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Reflections on public involvement: Adoptees shaping trauma-informed early life adversity research

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Method Article

Keywords: trauma-informed, adoption, adoptee, Patient and Public Involvement, childhood trauma, early life adversity

Posted Date: June 10th, 2026

DOI: https://doi.org/10.21203/rs.3.rs-9900345/v1

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Additional Declarations: The authors declare no competing interests.

Abstract

Biomedical and psychological researchers are increasingly working together to understand the lifelong effects of childhood trauma on the brain, immune system and mental health. This brings a growing need for Patient and Public Involvement and Engagement (PPIE) to understand the diverse needs of people who have experienced childhood trauma and minimise risks of re-traumatisation, burnout and distress during research participation.

This article outlines how trauma-informed principles can be translated from clinical practice into research through PPIE. It also reflects on a 2-hour online PPIE workshop used to inform the protocol design of an NIHR Manchester Biomedical Research Centre project. PPIE was essential given the wide range of assessments planned (brain scans, blood tests, mental health interviews, cognitive testing, trauma questionnaires); and high prevalence of trauma and mental health/neurodevelopmental conditions among the future adoptee research participants (aged 18–25).

Insights from six adoptees who attended the workshop shaped an inclusive, trauma-informed protocol. Concerns about lengthy mental health interviews led to flexible options, for shorter, online or in-person sessions. Feedback on trauma questionnaire wording prompted additional safeguards, and anxiety around medical procedures informed a modular design allowing participants to opt out without exclusion. This article was developed collaboratively with lived-experience co-authors.

Plain language summary

Childhood trauma can impact mental health and physical wellbeing throughout people's lives. Researchers want to understand these effects so they can uncover historical gaps in support and develop ways to support people better in future. Childhood trauma is a very personal and sensitive topic. Research in this area therefore needs to be planned carefully. If studies are not designed well, taking part can be distressing, overwhelming or even re-trigger difficult experiences. Working with people who have lived through childhood trauma is essential when designing this kind of research. It helps researchers understand what is safe and acceptable, as well as what might be difficult.

This article reflects on a 2-hour workshop conducted with a group of young, adopted people aged 18 – 30. The workshop was run by researchers and participant involvement/engagement experts, who were planning a study that adopted people would later be invited to take part in. The study aims to understand the potential long-term biological and psychological effects of childhood trauma. During the workshop, adopted people used their lived experience to shape how different areas of the research plan were completed and which parts should be made optional (for example brain scans, blood tests, mental health interviews, online games and trauma questionnaires).

Introduction

Research shows that experiencing trauma in childhood can affect brain development and disrupt the immune system, which protects the body from infection and illness (Danese & S, 2017; Ross et al., 2021). These traumatic early life experiences may increase a person's risk of developing mental health difficulties throughout their lives (McLaughlin et al., 2020; van Nierop et al., 2015). Childhood trauma has been linked to many different mental health difficulties, rather than being specific to one condition, and is therefore sometimes described as a "transdiagnostic" risk factor. Current research seeks to understand biological changes occurring following childhood trauma that could make people more vulnerable to mental health problems (McLaughlin et al., 2020). Understanding these changes could help address current gaps in support, by identifying people with mental health problems earlier and providing them with more effective treatments (Caspi et al., 2014).

Patient and Public Involvement and Engagement (PPIE) is essential for improving researchers' understanding of the priorities and needs of people with lived experience of childhood trauma. The National Institute for Health and Care Research (NIHR) defines PPIE as *"research that is done 'with' or 'by' the public, not only 'to', 'for' or 'about' them"* (NIHR, 2025). By working with people they plan to work with, researchers can incorporate their diverse perspectives, draw upon their lived experience and put their needs at the forefront of research design. Through PPIE collaboration, researchers can assess whether their projects are meaningful, relevant, tolerable, acceptable and respectful to those involved. When this is done at an early stage in the design process, the public can help shape the project plan based on their lived experience (Khan et al., 2024; NIHR, 2025).

PPIE supports trauma-informed research practices, by helping researchers understand how early life trauma can affect people during research. For example, it might influence their sense of safety, present difficulties when building trust with the research team and heighten sensory experiences. Speaking to people with lived experienced of trauma allows researchers to better understand and proactively minimise the risk of re-traumatisation among participants (BHT Sussex, 2022; OHID, 2022).

Despite the importance of trauma-informed practice, amongst clinical psychology courses, only around 5% of students have training on this topic (Foltz et al., 2023). Many researchers may therefore be unfamiliar with the trauma-informed principles of *1. Safety, 2. Trustworthiness and Transparency, 3. Peer Support, 4. Collaboration and Mutuality, 5. Empowerment, Voice, and Choice, and 6. Cultural, Historical and Gender Issues* (SAMHSA, 2014) (Table 1). Consequently, they may not know how to apply these principles in research to reduce potential risk and distress to both participants and themselves (Isobel, 2021; Komarnyckyj et al., 2026). Although the trauma-informed principles were originally developed by the Substance Abuse and Mental Health Services Administration (SAMHSA) for clinical practice (SAMHSA, 2014). Table 1 provides a brief guide of how these principles can be translated into actions for researchers interested in broader effects of trauma, and explains how they can be addressed and supported by PPIE.

Designing trauma-informed protocols requires researchers to challenge and rethink established practices. Researchers should be mindful that people who have experienced trauma may be

experiencing mental health, neurodevelopmental and trauma-related conditions, which increase the risk of sensory sensitivities, fatigue, burnout and hypervigilance. Routine procedures in biomedical research, like blood tests or magnetic resonance imaging (MRI) brain scans may therefore cause distress due to close physical contact, confined spaces or loud noises.

Studies often have a standardised protocol which may require participants to complete multiple tasks within a single, extended testing session, lasting several hours (Getz et al., 2020; Naidoo et al., 2020). This approach may be beneficial, by improving consistency between participants, ensuring scientific validity (i.e., capturing all data at one time point) and minimising travel burden on participants. However, such protocols may not be accessible for people who have lived through childhood trauma, or those with mental health or neurodevelopmental conditions, who have diverse physical and psychological needs.

Involving the public when developing and designing research protocols gives people with lived experience the power to make decisions about what is “acceptable” and “accessible” for them which creates an inclusive research environment. Without their involvement, research protocols may insufficiently respond to participants’ needs or be overly cautious, with risk of limiting autonomy or excluding individuals who might otherwise take part. Best practice involves incorporating trauma-informed principles (Table 1) and lived-experience perspectives into both research design and ethical review. In doing so, more nuanced decision-making can be supported, which balances risk minimisation with respect for participant agency and perceived need of the population.

This commentary reflects on a PPIE workshop carried out when designing the research protocol for the NIHR Manchester Biomedical Research Centre project, “Investigating the impacts of early life experience on the brain and behaviour”. We highlight the important influence young adult adoptees had in shaping a more trauma-informed protocol design and the positive impact this has had on research participants. We utilised the Guidance for Reporting Involvement of Patients and the Public in Research 2 (GRRIP2) to support consistency and transparency in PPIE implementation and evaluation (Staniszewska et al., 2017).

This article was developed in collaboration with young adopted and fostered adults, who joined the team as lived-experience co-authors. They ensured the accuracy of the protocol description based on their experience of taking part in the study, and revised draft manuscripts to ensure the language and framing were acceptable and respectful to the adoption community.

Table 1
Translating the Trauma-informed Principles into Research Actions

Trauma-informed Principle	Summary	Example Research Actions
Collaboration and Mutuality	Working with the public throughout the research process and sharing decision-making	This principle is strongly supported by public and patient interaction and engagement (PPIE), examples of which are given below: • Engaging with the public to identify research priorities. • Working with the public as co-applicants on projects and co-authors on research articles. • Working with the public to co-design or evaluate research protocols to ensure they are inclusive, tolerable, acceptable and respectful to those involved. • Co-developing public facing research materials (e.g., leaflets, posters, flyers). • Involving the public on project advisory or steering groups within projects.
Safety	Ensuring physical, psychological, and emotional safety of participants and researchers	• Providing trauma-informed training to research teams and ethics committees. • Designing studies which are sensitive to the needs of people with lived experience of trauma (supported and shaped through PPIE). • Developing protocols which minimise risk of re-traumatisation (supported and shaped through PPIE). • Embedding support mechanisms for all participants in case they are impacted by the research (e.g., psychological debrief, formal plans if anyone becomes distressed, signposting materials). • Embedding support mechanisms for researchers by secondary or vicarious trauma (e.g., reflective supervision, peer support, psychological therapy).
Trustworthiness and Transparency	Building trust between the participant and researcher	• Outlining sensitive topics covered in the study before enrolment and allowing participants to review sensitive questions. • Explaining potentially distressing or unfamiliar procedures before enrolment and providing information in a way that wis accessible for them e.g., verbal, videos, written information etc.

(BHT Sussex, 2022; NIHR, 2025)

Trauma-informed Principle	Summary	Example Research Actions
		• Promoting equality through use of informal language and clothing. • Giving participants the opportunity to meet with the interviewer before the research session, particularly where topics covered are potentially triggering.
Peer Support	Facilitating support and communication between those with lived experience of trauma	• Embedding people with lived experienced of trauma within research teams in roles where they interact directly with participants. For example, as lived experienced researchers or within advocacy roles. • Signposting participants to peer support trauma-related charities. • Integrating supported networking opportunities with appropriate safeguarding, within PPIE such as co-production or co-design activities.
Empowerment, Voice and Choice	Empowering the public by listening to their voices and offering them choices and control	• Giving people with lived experienced of trauma a voice when defining research priorities through (e.g. research priority-setting activities). • Developing protocols which balance risk minimisation of re-traumatisation with respect for participant agency (supported and shaped through PPIE). • Giving participants the choice over the time and format (online or face-to-face) of sessions. • Giving participants the choice to opt out of tasks they are not comfortable with, find triggering or distressing. • Giving participants the opportunity to feedback on the research process after taking part.
Cultural, Historical and Gender Issues	Enhancing inclusivity and accessibility for diverse community members	• Considering how cultural, historical and gender issues influence trauma experiences and responses. • Designing studies and interpreting research findings with support from diverse voices (supported and shaped through PPIE). • Reflecting on power dynamics and taking steps to address these to ensure people are
(BHT Sussex, 2022; NIHR, 2025)		

Trauma-informed Principle	Summary	Example Research Actions
		comfortable when taking part.
(BHT Sussex, 2022; NIHR, 2025)		

Method

Research Project Outline

This research examines how traumatic early life experiences can affect people later in life, for example, by influencing the brain, immune system, thinking styles and social relationships. Its long-term goal is to develop screening tools to identify young people who are vulnerable to developing future mental health problems.

At the time of writing, the study had ethical approval (University of Manchester Ethics Committee, 2024-17962-32800), was ongoing with 75% of data collection complete, and expected to conclude October 2026. The project is funded by the National Institute for Health and Care Research (NIHR) Manchester Biomedical Research and registered on ClinicalTrials.gov (NCT06823492)(Komarnyckyj & Elliott, 2025).

The study participants are young adults aged 18–25, including a:

- UK-adopted group (target n = 60) of individuals adopted before age 11 who may have experienced early life trauma (e.g., domestic violence, sexual abuse, physical abuse, physical and/or emotional neglect and parental substance use and/or mental health issues); and
- Control group (target n = 40) of non-adopted individuals without significant early life or severe adult trauma.

Biological psychiatry and neuropsychology methods used in the study (Fig. 1) are:

- Psychological assessment using the Structured Clinical Interview for DSM-5® (SCID-5) and Autism Diagnostic Observation Schedule (ADOS).
- Cognitive assessment using eight online games from EMOTICOM evaluating emotion, motivation, impulsivity, and social cognition (Bland et al., 2016).
- Online demographic, clinical, personality, childhood trauma and adoption questionnaires hosted by the Qualtrics platform.
- Functional MRI tasks including a Go/No-Go test of response inhibition (McGonigle et al., 2017), a Monetary Incentive Delay test of reward processing (Komarnyckyj et al., 2023), and an emotional face-processing task (Barraclough et al., 2019).
- Blood tests including whole blood, serum and ribonucleic acid.

PPIE Workshop Aims: GRIPP2-1

A PPIE workshop was conducted to explore the views of people who have lived experience of childhood trauma and adoption in relation to the biomedical research protocol (Fig. 1). The main goal was to help shape the design of the protocol prior to ethics submission, with the workshop conducted 5 months in advance of participant recruitment. Workshop discussions focussed on early ideas of the research plan, and the acceptability and feasibility of different types of assessments (including their content, timing, and methods). The insights gathered were used to refine the protocol and reduce risks such as re-traumatisation, fatigue, burnout and anxiety during future participation.

PPIE Workshop Method: GRIPP2-2

A 2-hour workshop was hosted via Zoom on 29/11/2023 from 6–8 pm. Public contributors could join via computers or phones, with their camera on or off. The workshop was hosted online to improve accessibility and comfort for those taking part. Sinduja Manohar, an experienced PPIE Manager (at Vocal) developed and facilitated the session with support from the lead Research Associate, Mica Komarnyckyj. The workshop included:

1. Welcome and introductions, including an icebreaker using a word-cloud activity to make people feel more comfortable, where they could share information briefly about their experiences of adoption (10-min).
2. A short PowerPoint presentation on the study aims, methods and the importance and value of their input during the session, followed by Q&A (15-min).
3. Short PowerPoint presentations on different aspects of the research protocol, followed by whole group or breakout discussions to share their views and feedback on the; a) proposed research idea; b) online questionnaires and games c) MRI scanning, blood sampling and session length; d) preferences for completing sensitive questionnaires about adoption, childhood trauma and early life adversity; e) optional parental involvement (1-hour including 10-min break).
4. Whole group discussion on reimbursement, travel and recruitment strategies (10-min).
5. Final reflections and next steps (5-min).

Six young adult adoptees (aged 20–27 years, demographics in Table 2 provided anonymously) were actively involved in the workshop as public contributors and were recognised for their involvement with payment via bank transfer (£50 plus £5 data allowance; in line with national guidance in 2023). A1-to-1 interview was also conducted via zoom with an adopted adult who could not attend the workshop. They were recruited through the Vocal network (wearevocal.org). The Principal Investigator for the project (Rebecca Elliott) and Clinical Psychology Research Fellow (Catherine Kay) were also in attendance.

In advance of the workshop, Sinduja Manohar conducted a brief onboarding call with all public contributors to explain what would be involved and ask if there was anything they would like to get out of the session. Following the workshop, all contributors were given the opportunity to provide feedback and give suggestions via an evaluation form.

Table 2
PPIE Workshop Public Contributor Demographics

	Percentage
Ethnicity	
Asian or Asian British Indian	17%
Asian or Asian British Bangladeshi	17%
Asian or Asian Chinese	33%
Asian or any other Asian Background	17%
Prefer not to say / Chose not to complete question	17%
Gender	
Female	83%
Male	17%
Self-identify as having a disability	
Yes	33%
Prefer not to say / Chose not to complete question	67%
Sexuality	
Prefer not to say / Chose not to complete question	100%
Working	
Yes	17%
Student	67%
Prefer not to say / Chose not to complete question	17%

PPIE Workshop Outcomes: GRIPP2-3 & GRIPP2-4

Below we summarise overarching insights from the PPIE workshop (GRIPP2-3) and how this activity influenced the overall protocol design and future research ideas (GRIPP2-4).

Taking part in the mental health assessment

Insights: The researcher provided an overview of the 2–3-hour SCID-5 mental health interview which covers personal and sensitive topics. In general, public contributors thought they would be comfortable answering questions of this nature but felt it would be too long to complete in one sitting. Format preferences varied, with some people sharing this would be more comfortable to complete in person, whereas others would prefer doing it online at home.

Influence: Our protocol gives participants the choice to complete the SCID-5 online or in-person, and the option to spread the interview across multiple sessions. These options are discussed at enrolment, and the researcher can also adapt in response to participants' feedback and behaviour during the sessions. During data collection, we found that ~ 45% of adopted participants chose to complete the SCID-5 online and ~ 70% over multiple sessions, for reasons including emotional, mental, or physical fatigue, risk of burnout, and childcare commitments. This trend reinforces the importance of offering flexible, trauma-informed options when completing lengthy clinical interviews.

Providing information about childhood trauma and adoption

Insights: Extracts were shown from the childhood trauma questionnaire (CTQ)(Bernstein et al., 1994), the adverse childhood experience questionnaire (ACE-Q) and an adoption history questionnaire developed by the research team. Some public contributors raised concerns that the CTQ and ACE-Q use very direct wording, which could be extremely triggering. They also noted that some people may not know some of this information depending on age at adoption. Furthermore, researchers must be mindful that during the study it could be the first time people have been directly asked about these topics, reflected on what has happened to them during childhood and been given names for their traumatic experiences. Some contributors said they would prefer having space to speak or write about their trauma histories rather than using checklists, while others favoured checklists for their anonymity and brevity.

Influence: In light of the study aims, the project team deemed it was essential to include the validated CTQ and ACE-Q without modification. Using these standardised measures would allow findings to be compared with research which uses the same questionnaires. However, to minimise risk while collecting sensitive trauma-related information, several measures were incorporated to address the concerns raised by workshop attendees:

(1) The participant information sheet summarises the types of trauma-related information collected. Before enrolment, the researcher checks if the participant is comfortable providing this via online questionnaires. Participants may review the questionnaires and can choose not to continue if they prefer.

(2) Trauma-related questionnaires can be completed during an online or in person meeting with the researcher, depending on participant preference. A support person such as a carer, adoptive parent or partner may help them complete the questionnaire. However, researchers must be aware that in this context participants may have difficulty answering questions honestly (e.g., questions relating to adverse childhood experiences in the presence of an adoptive parent).

(3) Participants can skip any CTQ or ACE-Q questions they do not know or do not wish to answer by selecting "don't know."

(4) With the participants' consent, an adoptive parent can complete the adoption history questionnaire on their behalf.

(5) Participants are given the option to explain to the researcher or write about the reasons why they were adopted whilst they are completing the adoption history questionnaires, providing more flexibility than checklist-only formats.

Providing biological data during physical tests at the University

Insights: Public contributors generally seemed interested, and in some cases excited, about MRI scans. They noted that the loud noise could be difficult for people with trauma histories or neurodevelopmental conditions due to hypersensitivity and overstimulation, and that staying still for the full 45-minute session may be challenging. Most were comfortable with a blood test, but a minority said they would not take part if blood sampling was required due to anxiety about the procedure.

Influence: To accommodate these concerns, our protocol takes a modular design in which participants can opt out of one or both biological procedures and it does not prevent their involvement in other aspects. At enrolment, the researcher describes MRI as a noisy and confined environment, shares a video and explains they can opt out now or later - even mid scan. The procedure is made up of five short scans (5–7 minutes) and between runs the researcher checks if the participant wants to continue. Participants may also bring non-metallic fidget toys into the scanner to help them stay still.

Providing information about experiences of childhood trauma and adoption

Insights: Public contributors thought the scope and content of the mental health and personality questionnaires (Fig. 1) were acceptable. However, they felt the purely quantitative format of these was limiting and said they would like the option to give open-ended responses about their feelings and opinions on these topics.

Influence: The proposed standardised questionnaires could, unfortunately, not be adapted without compromising their reliability. Due to the quantitative nature of the project and funding requirement to support the pre-defined aims, it was not feasible to include open-ended qualitative components in this study. However, in response to their feedback and ideas, the research team have developed two related qualitative projects due to start data collection in May 2026:

- Young Adult Adoptee Experiences and Perceptions of Mental Health and Mental Health Support: A Qualitative Approach (Ethics: 2026-24217-46291)
- Exploring attitudes to food and eating behaviours in young adults who were adopted in childhood (Ethics: 2026-25202-45667)

Reflections & Critical Perspective (GRIPP2-5)

Can a single research protocol meet the diverse needs of people with lived experience of trauma?

A key theme across our PPIE activity with young adult adoptees was the wide range of views on what they felt was inclusive and acceptable. Based on their lived experience and unique mental health and neurodevelopmental needs, people frequently had differing opinions on their preferred format for assessments and aspects they wished to opt out of. Conversations during the workshop reinforced that every adopted person has unique early life experiences which can affect in them in a variety of different ways throughout their lives. A rigid research protocol requiring full completion of all aspects is therefore not appropriate for this group of people, and we recommend this learning be applied to research with other populations who have experienced adult or childhood trauma. In response, we developed and secured ethical approval for an adapted, flexible protocol that better accommodates this diversity and supports inclusive research. For participants living with a health condition or disability, their accessibility and support needs may change over the course of a study, therefore optional and online formats are particularly important as they can help support continued participation.

What happens when PPIE comes later in the research process?

A key limitation of this PPIE, was that the project aims had already been defined during development of the funding proposal, which took place before public contributors were involved. Contributors were able to shape how the data was collected to minimise burden and risk to future research participants, but they had limited influence over the research questions. This is common across health research, where objectives are usually built from prior literature and focussed on current Government policy, and budget and time constraints pose barriers to conducting PPIE before the project begins (Khan et al., 2024).

Where possible research should aim to engage public contributors earlier in the design process, ideally before the funding is secured, which would further support *Collaboration* and *Empowerment* trauma-informed principles. This recommendation is, however, largely dependent on the availability of flexible PPIE funding which covers participant expenses, staff time and any additional resources required pre-application.

To address this limitation in our future research, the team has secured funding from the NIHR Manchester Biomedical Research Centre, to run a priority-setting exercise in 2026 (“Adoptees' Voices in Research”) led by adoptees to identify the research questions that matter most to them and involve them as partners in future research. At the time of writing (April 2026), four 1-to-1 interviews with adoptees and an in-person workshop with 13 adoptees had been completed for this priority setting project. The next phase will be a national online survey (May 2026) where the wider adoption community will rank research priorities.

Did our PPIE session provide benefits for public contributors?

The goal of this workshop was to gain feedback on the research protocol and therefore limited time was integrated for informal interaction (except for an initial ice breaker lasting 10 minutes). In the post-workshop evaluation forms, many public contributors mentioned they gained something during the event, such as being given the opportunity to share their story, meet other adoptees for the first time and no longer feeling alone in their experiences. However, they also mentioned they would have valued more time for networking and peer interaction. Although this did not arise during the onboarding calls, the inclusive and safe space created during the workshop, may have stimulated the desire for more social connection.

This highlights that when public contributors attend PPIE activities, they may also appreciate additional time scheduled alongside PPIE activities to network informally, particularly when they are unlikely to have met others with similar experiences before. This could take the form of a longer “meet and greet” at the start of the session, or an organiser-facilitated optional networking period after PPIE activities have concluded (with adequate safeguarding in place). Based on this learning, both Vocal and the research team have since incorporated optional informal networking into PPIE events for those who have experienced rare health conditions, and during an adoptee priority setting workshop.

Evidence of Positive Impact

We are extremely grateful to the public contributors, whose insights and guidance were essential in shaping a more trauma-informed and person-centred approach to our research. Specifically, conducting the PPIE workshop addressed the trauma-informed principle of *Collaboration* during the research design phase. Insights from the workshop enabled us to develop a protocol which gives research participants a genuine *Voice* and *Choice* in how they take part. The trauma-informed principles of *Safety*, *Trustworthiness* and *Empowerment* were promoted by adaptations made to the protocol following advice from public contributors. The quotes below from research participants illustrate that these principles were supported whilst they took part:

The researchers in the study were really polite. They were understanding. They were caring. And they were eager to listen and help out. They treat you like you should be treated, and like they don't rush you, they don't pressure you to do anything that you don’t want to do.

(Research Participant, 18 years old)

It was good because talking about your experiences it can get overwhelming. But I was allowed to pause, take a break, ask questions if I needed to. That really helped, because obviously you're talking about quite difficult stuff, and so it was a very supportive environment. It was very cathartic. And also, I felt kind of proud talking about it, because I knew that it would be going towards helping create better support systems for people like me.

(Research Participant, 22 years old)

Taking part in this study has been the biggest boost to [young person] self-esteem and sense of self-worth ever in recent years. You are the only person he's spoken to outside of family and a handful of online gaming friends since he was about 12.

(Parent of Research Participant, 22 years old)

Conclusion

This commentary demonstrates the value of Patient and Public Involvement and Engagement (PPIE) when designing research for people with lived experience of childhood trauma. Insights and ideas from young adult adoptees helped us ensure that our biomedical research protocol could be tailored to individual needs and highlighted which procedures should be made optional or more flexible. Ultimately this enhanced both inclusivity and accessibility of this early life adversity study. Engaging with people with lived experience stimulated additional activities designed to give power to adoptees voices including qualitative research ideas and a research priority setting exercise. Our adoptee (public) contributors directly informed a more responsive, trauma-informed approach by our research team, strongly aligned with the principles of *Safety, Trustworthiness, Collaboration, Empowerment, Voice, and Choice*.

Declarations

The protocol design online workshop event did not require consent as this was a PPIE activity and therefore ethics is not required by the University of Manchester ethics committee. All research participants consented to take part in the final research project.

Acknowledgement

We would like to thank the independent lived experienced co-authors Moo Keisha (Adopted & Fostered Person) and Jame Evans (Adoptee) for their time spent validating, reviewing and editing this article, and their time participating the research project. These co-authors were offered reimbursement of £100 for helping to develop this article.

Thank you to Lindsey Arrowsmith (Post Adoption Support at Centre for Fostering & Adoption Support) and Jamie Bennet (Chairperson at Adoption Matters) who also gave feedback on the research protocol design and helped guide recruitment materials and approaches.

Thank you to Annie Keane (PPIE Lead NIHR Manchester Biomedical Research Centre, and Director (interim) Vocal (www.wearevocal.org [wearevocal.org]) for providing advice and feedback during the development of this article.

We are grateful to all the agencies, networks, charities, and individuals who supported recruitment for this research study by sharing the advert, including Adoption UK, PAC-UK, How To Be Adopted, the Adult Adoptee Movement, The Potato Group, Adoption Counts, and Adoption Matters.

The views and opinions expressed in this article are our own and do not necessarily reflect of these individuals and organisations.

Funding

This research is funded by the National Institute for Health and Care Research (NIHR) Manchester Biomedical Research Centre (BRC) (NIHR203308). The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care. This research was supported by the National Institute for Health and Care Research (NIHR) Mental Health Translational Research Collaboration, hosted by the NIHR Oxford Health Biomedical Research Centre.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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Figures

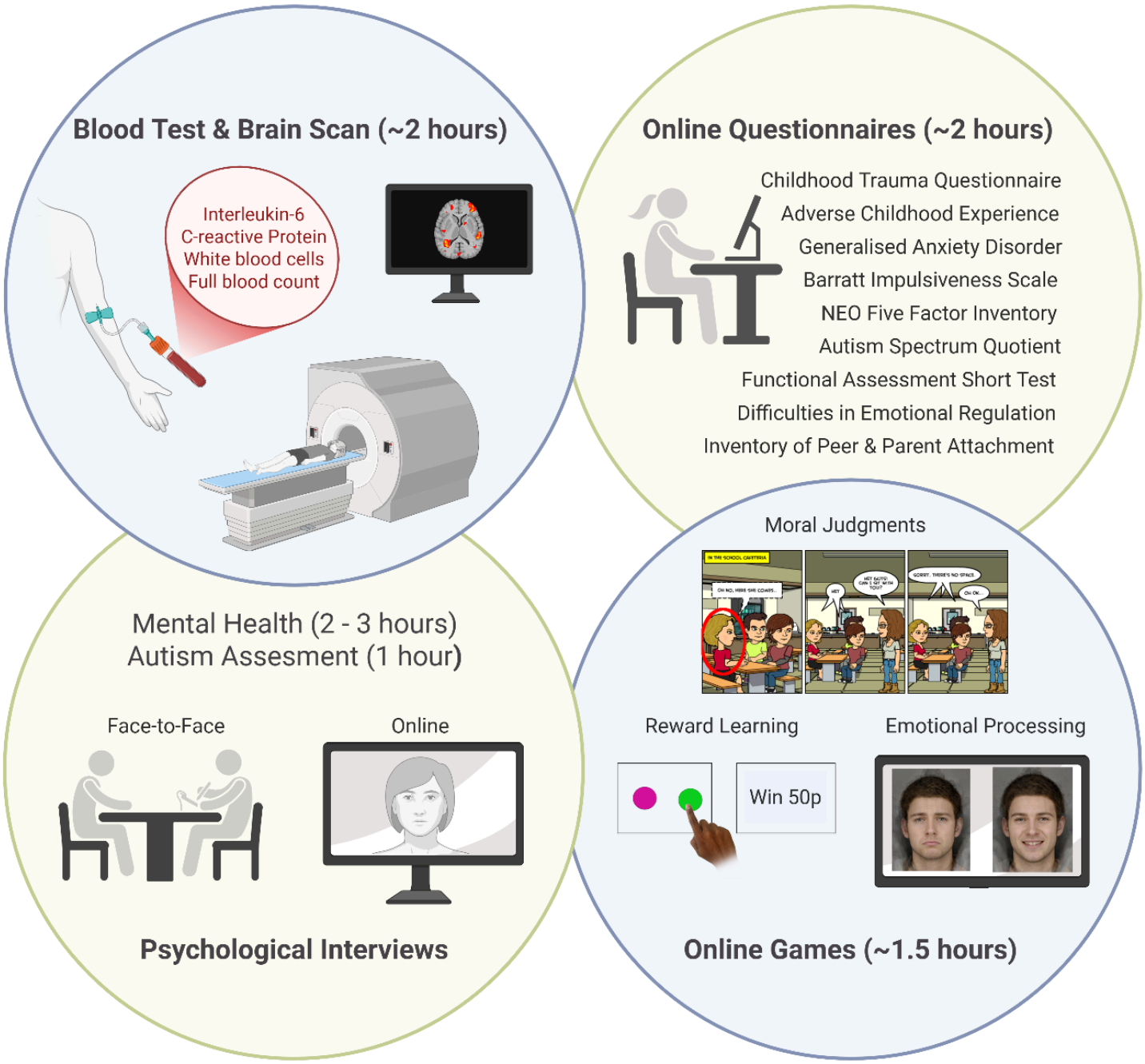


Figure 1

Study Protocol: Investigating the impacts of early life experience on the brain and behaviour (funded by NIHR Manchester Biomedical Research Centre)