will be written up into a final report (word document).
concet of create:	Participant consent forms will also be created (pdf) which will contain personal data (names). It is estimated that each pdf consent form will 50 KB.
	Prior to interview, email addresses will be collected for the purpose of arranging interviews via the researcher UEL email address. Following the interview, personal information may need to be collected for the purpose of reimbursement from UEL in the form of an amazon voucher which will be requested via the research UEL email.
	Recordings and transcripts may contain personal data (e.g. participant names) which will be pseudonymised by changing names to pseudonyms.
	List of identifiers and consent forms will contain personal data (e.g. participant names) which will be stored securely.
	It is possible that recordings and transcripts may also include special category data (e.g. personal data containing racial or ethnic

Ethics and Intellectual Property	
What documentation and metadata will accompany the data?	Through NVivo, codes and themes will be made and stored in NVivo. A blank consent form (pdf), participant information sheet (pdf), guide interview conditions (word doc), debriefing sheet (pdf) and file naming convention document (word document) will also accompany the data.
Documentation and Metadata	
How will the data be collected or created?	Interview data will be collected from individual participants via MS Teams and will be recorded and transferred to the interviewer's OneDrive in a .mp4 video format. Interviews will be conducted and recorded remotely using Microsoft Teams installed on the interviewer's UEL-managed laptop, with the resulting .mp4 files transferred to OneDrive. Recordings will be stored following the file-naming convention: [ProjectCode]-[InterviewerInitials]-[ParticipantNumber]-[Location]-[Date].Ext. An interview schedule will be developed so that the standard format is followed. Consent will be gathered in the form of electronically signed consent forms (pdf) that will be password protected. Attempts will be made to use the MS Teams transcription ad-in, however this will also be reviewed and corrected by hand where needed and will be stored as a word document.
	origin, political beliefs, religious or philosophical beliefs, sexual orientation). Any identifiers will be pseudonymised by changing names to pseudonyms.

Participants will be informed of the data management plans, plans for analysis, write up and publication of the final report prior to consenting to participate in the study. They will also be informed that the anonymised data will be retained for up to 3 years by the supervisor should the researcher wish to publish the study.

Participants will be informed of their right to withdraw and the limit of this (e.g. approximately 3 weeks after the interview has taken place, after which point analysis will have begun, the data will be anonymised, and it will not be possible to remove their individual data). They will be given the researcher's contact details should they wish to withdraw their consent.

If a participant decided to withdraw from the study within this 3week time period, they will be informed that their contribution (e.g. interview recording and transcript) will be removed and confidentially destroyed.

Identify any ethical issues and how these will be managed

Consent forms will be sent and received via a secure UEL email address in password protected files and stored on the encrypted UEL OneDrive.

Confidentiality of the data will be ensured at the transcription stage where the data will be pseudonymised by changing names to pseudonyms and other identifiable information such as geographical location will be replaced with a meaningful descriptive which typifies the location (e.g. 'Harrow' to 'North London'). Transcription will be undertaken only bt the researcher to protect confidentiality of the participant.

Steps taken when anonymising data after the 3-week time period will include clearly labelling replacements to be anonymised using [brackets]. If there is an increased risk of harm or disclosure, then statements will be redacted.

The participant information sheet and consent form will outline the plan to share anonymous transcript of interviews with research supervisor, along with information regarding the dissemination of the research data in the form of a thesis.

Recordings of interview will be destroyed as soon as they have been transcribed, in order to minimise the amount of data stored. Only anonymised transcripts of the interviews will be stored.

Identify any copyright and Intellectual Property Rights issues and how these will be managed	The interview schedule used to collect that data is original. Therefore, there are no issues of copyright.
Storage and Backup	
•	Recordings of interviews will initially be stored on the researcher's password protected Microsoft SharePoint.
How will the data be stored and backed up during the research?	During the active phase of the research, recordings of interviews (.mp4 data), transcripts (.docx data), consent forms (pdf) and list of identifiers (pseudonyms) (.docx data) will be stored separately on the interviewer's personal laptop which is password protected.
	The data will be backed up on interviewer's UEL OneDrive for Business which is secure and encrypted.
	Each audio file will be named with the participant pseudonym.
	Pseudonymised transcripts of the interview will be stored in a password protected word file separate from the identifiable interview recording scale. These files will be named using the given pseudonym. The list of identifiers (pseudonyms) will be stored separately on the UEL OneDrive until after the 3-week break period has passed.
	The completed consent form documents (pdf) will be stored in a separate place away from the identifiable data, in a separate password protected file in OneDrive for Business.
	Participant email addresses and any information needed for the reimbursement of the Amazon voucher will be stored in a separate place on OneDrive for Business away from the identifiable data, in a separate password protected file.
	The coding document (password protected word document) will also be stored in a separate file away from identifiable data.
	All of the data detailed above will be stored on the UEL OneDrive for Business which is encrypted and secure.

How will you manage access and security?	Anonymised data (e.g. transcripts) will be stored separately from the data that could reidentify someone (e.g. recordings of interview). They will be stored in separate files on the researcher's UEL OneDrive for Business which is secure and encrypted. Security will also be ensured by password protecting all documents and storing the data and meta data on UEL's OneDrive for Business which is secure and encrypted. Anonymised transcript data may be shared with the researcher's supervisor and with examiners if requested. If the data is to be shared, it will be shared via UEL's OneDrive for Business and file names will be anonymised using pseudonyms.
Data Sharing	
How will you share the data?	Extracts from the anonymised transcript will be written up into a research thesis which will deposited and shared via the UEL's Research Repository. Identifiable data will not be included in these extracts. Throughout, only me and my supervisor will have access to the transcripts. The examiners will also be provided with access at the point of examination, via OneDrive for Business, then access will be removed. The data will not be shared with anyone else.
Are any restrictions on data sharing required?	There is no intention or need to share the identifiable data with anyone (namely, MS Teams recordings of the interviews). The transcripts and the data will not be shared via the UEL data repository since the information gathered may be too sensitive even if anonymised and needs to be safeguarded. This may mean removing from the dataset.
Selection and Preservation	
Which data are of long-term value and should be retained, shared, and/or preserved?	Recordings will be destroyed once they are no longer needed for data analysis. A thesis will be written up using extracts of transcripts and this thesis will be stored in the research open access repository (as outlined in the UEL Research Data Management policy). Anonymised transcripts and analysis data will be retained for up to 3 years, stored by the supervisor on the UEL OneDrive, as the researcher may wish to submit the research for publication.

What is the long-term preservation plan for the data?	MS Teams recordings will be destroyed once they are no longer needed after data analysis.
	The thesis will be stored and deposited in the research open access repository (as outlined in the UEL Research Data Management policy).
	Anonymised data (e.g. transcripts) and metadata (e.g. consent forms, analysis data) will be moved and deleted from the researcher's UEL OneDrive for Business by October 2024 since the researcher will no longer have access to these UEL storage facilities as their course will have finished. They will be sent to the research supervisor who will store them on her UEL OneDrive for Business for up to 3 years.
	Anonymised data and metadata will instead be stored on the research supervisor's UEL OneDrive for business for up to 3 years as this data may be required if the thesis is to be reviewed for publication. Identifiable data (e.g. consent forms) will be stored separately from anonymised data (e.g. transcripts) and again, will be password protected and be stored in encrypted files for up to 3 years. After 3 years, all consent forms, anonymised data and all metadata will be deleted.
	Participants will be informed that consent forms and anonymised data will be kept by the research supervisor for up to 3 years. Consent forms may also be preserved for one year to ensure that participants consent can be explicitly checked at further stages of dissemination and review e.g. at stage of publication.
Responsibilities and Resources	
Who will be responsible for data management?	After thesis completion and marking, the research supervisor, Dr Hannah Eades, will be responsible for managing the data.
What resources will you require to deliver your plan?	A laptop, MS Teams access, UEL email account and UEL OneDrive for Business, research supervisors One Drive for Business.
Review	

	Please send your plan to researchdata@uel.ac.uk We will review within 5 working days and request further information or amendments as required before signing
Date: 05/01/2023	Reviewer name: Joshua Fallon Assistant Librarian RDM

Guidance

Brief information to help answer each section is below. Aim to be specific and concise.

For assistance in writing your data management plan, or with research data management more generally, please contact: researchdata@uel.ac.uk

Administrative Data Related Policies

List any other relevant funder, institutional, departmental or group policies on data management, data sharing and data security. Some of the information you give in the remainder of the DMP will be determined by the content of other policies. If so, point/link to them here.

Data collection

Describe the data aspects of your research, how you will capture/generate them, the file formats you are using and why. Mention your reasons for choosing particular data standards and approaches. Note the likely volume of data to be created.

Documentation and Metadata

What metadata will be created to describe the data? Consider what other documentation is needed to enable reuse. This may include information on the methodology used to collect the data, analytical and procedural information, definitions of variables, the format and file type of the data and software used to collect and/or process the data. How will this be captured and recorded?

Ethics and Intellectual Property

Detail any ethical and privacy issues, including the consent of participants. Explain the copyright/IPR and whether there are any data licensing issues – either for data you are reusing, or your data which you will make available to others.

Storage and Backup

Give a rough idea of data volume. Say where and on what media you will store data, and how they will be backed-up. Mention security measures to protect data which are sensitive or valuable. Who will have access to the data during the project and how will this be controlled?

Data Sharing

Note who would be interested in your data, and describe how you will make them available (with any restrictions). Detail any reasons not to share, as well as embargo periods or if you want time to exploit your data for publishing.

Selection and Preservation

Consider what data are worth selecting for long-term access and preservation. Say where you intend to deposit the data, such as in UEL's data repository (https://repository.uel.ac.uk) or a subject repository. How long should data be retained?

Appendix J – UEL risk management plan



UEL Risk Assessment Form

Pioneering Futures Since 1898

Name of	Alex Turner	Date of	31/3/2023
Assessor:		Assessment:	
	Thesis interviews	Location of	Online via video (Microsoft Teams)
Activity		activity:	
title:			
Signed off		Date and time:	March – December 2023
by	XXXXXXX	(if applicable)	
Manager:			
(Print			
Name)			

Please describe the activity/event in as much detail as possible (include nature of activity, estimated number of participants, etc.).

If the activity to be assessed is part of a fieldtrip or event please add an overview of this below:

Online interviews with participants about their experience of implementing trauma-informed care within UK services (e.g. mental health, homelessness, drug & alcohol).

This is being undertaken as part of a doctoral thesis within UEL's professional doctorate in clinical psychology.

Each interview will last between 30 – 60 minutes.

Overview of FIELD TRIP or EVENT:

N/A

Guide to risk ratings:

a) Likelihood of Risk	b) Hazard Severity	c) Risk Rating (a x b = c)
1 = Low (Unlikely)	1 = Slight (Minor / less than 3 days off work)	1-2 = Minor (No further action required)
2 = Moderate (Quite likely)	2= Serious (Over 3 days off work)	3-4 = Medium (May require further control measures)
3 = High (Very likely or certain)	3 = Major (Over 7 days off work, specified injury or death)	6/9 = High (Further control measures essential)

	Hazards attached to the activity								
Hazards identified	Who is at risk?	Existing Controls	Likelihood	Severity	Residual Risk Rating (Likelihood x Severity)	Additional control measures required (if any)	Final risk rating		
For participants, discussing their experience could potentially be upsetting or distressing.	Particip ants	Participants will be provided with an information sheet before the interview outlining what is involved and example questions so they are aware of the aims of the interview and what is involved.	2 moderat e	1 sligh t	2 minor	In the case of emotional discomfort during the study, researcher will be available immediately afterwards to offer support and can provide a list of supporting agencies.	2 minor		
For the researcher, interviewing participants who are distressed may potentially be upsetting or distressing.	Researc her	Should any of the interviews prove to be upsetting or distressing, I will contact my supervisor and request a debrief and support.	2 moderat e	1 sligh t	2 minor	I will consider pausing future interviews if they are highly distressing for me. I will ask my supervisor for advice on how to proceed and will consider more formal emotional support before deciding to continue.	2 minor		

Appendix K – Study interview schedule and questions



Interview Schedule and Questions

Implementing trauma-informed care: what is it like for experts by experience?

IRAS: 325470 25.04.2023 Version Number: 2

Verbal instruction (researcher):

Thank you again for consenting to participate in this study. I have a list of questions I will ask and I am very interested to hear your answers. My hope is that the interview will feel like an informal conversation. Please feel free to answer in a way which feels comfortable and natural to you.

Some questions may cover things you have already said but I am asking again just in case there is anything else you would like to add.

The interview will last between 30-60 minutes, please let me know if you would like to take a comfort break at any point.

There may be similarities and differences between us, for example in terms of gender, race, age, class, culture, which could influence the type of conversation we have.

I am acknowledging this at the beginning of the interview in case you would like to reflect and be curious about these aspects and how they come into our discussion, because as I feel it is important as a researcher to create a space which allows for you to bring as much of your full experience, as you wish.

Any you happy to begin the interview?

1.General Questions

'Can you tell me a bit about the trauma-informed care changes were you were involved with, and what being involved with this work was like?

Prompt questions (if required):

'What were your initial motivations for getting involved in trauma-informed care?'

'What was your role in this work?'

'Has there been anything which you found meaningful about this work?'

2. Emotional Experience Questions

'How would you describe your emotional experience of this work?'

Prompt questions (if required):

'Was there anything you anyone or anything that helped with difficult emotions?'

'What advice would you have for someone else who was interested in getting involved in this work?'

CHECK POINT

'Are you happy to continue with the interview or would you prefer to stop?'

3. Barriers and Facilitators Questions

'Have there been any challenges or barriers to implementing trauma-informed care?' 'And the opposite, anything that has helped or facilitated it to be implemented?'

Prompt questions (if required):

'Was there anything that helped move beyond those challenge or barriers?'

CHECK POINT

'Are you happy to continue with the interview or would you prefer to stop?'

4. Relationships Questions

'Has being involved in this work has impacted your relationships with professionals or services?'

Prompt questions (if required):

'For example, impacted the relationships positively or negatively?'

'How have you found the balance of power between everyone involved in this work?'

'Have you felt supported during this work?'

CHECK POINT

'Are you happy to continue with the interview or would you prefer to stop?'

5. Final Questions

'Is there anything else about this work we've not spoken about and is important to add?

Prompt questions (if required):

'How have you found answering these questions?

TRAUMA-INFORMED

NHS

CARE RESEARCH



I'M LOOKING TO SPEAK WITH EXPERTS BY EXPERIENCE...

(people with lived experience of mental health services, either directly themselves or as a carer for someone else)

...WHO HAVE SUPPORTED SERVICES
TO IMPLEMENT
TRAUMA
INFORMED-CARE

I'D LIKE TO HEAR
ABOUT YOUR
EXPERIENCE
OF THIS WORK..

..DURING A A 30 - 60 MINUTE INTERVIEW

£10 Amazon voucher available for each participant

CONTACT
<u>u2195636@uel.ac.uk</u>
to find out more



I'm Alex Turner
Trainee Clinical Psychologist
with University of East London

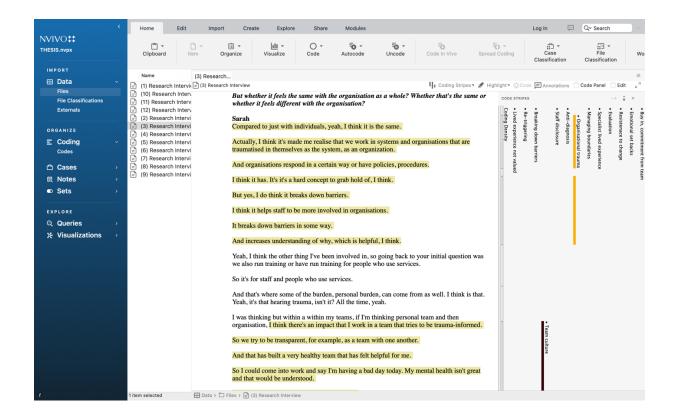


This study is being undertaken as part of a Doctorate in Clinical Psychology

Appendix M - NVivo coded transcript

Each interview transcript was read through using the software NVivo and where something unique within the data was identified, it was assigned a code. An example of a coded transcript is provided below in Figure B.

Figure B – NVivo coded transcript from analysis



Appendix N – Nvivo codes within transcript

Following initial code generation, transcripts were re-read and codes were re-considered. Several candidate codes overlapped and were merged. Care was taken to ensure that important information represented by codes was not lost by re-reading transcripts and codes in context. An example of initial candidate code and corresponding quotes are provided below in Figure C.

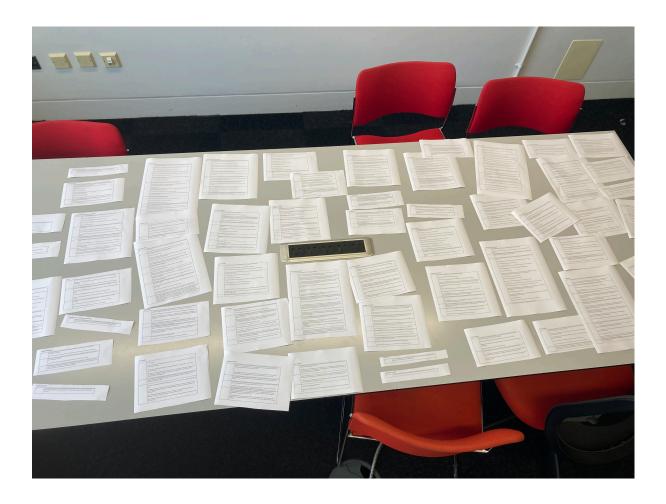
Figure C – Example of initial candidate code and corresponding quotes

Files\(\(\(\frac{1}{2}\)\) Research Interview - \(\§\) 4 references coded [4.32% Coverage] Reference 1 - 0.85% Coverage But also the opportunity for people to co-produce a local level. So, they can explain and help to create and maintain services that keep the stories of patients at the centre. Reference 2 - 1.45% Coverage So, like sustainability through their being that pressure and that input at our local level, if you like. And hopefully that collaboration to co-produce training, to coproduce the resources that mental health So that it becomes trauma informed and stays trauma informed. Reference 3 - 1.04% Coverage Respecting that you develop your own knowledge base and experience from being in this lived experience world. Because you end up being sort of here, there and everywhere more than mental health workers often can. Reference 4 - 0.99% Coverage \underline{So} a lot of these roles are called like 'patient represent'. Like the word 'representative' and it's kinda like we're not, you know, I'm not representative of anyone but me to be honest, in a useful sense. Files\\(3) Research Interview - § 2 references coded [3.32% Coverage] Reference 1 - 2.28% Coverage And involving people who have lived experience and the right people. Yeah, it's having people with relevant lived experience to that piece of training from care. $\underline{\underline{So}}$ I'm thinking about the custody suites. You need someone who's used a custody suite. If you're thinking about training for trimming from care and autism, you need someone who has a Reference 2 - 1.04% Coverage I couldn't be rolled out for every everything, I don't have lived experience in everything. So it's I think it's success is also founded in relevant lived experience. Files\(\(\(\frac{1}{2}\)\) Research Interview - \(\§\) 1 reference coded [2.92% Coverage] Reference 1 - 2.92% Coverage And there were many people who were very vocal, asking what is trauma-informed care? Because we always hear about this, but we don't understand the concept. So at this stage I prepare a couple of slides, letting them understand what it was in a very simple way,

Appendix O – Initial theme construction

After this first review, quote segments for each code were then printed and arranged in order to help arrange codes in potential themes. Figure D below illustrates this stage of the analysis.

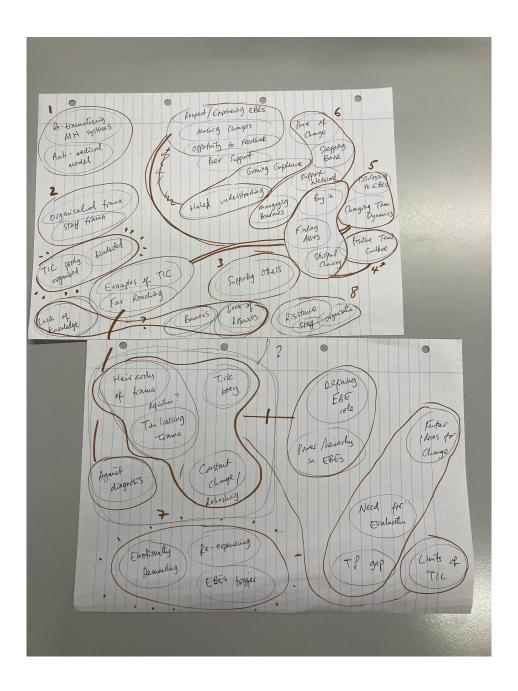
Figure D – Process of arranging candidate codes and potential themes



Appendix P – Thematic map

After initial themes were constructed, a thematic maps was created which allowed me to consider how these initial candidate themes interconnected and what this may represent about them and the data. From this exercise I was able to see how subthemes connected and could be grouped under different categories. An illustrative example is provided below in Figure E.

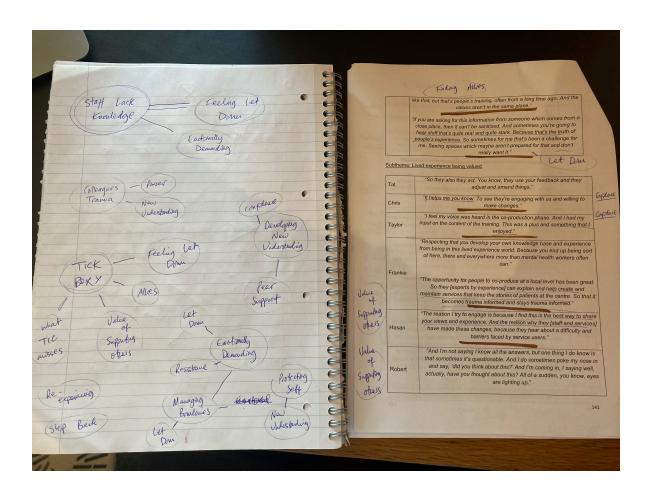
Figure E – *Thematic map*



Appendix Q - Thematic map and extracts

Thematic maps helped to distinguish between themes and subthemes, as well as how these overlapped and interconnected with one another. This phase also involved reading all the collated quotes for each theme to check that they form a coherent pattern. The validity of individual themes was also considered in relation to the data to check that they represent an accurate representation. Figure F highlights this stage of the analysis.

Figure F – Thematic map and corresponding quotes



Appendix R – Excerpt from reflexive diary

Below are adapted excerpts from the journal I used to document reflections or feeling I had during the study.

Following the interviews

It has been a huge privilege to speak with participants, and I have been overwhelmed by their generosity and the richness of what they shared. At times it was difficult to hear participant's descriptions of being re-traumatised whilst implementing TIC. As a mental health practitioner, I felt the urge to apologise on behalf of my colleagues and the services I felt I represented within this study. During our conversations I have noticed myself trying to strike a balance between validating the participant's experiences whilst also not letting my own guilt become the focus of our conversation. At times I have felt uncomfortable at the level of privilege I have hold, not only at work, but also in other spaces and ignorant of the harm that others have ben simultaneously been experiencing. I feared participants feeling the need to reassure me and undermine the purpose of our discussion. While analysing the data, I felt a great pressure to do justice to the testimonies of participants and been at great pains to let go of certain quotes. I have found myself caught between trying to centre the voices of participants who have experienced harm as a result of implementing TIC whilst also wanting to remain compassionate towards members of the wider team who themselves may have experiences of trauma and are attempting to undertake this work within a service landscape which is under-resourced. I have wondered how the research will be received by colleagues and similar to participants in this study, I have felt the pressure to sanitise some of the study's results for fears of being met with resistance.

Appendix S – Full quote per theme

Theme one: Implementing TIC is distressing and traumatising

Subtheme one: Lived experiences are side-lined and silenced

"If you are asking for this information from someone which comes from a close place, then it can't be sanitised. And sometimes you're going to hear stuff that's quite real and quite stark. Because that's the truth of people's experience. So sometimes for me that's been a challenge. Seeing spaces which maybe aren't prepared for that and don't really want it, was just awful."

"A lot of these roles are called like 'patient representative' but it's like, I'm not representative of anyone but me to be honest."

"And it's a challenge sometimes where you feel like 'I know you agree with me, please don't leave me out on a limb here being the only person making this point."

Frankie

"You need diversity in the group of experts by experience. This world of experts by experience, and I add to this, is very White. Quite middle class...I suppose is very straight, very cis. So I think for us to work better on these issues we need greater diversity within the Expert by Experience group...Are we closing it off to other people? Are we forming our own sort of hierarchy here of well connected people in this Expert by Experience world. And this is against the backdrop at professionalisation of this whole area, so it carries a lot of challenges as well as advantages."

"Another challenge in the work is the two-dimensional views and stereotyping from others that can sometimes follow from talking about specific instances or cases trauma whilst being 'a person with a serious mental illness who has experienced trauma'. This stereotyping can come from other Experts by Experience as well as clinicians."

"This is another reason why I think having lived experience in 'parcelled out' roles carry major disadvantages as well as advantages. It gives the false idea that 'lived experience' is for 'those patients over there' rather than 'also within us clinicians'."

"And so, sometimes I think what happens, is that a concept is attached to something at a particular point in time. And all the resources and all the thinking goes there. And then in the process you then missed something else over here. So I think just trying to have this idea of whatever you call it. Asking about what people have been through, rather than what's wrong with them. Trying to have that run through everything. Rather than chasing the funding streams or chasing the research or whatever, is attached to a particular concept of a particular time." "There is a barrier to meaningful involvement of lived experience in trauma informed practice, and that could be a barrier to it being implemented fully. That tick-box of 'yes, we have someone with lived experience'. But you know signing off on some training when it's already been written is very different to have different voices in it from the beginning. Or having someone with lived experience co facilitating it all the way through. So meaningful involvement of lived experience in trauma informed care is not ideal, as it isn't in many areas of the UK currently." "I think another barrier can be the leadership aspect from a lived experience perspective. Although the model should be collaborative, it is often lead by clinical staff. There is still a hierarchy there, which goes against trauma, informed principles. And I think we're done a lot of work to Sarah try and reduce the hierarchy in our organisation, but it still exists." "I couldn't be rolled out for everything. I don't have lived experience in everything. So I think it's success is also founded in involving people with relevant lived experience. So for example with custody suits, you need someone who has used a custody suite. If you're thinking about training trauma informed care for autism, you need someone who has a diagnosis of autism." "Trauma informed practice, its not a tick-box exercise, its an ongoing cultural change piece. But unfortunately it can be tokenistic." "Again it's just about being appropriate, it would be more appropriate for someone who is bereaved to be working as an Expert by Experience in a grief or bereavement or depression group. For me, I found it really Tat demoralising because I thought it's kind of diminishing what I've experienced." frankiecfac

"Then that makes me feel crap because this isn't what we're here for. I'm just concerned. I thought to be a bit more discussion here about if somebody maybe experienced psychosis or dissociation... but there was pretty much nothing."

"The person involved in trauma informed care actually worked in the service where I used to see my psychiatrist, which did not really help."

And I came away feeling really demoralised. I am not your tick-box but also you have really brought down my confidence in in trauma-informed care, it was very demoralising. I've had enough shit. I don't need to. I found it extremely frustrating, demoralising and so unprofessional. Just so many things."

"What can be frustrating is 'trauma' can become a bit of a throwaway word...Some Experts by Experience say they've had a trauma because they had a sudden loss maybe two years ago. Okay, now that is traumatic to that person, however that's not then triggered any major mental health issue."

"I find it frustrating. Trauma informed is kind of becoming a tick-boxy thing. Lets rush it through. I'm aware, whether it's services or organisations, it's another great tick-box for them to say they're trauma informed. It is so frustrating"

"When it's badly done I find it even more damaging. Now for me, you're better off not having Trauma-Informed Care than saying it's trauma-informed and it's badly done. I think it can be so damaging, so damaging and very re-traumatising."

So I want to do it with people that do it well. So it's meaningful, it's purposeful. It's there to serve the people that it needs to serve."

Maria

"I feel serious mental health issues are diluted in the general population. It's become so diluted that someone who felt very lonely or a bit under the weather, they all go into a big pot, along with people with severe mental health problems are just pushed into a corner."

"We had to fight for a voucher for a woman who participated in our trauma informed research. The organisation had a lot of money but they didn't want to provide vouchers."

	"I've witnessed some Trauma-Informed Care training on fight or flight' and that is just ticking a box. That's my concern really, about simplifying things. And making things so simple and so quick to get fixed. I'm scared of them closing down services because you cannot do like five sessions of this or that when people really need in depth treatment for trauma. My concern is not having good services for post-traumatic stress disorder. Since Trauma-Informed Care some well-established services have been diluted." "People attend the trauma informed training, but there is no evaluation. They don't have any assessment. You could train people up, but its about how you put it into practice and how it's received. And the quality of the
	training and practice, the quality of how you implement it. That is missing."
Hasan	"I'll be honest, there are certain services where you have the option, the opportunity to feedback. But there are some places where there is absolutely no way to feedback your experiences."
Elaine	"It was a kind of clash of cultures. It was very interesting to what extent any kind of trauma informed care could be conceived or implemented within forensic setting, because it didn't fit at all with how services are operationalised. Or indeed how patients were conceptualised and treated. There was a head on clash. Between, you know decades of thinking and operations in secure forensic settings. So it's like, a bucket of water hitting a brick wall. The brick wall gets a bit wet, but it'll soon dry."
	"In some forms, I think it's a re-branding of what people have, in essence, been trying to do for decades. Which is humane, patient centred care, taking into account the individual as a whole. So it's virtually a rebranding."
Chris	"Yeah, I don't think it sort of looks at the patient. Because it's almost like a tick-box exercise, where OK, the doctor needs to get experience here and there and everywhere. Rather than sort of thinking, you know, does a set of patients need to doctor who's going to, you know, be here for a long time period. So that they can trust the team and you know and get more out of treatment."

Subtheme two: Connecting with traumatic experiences

Muleya	"It's really tough sometimes and it's very emotional. There are times when I have flashbacks of what I went through."
Sarah	"You are living, breathing trauma every day. I go to work and it is difficult not to think back to traumatic experiences. I think there have been some training sessions that I've delivered where I might have dissociated through it because something has come up that's so relevant to me or just happens to be a day when I'm tired and can't deal with the content so much. I've been in meetings where I've flashbacks of past things." "You are then working in a system that is saying there should not be power imbalances, but there are power imbalances. And you're in a lived experience role where you may not have great belief in yourself or selfworth. I think it has a big, negative personal impact." "I actually think in a lived experience role, I've found staff can be more likely to talk to you about their trauma, more than they may talk to another
	clinical member of staff. Because you're there as a lived experience person, talking about your experiences, there's a connect there. It's different from like a psychologist to a psychologist in that setting, where there's a bit more stigma associated with sharing experiences. But the emotional burden can be quite high at times. It can be a burden I guess, because you don't have any clinical training for what to do with it."
	"I've realised that we work in systems and organisations that are traumatised themselves as a system, as an organisation. And organisations respond in a certain way or have policies and procedures due to this trauma."
	"I supervise other people with lived experience. I hear and have to support them on a daily basis. You hear things from them which can be very hard."
	"Even though you don't necessarily have to be talking directly about traumatic experiences in the role I'm involved with, but it comes up because you're talking about the topic of trauma in general. So I think the emotional burden can be high at timesAnd it does mean you can't leave your past behind, or leave your trauma behind. And how healthy that is, I'm not sure."

"It was so easy to get triggered by something else, it really affected me.

There was one occasion when the mental health staff who had mental
health problems, they were speaking about their trauma and it was hard
to listen to. It was triggering. I was a bit shocked."

"I was a bit shocked and said they [staff] should know better. You cannot conduct this meeting, these kind of events, talking about really difficult subjects, when there are vulnerable people listening to it. And not thinking or caring about the effect you're causing other people. It is good to share about everyone's experience, but sorry, there was only so much I could hear. It was full on."

"They weren't thinking or caring about the effect it would be causing other people. I just don't feel happy sometimes about the way these events have gone and what I've been involved with. There was no warning signs, no trigger warnings."

Maria

"I've been re traumatised just through hearing and observing the experiences of others. I could really relate to the experiences of these women who were denied a service and were unable to register with a GP. I think there is so much reliance on lived experience and sharing, but it's not always good for the person or the person listening."

"Using people in that manner, it's not like we're monkeys in a zoo. The person is sharing heavy stuff and then we immediately move on to like 'okay we are now going to have some lunch, we're going to watch a video'. And that person is in tears, they're suffering. I could see someone was affected and there's no support for them."

"I'm proud that I took part in it [trauma informed care work] but it did affect me for a while. So I did take a break and looked after myself."

"I just turned off the volume and camera. I thought, this is going to affect my whole day, my whole week. Otherwise it will re-traumatise me, it will trigger me."

Tat

"What was even more disconcerting, there was no preamble. There was no warning 'this might be triggering'. I had no idea they were going to begin talking about abuse at that point...That could send somebody over the edge. Because it completely wobbled me and that was at a time when I was feeling really well."

"I think it can be so damaging, so damaging and very re-traumatising. I kind of made my own decision, thinking, right I don't want to do the next session because this is really really triggering and really hard."

"Because if you if you've experienced trauma. And you think, oh, I'm going to go to trauma informed yoga session or mindfulness session because it gives you a sense of safety...But it actually isn't. It's more likely to trigger something than not, if that makes sense."

"...there was no preamble. There was no kind of 'this might be triggering'.

I had no idea they were going to talk about childhood sexual abuse at that point. It wasn't the kind of session that you would expect to touch on childhood sexual abuse..."

"I kind of make my own decisions right. I might not want to do the next session because this is really really triggering and really hard. Ordinarily as a person, I would feel well, I want to give them feedback on this and say why and improve it. But to be honest, when you spend so much time banging on doors trying to get the right treatment, I was just like. I had to put myself first, which I'm learning to do more."

"It can feel like fighting one battle after another. So stepping into that space it can be like, gosh, why do I need to fight this battle again? Why does this need to be put at the centre again?

"When I encounter, let's say somebody like, I sometimes read like case notes, you know, reports proceeding, suicides or serious incidents from my job. For me, the more triggering one is like a young adult who might be having similar experiences, who doesn't know what's going on. And feeling quite alone with it or whatever. It's those cases when I see them and that can require me to like stop."

Frankie

"I sometimes read like case notes, you know, reports proceeding, suicides or serious incidents from my job. Not right then and there, but I need to take some time in the day just to be able to feel upset about that. So I think I do sometimes read people cases of people in that place and that that's what sort of impacts me."

"For me it can be triggering to read about a young adult with similar experiences, who, you know, does not know what is going on. Who is feeling alone. Reading this, sometimes I need to just stop and be in a place on my own."

	"Me personally, I can compartmentalise and am generally not negatively affected emotionally by reading about even quite graphic details of specific cases."
Adam	"Thinking about it, emotionally it has been a bit intense at times. Everyone using heavy terms or speaking about upsetting experiences. And obviously considering why I was there in the meetings, it didn't feel pleasant at all, sort of bringing it back round full circle. It's been a mixed picture."
	"Umm, it's been quite interesting but also a bit triggering. Umm, when hearing about others experiences."
	"Earlier today I had to deliver some training with another Expert by Experience. She was oversharing about her personal life and, I don't want to blame anyone, but sometimes what other people are saying can, you know, be too much for us."
Taylor	"I try to absorb and learn from other people, however I don't want other people throwing a stone on me, like we say in Italian. Every evening I just log off and I don't want to hear about them anymore. Because if I start to care too much of what is happening around me, I couldn't cope. I already have enough challenges. I try to protect myself because sometimes it is too much."
	"So listening and supporting people around trauma can be quite triggering for an individual because it elicits your own trauma, can elicit your own trauma as well."
Stephen	"In my experience of delivering Trauma-Informed Care, it was so important that I had that support network and that I care for myself alongside it. And I think I was lucky in my job because we had quite a lot of support available within the team. We would have one to one supervision, team supervision, weekly staff meetings. And we also had access to a counsellor if we needed it."
Elaine	"You emotionally protect yourself. Because you know that anything with regards to forensic services will be a rough ride. Everything about it is predisposed to mitigate against positive change. So you keep your own emotions out of it for your own protection. You just hope for the best, but you're prepared for less than the best. Put it that way. Yeah, you don't get emotionally involved, that would not be sensible."

Robert	"I have to resist the trauma happening again. I have to ensure I am in a safe place, surrounded by safe relationships. So that I'm protected from the trauma happening again."
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Tat	"Some can be well intentioned but it they don't have the knowledge it can become very patronising. You know saying things like 'oh that must have been awful' which is the last thing you want to hear. It's not a support group, I'm here to impart my expertise." "So one of the things came up and it was about disclosing childhood sexual abuse and one of the titles. First one was 'why don't people tell?' Right. Say for start it was like whoa, why don't people tell? And that in itself is like OKbut then I can't remember the exact details, but some of the reasons underneath were just appalling. They were just appalling. It was really patronising. It was totally broad based and like guess work. And it was almost things like 'embarrassment' 'shame'." "Or even more frustrating when the intentions are really, really good. But the person that they put into run it doesn't have them skills. And again, unfortunately, I've and somebody else say with has at times of sort of stepped in. And again it's like, well, that's not what we're here for." "To be honest, the organisation was tick-boxy. They didn't have the right person leading the group because he didn't have the skills or the
Stephen	confidence or the knowledge." "If we talk about barriers, I would say trying to work in partnership with other organisations who didn't have a basic understanding of trauma informed care. That was very difficult."
Robert	"And a big one I am sorry to say that people often forget in this country and are ignorant to it, is the cultural consideration. Empowering people is part of it, but that cultural consideration is always forgotten about." "When you are traumatised, it doesn't necessarily mean you need to see a psychiatrist. That is not correct. I think trauma and mental health should be treated as two separate things. I do find that when I'm talking to colleagues, there is utter confusion about why trauma needs to be treated as a separate entity as opposed to PTSD." "As practitioners, I always believe it doesn't matter what field you're in, but you have to have a basic understanding of the practice before you can support others. It's exactly what I was saying earlier you can't run before you can walk. And you can't just recite out of a textbook to help other people. And unfortunately that is what happens."

	"Services and my colleagues do find it very challenging when they are faced with a trauma informed scenario and it's not in the textbook. They find it is either A or B or C and that has to be in the book. When it is D and it's not in the book and it's a challenging case, people don't really want to be bothered or listened. Because if google hasn't got it and the textbook hasn't got it, well sod it, it can't be real. That sort of approach." "I find that there's not enough time now these days to actually delve into the topic and deal with the situation, because of the restraints that are being currently put on NHS practice."
Taylor	"GP, psychologist, psychiatrist. They're not open to any sort of compensation, there is not understanding. Everyone is thinking about their own business and there is not an overall understanding of what is the impact of being a victim of trauma. And there were many people who were very vocal, asking what is trauma-informed care? Because we always hear about this, but we don't understand the concept." "Professionals are not understanding how to work with people that experience trauma. I often have to say to a group 'what about this person's culture?"
	"We tend to use inappropriate language and it's very difficult for them even to describe what they feel or what they are or how they react to things. Because these words don't exist in their language about mental health."
	"The very first thing we asked the newly qualified doctors is 'how do you feel today?'. Any many people say, before even starting their shift, they say 'I'm in the red zone. I didn't sleep. I arrived late to work.' So there all these things going on. These people are delivering care for others. So what does that mean? That they have a big baggage of breakstone on their shoulder and they need to face a shift. How much room do they have for thinking about trauma informed care?"
Muleya	"It just like medication, medication, medication. But they [staff] didn't really understand that trauma is not only helped with medication. There are many other ways which service users can be helped. I think a barrier is putting all the focus on medication."
Chris	"So different cultures actually deal with things like trauma and previous experiences in different ways. Some cultures might be very sort of, forget about the past and sweep it under the carpet kind of mindset. Whereas

other cultures might actually be a lot more reflective and open to sort of talking about these sorts of things. So I guess it makes it quite difficult to come up with like a, a general consensus between like myself, therapist and the rest of the team on what trauma is. And it can be quite difficult to like, have the same approach."

"There are so many other things to do really. I don't want to say they are more essential, but more sort of like, you know, legal things or things focused on patient safety. So yeah, it's kind of other tasks getting in the way of focusing on trauma informed care."

"Yeah, it's sort of the continuity of care is really important. And obviously it's difficult to to always have that. But yeah, like you say, it's difficult, you can put things on like electronic systems to put on notes and let people know, like the history of someone, or the stories of someone.

But then you still need to repeat things with another professional with your, you know, making a new relationship with someone.

Because I know from my experience, it's difficult because but most ward doctors are like on a rotation. So they only have like a six month placement and then they're onto the next one."

"When the new set of doctors come in, patients have to explain themselves again. Which can be quite disheartening I guess and make it harder to open up about deeper things, because, I don't know, what's the point? I'm going to share this and then you're going to go and I'm stuck. And then I'm going to have to share it again. It makes people a lot more reluctant to share because of that constant change in professionals."

"Yeah, I think that it's, you know obviously demand with healthcare is really challenging for everyone I guess. So it's not anyone's fault, obviously, but I do think sort of time is the main barrier really."

"The sort of pressure that professionals are under, it can be quite challenging to actually get any time to reflect or do any sort of trauma informed care."

Frankie

"I think sometimes it would be good if there was a greater understanding from staff and organisations. For example, knowing it is going to be normal for people to react in a way that's from a place of upset and real harm. That was lacking." "You know the high level NHS plans, they stick for a little bit until they're replaced by another concept. One is complex trauma and another is trauma-informed. You feel like nothing kind of sticks and then you're onto the next thing."

"I think the other main challenge is, just sort of as I was saying before, the number of competing priorities. And here I sympathise. Because like, you know, crisis services have to meet like Core 24 standards or like let's say for psych liaison services. So everything gets rushed into making that happen.

So we do the thing that's quickest, because we want to keep them most number of people safe, even if that means that each individual person has less good care."

"What is going on is these mental health teams are needing to meet all sorts of demands placed upon them. Statutory stuff, stuff to do with NICE [National Institute for Health and Clinical Excellence]. Stuff to do with targets, stuff to do with waiting times. There's a defensiveness and people don't want to be blamed if something bad happens."

"So I think I think a barrier is just trying to keep banging the drum to say just because we call personality disorder, this sort of complex trauma, doesn't mean that we don't then think about the trauma of people's lives if they have a mood disorder...Like many people, many, many people with severe mental illness, high percentages, have also experienced childhood trauma.

And I experienced that too.

And so, sometimes I think what happens, is that a concept is attached to something at a particular point in time.

And all the resources and all the thinking goes there. And then in the process you then missed something else over here."

"There is a backdrop of scarcity of resources. Too little supply for too much demand. So I think that's a challenge. There's no easy solution to that, do you know what I mean. It's like everyone agrees and no one can do anything about it. And that's a challenge because there's a certain futility in that...And its difficult to know what to say back to that. Because people are genuinely saying we can only do what we can do. We're not superhuman."

Sarah

"I think barriers can be, in healthcare there's so much change. Trauma-Informed Care is another change, and people are just tired of change."

Maria	"There comes this little mantra in mental health services. This is Trauma- Informed Care and everyone's doing it and then move on. So I just feel a bit weary of why suddenly something popped up and why everyone is so excited about trauma informed care."
Elaine	"So although in MDT [multi-disciplinary team] discussions there can be some lip service paid to what is Trauma-Informed Care, inevitably risk concerns and risk perceptions will usually trump any kind of trauma informed approaches will always be secondaryThe actual traumatising nature of services hasn't changed. They're just trying to be a bit more trauma informed within all the trauma they create. It's not ideal, really not ideal." "Forensic services have a national staffing shortage. So frontline staff are very sparse and stretched to the max. They don't have any time to do therapeutic work, it's basically just firefighting."
Adam	"I would say the main challenge has been time. Time being provided or allocated to it. Due to workload demands. Sometimes some staff have had to reschedule, or suddenly cancel. Some of the planned work on it has been delayed over and over." "I know, there's a NHS staffing crisis, so that's got to impact the whole organisation to some degree."

Theme two: Positive changes from implementing TIC

Subtheme four: Using the distressing moments

Tat	"I've been able to use a lot of really crappy parts of my life when working with one particularly team who have just been phenonmenal. They give me faith back in the human race. They really listened to what I had to say. And they also they act. You know, they use your feedback and they adjust and amend things."
	"It gives me confidence, I get a lot of satisfaction from it. So when it is done well, it's been so empowering. I feel like I've got a lot to contribute because of my experience. I think it's really good because I've lived with this for such a long time and I'm quite a reflective person. Having a chance to share this, it's been life changing for me in many ways."
	"Yeah, very much so. It makes you feel very purposeful, cause at the moment I'm not working. I've always like worked on and off because of my mental health. That's done in, you know and voluntary or, you know, paid whatever vouchers to do that. But it's also and something I feel comfortable and confident talking about as times gone on."
	"The trauma informed stuff is it's really helped to keep me rooted in understanding these things have impacted this. And I can sort of change how that's impacted my mental health. You know, I'm not fundamentally 'a nutter', excuse the word."
Chris	"It helps me you know. To see they're engaging with us and willing to make changes."
	"Being involved in trauma informed work has helped me, you know, feel more confident. But it also makes me feel more purposeful."
Taylor	"I feel my voice was heard in the co-production phase. And I had my input on the content of the training. This was a plus and something that I enjoyed."
	"I've learnt a lot. And I use this confidence to demand things for my in laws, to demand things for my sister. To make my voice heard."
	"I have a way of thinking which is totally different from them [staff and organisations] and I've developed the confidence to bring my voice to many spaces."

	"I joined a group and learnt from others. And what I'm learning is benefitting my whole life. I started to become curious, you know, trying to learn from others and get involved in as many sessions as I could. One lady in the group said something that really touched me, she explained that we don't need to pathologise or label trauma."
Frankie	"Respecting that you develop your own knowledge base and experience from being in this lived experience world. Because you end up being sort of here, there and everywhere more than mental health workers often can." "The opportunity for people to co-produce at a local level has been great. So they [Experts by Experience] can explain and help create and maintain services that keep the stories of patients at the centre. So that it becomes trauma informed and stays trauma informed."
	"Like I've got a whole other working life, if you like. And so I can be bold and I can say things, and it's not going to affect me."
Hasan	"The reason I try to engage is because I find this is the best way to share your views and experience. And the reason why they [staff and services] have made these changes, because they hear about a difficulty and barriers faced by service users."
	"I find it very interesting because it is not only about sharing my story and our family story. Also, it is an opportunity to hear what other people are going through and what other people have to say."
	"It has given me confidence, being able to participate in different focus groups and know there are different ways of tackling these issues."
	"A good thing about trauma informed care work, you see everyone has their own way of struggling or their struggles. It's a great way to learn from people, the difficulty they have been through and your own trauma."
Robert	"And I'm not saying I know all the answers, but one thing I do know is that sometimes it's questionable. And I do sometimes poke my nose in and say, 'did you think about this?' And I'm coming in, I saying well, actually, have you thought about this? All of a sudden, you know, eyes are lighting up."

	"I am at the age now, nearly 60, I've been doing this work for 30 years. And now I do it on a voluntary basis. But I will tell you, I have found it extremely, extremely rewarding. Because if trauma informed care is done in the correct manner, for me it is a win win situation. I feel it's helping me with my mental health in supporting and helping others from a professional perspective. And it's helping the client, its what they're wanting."
Muleya	"Being there as part of the team, it has helped because we share our lived experience. And you know it changes their [staff's] attitudes and the way they you know treat service users. And it's like 'ohh I never really knew that's what people go through'. It's like educating them. They're ignorant but open to learning. So they can improve their services to people who have gone through trauma."
	"Because, even though it's medication is good, I'm still taking medication. But it's to help somebody to understand the trauma they have gone through and make them aware of, you know, the trauma they have gone through."
Stephen	"The trauma informed work I was involved in was in my local NHS service user participation group. As a patient I was receiving treatment and intervention from them and for my lived experience that I went through. In order to try and help me recover and to just feel connected with other service users and people who've been in a similar situation, which really helped."
Sarah	"Actually it has helped me really make sense of some of my behaviours and understand where they were coming from. You know, despite having been through lots of services, a lot of therapy, I just hadn't made some of those links. So actually, at a personal level, I think just understanding trauma informed approaches has helped me move forward in my recovery. I'd gone through services for a long time with various diagnosis, trauma being one of them, but it was a bit of a light bulb moment of, actually the diagnosis doesn't have to be label."
Maria	"I've experienced trauma personally and been involved in trying to improve the mental health services by talking to someone like you who is doing research, and it has really helped me verbalise things and see things from different perspectives."

Subtheme five: Improved relationships and positive team culture

"Within our staff team, you had people with lived experience but also a wide range of professionals. So there was people who were doctors, psychologists, counsellors. Trauma-Informed Care sort of becomes ingrained, you practice what you preach. So if we support each other and other individuals, that culture develops, it is natural. We practice trauma informed care amongst ourselves, and that's why we have Stephen strong, positive relationships develop within the team." "I think within the organisation, we had quite a strong staff team. In a sense because of the work was demanding, the work was emotionally taxing, I think it bonded us stronger. Yeah, the bond was stronger." "I think, generally, it's lead to kind of fuller, richer relationships with people that I work with. That's what I would say. I think it's helped to see people in three dimensions. Seeing their context." "So I think it's just like, this context is like, treating people as fully equals, doing this work, part of that is respecting people enough to disagree...The relationship develops which is like 'I need something from you'. You are not providing it and I need to make my case so I can get it. And that kind of relationship, it can become a supportive relationship where it doesn't affect their view of you." "Over time I think I've tried to develop the skills of planting seeds and developing allies. So who can you bring along on the journey? So when you're at decision points, like amending quality standards, you already Frankie have got three or four of you and one of them is clinical and one of them is a service manager. So stuff happens and changes because you're not a lone voice. And so I think the ally-ship, for want of a better word, and the use of power is so important." "I think it's about steadily building a skillset over time, which is more like working away at these issues steadily and finding allies amongst clinicians and health bodies to push this forward." "I think chairs. And people in in positions of power and influence who are onside to begin with. And who really believe in it. I had a really good chair on a committee that I finished with quite recently. And her values and way of working was like, 'everyone is equal on this committee' We

won't carry on the meeting without our patient and carer

representatives'. So when you have someone like that, because they hold the power, then stuff happens. That comes from their values set." "It starts to break down some of those barriers. Because you're on a topic that is common ground for many people. I can only compare it to personality disorder services that I've worked in where I'm aware the divides are huge. Trauma informed doesn't feel like that. It feels like the divides are broken down rather than built up. I do think it breaks down barriers. I think it helps staff to be more involved in organisations. It breaks down barriers in some way. And increases understanding of why, which is helpful. So I think it has changed my perception of other staff, clinical staff. And to a more positive healthy relationship I would sav." "I think there's an impact on the team I work for. We try to be transparent, for example, as a team with one another. And that has built a very healthy team that has felt helpful for me. So I could come to work and say 'I'm having a bad day today. My mental health isn't great'. And that would be understood. I've not worked in teams like that before. So I think being a trauma informed team or trying to operate in a trauma Sarah informed way has allowed me to come to work as I am." "I now have a better understanding of why some staff behave in a certain way. And I have a much better understanding that staff have experienced their own trauma, which I didn't have a clue before, despite having been in services for a very long time." "I've realised that we work in systems and organisations that are traumatised themselves as a system, as an organisation. And organisations respond in a certain way or have policies or procedures due to this trauma." "I think you need people who personally want to try to work in a trauma informed way on an ongoing basis. And I guess it is that piece of trauma informed practice, it's not a tick-box exercise. So you need to be in a team where team members are committed to try and continually be trauma informed." "Because you're not just doing the basics, it's more purposeful work. So the dynamic does change for the better, if you're looking at work meaningful work together." Chris

	"So, I personally would still say that you know, even if people don't sort of necessarily listen or agree with the term, it's still it's still a very good way of working."
	"Yeah. I mean, I think what enables more discussion around trauma, I think is obviously like having more sort of like team meetings and like reflective spaces between colleagues and to actually talk about those sorts of things. You can like hand over that information and discuss it in a forum."
Adam	"It has enabled us to be more cooperative, and to look closer at different points of view and ideas."
Tat	"It is brilliant you meet a wide variety of people. We might not necessarily agree on certain things or me might not have the same view, but it doesn't matter. It's when the respect is there. So you don't feel alone. It's helped me to feel more normal, if that makes sense. Meeting other people, who you know have also experienced trauma, make me feel more normal."
	"I think one of the main things that helps is when it is done by people who have got integrity, who really care, who want to make change. But also aren't lived experience as a tick-box. You can smell it. It's kind of like the integrity of whoever involved. There's also a lot of good people and good people in it for the right reasons, you know."
	"I experienced it where you've got somebody who is really skilled, really knowledgeable chairing. The person chairing has got that understanding that you're talking about trauma and mental health. The people around the table have got valued lived experiences. It's about a chair who has those skills to bring in people to it. For it to be held for it to be safe for it to be boundaried. And also a recognition that you're talking about things that have messed people's lives or and are detrimental."
Robert	"I always try to make sure that everyone is on the same page as I am when we talk about trauma-informed practice. Once we've done that, then I find that, I normally have extremely good buy in."
Elaine	"I think people liked the ideas, they liked the thought of it [trauma informed care]. So people were eager to participate. It was very good, because we were all interested in making things work as well as they

could do. So you know, we worked well together, we were on common
ground."

<u>Appendix T – Example questions to support discursive reflection (Shimmin et al., 2017)</u>

Questions for research project team (both Researchers and Public Research Partners):

- 1. What are my own personal values, experiences, interests, beliefs and political commitments in the area of health we will be researching?
- 2. How do these personal experiences relate to social and structural locations (e.g. gender identity, race, ethnicity, Indigeneity, socioeconomic status, sexuality, gender expression, age, sexual orientation, immigrant status, religion) and processes of oppression (e.g. patriarchy, colonialism, capitalism, racism, heterosexism, ableism) in the area of health in which we will be researching?
- 3. What are my personal values, assumptions, perspectives and experiences with regard to people living with the health condition(s) or issue(s) in which we will be researching?
- 4. From your perspective, what current health inequities (i.e. avoidable and unjust inequalities in health between and within groups of people) exist with regard to the area of health in which we will be researching?
- 5. How do you think people with lived experience in this area of health would prefer to be involved in research and why? What types of challenges do you think would need to be addressed in order to make it easier for people living with this health condition or issue, as well as their families and communities to become involved in research?
- 6. Working together, how can we become more aware of and take advantage of opportunities where we can challenge each other's ideas and renegotiate power within our project team? What does building resilience look like, feel like, and sound like to you?

- 7. How do you think the issue of trauma may impact the area of health in which we will be researching? (Remember to think about it both on the level of violence within relationships but also on the larger level of colonialism, racism, sexism, homophobia, capitalism, ableism, etc.)
- 8. What do you think are some of the ways in which we can make sure everyone feels safe when working together on this research project? What does physical safety mean to you? Look like to you? Feel like to you? What does emotional/psychological safety mean to you? Look like to you? Feel like to you? What are some of the best ways we can work together to address trauma?