# Investigating the acceptability of co-produced interventions for parents/carers of children with Acquired Brain Injury (ABI)

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## Abstract

Acquired Brain Injury (ABI) in children and young people (CYP) can lead to complex, long-term challenges across emotional, cognitive, physical, and social domains. These changes often have a profound impact on family life, with parents/carers taking on extensive caregiving and advocacy roles. Despite their central involvement, parents'/carers' perspectives are frequently underrepresented in the design of interventions aimed at supporting CYP with ABI and their families.

This thesis portfolio explores how creative, participatory approaches can support parents/carers following ABI. It comprises a systematic review and an empirical study, designed and conducted in parallel, alongside a bridging chapter and extended reflections. The portfolio is grounded in a commitment to family-centred care, collaborative approaches, and engaging meaningfully with lived experience.

The systematic review uses thematic synthesis to examine qualitative and mixed-methods studies exploring parents'/carers' experiences of interventions following paediatric ABI. It identifies key features parents/carers value – such as timely support, emotional connection, and practical strategies – and highlights the need for more inclusive, co-produced approaches.

The empirical study investigates how parents experienced engaging with a creative materials-based storytelling approach. Using reflexive thematic analysis, it explores how parents related to the process, including what supported or constrained their participation. The analysis highlights emotional, relational, and identity-related aspects of engagement, offering insight into what made the approach feel safe, meaningful, or challenging to parents.

Taken as a whole, the portfolio contributes to the growing evidence base for participatory and emotionally responsive approaches in paediatric neurorehabilitation. It offers practical and theoretical insights into how support for families can be made more inclusive, flexible, and grounded in what matters to parents/carers themselves.

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To the team at our recruitment site – thank you for everything. For introducing the research to parents and carers, for your time, for putting up posters, helping with logistics, and supporting us so generously at every step. I know how busy you are, and I'm so grateful. Your support made a real difference, and it was an absolute pleasure to work with you.

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# Chapter One: Introduction to the Thesis Portfolio

## Introduction to the Thesis Portfolio

Acquired Brain Injury (ABI) describes any brain injury sustained after birth and includes injuries arising from both traumatic events (e.g., falls or accidents) and non-traumatic causes (e.g., infections or brain tumours). Determining the exact number of children and young people (CYP) affected by ABI annually in the UK is challenging due to variations in data collection and reporting. However, the UK incidence of paediatric ABI is estimated to be just under 40,000 per year. This includes 35,000 CYP admitted to hospital for Traumatic Brain Injury (TBI) annually as well as hospital admissions for encephalopathy (approx. 4,000), paediatric brain tumour (PBT; approx. 525), and stroke (approx. 300; United Kingdom Acquired Brain Injury Forum, 2018).

ABI in CYP can have profound and lasting effects, often reshaping family life in complex ways. Parents take on critical roles in supporting their child's recovery, yet their perspectives are frequently underrepresented in the development of interventions. This thesis portfolio explores how co-produced, creative, emotionally attuned approaches underpinned by the values of co-production can support parents following ABI – with a particular focus on interventions addressing both rehabilitation for the injured CYP and parents' own needs in adapting to life post-injury, including opportunities to reflect on and share their stories.

The portfolio comprises two main components: a systematic review and an empirical study, designed and conducted in parallel. Both components were shaped by shared aims and values, including a focus on relational working, engaging meaningfully with families' lived experiences, and being informed by principles of co-production.

The systematic review uses thematic synthesis to examine qualitative and mixed-methods research on parents'/carers' experiences of interventions following paediatric ABI. It identifies key features that parents/carers value – such as timely support, emotional connection, and interventions tailored to their child's and family's needs. The review also highlights gaps in the literature, including the limited inclusion of diverse voices and a lack of participatory approaches. This review was prepared for submission to *Disability and Rehabilitation*.

The empirical paper explores how parents engaged with a creative materials-based storytelling intervention. It examines both the stories they shared and the process of storytelling itself – including what helped or hindered participation, and how parents used the opportunity to reflect, communicate, and make sense of their experiences. Reflexive thematic analysis was used to explore patterns of meaning within and across parents' accounts. This paper was prepared for submission to the *Journal of Health Psychology*.

A short bridging chapter outlines how the two papers are conceptually and methodologically linked. The portfolio also includes extended methods and discussion chapters to provide a more in-depth account of design decisions, critical reflections, and implications for practice and research.

Together, the portfolio contributes to growing evidence for participatory and emotionally responsive approaches in paediatric neurorehabilitation. By centring parents' perspectives and exploring both what support is offered and how it is experienced, the thesis offers practical and theoretical insights into designing more inclusive and meaningful interventions for families living with ABI.

# References

United Kingdom Acquired Brain Injury Forum. (2018). *All-Party Parliamentary Group on Acquired Brain Injury Report*. www.ukabif.org.uk

# Chapter Two: Systematic Review

Prepared for submission to Disability and Rehabilitation
(Author guidelines included in Appendix A. An earlier version of this review was submitted to Disability and Rehabilitation on 7 March 2025. The journal editor's decision and reviewers' feedback are included in Appendix B.)

# A thematic synthesis of parents'/carers' perspectives regarding the development and content of interventions aimed at supporting children and young people with acquired brain injury and their families

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## Abstract

**Purpose**: This thematic synthesis explores parents'/carers' perspectives on the development and content of co-produced interventions aimed at supporting children and young people (CYP) with Acquired Brain Injury (ABI) and their families. Understanding their perspectives can inform the design of family-centred interventions that address families' practical and emotional needs.

**Materials and methods**: A systematic review of qualitative and mixed-methods studies was conducted. Searches in MEDLINE, PsycINFO, CINAHL, OpenDissertations, AMED, and Scopus identified studies reporting parents'/carers' perspectives on ABI interventions. Thematic synthesis was used to analyse findings, and study quality was assessed using the Critical Appraisal Skills Programme (CASP) tool.

**Results**: Thirteen studies were included. Two overarching themes were identified: 1) Feeling supported, highlighting the importance of emotional reassurance, peer connections, and sustained access to support; and 2) Equipping parents/carers and others, underscoring the need for accessible, structured, and culturally responsive interventions to help families navigate ABI recovery. Parents/carers valued flexible, inclusive, and tailored interventions that adapted to their evolving needs.

**Conclusions**: Findings underscore the importance of interventions that provide both emotional and practical support while remaining accessible and responsive to diverse family circumstances. These insights contribute to the development of family-centred rehabilitation programmes that enhance parent/carer well-being and engagement in CYP's recovery.

**Keywords**: Acquired brain injury (ABI); systematic review; thematic synthesis; interventions; children and young people; parents and carers; qualitative research; family-centred support

## Implications for Rehabilitation

- Parents/carers of children and young people (CYP) with acquired brain injury (ABI) could benefit from interventions that provide both emotional and practical support, with flexibility to engage at different points according to individual readiness and evolving needs.
- Incorporating peer support and ensuring sustained access to intervention options could help parents/carers feel more validated, equipped, and prepared for long-term caregiving challenges.
- Offering a flexible ‘menu’ of structured, engaging intervention components, developed in collaboration with experienced professionals, could assist parents/carers in acquiring the knowledge and skills needed to support CYP’s recovery, promote independence, and navigate complex systems such as education and healthcare.
- Greater communication and collaboration between rehabilitation services, parents/carers, educators, and healthcare providers could enhance shared understanding of ABI’s hidden challenges and facilitate more family-centred support.

# Introduction

Acquired Brain Injury (ABI) describes any brain injury sustained after birth and includes injuries arising from both traumatic events (e.g., falls or accidents) and non-traumatic causes (e.g., infections or brain tumours). Determining the exact number of children and young people (CYP) affected by ABI annually in the UK is challenging due to variations in data collection and reporting. However, the UK incidence of paediatric ABI is estimated to be just under 40,000 per year. This includes 35,000 CYP admitted to hospital for Traumatic Brain Injury (TBI) annually as well as hospital admissions for encephalopathy (approx. 4,000), paediatric brain tumour (PBT; approx. 525), and stroke (approx. 300; United Kingdom Acquired Brain Injury Forum, 2018).

Paediatric ABI profoundly affects families, disrupting their emotional well-being, family dynamics, and social and financial stability. Parents/carers often struggle with grief for their CYP's "pre-injury" self as well as uncertainty about their recovery, and this can lead to mental health problems such as anxiety, depression, and burnout (Gracey et al., 2009; Tyerman et al., 2017). These emotional challenges are compounded by significant disruptions to family roles, with one parent/carer often becoming the primary caregiver to the injured CYP, a situation that can strain the parents'/carers' relationship. Siblings of CYP with ABI may feel neglected or be required to take on caregiving responsibilities, both of which could negatively impact on their emotional well-being and development (Tyerman et al., 2017; Yeates et al., 2007).

Social isolation is a common experience among parents/carers of CYP with ABI, as caregiving responsibilities often limit opportunities for making connections and finding support. Stigma and misunderstanding surrounding "invisible" injuries, such as cognitive or emotional impairments, can further exacerbate feelings of isolation (Andersson et al., 2016; Roscigno & Swanson, 2011). Financial burdens also weigh heavily on parents/carers. The high costs of medical care, therapy, and rehabilitation, combined with reduced work capacity due to caregiving responsibilities, often lead to significant economic strain (Hickey et al., 2016; Miley et al., 2022). Practical challenges such as managing therapies, coordinating school accommodations, and navigating healthcare systems further increase the strain on parents/carers (Andersson et al., 2016; Cole et al., 2009).

The development of interventions aimed at supporting CYP with ABI has typically been undertaken without the involvement of parents/carers. However, parents/carers are central to a CYP's recovery. If the aim is to develop interventions that effectively address the needs of both CYP and families, it is essential that parents'/carers' perspectives are understood and integrated into the intervention development process. By emphasising parents'/carers' voices, interventions can be designed to reflect the priorities of those most directly involved in the injured CYP's care, making them more practical, relevant, and effective. Through a process of distilling parents'/carers' perspectives into actionable recommendations, this review aims to provide clear guidance to healthcare professionals, schools, and policymakers for developing effective interventions aimed at supporting CYP with ABI and their families. To this end, this review addresses the question: What are parents'/carers' perspectives regarding the development and content of interventions aimed at supporting children and young people with acquired brain injury and their families?

## Materials and Methods

### Methodology

A thematic synthesis of qualitative research, as described by Thomas and Harden (2008), was undertaken following systematic searches and eligibility checks. Thomas and Harden's approach involves coding primary study findings line by line, grouping the codes into descriptive themes, and then generating analytical themes that move beyond the original findings to provide new interpretive insights. Their method balances staying close to the data with broader interpretation, making it particularly useful for addressing questions about people's experiences and perspectives regarding intervention need, appropriateness, and acceptability. The review process was situated in a critical realist perspective, with a main aim of understanding, rather than simply describing, parents'/carers' perspectives. The protocol for this review was registered with the International Prospective Register of Systematic Reviews (PROSPERO) in October 2023 (registration number: CRD42023468023).

### Paper identification and search strategy

Sources of papers for the synthesis included bibliographic and other databases (MEDLINE, APA PsycINFO, CINAHL, OpenDissertations, AMED, Scopus), reference lists of eligible studies and review articles, key journals (e.g., Disability and Rehabilitation, Neuropsychological Rehabilitation, Brain Injury, Archives of Physical Medicine and Rehabilitation, International Journal of Nursing Studies), conference proceedings, and contact with study investigators. Unpublished studies (e.g., doctoral theses) were also sought. There were no restrictions (e.g., language, date range) on the searches; however, the review only included studies that were written in English.

The SPIDER (Sample, Phenomenon of Interest, Design, Evaluation, Research type) framework (Cooke et al., 2012) was used to define the key components of the review question and inform and standardise the search strategy. Search terms combined words/phrases that represent “family”, “child”, “brain injury”, “intervention”, “perspectives”, and “qualitative or mixed methods”. The initial search strategy was developed for MEDLINE (appendix C) and then adapted for the other searches. MeSH terms or their equivalent, where supported, were included. The final searches were completed in October 2024.

### Eligibility criteria

The review included peer-reviewed primary research that employed qualitative or mixed methods, including feasibility and acceptability studies. Mixed methods studies were included only if the study reported qualitative data. Study aims had to include developing an intervention aimed at supporting CYP with ABI and/or their families post injury. In achieving this aim, the study had to recruit parents/carers of CYP with ABI as participants and involve them in the development of the content of an intervention. Eligible studies had to produce qualitative data that reflected family members’ views of the intervention or of how the intervention should be. In this review, CYP with ABI were defined as individuals aged between 2 and 18 years at the time they sustained a clinically significant ABI as defined by Turner-Stokes (2003). Guided by this definition, studies were included if the CYP continued to experience persistent difficulties secondary to the ABI.

The review excluded secondary research (e.g., reviews, meta-syntheses) and primary research without a qualitative element (e.g., quantitative research, meta-analyses). Also excluded were studies where the focus of parents’/carers’ involvement was predominantly on gathering feedback on the outcome of an intervention or within a routine service context (e.g., for purposes of fine tuning service delivery). Studies that involved developing interventions that did not specifically focus on managing the consequences of clinically significant ABI were also excluded, as were studies involving CYP with post traumatic amnesia or disorders of consciousness, or who were still in critical or intensive care.

Ambiguous cases were discussed with FG and CW until consensus was reached. Twenty percent of the unique records returned by the searches were independently screened by two researchers undertaking doctoral training in clinical psychology, who achieved 99.2

percent agreement. Cases for which there was disagreement were discussed and used to clarify the eligibility criteria.

### Quality assessment

Following Whiffin et al. (2021), the studies included in the current synthesis were classed as “core”, “central”, or “peripheral” based on their relevance, resonance, and rigour (table 1). Relevance was evaluated based on how closely aligned a study’s research question and study participants were to those of the current synthesis; resonance was evaluated based on the richness and complexity of a study’s findings and the extent to which the findings contribute to the evidence base; and rigour – i.e., a study’s methodological congruence and the appropriateness with which qualitative methods were used – was evaluated using the Critical Appraisal Skills Programme tool (CASP; Noyes et al., 2019; The CASP Team, 2018). With the CASP tool, studies are evaluated using responses to ten questions designed to help the appraiser think systematically about issues relating to the rigour with which the data were collected, analysed, and reported, as well as the validity and value of a study’s results (table 1 and appendix E). One of the included studies (Raj et al., 2018) used a mixed-methods design. In this case, the CASP tool was applied only to the qualitative components of the paper, consistent with guidance for synthesising qualitative data (Noyes et al., 2019).

**Table 1.** Criteria for classifying studies as core, central, or peripheral based on their relevance, resonance, and rigour

| | Relevance | Resonance | Rigour |
|---|---|---|---|
| Core | Research question and participants are explicitly aligned to the review question and participants. | Findings are rich, complex, and evocative; they make a meaningful and insightful contribution to advancing the evidence base. | Methodologically congruent; qualitative methods are appropriately applied. Responses to CASP tool questions are predominantly "Yes", with no "No" responses. |
| Central | As above, but may fail to meet one or more of the criteria in its fullest sense. | As above, but may fail to meet one or more of the criteria in its fullest sense. | As above, but may fail to meet one or more of the criteria in its fullest sense. Responses to CASP tool questions are predominantly "Yes"; one "No" response permitted. |
| Peripheral | Research findings and participants are relevant but the research question is not completely aligned to the review question. | Findings are superficial, thin, or expected and do not advance the evidence base in a meaningful way. | There may be questions about the methodological congruence of the study and whether qualitative methods were appropriately applied. Responses to CASP tool questions are predominantly "Can't tell" or "No". |

*Note*. Adapted from Whiffin et al. (2021, p. 4, Table 2).

### Data extraction

NVivo Release 15.0.0 was used to extract, manage, and analyse the data. Data for characterising the studies and assessing their quality were extracted from the Abstract, Methods, and Results sections of each paper. Data for the thematic synthesis were extracted from the Results section(s) and comprised lines of text, information presented in tables, and information presented in figures. Data in Results sections that did not address the review question were not extracted.

### Thematic synthesis

Adopting Thomas and Harden's (2008) approach, the thematic synthesis was comprised of three stages:

#### *Stages 1 and 2: Coding text and developing descriptive themes*

Initial codes were created to represent each theme identified in a given paper. These codes were then assigned to phrases, sentences, or groups of sentences that conveyed the idea or meaning encapsulated by the theme to which they had been assigned. This process was repeated for each paper included in the synthesis.

Each phrase, sentence, or group of sentences was then assigned one or more new codes to encapsulate its meaning. Papers classed as "core" were coded first, followed by the "central" papers, and finally the "peripheral" papers. The majority of new codes were derived from the core papers and formed the basis of the codebook. The central papers contributed additional codes but added fewer new codes relative to the core papers. Few new additions or changes to the codebook came from the peripheral papers, which primarily served to confirm existing themes. Codes were assigned on a line-by-line basis using NVivo Release 15.0.0, with the "memos" feature being used to record reflections whilst coding. The codebook was constantly under reflection and being updated throughout these first two stages of the analysis.

#### *Stage 3: Generating analytical themes*

During the final stage of the analysis, patterns in the coding were used to merge codes which shared largely similar meanings into a number of analytical themes (appendix F). In so doing, the synthesis moved beyond the findings of the included studies to develop an understanding of parents'/carers' perspectives regarding the development and content of interventions aimed at supporting CYP with ABI and their families.

## Trustworthiness

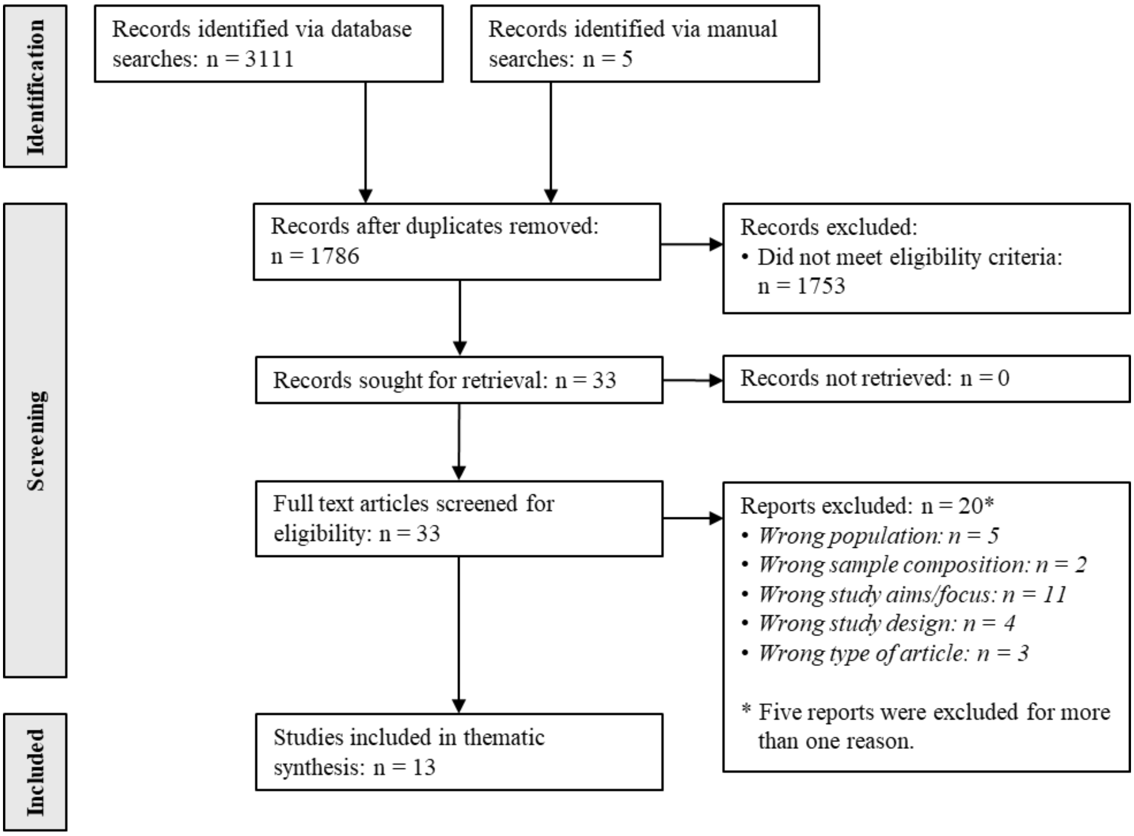
Trustworthiness in the research was attained by proactively incorporating processes to ensure its credibility, dependability, transferability, and confirmability (Lincoln & Guba, 1985). Credibility was attained through immersion in the analysis whilst remaining critically reflexive – e.g., maintaining an awareness of how researcher positionality could bias interpretation of the data. This process was facilitated by keeping a reflexive journal and routinely discussing the research within the research team. Dependability was attained by developing, documenting, and using systematic and transparent processes for searching, appraising the quality of papers, analysing the data, and reporting the findings. The transferability of the findings was attained through the use of thick description – i.e., providing the reader with detailed quotes that are rich with meaning, and situating these quotes within the context in which they occurred. Confirmability was attained through the transparent reporting of all decisions – theoretical, methodological, and analytical – related to the research.

# Results

## Search outcome

The database searches identified a total of 3,116 records. After removal of duplicates, 1,786 records remained for screening. Of these, 1,753 were excluded based on title and abstract, and 33 full-text articles were assessed for eligibility. A further 20 were excluded, leaving 13 studies that met the inclusion criteria and were included in the synthesis. The screening and selection process is summarised in figure 1 and appendix D.

**Figure 1.** PRISMA flow diagram depicting the screening and selection process



## Quality assessment

Most studies were evaluated as having moderate to high relevance and resonance. However, one study (Gauvin-Lepage et al., 2015) was rated as having low resonance due to the superficial presentation of its findings. Details of the CASP tool assessment, which evaluated rigour, are provided in table 2. The primary reasons for rating some studies as less rigorous were: 1) insufficient consideration of the relationship between researchers and participants (n = 8), and 2) a lack of evidence demonstrating that ethical issues were adequately considered (n = 7). Four studies were assessed as core, six as central, and three as peripheral.

**Table 2.** Critical Appraisal Skills Programme (CASP) tool responses for included studies grouped by quality assessment classifications

| | **Core** | | | | **Central** | | | | | | **Peripheral** | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Al-Hakeem et al. (2024) | Drake et al. (2024) | Gilmore et al. (2023) | Svendsen et al. (2023) | Bedell et al. (2017) | Bennett et al. (2023) | Brown et al. (2013) | Jacobs-Nzuzi Khuabi et al. (2019) | Raj et al. (2018) | Shore et al. (2022) | Aitken et al. (2004) | Gan, Gargaro, Kreutzer, et al. (2010) | Gauvin-Lepage et al. (2015) |
| | Section A: Are the results of the study valid? | | | | | | | | | | | | |
| 1. Was there a clear statement of the aims of the research? | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes |
| 2. Is a qualitative methodology appropriate? | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes |
| 3. Was the research design appropriate to address the aims of the research? | Yes | Yes | Yes | Yes | Can’t tell | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes |
| 4. Was the recruitment | Yes | Yes | Yes | Yes | Yes | Can’t | Yes | Yes | Yes | No | Can’t | Can’t tell | No |

| | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| strategy appropriate to the aims of the research? | | | | | | tell | | | | | tell | | |
| 5. Was the data collected in a way that addressed the research issue? | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Can’t tell | Yes | Yes |
| 6. Has the relationship between researcher and participants been adequately considered? | Yes | Yes | Yes | Yes | No | Can’t tell | Can’t tell | Can’t tell | Can’t tell | Yes | Can’t tell | Can’t tell | Can’t tell |
| | Section B: What are the results? | | | | | | | | | | | | |
| 7. Have ethical issues been taken into consideration? | Can’t tell | Yes | Yes | Yes | Can’t tell | Can’t tell | Yes | Yes | Can’t tell | Yes | Can’t tell | Can’t tell | Can’t tell |
| 8. Was the data analysis sufficiently | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | No | No | Yes |

| | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| rigorous? | | | | | | | | | | | | | |
| 9. Is there a clear statement of findings? | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes |
| | Section C: Will the results help locally? | | | | | | | | | | | | |
| 10. How valuable is the research: Will the results help locally? | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes | Yes |

## Characteristics of included studies

Interest in this research area is relatively new, as reflected by the publication dates of the studies included in the synthesis (table 3). All but one (Aitken et al., 2004) were published within the last 15 years and six of the 13 were published within the last two years. The papers originated mainly from Australia (n = 3), Canada (n = 4), and the USA (n = 3), with one paper each originating from Norway, South Africa, and the UK.

Nine of the 13 included studies investigated the characteristics or features that impacted the acceptability or feasibility of a particular intervention. The other four studies investigated the needs of parents/carers and/or CYP in relation to services or interventions.

Although one study collected qualitative responses to open-ended questions on an online survey (Bennett et al., 2023), qualitative data were largely collected via semi-structured interviews with individual participants (n = 6), focus groups using semi-structured interviews (n = 2), or a combination of the two (n = 4). Of these, two additionally collected qualitative responses to open-ended questions on a survey (Bedell et al., 2017) or questionnaire (Gan, Gargaro, Kreutzer, et al., 2010). Qualitative data were largely analysed using some form of thematic analysis (n = 6) or content analysis (n = 5), although one study used a hybrid of the two (Svendsen et al., 2023) and another used inductive comparative analysis (Jacobs-Nzuzi Khuabi et al., 2019).

The number of parents/carers who participated in the studies ranged from three (Shore et al., 2022) to 31 (Bennett et al., 2023; Gilmore et al., 2023), with most studies recruiting between five and ten parents/carers, most of whom were mothers. Most studies recruited parents/carers of CYP with any type of ABI (n = 5) or who had sustained a TBI (n = 5). Two studies recruited parents/carers of CYP with persistent symptoms related to a sustained concussion (Al-Hakeem et al., 2024; Shore et al., 2022) and one recruited parents/carers of CYP who had survived a paediatric brain tumour (Raj et al., 2018). The CYP ranged between 2 and 18 years at time of injury.

**Table 3.** Characteristics of included studies

| Paper | Publication type | Country | Study focus | Method(s) used to collect qualitative data | Qualitative approaches used in the analyses | Parent/carer participants: Description | Parent/carer participants: Sample size | Age of injured CYP at time of injury (years) | Findings/themes |
|---|---|---|---|---|---|---|---|---|---|
| The themes of the following papers relate to needs of parents/carers and/or CYP in relation to services or interventions. | | | | | | | | | |
| Aitken et al. (2004) | Peer-reviewed journal article | USA | Identify needs of CYP and families post injury | Focus groups with semi-structured interviews | Thematic analysis | Mothers of children with moderate to severe TBI | N = 10 mothers | 5-18 | Communication with professionals; Accessing and understanding systems of care; Parental burden; Need for social support |
| Bennett et al. (2023) | Peer-reviewed journal article | UK | Understand parents' perspectives around CYP returning to education post ABI | Service evaluation with online survey | Thematic analysis | Parents of CYP with ABI (concussion/mild TBI, moderate/severe TBI, stroke/arteriovenous malformation (AVM), brain tumour, infection, hypoxia, or not specified) | N = 31 parents | 2-17 | Parental mindset and growth; Specialist support and information; What do the CYP need now; Talk and share; Challenges of new and hidden needs; Don't forget the CYP |
| Brown et al. (2013) | Peer-reviewed journal | Australia | Explore experiences, challenges, and | Focus groups or interviews | Inductive thematic analysis | Parents/carers of children with moderate to severe | N = 7 mothers, 1 father, 1 | 2-9 | TBI has a wide-ranging impact on a child; Parents' |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | article | | needs of parents of children with TBI to inform intervention research | | | TBI | stepfather, 1 grandmother | | emotional experience is intense, overwhelming and ongoing; Effective parenting becomes more challenging; Burden of care; Relationships with family and friends; Perceptions of support; Connection and empowerment; Parents' strategies for coping |
| Jacobs-Nzuzi Khuabi et al. (2019) | Peer-reviewed journal article | South Africa | Identify where occupational therapists' efforts vis-à-vis young people (YP) returning to education post TBI are needed | Semi-structured interviews | Inductive comparative analysis | Primary caregivers of YP with mild to severe TBI | N = 5 mothers, 1 grandmother, 2 not specified | 14-17 | Change in former sense of self; The meaning and value of participating in school; Strategies used to adapt and resume participation in school; Journey of personal growth and perseverance; Support needs for re-entrance and participation in school post TBI |
| The themes of the following papers relate to characteristics or features that impact the acceptability or feasibility of an intervention. | | | | | | | | | |
| Al-Hakeem | Peer-reviewed | Canada | Explore feasibility of a | Semi-structured | Content analysis | Caregivers of YP with PPCS | N = 9 mothers | 8-18 | Caregiver background; |

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| et al. (2024) | journal article | | virtual group-based intervention for parents/carers of YP with persistent post-concussion symptoms (PPCS) | interviews | | | | | Intervention structure; Intervention engagement; Key takeaways |
| Bedell et al. (2017) | Peer-reviewed journal article | USA | Inform design of intervention to promote social participation in YP with TBI | Interviews or focus groups, surveys | Content analysis | Parents of teenagers with mild to severe TBI | N = 5 mothers, 2 fathers | 12-16 | Social participation barriers, supports, and strategies; Interacting with coaches; Using and interacting with smartphones and apps; Use of chat rooms; Parent involvement |
| Drake et al. (2024) | Peer-reviewed journal article | Australia | Explore parents'/carers' perspectives regarding usability, acceptability, and implementation of intervention for families of CYP with ABI | Questionnaires, semi-structured interviews | Descriptive statistics, inductive content analysis | Parents/caregivers of CYP with ABI (TBI, hypoxia, or stroke) | N = 9 mothers, 1 father | 4-16 | Feeling satisfied with HOPE (Appreciating the family centredness of HOPE; Evaluating HOPE's online delivery; Getting something out of HOPE); Optimising HOPE (Increasing storyteller diversity; Expanding HOPE's content; Suggesting |

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| | | | | | | | | | further support); Guiding implementation (Thinking about how HOPE should be introduced to families; Considering how HOPE could be used by families; Seeing HOPE's potential to educate others) |
| Gan, Gargaro, Kreutzer, et al. (2010) | Peer-reviewed journal article | Canada | Evaluate and adapt an intervention for YP with ABI and their families | Questionnaires, semi-structured interviews | Content analysis | Family members of YP with ABI (TBI, aneurysm, stroke, or encephalitis) | Stage 1: N = 5 parents;<br>Stage 2: N = 7 mothers, 1 father, 1 male partner;<br>Stage 3: N = up to 5 parents | 13-18 at time of study (.5 to 14 years post injury) | Structure of intervention; Format of intervention; Timing of intervention delivery; Value of family system approach; Validation of participants' experiences; Sibling perspectives; Clinician perspectives |
| Gauvin-Lepage et al. (2015) | Peer-reviewed journal article | Canada | Identify, prioritise, and validate building blocks of intervention to support | Semi-structured interviews, focus groups | Inductive thematic analysis | Parents of teenagers with moderate to severe TBI | N = 6 mothers, 1 father | 14-17 at time of study (1 to 18 months post | Family characteristics and its influences; Positive family strategies; Family and social support; |

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| | | | resilience in families post TBI | | | | | injury) | Management of occupational aspects; Contribution of the community and health professionals |
| Gilmore et al. (2023) | Peer-reviewed journal article | Australia | Explore YP with ABI or cerebral palsy and caregivers' experiences of a social skills group intervention | Focus groups with semi-structured interviews | Thematic analysis | Parents of YP with ABI (injury type not specified) | N = 25 mothers, 6 fathers | 11-17 at time of study (12+ months post ABI) | Challenging families and meeting expectations; Learnt new skills; Connecting, belonging and understanding "that's our normal"; Confidence in knowing and doing; Where to from here? |
| Raj et al. (2018) | Peer-reviewed journal article | USA | To develop a web-based intervention to improve psychosocial functioning in adolescent and young adult (AYA) survivors of paediatric brain tumours (PBT) | Focus groups, interviews | Directed content analysis | Parents of AYA PBT survivors | N = 4 mothers, 2 fathers | 16-23 at time of study (2+ years post treatment) | Concerns include fatigue, memory deficits, poor mood, health, challenging peer relationships; Interventions need to be customisable; Want interventions that target psychosocial functioning and late effects; Web-based interventions preferred |

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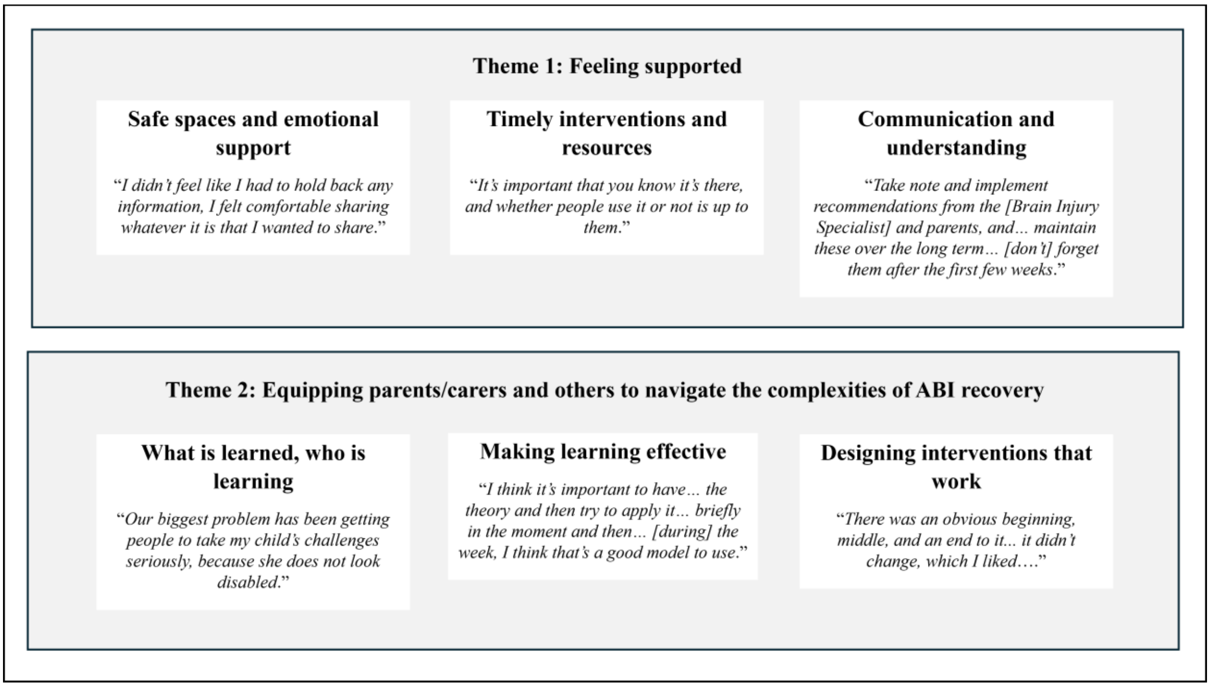
| Shore et al. (2022) | Peer-reviewed journal article | Canada | Explore YP with concussion and their parents' experiences of a remotely-delivered rehabilitation intervention | Semi-structured interviews | Thematic analysis | Parents of YP with concussion | N = 3 mothers | 14-17 at time of study (5 to 24 weeks post injury) | Enabling access to active rehabilitation; Focusing on individual needs; Learning to take responsibility for recovery; Convenience and comfort of engaging in rehabilitation from home |
| Svendsen et al. (2023) | Peer-reviewed journal article | Norway | Explore experiences of participation in, and acceptability and adaptability of, a home-based tele-rehabilitation intervention | Semi-structured interviews | A hybrid of content analysis and thematic analysis | Parents of YP with ABI (TBI, anoxia, brain haemorrhage) | N = 5 mothers, 6 fathers | 11-15 at time of study (1.5 to 13 years post injury) | Expectations and experiences with participation in the intervention; Usefulness, benefits and concerns related to the strategies developed in intervention; Experience with the digital solution and user involvement |

## Themes drawn from analysis

The themes and subthemes presented here reflect parents'/carers' perspectives on the development and content of interventions aimed at supporting CYP with ABI and their families. These findings are organised into two overarching analytical themes: 1) *Feeling supported*, and 2) *Equipping parents/carers and others to navigate the complexities of ABI recovery*. Each analytical theme comprises three interconnected subthemes. A summary diagram of these themes and subthemes is presented in figure 2. To enhance clarity and accessibility, tables are used throughout this section to summarise key findings, highlight illustrative quotes, and/or present practical recommendations.

**Figure 2.** Summary of overarching themes and subthemes



**Theme 1: Feeling supported**

**Safe spaces and emotional support**

*"I didn't feel like I had to hold back any information, I felt comfortable sharing whatever it is that I wanted to share."*

**Timely interventions and resources**

*"It's important that you know it's there, and whether people use it or not is up to them."*

**Communication and understanding**

*"Take note and implement recommendations from the [Brain Injury Specialist] and parents, and… maintain these over the long term… [don't] forget them after the first few weeks."*

**Theme 2: Equipping parents/carers and others to navigate the complexities of ABI recovery**

**What is learned, who is learning**

*"Our biggest problem has been getting people to take my child's challenges seriously, because she does not look disabled."*

**Making learning effective**

*"I think it's important to have… the theory and then try to apply it… briefly in the moment and then… [during] the week, I think that's a good model to use."*

**Designing interventions that work**

*"There was an obvious beginning, middle, and an end to it... it didn't change, which I liked…."*

### *Feeling supported*

Parents/carers emphasised the importance of feeling supported throughout their CYP's recovery. This included access to safe spaces for emotional support, where parents/carers could share experiences, receive psychological support, and feel validated by peers and professionals. Feeling supported also meant accessing timely support and resources, ensuring that interventions were available when needed, with opportunities between sessions to apply new knowledge and skills. Finally, parents/carers highlighted the role of proactive communication and sustained understanding from key professionals and systems, including tailored educational support, long-term adjustments, and increased awareness of ABI’s hidden challenges. The following sections explore these aspects of feeling supported in greater detail.

***Safe spaces and emotional support***. Parents/carers emphasised the need for psychological support, safe spaces for sharing, and opportunities for peer connection.

Parents/carers wanted ongoing psychological support to address the emotional and systemic challenges surrounding their CYP’s injury and recovery. This need was evident across studies conducted in diverse geographic and cultural contexts, including Australia (Brown et al., 2013; Drake et al., 2024), Canada (Gan, Gargaro, Kreutzer, et al., 2010), and South Africa (Jacobs-Nzuzi Khuabi et al., 2019), reflecting a range of healthcare systems and rehabilitation service models. The studies recruited parents/carers of CYP with moderate to severe ABI or PPCS ranging in age from early childhood to late adolescence. Although most studies included predominantly mothers, there was some variation in caregiver roles, highlighting the universal nature of parents’/carers’ emotional support needs across different family dynamics and cultural settings. Parents/carers highlighted the emotional burden of navigating ABI recovery, likening it, in more severe injury contexts, to bereavement: “*It’s nearly like going through death, watching somebody die*” (step-father of 17-year-old girl with TBI; Brown et al., 2013, p. 1574). Parents/carers described the journey of adapting to life post ABI as emotionally complex, involving grief and uncertainty, and found themselves mourning their pre-injury expectations for their CYP whilst simultaneously navigating their new reality: “*Every year around the... anniversary of when it happened, that’s always a bit of a drama, because we’re sort of always thinking, how it could’ve been so different*” (mother of 10-year-old girl with severe TBI; Brown et al., 2013, p. 1575). Tailored emotional support was essential to help families reframe expectations and build resilience over time.

Parents/carers valued safe, non-judgmental spaces to process emotions and connect with others. Here, “safe spaces” refers not to physical settings but to relational conditions that enabled parents to feel emotionally safe, validated, and able to share openly – e.g., through non-judgmental listening, flexibility, and peer and professional validation. This finding was evident across studies from Australia (Drake et al., 2024), Canada (Al-Hakeem et al., 2024; Gan, Gargaro, Kreutzer, et al., 2010), and the USA (Aitken et al., 2004), reflecting healthcare systems with structured rehabilitation services. These studies focused on parents/carers of CYP with moderate to severe TBI or PPCS, with participants primarily being mothers caring for children and adolescents. Despite differences in study focus – e.g., online peer support (Drake et al., 2024) versus in-person group interventions (Al-Hakeem et al., 2024) – and participant demographics – e.g., inclusion of both mothers and fathers (Gan, Gargaro, Kreutzer, et al., 2010) versus predominantly mothers (Aitken et al., 2004) – parents/carers consistently highlighted the importance of spaces where they could process emotions and connect with others without fear of judgment. One attendee of a group intervention for parents/carers noted, "*I didn't feel like I had to hold back any information, I felt comfortable sharing whatever it is that I wanted to share*" (mother of 15-year-old girl with PPCS; Al-Hakeem et al., 2024, p. 223).

Connecting with peers enabled parents/carers to exchange strategies and feel validated. This was evident across studies from Australia (Drake et al., 2024), Canada (Gan, Gargaro, Kreutzer, et al., 2010), and the USA (Aitken et al., 2004), reflecting healthcare systems with established rehabilitation services. Parents/carers of CYP with moderate to severe TBI or PPCS, primarily mothers, described how peer connections provided emotional relief, practical insights, and a sense of validation through shared experiences. Despite differences in study focus – e.g., online peer education (Drake et al., 2024) versus informal hospital-based support (Aitken et al., 2004) – and participant demographics – e.g., inclusion of both mothers and fathers (Gan, Gargaro, Kreutzer, et al., 2010) versus predominantly mothers (Aitken et al., 2004) – the benefits of peer support were consistently valued. Parents/carers appreciated diverse perspectives within peer groups, finding comfort in shared experiences: "*It was good to see other families, how they've navigated it... I could definitely relate*" (mother of 14-year-old stroke survivor; Drake et al., 2024, p. 8). One parent reflected that informal peer visitation interventions during hospital stays might provide more immediate emotional support and relatability: "*Maybe if I had somebody to talk to that had a child with a similar injury... it might have been helpful*" (parent of CYP with TBI; Aitken et al., 2004, p. 570).

***Timely interventions and resources***. Parents/carers emphasised the importance of accessing support at the right time, having opportunities between sessions of an intervention to apply new knowledge and skills, and utilising independent resources.

Studies from Australia (Drake et al., 2024), Canada (Brown et al., 2013; Gan, Gargaro, Kreutzer, et al., 2010), Norway (Svendsen et al., 2023), and the USA (Raj et al., 2018) – all countries with structured rehabilitation services – highlighted how timing shaped parents'/carers' experiences with interventions. Parents of CYP with moderate to severe TBI or PPCS, primarily mothers, valued flexible support tailored to different stages of recovery. Despite differences in study focus – e.g., flexible online resources (Drake et al., 2024) versus the challenges of accessing support when needed (Raj et al., 2018) – and participant demographics – e.g., inclusion of both parents (Svendsen et al., 2023) versus predominantly mothers (Brown et al., 2013) – the importance of adaptable, timely interventions was consistently emphasised. Early resources were valued even if not immediately used: "*It's important that you know it's there, and whether people use it or not is up to them*" (mother of 5-year-old stroke survivor; Drake et al., 2024, p. 9). Conversely, some parents/carers preferred staggered information delivery to avoid feeling overwhelmed (Brown et al., 2013). Flexibility was essential, as some parents/carers found interventions beneficial years post injury, particularly during key transitions such as changing schools or transitioning out of education (Gan, Gargaro, Kreutzer, et al., 2010; Raj et al., 2018).

Interventions primarily designed to support the rehabilitation of CYP – including studies from Canada, the USA, and other high-income countries (Al-Hakeem et al., 2024; Bedell et al., 2017; Gan, Gargaro, Kreutzer, et al., 2010; Gilmore et al., 2023; Raj et al., 2018; Shore et al., 2022; Svendsen et al., 2023) – also highlighted how parents/carers valued opportunities to apply intervention content in their daily lives. Interventions ranging from structured programmes (Gilmore et al., 2023) and web-based resources (Raj et al., 2018) to app-based coaching (Bedell et al., 2017) encouraged real-world practice, with structured homework tasks and goal-setting between sessions viewed as motivating and effective. One parent reflected that this approach "*sort of got you thinking about the theory and trying to apply it, which I think is helpful*" (mother of 13-year-old girl with PPCS; Al-Hakeem et al., 2024, p. 223). Despite differences in intervention delivery – e.g., tele-rehabilitation (Shore et al., 2022) versus in-person family system therapy (Gan, Gargaro, Kreutzer, et al., 2010) – and participant demographics – e.g., diverse family structures (Svendsen et al., 2023) versus primarily mothers (Al-Hakeem et al., 2024) – parents/carers consistently valued the opportunity to reinforce learning through everyday activities.

Studies from Australia (Drake et al., 2024), Canada (Gan, Gargaro, Kreutzer, et al., 2010), Norway (Svendsen et al., 2023), and the USA (Aitken et al., 2004; Bedell et al., 2017; Raj et al., 2018) highlighted how parents/carers consistently valued curated resources and peer support mechanisms. Interventions such as online programmes (Drake et al., 2024), app-based coaching (Bedell et al., 2017), and structured family sessions (Gan, Gargaro, Kreutzer, et al., 2010) provided practical tools like take-home handouts, online forums, and resource directories: "*It was good to see other families, how they've navigated it... I could definitely relate*" (mother of 14-year-old stroke survivor; Drake et al., 2024, p. 8). Follow-up interventions, including resource-sharing calls (Raj et al., 2018) and app-based check-ins (Bedell et al., 2017), offered valuable long-term support, helping to reduce feelings of isolation and overwhelm. Despite differences in intervention delivery – e.g., online resources

(Raj et al., 2018) versus in-person family therapy (Svendsen et al., 2023) – and participant demographics – e.g., diverse family structures (Svendsen et al., 2023) versus predominantly mothers (Aitken et al., 2004) – parents/carers consistently valued access to resources and ongoing support mechanisms.

***Communication and understanding***. Parents/carers highlighted the importance of proactive and responsive communication with educators and healthcare providers, tailored educational support, sustaining adjustments over time, recognising ABI's hidden challenges, and investing in training and awareness for fostering understanding, communication, and support for families of CYP with ABI. A summary of these key strategies is provided in appendix G, table A3.

Studies from Australia (Drake et al., 2024), Norway (Svendsen et al., 2023), South Africa (Jacobs-Nzuzi Khuabi et al., 2019), the UK (Bennett et al., 2023), and the USA (Aitken et al., 2004) highlighted the importance of proactive and responsive communication with educators and healthcare providers throughout CYP's recovery. Parents wanted clear, ongoing dialogue, particularly during key transitions such as returning to school (Bennett et al., 2023; Jacobs-Nzuzi Khuabi et al., 2019) and navigating healthcare follow-up (Aitken et al., 2004; Drake et al., 2024). As one parent explained, "*There should have been some direct communication between hospital and school. School knew nothing about what had happened or what should be in place*" (parent of CYP with ABI; Bennett et al., 2023, p. 633). Despite differences in healthcare and education systems – e.g., multidisciplinary collaboration in Norway (Svendsen et al., 2023) versus resource-limited contexts in South Africa (Jacobs-Nzuzi Khuabi et al., 2019) – and participant demographics – e.g., inclusion of both parents (Svendsen et al., 2023) versus predominantly mothers (Aitken et al., 2004) – parents/carers consistently emphasised the need for sustained, proactive communication to reduce feelings of uncertainty during recovery.

Parents/carers also wanted schools to actively address their CYP's unique needs by implementing tailored educational support. Parents across studies from Norway, South Africa, and the UK highlighted the importance of adjustments such as flexible timetables, reduced workloads, and mental health support, alongside the need for educators to understand the less visible impacts of ABI (Bennett et al., 2023; Jacobs-Nzuzi Khuabi et al., 2019; Svendsen et al., 2023). As one parent shared, "*I would've liked teachers to follow the advice of the clinical psychologist report, by giving [CYP] time to process the subject matter... and understand how fatigued he would be*" (parent of CYP with ABI; Bennett et al., 2023, p. 631).

Parents/carers furthermore stressed the importance of educators sustaining tailored adjustments over time: “Take note and implement recommendations from the [Brain Injury Specialist] and parents, and… maintain these over the long term… [don’t] forget them after the first few weeks” (parent of CYP with ABI; Bennett et al., 2023, p. 629). Parents/carers described how systemic barriers, such as limited teacher training and resource constraints in South Africa (Jacobs-Nzuzi Khuabi et al., 2019), often left them feeling unsupported, while in the UK (Bennett et al., 2023) and Norway (Svendsen et al., 2023), more formal reintegration processes and tele-rehabilitation models were seen as helpful in addressing CYP’s needs.

In addition, parents/carers across studies from Norway, South Africa, the UK and consistently highlighted the need for schools to recognise the hidden challenges of ABI (Bennett et al., 2023; Jacobs-Nzuzi Khuabi et al., 2019; Svendsen et al., 2023). They described their frustration when schools dismissed their CYP’s needs because symptoms were not physically visible. One parent explained, “*The tumor was just the tip of the iceberg… [late effects were] a lot harder to deal with as you’re fighting something that’s invisible*” (parent of PBT survivor; Raj et al., 2018, p. 191).

And finally, parents/carers stressed the importance of teacher awareness and training, noting that without such an investment, schools were often unable to provide appropriate support (Bennett et al., 2023). As one parent noted, “*Until the brain injury specialist went into school, they were clueless... I think it’s easy for them to forget that because he looks ok doesn’t mean the ABI isn’t there*” (parent of CYP with ABI; Bennett et al., 2023, p. 634). While barriers such as limited teacher training were a significant concern in South Africa (Jacobs-Nzuzi Khuabi et al., 2019), more structured support systems in the UK (Bennett et al., 2023) and innovative approaches like tele-rehabilitation in Norway (Svendsen et al., 2023) were seen as effective in addressing these challenges.

### ***Equipping parents/carers and others to navigate the complexities of ABI recovery***

Parents/carers wanted interventions that provided them, their CYP, and key people in their CYP’s life with the knowledge, skills, and strategies needed to navigate ABI recovery. They emphasised both what is learned – the knowledge and skills to support their CYP and strengthen family functioning – and who is learning, including parents/carers, their CYP, and key figures such as family members, educators, and healthcare professionals. They also highlighted the conditions that make learning successful, including knowledgeable professionals, flexible and engaging content, and opportunities for active involvement.

Finally, they stressed the importance of well-designed interventions, valuing clear session structures, appropriate pacing, flexible delivery formats, and inclusive content. The following sections explore these aspects in greater detail.

***What is learned, who is learning***. Parents/carers wanted interventions that equipped them and others with the knowledge and skills needed to support their CYP post ABI. Their learning priorities focused on three interconnected goals: acquiring the knowledge and skills to directly support their CYP; acquiring the knowledge and skills to create and sustain a supportive environment by strengthening family functioning and prioritising parents'/carers' well-being; and equipping key figures such as family members, educators, and healthcare professionals to effectively support their CYP and family.

***Knowledge and skills to support CYP***. Parents/carers emphasised the importance of acquiring knowledge and skills to address their CYP's specific needs post ABI. This finding is reflected in studies conducted across diverse geographic and cultural contexts including Australia (Brown et al., 2013; Drake et al., 2024; Gilmore et al., 2023), Canada (Gan, Gargaro, Kreutzer, et al., 2010; Gauvin-Lepage et al., 2015; Shore et al., 2022), Norway (Svendsen et al., 2023), South Africa (Jacobs-Nzuzi Khuabi et al., 2019), the UK (Bennett et al., 2023), and the USA (Aitken et al., 2004). These studies reflect a range of healthcare systems and societal influences, highlighting the evident importance across contexts of understanding ABI, managing CYP's emotional and cognitive challenges, promoting CYP's independence post ABI, and supporting CYP's physical and social recovery (table 4). The studies focused on various injury types, primarily moderate to severe TBI and other forms of ABI, in CYP aged between 2 and 18 years. Parent/carer participants were predominantly mothers, though some studies included fathers, step-parents, and grandparents, highlighting the diversity of family roles and caregiving experiences. Parents/carers valued clear and actionable guidance on navigating ABI recovery, particularly during key transitions, such as returning home or to school (Aitken et al., 2004; Bennett et al., 2023; Shore et al., 2022). One parent reflected on the structure of a helpful intervention: "*I loved how it was broken down into the areas of life in hospital, coming home, looking after yourself, finding the right resources, those key areas were spot on… they're the areas that you want help with, because they're definitely the areas at the time that we were looking for support in*" (parent of 15-year-old stroke survivor; Drake et al., 2024, p. 8).

**Table 4.** Knowledge and skills parents/carers seek to support CYP post ABI

| Key domain | Knowledge and/or skills sought | Illustrative quotes |
|---|---|---|
| Understanding ABI | Symptoms, recovery stages, and long-term consequences; managing transitions (e.g., hospital to home, return to school) | "*We now have a clearer understanding about the brain injury and are more capable of delineating between the problems connected to sequela after the ABI, or problems separate from that*" (mother of teenage girl with ABI; Svendsen et al., 2023, p. 7). |
| Emotional well-being | Strategies to address stress, anxiety, mood swings; tools for emotion regulation and resilience | "*It is not only about physical effects but also the long-term recovery of personality*" (parent of CYP with ABI; Bennett et al., 2023, p. 634).<br>"*He'll just lash out for no apparent reason, and... you're just on your guard all the time because you don't know what's going to happen*" (mother of 7-year-old boy with severe TBI; Brown et al., 2013, p. 1573). |
| Learning/cognition | Strategies for memory, attention, and academic tasks; strategies for complex tasks, skills reinforcement, and progress tracking | "*The fatigue and memory loss has been very difficult. He struggles to retain information in all subjects… maths especially*" (parent of CYP with ABI; Bennett et al., 2023, p. 634).<br>"*The SMART goals helped to break down the problem into manageable parts. Of course, we did see all the overarching challenges but having to start with the minor things that contribute to making it better, was important*" (father of YP with ABI; Svendsen et al., 2023, p. 7). |
| Independence | Promoting self-advocacy, self-monitoring, and autonomy; supporting transitions (e.g., school, independent living) | "*We've gotta take the cotton wool off*" (mother of 7-year-old boy with moderate TBI; Brown et al., 2013, p. 1576).<br>"*[She is learning] to self-monitor her health as she goes along to know when, you know, she's hit that limit…*" but also "*to kind of do these things… for the long run*" (mother of 17-year-old girl with PPCS; Shore et al., 2022, p. 1144). |
| Physical challenges | Managing fatigue, pain, sleep, and balance and coordination issues | "*Fatigue, anxiety – in particular in relation to keeping up with the workload and perceived teachers' expectations. Pacing – learning to manage fatigue*" (parent |

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| | | of CYP with ABI; Bennett et al., 2023, p. 634). |
| Social skills | Building friendships and managing conflicts; navigating social and romantic relationships | "*She lost all her friends… and she did not know how to make friends*" (mother of 19-year-old girl with severe TBI; Jacobs-Nzuzi Khuabi et al., 2019, p. 10).<br>"*Having one close friend who accepted [CYP] just as she was, and didn't judge even if [she] said upsetting things*" (parent of CYP with ABI; Bennett et al., 2023, p. 635).<br>"*Now I can honestly say he has his tribe at school, he has his group of friends, they are stable, solid, they have common interests. He's having, you know, outings and the conversations and chats, catch-ups with them. It's been transformative*" (female caregiver of 14-year-old boy with ABI; Gilmore et al., 2023, p. 5). |

***Knowledge and skills to create a supportive environment***. Parents/carers emphasised the importance of acquiring the knowledge and skills to create and sustain a supportive environment by strengthening family functioning and prioritising their own well-being. A summary of the key focus areas is provided in appendix H, table A4.

Support for family functioning was viewed as essential, particularly for parents/carers of CYP who had sustained more severe injuries (e.g., Aitken et al., 2004; Brown et al., 2013; Gan, Gargaro, Kreutzer, et al., 2010; Gauvin-Lepage et al., 2015; Jacobs-Nzuzi Khuabi et al., 2019). Studies conducted in Australia (Brown et al., 2013), Canada (Gan, Gargaro, Kreutzer, et al., 2010; Gauvin-Lepage et al., 2015), and South Africa (Jacobs-Nzuzi Khuabi et al., 2019) highlighted the importance of practical tools to support family functioning including strategies for managing conflict, navigating shifting family dynamics, improving communication, and addressing grief or trauma following a CYP's ABI. While Brown et al. (2013) and Jacobs-Nzuzi Khuabi et al. (2019) focused their research on understanding parental challenges, Gan, Gargaro, Kreutzer, et al. (2010) and Gauvin-Lepage et al. (2015) evaluated structured interventions aimed at strengthening family functioning. Despite differences in injury severity, CYP age, and context, all four studies emphasised the need for family-centred support to help parents/carers navigate the emotional and practical complexities of ABI recovery. As one parent explained, "*As a family we had zero support… we all were traumatised with it, but there was no one that came to us. We had to go and pay people to assist us as [a] family, because it made an impact on our lives as well*" (mother of teenage boy with TBI; Jacobs-Nzuzi Khuabi et al., 2019, p. 9).

Irrespective of study focus – which ranged from coping strategies (Brown et al., 2013; Gauvin-Lepage et al., 2015) to family interventions (Gan, Gargaro, Kreutzer, et al., 2010) and school re-entry support (Jacobs-Nzuzi Khuabi et al., 2019) – positive parenting techniques, self-care strategies, and advocacy skills were highly valued, with parents/carers seeking guidance to sustain their own well-being over time and to navigate confidently and advocate effectively within complex systems such as healthcare and education.

***Educating and equipping important others***. Parents/carers wanted service providers to equip key figures such as family members, educators, and healthcare professionals to effectively support their CYP and family. Parents/carers from diverse geographic and cultural contexts – including Australia (Brown et al., 2013; Drake et al., 2024), South Africa (Jacobs-Nzuzi Khuabi et al., 2019), the UK (Bennett et al., 2023), and the USA (Aitken et al., 2004; Bedell et al., 2017; Raj et al., 2018) – stressed the importance of educating teachers, peers, and extended family to promote understanding and reduce stigma around ABI. Across studies, parents/carers highlighted the need for greater awareness in schools, healthcare, and communities, particularly regarding ABI's hidden challenges. Some emphasised structured training for teachers and education professionals (e.g., Bennett et al., 2023; Jacobs-Nzuzi Khuabi et al., 2019), while others noted frustration with family and peers who struggled to recognise the ongoing impact of ABI (e.g., Brown et al., 2013; Drake et al., 2024; Raj et al., 2018). One parent described the frustration of their CYP's needs being dismissed because their disability wasn't visible: "*Our biggest problem has been getting people to take my child's challenges seriously, because she does not look disabled*" (parent of PBT survivor; Raj et al., 2018, p. 191).

***Making learning effective***. Parents/carers identified the conditions necessary for effective learning and engagement in interventions for CYP with ABI and their families. They emphasised the importance of knowledgeable and empathetic professionals, active parent/carer involvement in intervention planning and implementation, flexible delivery models, engaging and practical content, and the active participation of CYP in interventions. A summary of these key components is provided in appendix I, table A5. These elements were valued for making interventions more relevant, accessible, and impactful for families navigating ABI recovery.

Across diverse geographic and clinical contexts, parents/carers valued interventions designed and delivered by experienced health professionals who could tailor content to CYP's age, injury type, and family circumstances. Studies from Australia (Drake et al., 2024), Canada (Al-Hakeem et al., 2024; Gauvin-Lepage et al., 2015; Shore et al., 2022), Norway (Svendsen et al., 2023), and the USA (Raj et al., 2018) highlighted the need for professionals who provided both clinical expertise and individualised support. The ability of health professionals to tailor interventions was particularly valued in tele-rehabilitation and web-based interventions (Raj et al., 2018; Shore et al., 2022; Svendsen et al., 2023) and in family-based approaches where professionals facilitated navigation of complex systems and incorporated parent/carer perspectives (Drake et al., 2024; Gauvin-Lepage et al., 2015; Svendsen et al., 2023). Empathetic and knowledgeable clinicians who could build trust were particularly valued: "*I think, afterwards, you'll have a lot of questions, and having somebody to be able to ask those questions to and give you the comfort that there is support…*" (mother of 16-year-old stroke survivor; Drake et al., 2024, p. 10). This need spanned the full spectrum of injury severity.

Involving parents/carers in intervention planning and development was also seen as key to ensuring intervention content aligned with family needs and experiences.

Collaborative approaches allowed parents/carers to share their insights and feel empowered in shaping the support they received. One parent shared, "*I found it exciting to be a part of it. And when we've mentioned something, it's been taken care of, so it's worked out well*" (father of teenage girl with ABI; Svendsen et al., 2023, p. 6). Studies from diverse geographic and clinical contexts, including Australia (Drake et al., 2024), Canada (Gauvin-Lepage et al., 2015), Norway (Svendsen et al., 2023), and the USA (Bedell et al., 2017; Raj et al., 2018), highlighted the importance of parent/carer involvement in making interventions more relevant and effective. While some interventions actively co-designed content with parents (Drake et al., 2024; Gauvin-Lepage et al., 2015), others sought their feedback to refine implementation (Bedell et al., 2017; Svendsen et al., 2023). This involvement was particularly valued in web-based and tele-rehabilitation interventions, where parents played a key role in ensuring content met their CYP's evolving needs (Raj et al., 2018; Shore et al., 2022). Across intervention formats and injury severities, these studies reinforced that tailoring interventions through parent/carer input helped make them more accessible, family-centred, and reflective of real-world challenges.

Flexibility in delivery was another priority, allowing families to engage at their own pace. One parent described a self-paced intervention as a "*gentle step into this world of brain injuries, support, and families. Because it's up to you how far you go*" (mother of 6-year-old child with TBI; Drake et al., 2024, p. 10). Another highlighted the intervention's modular design: "*You could have as much or as little... you can pick up where you left off. So you can consume it all at once in large chunks, or you can consume it in small chunks*" (mother of 16-year-old with TBI; Drake et al., 2024, p. 8). Studies across different healthcare and intervention models reinforced the importance of flexible delivery. In self-paced digital interventions (Drake et al., 2024; Raj et al., 2018), parents/carers valued the ability to engage at their convenience. Tele-rehabilitation programmes (Shore et al., 2022; Svendsen et al., 2023) blended structured sessions with individualised pacing to accommodate fluctuating recovery needs. Structured yet adaptable virtual programmes (Al-Hakeem et al., 2024) offered group-based learning with space for tailored participation. Across formats, flexibility enabled parents/carers and CYP to engage in ways that suited their circumstances, highlighting the need for adaptable interventions post ABI.

Engaging and practical content was also valued. For example, parents/carers completing an online group intervention in a Canadian study appreciated visual aids, such as annotated slides, which made information clearer and more engaging: "*I love a slideshow, haha, especially with the annotating in it … when you see your ideas written down you feel* *more engaged*" (Al-Hakeem et al., 2024, p. 222). Combining theory with real-world application, such as through role-plays and interactive activities, was also viewed by these parents/carers as effective: "*I think it's important to have… the theory and then try to apply it… briefly in the moment and then… [during] the week, I think that's a good model to use*" (mother of 13-year-old girl with PPCS; Al-Hakeem et al., 2024, p. 223). Studies across different intervention formats reinforced the value of interactive and applied learning. In digital interventions, structured tools such as app-based coaching (Bedell et al., 2017) and visually guided online modules (Raj et al., 2018) helped make content engaging and accessible. Group-based programmes, including social skills training (Gilmore et al., 2023) and structured family interventions (Gan, Gargaro, Kreutzer, et al., 2010), incorporated role-plays and real-world scenarios to enhance practical learning. Across these models, interventions that combined structured information with opportunities for active participation were preferred, underscoring the need for content that is both engaging and applicable to daily life.

Finally, parents/carers stressed the importance of actively involving CYP in interventions, particularly in planning and goal-setting. This approach was seen as essential for promoting CYP's engagement and ensuring interventions were meaningful. One parent explained, "*It was very important to us… to include [CYP] in the team… it [was] important to focus on something… important to him*" (father of teenage boy with ABI; Svendsen et al., 2023, p. 7). Across different intervention models, actively involving CYP helped tailor support to their needs and encourage ownership of their recovery. In digital interventions (Bedell et al., 2017; Raj et al., 2018), CYP set and tracked their own goals, while peer-based programmes (Gilmore et al., 2023) used goal-setting to enhance motivation. Family-inclusive approaches, such as home-based rehabilitation (Svendsen et al., 2023) and co-designed online programmes (Drake et al., 2024), ensured CYP had a voice in shaping their experience. Regardless of format, CYP's participation was key to making interventions relevant and engaging.

***Designing interventions that work***. Parents/carers emphasised the importance of well-designed interventions that considered their needs and provided practical support (table 5). They valued clear session structures, appropriate session lengths, flexible delivery formats, and inclusive content. These features were seen as essential for maintaining engagement, promoting learning, and addressing diverse family circumstances.

**Table 5.** Key features of effective intervention delivery and design

| Key component | Description | Examples of preferences |
|---|---|---|
| Session structure | Clear and consistent format to maintain focus and engagement | Defined introductions, activities, and conclusions |
| Session length | Optimal length to balance engagement and avoid fatigue | 45–60 minutes per session |
| Intervention duration | Regularly scheduled programmes over weeks or months to allow for gradual skill development | Weekly or biweekly sessions delivered over several months to sustain learning while accommodating recovery timelines |
| Delivery format | Flexible modes of delivery to suit diverse needs and preferences | Online sessions for convenience and reduced logistical burdens; in-person sessions for stronger peer/provider connections; hybrid models combining online convenience with in-person opportunities |
| Inclusivity | Content and formats reflecting diverse family structures, cultural backgrounds, and experiences | Tailored interventions to ensure relatability and representation |
| Peer support | Opportunities for interaction and shared experiences among participants | Group sessions, mentoring, and forums to build trust and relatability among families |

Parents/carers highlighted the importance of structured sessions with clear beginnings, activities, and conclusions to help maintain focus and engagement. One parent noted, *"There was an obvious beginning, middle, and an end to it... it didn't change, which I liked…"* (mother of 16-year-old girl with PPCS; Al-Hakeem et al., 2024, p. 222). Some preferred session lengths of 45–60 minutes, which were seen as long enough to explore topics without causing fatigue (Bedell et al., 2017; Gan, Gargaro, Kreutzer, et al., 2010). Regularly scheduled programmes, delivered over weeks or months, allowed families to gradually develop skills and adapt strategies over time while accommodating recovery timelines. Across different intervention models, structured session formats were valued for providing clarity and consistency. In digital interventions (Al-Hakeem et al., 2024; Drake et al., 2024), parents/carers appreciated predictable content flow, while in manualised family-based programmes (Gan, Gargaro, Kreutzer, et al., 2010; Gauvin-Lepage et al., 2015), structured discussions and activities facilitated engagement. App-based interventions (Bedell et al., 2017) benefited from step-by-step session guides, helping CYP and parents/carers track progress.

Flexibility in delivery formats was also important. Online sessions were appreciated for their convenience and ability to reduce logistical burdens, such as travel time (Al-Hakeem et al., 2024; Drake et al., 2024; Raj et al., 2018; Shore et al., 2022; Svendsen et al., 2023). However, some parents/carers valued in-person sessions for the stronger peer and provider connections they facilitated (Al-Hakeem et al., 2024; Svendsen et al., 2023). Hybrid models, combining online convenience with occasional in-person sessions, were suggested as a compromise (Al-Hakeem et al., 2024; Svendsen et al., 2023). Across different intervention types, flexibility in format ensured that families could engage in ways that suited their needs. Self-paced digital interventions (Drake et al., 2024; Raj et al., 2018) allowed participants to access content at their own rhythm, while tele-rehabilitation models (Shore et al., 2022; Svendsen et al., 2023) provided structured support with the adaptability to accommodate individual schedules. Group-based virtual interventions (Al-Hakeem et al., 2024) balanced structured content with opportunities for self-directed engagement. Regardless of format, ensuring flexibility helped families integrate interventions into their daily lives and recovery journeys.

Inclusivity was highlighted as an important component of effective intervention design, with parents/carers advocating for content and formats that reflected diverse family structures, cultural backgrounds, and lived experiences. Studies reinforced this need across different contexts. In Norway, a tele-rehabilitation model acknowledged how cultural and family structures shape intervention feasibility (Svendsen et al., 2023). A South African study emphasised economic and systemic barriers to school reintegration post TBI, highlighting the need for culturally attuned support (Jacobs-Nzuzi Khuabi et al., 2019). In Canada, family resilience research underscored the role of spirituality, financial stability, and social networks in shaping recovery (Gauvin-Lepage et al., 2015). A USA-based web intervention for PBT survivors prioritised cultural sensitivity and accessibility (Raj et al., 2018). In Australia, parents stressed the importance of diverse representation in peer-led video interventions to ensure relevance across families and injury severities (Drake et al., 2024). Across these studies, parents/carers also valued peer support, such as group sessions and forums, as practical ways to enhance engagement and shared learning. These elements were seen as essential for making interventions relatable and accessible to families post ABI.

## Discussion

This review aimed to explore parents'/carers' perspectives on the development and content of interventions designed to support children and young people (CYP) with acquired brain injury (ABI) and their families. By synthesising findings from 13 qualitative and mixed-methods studies, two overarching analytical themes emerged: first, the importance of feeling supported, and second, the need to equip parents/carers and others with the knowledge and tools to navigate the complexities of ABI recovery. These findings provide insights into how interventions can be more responsive to the lived experiences of parents/carers, ensuring that they address parents'/carers' emotional and practical needs in a way that is meaningful and sustainable.

### Feeling supported

The findings of this review suggest that feeling supported can create conditions that make it easier for parents/carers to engage with interventions. Beyond simply receiving help, feeling supported involves psychological reassurance, validation from professionals and peers, and structured guidance through the uncertainties of ABI recovery. These findings align with prior research demonstrating that families of CYP with ABI experience emotional distress, including grief for their CYP's pre-injury self, uncertainty about long-term outcomes, and social isolation due to caregiving demands (Tyerman et al., 2017; Yeates et al., 2007). Interventions that prioritise emotional support, particularly through peer connections, have been linked to increased parental confidence and coping (Braga, 2009; Wade et al., 2009). Given these complexities, ensuring that parents/carers feel adequately supported may play an important role in facilitating their engagement with interventions, ultimately shaping their ability to access and benefit from the resources available to them.

The findings of this review further emphasise the importance of peer interactions in promoting a sense of feeling supported. By sharing experiences with others who understand the complexities of ABI, parents/carers are able to normalise their emotions, reduce feelings of isolation, and feel empowered in the face of uncertainty. Structured interventions that incorporate peer support have been shown to enhance parental confidence, improve coping, and provide reassurance that parents are not alone (Braga, 2009; Braga et al., 2005; Wade et al., 2009). Online and community-based programmes, in particular, offer accessible opportunities for parents/carers to exchange experiences and receive emotional validation from those in similar situations (McKinlay et al., 2016; Svendsen et al., 2023; Ylvisaker et al., 2005).

Beyond peer connections, parents/carers emphasised the importance of knowing that support will be available when it is needed. This assurance is particularly important in the context of ABI, where unpredictable and invisible challenges often leave parents/carers feeling isolated and overwhelmed. Accessible support alleviates this emotional burden, offering validation and reassurance during moments of crisis or transition (e.g., Andersson et al., 2016). An important contribution of this review is the emphasis on long-term access to support. Many parents/carers described frustration with short-term interventions that did not provide continuity as their CYP’s needs evolved. This aligns with evidence from ABI rehabilitation research suggesting that recovery does not follow a linear trajectory and that new challenges – such as school transitions, emerging adolescence, and emerging adulthood – can introduce fresh demands on families years post-injury (Braga et al., 2005; Gan, Gargaro, Brandys, et al., 2010; McKinlay et al., 2016; Tyerman et al., 2017). Sustained access to support, whether through structured follow-ups, online peer networks, or periodic check-ins, may assist families in managing these ongoing changes.

Another important consideration highlighted by this review is the need for interventions to be sensitive to family circumstances. While most parents/carers appreciated the core elements of feeling supported and being equipped with knowledge, different preferences emerged based on individual family situations. For instance, some parents/carers valued structured, in-person interventions, while others found online and self-paced formats more accessible. Future interventions may benefit from balancing customisation to individual family needs with the provision of universally beneficial core elements that ensure all families feel supported regardless of their circumstances.

### Equipping parents/carers and others to navigate ABI recovery

Alongside feeling supported, parents/carers underscored the importance of acquiring the knowledge and skills to support their CYP's recovery and advocate effectively within complex systems. This review highlights a gap in accessible, structured, and practical education for parents/carers, reinforcing prior research that has identified a lack of guidance during critical transitions such as hospital discharge and school reintegration (Andersson et al., 2016; Moore et al., 2015). The findings suggest that interventions could offer staggered learning opportunities that allow parents/carers to absorb information at their own pace, addressing concerns that families can feel overwhelmed when provided with extensive resources too soon after injury (Brown et al., 2013).

Parents/carers also highlighted the need for services to educate others, particularly teachers and healthcare providers, about the long-term and often invisible effects of ABI. This finding is consistent with studies indicating that misunderstandings about ABI, particularly in educational settings, can lead to inadequate accommodations and additional stress for families (Bennett et al., 2023; Jacobs-Nzuzi Khuabi et al., 2019). Tailored training for professionals, alongside tools to help parents/carers advocate for their CYP's needs, may enhance awareness and responsiveness within these key support systems.

Similar to others (e.g., Moore et al., 2015; Roscigno & Swanson, 2011), our findings highlight the importance of culturally responsive interventions that consider families' diverse lived experiences. For parents/carers of CYP with ABI, this is especially important because the challenges of ABI recovery intersect with cultural values, beliefs, and norms in unique ways. ABI recovery often requires navigating complex healthcare and educational systems, which may not always align with families' cultural expectations or practices (Roscigno & Swanson, 2011). This misalignment can exacerbate feelings of marginalisation or misunderstanding, particularly for families from culturally and linguistically diverse backgrounds. Culturally responsive interventions not only enhance accessibility but also ensure that families feel respected and understood (Moore et al., 2015). For example, recognising the importance of family roles in caregiving or incorporating culturally appropriate communication styles can build trust and engagement (Roscigno & Swanson, 2011). By addressing these dimensions, interventions are better positioned to meet the unique needs of families while promoting equity in recovery outcomes.

## Limitations

This review has some limitations that could affect how its findings are understood and applied. Including only English-language studies may have excluded important perspectives from families who speak other languages, limiting diversity in the findings. The reviewed studies also predominantly represented mothers’ experiences, offering limited insight into the perspectives of fathers and non-parent carers. The parents/carers in the reviewed studies may also have had a relatively higher level of functioning compared to many parents/carers of CYP with ABI, suggesting a potential bias towards recruiting parents/carers who have the capacity or support to engage in research.

In addition, many studies didn’t include enough detail about participants, such as how severe the CYP’s ABI was or what stage of recovery the CYP was in. This omission makes it difficult to determine how specific factors might shape preferences for structured versus flexible interventions. The inherent variability of ABI presentations, including differences in severity and recovery trajectories, further complicates the generalisability of findings.

Finally, although the CASP tool was used to assess quality, relying on reported data might have introduced some bias, as the studies may not fully reflect all aspects of parents’/carers’ experiences. These limitations underscore the need for cautious application of the review’s findings and highlight areas requiring further investigation.

## Clinical implications

This review directly informs clinical practice, offering insights into what parents/carers want from future interventions and what they found valuable about existing ones. These findings can guide the development of interventions that are subsequently evaluated, with the results of these evaluations informing clinical practice. This iterative process ensures that interventions align with the real-world needs and preferences of families while also contributing to the evidence base for effective interventions.

The findings from this review indicate that interventions embedding emotional and peer support could help parents/carers connect with others who share their experiences. These connections, whether through structured mentorship, online forums, or hybrid support groups, provide reassurance and validation. Sustained engagement may also be valuable; rather than offering one-off or time-limited interventions, support that remains accessible over time and adapts to the evolving needs of CYP and their families could be more beneficial. Accessibility and flexibility are also key considerations, as digital and hybrid models may allow families to engage with support at their own pace, reducing logistical barriers while maintaining opportunities for direct interaction with professionals and peers. Taken together, these findings suggest the potential value of offering a flexible ‘menu’ of intervention options, which parents/carers can draw on at different points according to individual readiness and circumstance. Additionally, embedding advocacy and education components into interventions may empower parents/carers with the knowledge and confidence to navigate healthcare and education settings, ultimately improving outcomes for CYP with ABI. Cultural responsiveness and inclusivity could also enhance accessibility, ensuring interventions are representative of the diverse backgrounds of families affected by ABI. While certain elements of intervention design are broadly beneficial, choice and readiness-based timing appear to be important features for supporting engagement across different family contexts.

## Future research

Several gaps in the current evidence base remain. The studies included in this review predominantly reflected the perspectives of mothers, highlighting the need for research that explores the experiences of fathers, non-parent carers (e.g., grandparents, foster carers), and families from culturally diverse backgrounds. Beyond general diversity considerations, future research may benefit from exploring how social, cultural, and psychological factors interact to shape families’ access to and engagement with support. This includes differences in readiness for particular interventions, how families interpret and utilise resources, and the psychological and structural barriers that influence uptake. Socio-economic disparities also play a role in shaping intervention accessibility. Liaising with schools and engaging with healthcare providers may vary significantly depending on families' socio-economic status and the availability of resources in their community. Future research could examine how interventions are tailored to support families in under-resourced settings where standard approaches may not be feasible. Additionally, there is limited evidence comparing different intervention formats (e.g., online versus in-person; structured versus self-paced), and research examining the effectiveness of these models across different family needs and recovery stages would be valuable. Longitudinal studies may provide further insight into how parents’/carers’ needs evolve over time. Understanding how support preferences shift from acute recovery to long-term adaptation could inform more responsive interventions. Finally, given the expressed preference for flexible engagement, future studies may investigate how modular and hybrid intervention designs influence engagement, satisfaction, and outcomes.

## Conclusion

This review highlights the pivotal role of parents/carers in supporting CYP with ABI and underscores the importance of interventions that emphasise emotional support, practical skill-building, and inclusivity. By addressing the unique and evolving challenges parents/carers face, including the unpredictable nature of ABI and the emotional toll it imposes, interventions can better align with parents'/carers' needs and preferences. This review has directly addressed the aim of exploring parents'/carers' perspectives by synthesising findings from studies that utilised principles of co-production to identify what parents/carers value in intervention design. In doing so, it contributes actionable recommendations regarding how interventions can be adapted to promote resilience, sustain support, and equip parents/carers with essential tools and knowledge.

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# Chapter Three: Bridging Chapter

# Bridging Chapter

The empirical study that follows was developed alongside the systematic review as part of a wider programme of research exploring how families can be more effectively supported after childhood ABI. Although the two studies were designed concurrently, they addressed related but distinct aspects of support. The systematic review examined what parents/carers say they want and need from interventions – spanning both rehabilitation for the injured child and support for parents'/carers' own adjustment – highlighting the value of flexible, emotionally safe approaches grounded in lived experience.

The empirical study, by contrast, explored parents' experiences of taking part in an earlier research study, in which parents used a creative materials-based storytelling approach – the *Wool and Stones* – to share and reflect on their experiences of their child's ABI. The empirical study presented here examined how parents experienced sharing their stories in this way, the kinds of stories told, and their views on the potential for the approach to be adapted for therapeutic use in the future.

This work was conducted in parallel with a related programme of research within the same team, which is exploring the use of physical materials to support therapeutic storytelling with family members of adults with ABI (Whiffin et al., 2025; Whiffin et al., 2024). Together, these projects reflect a wider movement towards developing creative materials-based approaches that enable families affected by ABI to share and make sense of their experiences.

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# Chapter Four: Empirical Study

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(Author guidelines included in Appendix J)

# "Wool and stones": A qualitative study of how parents of children with acquired brain injury experience a creative materials-based storytelling approach

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## Statements and Declarations

### Ethical considerations

This study was approved by the South Central – Berkshire Research Ethics Committee (REC reference 23/SC/0068) on March 27, 2023, and the NHS Health Research Authority on April 17, 2023.

### Consent to participate and for publication

All participants gave written informed consent to take part in the study and to allow publication of anonymised data. No identifiable information or images are included in the manuscript.

### Declaration of conflicting interest

The authors declare no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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### Data availability

The dataset generated and analysed during this study is not publicly available due to the inclusion of verbatim transcripts that could compromise participant anonymity.

## Abstract

Parents of children with Acquired Brain Injury (ABI) often face challenges in processing their experiences and constructing coherent narratives. Creative materials-based approaches have been proposed to support reflection, expression, and meaning-making. This study explored how parents experienced a storytelling task using wool and stones. Semi-structured interviews with seven parents were analysed using reflexive thematic analysis within a critical realist framework. Two themes were developed: *Piecing together the story* described how materials supported sequencing, sense-making, and narrative ownership; *Engaging with the process* captured emotional safety, ambivalence, and connection. While some parents found the task helpful and meaningful, others described discomfort or disconnection. Findings suggest that creative materials-based approaches may support narrative development for some parents following ABI, particularly when emotional safety, flexibility, and choice are prioritised. Further research is needed to explore their impact and broader applicability.

**Keywords:** Acquired brain injury, Parents, Storytelling, Creative methods, Reflexive thematic analysis, Qualitative research

## Introduction

When a child sustains an Acquired Brain Injury (ABI), the psychological and social consequences often extend far beyond the child themselves – deeply affecting parents, carers, and family life. In England, it is estimated that over 40,000 children and young people (CYP) experience an ABI each year (NHS England, 2018). These injuries, whether sustained through trauma, infection, or other causes, can lead to long-term cognitive, emotional, social, and physical challenges. As a result, families must navigate an unfamiliar landscape of rehabilitation, education, and social reintegration while coping with grief, uncertainty, and disrupted expectations of the future (Tyerman et al., 2017).

Quantitative studies have highlighted the prevalence of emotional distress in families following child ABI. For example, Yehene et al. (2021) found that parents of CYP with more pronounced behavioural changes reported more distressing emotions. However, most existing studies are limited by small samples or cross-sectional designs, which constrain insight into evolving experiences over time. Qualitative research offers deeper understanding, revealing how parents experience shifts in identity, connection, and family dynamics (Roscigno and Swanson, 2011; Tyerman et al., 2017). These findings echo themes identified in research with families of adults with ABI, including feelings of isolation, disorientation, and the challenge of adjusting to a ‘new normal’ (Whiffin et al., 2021; Couchman et al., 2014).

Narrative-based approaches have been proposed as a means of supporting emotional adaptation following life-altering injuries. The Life Threads Model (Ellis-Hill et al., 2008) conceptualises recovery as a process of narrative reconstruction, wherein people seek to reconnect disrupted threads of identity, future expectation, and meaning. This model has informed the development of creative and embodied methods – such as the ‘wool and stones’ approach – which were initially implemented as participatory research tools to help participants represent and make sense of their experiences (Ellis-Hill et al., 2021; Galvin et al., 2020). While not designed as a therapeutic intervention per se, this approach shares features with other creative methods used in health settings, such as Arts and Health initiatives (e.g., Ellis-Hill et al., 2019), and may offer accessible ways to support meaning-making and emotional processing. A growing body of evidence supports the value of such approaches: for example, a World Health Organisation scoping review highlighted how arts-based interventions can help people express emotion, process complex experiences, and make meaning following neurological or long-term health conditions (Fancourt and Finn, 2019). By enabling embodied forms of expression that complement verbal narration, creative materials-based methods draw on phenomenological understandings of lived experience as both bodily and situated (e.g., Husserl, 1931; Merleau-Ponty, 1962), and have shown early promise in eliciting rich, metaphorical narratives and supporting adaptive reframing in contexts such as stroke recovery and rehabilitation (Galvin et al., 2020; Ellis-Hill et al., 2021). It is within this phenomenological and humanising tradition that the present study is situated. Accordingly, the 'wool and stones' approach is positioned primarily within a lifeworld-led phenomenological and humanising framework, which prioritises embodied, relational, and temporal aspects of experience (Galvin et al., 2020; Ellis-Hill et al., 2021). Although the method supports narrative expression, narrative is understood as one way in which embodied, situated experience becomes articulated rather than as the dominant theoretical frame; the approach is first and foremost a sensory, materials-based invitation to share lived experience.

Such methods also align with calls for greater co-production in psychological and health services. Co-production is understood as "a relationship where professionals and citizens share power to plan and deliver support together, recognising that both partners have vital contributions to make in order to improve quality of life for people and communities" (Slay and Stephens, 2013: 3). Involving people in shaping interventions has been associated with valuing lived experience and promoting more responsive forms of support, with some evidence suggesting it may reduce stigma, enhance social connectedness, and contribute to improved outcomes at both individual and systemic levels (Needham and Carr, 2009; Smith et al., 2022). Creative materials-based approaches may provide one potential avenue for accessible, collaborative involvement in meaning-making and reflection, and could be explored further in the context of co-producing future psychological support with families.

Despite the promise of such approaches, we are aware of no previous research that has explored how parents/carers of CYP with ABI experience using creative materials to share and shape their narratives. Given the embodied, relational, and emotional dimensions of parenting after ABI – and the need for interventions that support narrative identity and recovery – this gap represents an important opportunity for innovation. The present study aimed to explore how parents/carers of CYP with ABI experience and engage with a creative materials-based storytelling approach. Specifically, it asked: How do parents/carers of CYP with ABI experience and make use of a creative materials-based approach when sharing their story?

# Methods

## Design

This qualitative study was underpinned by a critical realist epistemology, which recognises that participants' accounts are socially and linguistically constructed, yet shaped by underlying material realities (Bhaskar, 1975; Maxwell, 2012; Pilgrim, 2014; Sims-Schouten et al., 2007). We used Reflexive Thematic Analysis (RTA; Braun and Clarke, 2006; Braun and Clarke, 2013; Braun and Clarke, 2022) to explore how parents/carers experienced and made use of a creative materials-based approach following their child's ABI. RTA was selected for its flexibility and emphasis on researcher subjectivity as a resource in meaning-making.

This paper reports the second part of a two-stage project. Part 1 (P1; Davies, 2024) involved interviews with parents who used a selection of wool and stones – varying in colour, texture, size, and shape – to share their experience of their child's ABI (appendix K). The present study (P2) draws on interviews conducted approximately one week later, which explored parents' reflections on their experience of engaging with the creative materials-based approach, including its emotional impact, ongoing relevance, and any change in perspective. This analysis was conducted independently by DS, who was not involved in P1 data collection or analysis, using RTA.

## Participants

Eligible participants were parents/carers aged 18 or older who shared a living space with, and held caregiving responsibilities for, a child or young person with ABI. Eligible CYP had sustained their injury between the ages of 2 and 19 years, reflecting a wide range of neurodevelopmental stages and mirroring common referral patterns within National Health Service (NHS) services. To support emotional readiness and ensure parents/carers had sufficient time to begin making sense of life post-injury, only those whose child had sustained their ABI at least 12 months prior to recruitment were eligible to take part. This time frame also avoided involving families during the acute and often most distressing stage of post-ABI adjustment.

Participants were recruited through an NHS-based community neuropsychology service for CYP with ABI in the UK (appendix L). Recruitment aimed to reflect diversity in injury circumstances, age of injured child, and family socioeconomic and demographic background. One parent/carer per family was invited to participate in both parts of the study. Seven parents (six mothers, one father), all of whom had completed a P1 interview, took part in the P2 interviews. All participants identified as White British. Additional participant information can be found in Table 1.

**Table 1.** *Overview of participating parents and details of their child's ABI.*

| Participant | Relationship to injured child | Gender of injured child | ABI type and description | Age at injury (years) | Time since injury |
|---|---|---|---|---|---|
| P1 | Mother | Male | TBI, fall while participating in recreational activity | 14 | 2 years, 3 months |
| P2 | Mother | Female | ABI, brain haemorrhage | 11 | 2 years, 5 months |
| P3 | Father | Female | ABI, brain haemorrhage | 10 | 2 years, 1 month |
| P4 | Mother | Female | TBI, assault while participating in recreational activity | 15 | 1 year, 9 months |
| P5 | Mother | Female | TBI, fall while participating in recreational activity | 7 | 1 year, 8 months |
| P6 | Mother | Male | TBI, car accident | 17 | 1 year, 2 months |
| P7 | Mother | Male | TBI, cycling accident | 10 | 4 years, 6 months |

## Procedure

Ethical approval for this research was granted by the South Central – Berkshire Research Ethics Committee (REC reference: 23/SC/0068) on 27th March 2023, followed by approval from the NHS Health Research Authority on 17th April 2023, in accordance with national legislation (appendix M). All participants gave written informed consent to take part in the study and to allow publication of anonymised data (appendix N). No identifiable information or images are included.

As described by Davies (2024), P1 involved a one-to-one, semi-structured interview in which parents were invited to use a selection of wool and stones of varying colours, sizes, weights, and textures to represent and share their experience of their child's ABI. Parents were introduced to the materials and given time to explore them freely before being invited to arrange the wool and stones in any way that felt meaningful to them. They were encouraged to talk through their arrangement as they worked, with prompts used only to support reflection, elaboration, or clarification. The materials were used flexibly, with no prescribed meanings attached, allowing parents to generate their own metaphors and representations of relationships, events, emotions, and change over time (Davies, 2024).

P2 interviews took place approximately one week after P1. All were conducted by DS, either in a clinic room at the neuropsychology service or in participants' homes, depending on preference. A topic guide was used to explore parents' reflections on using the wool and stones. Questions covered perceived meaning and emotional impact, any changes in perspective since P1, how the materials had been used or thought about in the interim, and views on the approach's relevance or adaptability (appendix O). Interviews lasted between 34 and 63 minutes (mean = 48 minutes), were audio-recorded with consent (appendix N), and transcribed verbatim by DS. One interview was not recorded due to technical failure; this interview was conducted with the only male participant in the sample. Detailed written notes were taken at the time and were included in the analysis, with his contribution incorporated through paraphrased extracts in order to preserve anonymity.

### Data analysis

Data were analysed using RTA, following Braun and Clarke's six-phase framework (Braun and Clarke, 2006; Braun and Clarke, 2019; Braun and Clarke, 2022). A primarily inductive, semantic approach was used, attending to the explicit meanings conveyed by participants rather than searching for underlying assumptions. This approach was selected to remain grounded in participants' accounts and to reflect their perspectives on how the creative materials-based process supported their storytelling. At the same time, the analysis acknowledged the active role of the researcher in interpreting and shaping the data, in line with the subjective and reflexive principles of RTA.

NVivo (release 15.0.0) was used to organise and analyse the data. Attention was paid to both patterns and variation across the dataset. Interpretation was conducted at the semantic level during coding, with further meaning developed during theme generation. Reflexivity was supported through reflective journalling, peer discussion, and supervision. The final thematic structure reflected both converging and divergent experiences and aimed to prioritise clarity and resonance with participants' accounts.

### Researcher reflexivity

The analysis was conducted by DS, a British citizen originally from the USA who has lived in the UK for over 25 years and raised a family there. Prior to clinical psychology training, she spent more than a decade as an academic researcher in gender development, including work with individuals and families affected by rare genetic conditions. This experience shaped her broader interest in how families make sense of life-altering experiences.

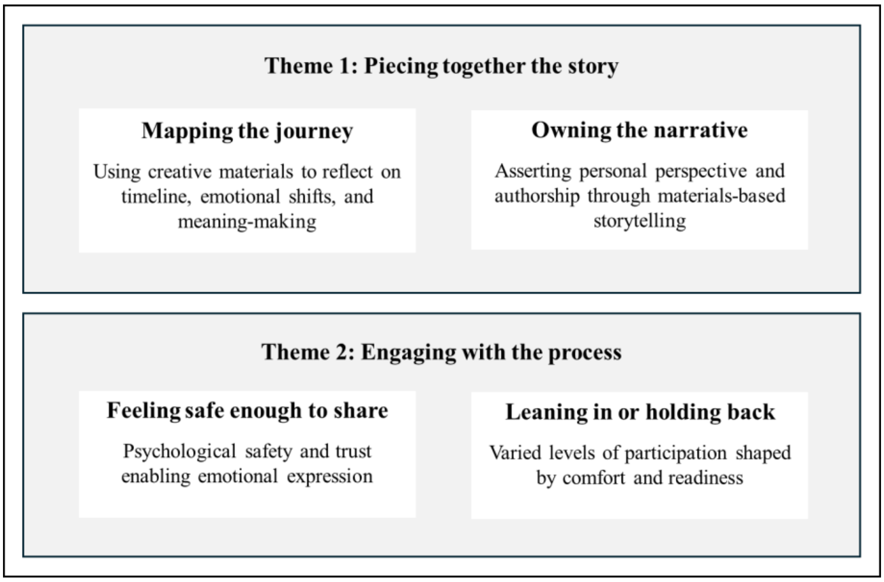
Although she had no prior clinical experience with families affected by ABI, she approached the study with openness and a commitment to privileging participants' perspectives. Reflective journalling supported awareness of how her assumptions and emotional responses influenced the research process – including the questions asked, the way she listened, and the lens through which meaning was constructed.

## Results

Sixteen codes were developed and clustered into themes through an iterative, reflexive process. Two themes were developed: *Piecing together the story* and *Engaging with the process*. Together, they explore how parents of CYP with ABI experienced and made use of the wool and stones. The analysis highlights both what the approach enabled – such as emotional expression, narrative structuring, and personal reflection – and how parents engaged with the process itself.

Each theme is supported by illustrative quotes that reflect the diversity of parental experience, including both strong moments of resonance and more tentative or limited engagement. The themes are not mutually exclusive but offer complementary insights into how parents made meaning, navigated emotion, and responded to an unfamiliar reflective task. Additional quotes that further illustrate each theme and subtheme are provided in Table A6 (appendix Q). Figure 1 provides an overview of the two themes and their associated subthemes.

**Figure 1.** *Overview of themes and subthemes developed through reflexive thematic analysis.*



## Theme 1: Piecing together the story

This theme explores how parents made sense of their experiences following their child's ABI. The storytelling process often enabled them to externalise difficult emotions, organise events, and begin constructing a coherent narrative. Two subthemes are presented: *Mapping the journey* and *Owning the narrative*.

### *Subtheme 1.1: Mapping the journey*

This subtheme captures how parents used the wool and stones to impose structure on experiences that had often felt chaotic, fragmented, or emotionally overwhelming following their child's ABI. Several parents used the wool and stones to represent emotional shifts and changes over time following their child's ABI. Some laid out a clear chronological path from "before" to "after" the injury, segmenting the journey into phases of disruption, adjustment, and current coping.

> *"So mine was more the journey … this bit was the start, when it first happened. It's all kind of chaotic. And then, you know, we came out of hospital. And it kind of got much worse. And then as we kind of found [support] here … and then the stones were … us now … plodding along." (P6)*

Others focused less on linear time and more on the emotional or relational meanings of particular moments. These meanings were often conveyed through the sensory and symbolic properties of the materials – such as colour, texture, size, or shape – allowing emotional content to emerge in embodied or intuitive ways.

> *"For me, like the red was the anger. And the frustrations of what had happened, because you do feel angry in some ways about it." (P2)*

> *"This one reminded me of when ... when my daughter was suicidal and I was terrified she was going to ... I think it was just the texture that brought that to my mind." (P4)*

For some, creating a physical layout helped them reflect on experiences they had not previously processed or articulated. The act of arranging and narrating the materials created a sense of emotional distance or containment.

> *"I was able to kind of tie it up. That's what happened. It happened. We survived. That's where I am now." (P1)*

Not all parents engaged with the materials in this way. Some struggled to relate to the task or participated more tentatively. Several parents described initially feeling uncertain about how to use the materials, but reported that once they began moving or arranging them, a story started to emerge. Even so, brief interactions could still prompt reflection or spark new lines of thought.

> *"Once I started moving things around, I realised I was actually telling a story." (P4)*

This subtheme illustrates the varied ways in which parents engaged in sense-making. For some, the wool and stones offered structure and clarity; for others, they enabled expression of emotions that were difficult to articulate in words. Across accounts, translating experience into a physical, spatial arrangement appeared to support both emotional containment and cognitive organisation, allowing parents to hold together past events, present coping, and future uncertainty within a single symbolic space.

### *Subtheme 1.2: Owning the narrative*

This subtheme highlights how parents used the creative task not only to reflect on their experience, but also to reclaim authorship and personal control over how their story was represented and understood. Alongside mapping the journey, parents also described a strong sense of authorship and personal ownership over what they created with the wool and stones. The open-ended nature of the task meant there were no rules or expectations, allowing parents to shape their story in a way that felt meaningful and manageable.

> *"There's no right or wrong to it. That's my interpretation." (P2)*

This creative freedom was often contrasted with other aspects of parenting after ABI, where professional input and the child's needs tended to dominate. In this space, the story was theirs to tell – or not tell. Several parents chose to keep their creation private or partially unexplained, valuing the ability to decide how much to reveal.

> *"I kept it really quite private. But that was really nice." (P1)*

For some, this sense of control extended to the emotional content of the session. The task enabled them to choose when and how difficult feelings surfaced. One parent reflected that it was their decision to engage with these feelings at that moment:

> *"It would have come to surface sometime. And I think it was my choice that it come to surface last week. So I'm in control of it." (P7)*

Another described how being able to visualise the experience and then "move it away" gave them a sense of containment:

> *"It was in perspective, and then move it away. It's control. I'm a control freak." (P1)*

This subtheme highlights how creative expression enabled parents to reclaim agency in telling their story – on their own terms, and in a space where their emotional experiences were not secondary to their caregiving role. Across accounts, ownership of the materials and the narrative appeared to function as a way of restoring control in a context where many aspects of family life had become dominated by injury, uncertainty, and external demands.

## Theme 2: Engaging with the process

This theme explores how parents experienced and responded to the invitation to share their story using the wool and stones. While some found the process immediately resonant, others engaged more cautiously or held back. These varied responses reflected differences in emotional readiness, perceived safety, and length of time post ABI. Two subthemes are presented: *Feeling safe enough to share* and *Leaning in or holding back.*

### *Subtheme 2.1: Feeling safe enough to share*

This subtheme captures how emotional safety and trust in the interview space shaped parents' willingness to engage with the creative task and to disclose aspects of their experience that were otherwise rarely shared. A few parents described the P1 interview as one of the few spaces where they felt able to speak openly about their experiences. A combination of skilled facilitation, a private setting, and the non-judgemental nature of the task created a sense of emotional safety.

> *"It was really nice to talk about the journey with someone that doesn't know me ... there's no judgement." (P4)*

> *"So yeah, it's been hard to talk about things and unpick everything – but positive as well. I don't regret it in the slightest." (P2)*

This sense of safety enabled some parents to access and express feelings they had previously kept buried. The creative task was experienced not only as expressive but also as containing – something they could engage with and then "put away."

> *"It was the right time to do it. I was too afraid before. I was concentrating on how we were going to manage." (P7)*

> *"It makes you address those emotions that are quite buried, and that was really hard. Really draining. I was exhausted." (P2)*

For others, it was the first time they had been asked about their own experience – rather than their child's – in a health-related context. Simply being listened to was described as powerful and validating.

> *"It's the first time I've done something like that, where I haven't talked about everyone else. It was about me." (P1)*

> *"Not being asked, 'How are you?' That's a big thing." (P2)*

Across accounts, feeling emotionally safe appeared to be a key condition for accessing difficult material, with the combination of relational trust and the containment offered by the task enabling parents to approach experiences that had previously felt too risky or overwhelming to revisit.

#### ***Subtheme 2.2: Leaning in or holding back***

This subtheme reflects how parents varied in the extent to which they were able or willing to engage with the creative task, with responses shaped by emotional readiness, comfort with symbolic expression, and prior processing of their experiences. Parents described varied levels of engagement with the wool and stones. Some immersed themselves in the task, while others approached it more cautiously. For several, the process became absorbing once they got started – a tactile and symbolic way of making sense of their experience.

> *"I didn't look at the time. I could have sat there for six and a half hours. It was very… free." (P7)*

> *"You don't realise how much comes out until you start talking through what each bit means." (P2)*

Physical interaction with the materials often supported emotional release or insight. Even those who didn't initially identify as creative sometimes found the task unlocked unexpected feelings or memories.

> *"You're using your brain as well as the materials… you've got that sensitivity on your fingers… and I think it just flew." (P7)*

*“I felt like I was wrapping it up… even in my messy, scrappy world in my head, I still liked things completed.” (P1)*

Not all parents found the approach helpful. A few struggled to connect with the materials or preferred more verbal approaches. Their participation was shaped by factors such as emotional readiness, comfort, expectations, or previous processing. Some parents, for example, felt they had already done the emotional work needed prior to study participation and therefore gained no new insights.

*“It didn’t really bring up anything new, I don’t think.” (P6)*

Post-session engagement also varied. Some continued to reflect on the materials – keeping them visible, revisiting them mentally, or sharing them with others. One parent described how they and their injured child interacted with the wool and stones between sessions:

*“She got all the stuff out ... and started explaining to me how she felt after her injury.” (P5)*

Others left the materials unused. One parent described feeling unsure what to do with the bag once it was home:

*“I did keep looking at the bag, but in my head, I was like, I don’t know what to do with it.” (P4)*

These varied patterns of engagement show that the approach invited reflection, but also required emotional readiness and individual fit. The process was not universally transformative, but for several parents, it was meaningful in subtle or lasting ways – offering a rare opportunity to reflect on personal experience in a supportive context. Taken together, these accounts suggest that the creative task functioned less as a uniform intervention and more as an invitation that parents could either enter into, adapt, or decline depending on their emotional position and personal preference at that point in time.

## Discussion

This study aimed to explore how a creative materials-based approach was experienced by parents of children with ABI. In this section, we consider the findings in relation to existing literature, highlight implications for clinical practice and future research, and reflect on the strengths and limitations of the study.

### Constructing meaning through expression, containment, and agency

Parents described how the creative materials-based approach offered a distinctive way of sharing their story following their child's ABI. For many, the process supported emotional expression, containment, and narrative agency. Parents used the wool and stones to communicate their experience in symbolic and embodied ways – sometimes externalising feelings they had previously kept private or unspoken. The opportunity to 'map out' their journey was particularly valuable, helping some to sequence events, make meaning of what had happened, and regain a sense of perspective and control. For others, it was the act of arranging and handling materials that gave shape to difficult emotions.

These findings align with research on arts-based methods in health contexts, which suggest that creative approaches can help individuals integrate complex or traumatic experiences. For example, the World Health Organisation scoping review by Fancourt and Finn (2019) highlights how arts-based interventions can support emotional expression and meaning-making across a range of clinical populations, including those with neurological conditions. Similarly, Galvin et al. (2020) found that an arts-based intervention following stroke helped participants reconnect with identity and reframe their experience in personally meaningful ways. Regan et al. (2022), writing from an integrative arts psychotherapy perspective, also emphasise the role of symbolic and embodied expression in processing overwhelming experiences – particularly when supported by a safe therapeutic framework.

In addition to research on arts-based interventions more broadly, our findings also resonate with work on storytelling and identity reconstruction following ABI. Daisley et al. (2014) describe how narrative approaches can help individuals reassemble fragmented experiences and reclaim authorship over their story. Galvin et al. (2020) similarly note that storytelling within a group setting can promote reflection, shared understanding, and new perspectives. Although many existing approaches focus on verbal reflection, our study contributes to a smaller but growing literature suggesting that tactile, symbolic tools can offer alternative ways to meaning-making – particularly when supported by skilled facilitation and emotional safety (Daisley et al., 2014; Ellis-Hill et al., 2019; Galvin et al., 2020; Regan et al., 2022).

### Emotional readiness, safety, and individual fit

Parents’ engagement with the wool and stones varied depending on emotional readiness, perceived safety, and length of time post ABI. For some, this was the first time they had been invited to reflect on their own experience – rather than their child’s – in a healthcare context. Having a private, non-judgemental space was described as powerful and validating, echoing previous findings that story-sharing can surface unspoken emotions and provide a meaningful space for self-expression (Butera-Prinzi et al., 2014; Haselhurst et al., 2021).

Others valued the opportunity to do something creative and contained, especially if they had felt overwhelmed in the past. The process helped some access ‘buried’ emotions, while also managing their intensity through structured engagement and the ability to step away. These reflections align with Daisley et al. (2014), who caution that creative materials can evoke strong emotional responses and must be offered in ways attuned to an individual’s stage of processing and readiness.

This emphasis on individual readiness is echoed in wider evidence that story-sharing interventions must be attuned to people’s emotional state and broader life context (Daisley et al., 2014; Ellis-Hill et al., 2021; Haselhurst et al., 2021; Drake et al., 2024). Ellis-Hill et al. (2021) emphasise that emotional availability can shift depending on broader life context. Similarly, Daisley et al. (2014) highlight the need to match creative methods to each person’s capacity and readiness. Haselhurst et al. (2021), in their evaluation of the Tree of Life intervention, found that some parents engaged cautiously or minimally – reinforcing the need for flexible delivery and respect for pacing. Drake et al. (2024) found that parents valued the ability to control how and when they engaged with a video-based intervention, describing it as a “soft entry” into stories that were often emotionally difficult. Our findings similarly suggest that creative approaches can support engagement by offering gentle, flexible ways to begin sharing experiences that may otherwise feel overwhelming.

A key strength of our study was its reflexive attention to variation: not all parents found the materials resonant, and a few engaged only tentatively or briefly. While the approach invited reflection, it also required emotional readiness and alignment with individual preference – highlighting the value of flexible, choice-based methods in both clinical and research contexts.

## Clinical and research implications

Our findings suggest that creative materials-based approaches may hold particular value within services supporting families of CYP with ABI. While verbal interventions remain essential, some parents/carers may benefit from non-verbal or multimodal alternatives for expression and reflection. Symbolic and tactile methods may support narrative agency and meaning-making, especially when paired with careful pacing and emotional containment. This aligns with findings from arts therapies and narrative interventions, which show that structured creative processes – such as songwriting (Roddy et al., 2020; Tamplin et al., 2016), visual arts (Laird and Mulvihill, 2022), and music therapy (Pfeiffer and Sabe, 2015) – can help individuals explore and externalise difficult emotions while preserving a sense of control.

Creative approaches may also offer therapeutic value within research settings, blurring the boundaries between data collection and emotional support. For example, D’Cruz et al. (2020) and Chan et al. (2012) demonstrate how story-based or visual-narrative methods can facilitate personal insight and reconnection with identity after ABI and/or trauma. In our study, several parents described the storytelling process as emotionally meaningful in its own right – a finding echoed by Hunter (2019), whose work with military veterans highlights the role of symbolic creative acts in processing trauma.

However, our findings also caution against assuming universal fit. Parents’ readiness to engage was shaped by timing, emotional state, and personal preference – echoing theoretical models of acceptability, which emphasise factors such as affective attitude, ethical alignment, and perceived burden (Sekhon et al., 2017). Flexibility, choice, and containment appear central to making such approaches safe and accessible. Ellis-Hill et al. (2021) similarly note that emotional availability fluctuates depending on context, and that story-sharing must align with where people are in their psychological journey. This suggests a need for adaptable delivery, as supported by research across stroke, trauma, and arts psychotherapy contexts (Ellis-Hill et al., 2019; Galvin et al., 2020; Laird and Mulvihill, 2022; Regan et al., 2022; Vaculik and Nash, 2022). Adaptability may involve not only timing and format, but also opportunities for both individual and group engagement. While individual storytelling can provide privacy and emotional safety, group-based creative approaches allow for shared reflection, mutual support, and collective meaning-making. Offering parents the choice between these modes may enhance accessibility and ensure the approach meets diverse needs.

Recruitment to this study was conducted through a single NHS-based community neuropsychology service for CYP with ABI, which supported the identification of parents who were known to services and judged to be emotionally ready to engage in reflective research. While this was ethically appropriate, it may also have shaped the breadth of the sample and limited participation from families who were less engaged with services, more socially isolated, or from culturally minoritised backgrounds. This has implications for how creative materials-based approaches are evaluated and developed in future research. Wider recruitment across community settings, third-sector organisations, and culturally specific networks may be necessary to better understand the accessibility, acceptability, and relevance of such approaches across diverse parent and family groups.

### Limitations and future directions

This was a small-scale qualitative study involving a single encounter with each parent, which limits the generalisability of the findings. The sample may reflect a self-selecting group of parents already inclined toward reflection, creativity, or emotional processing. Others who might have found the task uncomfortable, irrelevant, or too confronting may not have chosen to take part. This highlights an important consideration for future research: who engages with creative approaches, and why? Similar questions have been raised in wider discussions on intervention acceptability and emotional readiness (Daisley et al., 2014; Ellis-Hill et al., 2021; Sekhon et al., 2017).

A further limitation concerns the demographic composition of the sample. The majority of participants were mothers, with only one father represented, and all participants identified as White British. This limits the extent to which the findings can speak to gendered, cultural, and socio-contextual differences in how parents/carers experience and make sense of creative materials-based storytelling following child ABI. Cultural values around help-seeking, privacy, and trust in services may shape engagement with both research and intervention approaches and may not be adequately captured here. Future research would benefit from purposive recruitment strategies that engage more diverse parent/carer groups, including fathers and families from minoritised ethnic backgrounds, through community-based and culturally responsive recruitment pathways.

While many parents appeared to gain meaning and connection through interacting with the wool and stones, the structured nature of the task may have constrained others. Some may have preferred more open-ended conversation, alternative metaphors, or different forms of reflection. This reinforces the importance of offering creative approaches with flexibility and choice so that they can be tailored to individual preferences and ways of meaning-making.

Future research could explore how creative approaches are experienced by CYP and other family members, and examine their longer-term impact on coping and family adjustment. There is also scope to investigate how such methods might be embedded into ongoing support or adapted across developmental stages and family contexts. As creative approaches become more integrated into health services, further research will be needed to ensure they are inclusive, sustainable, and grounded in co-produced principles.

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# Chapter Five: Extended Method

# Extended Method

## Epistemological stance and methodological rationale

The empirical study was situated within a critical realist framework, which acknowledges the existence of a real world while recognising that our understanding of it is shaped by context, perspective, and interpretation (Bhaskar, 1975; Braun & Clarke, 2022). This was important given the dual focus on participants' meaning-making and the broader structural conditions shaping their stories. The use of reflexive thematic analysis was well aligned with this stance, offering both flexibility and rigour in exploring experiential, interpretive themes. While the study was not co-produced, its design was informed by principles of participatory, person-centred inquiry. The *Wool & Stones* approach has previously been used within participatory action research (e.g., Ellis-Hill et al., 2021), and this history of application helped shape its use here as a method that could support participant agency, openness, and reflective meaning-making. Participants were invited to tell their stories in their own way, using creative materials as they saw fit. This open, exploratory approach was chosen to support narrative agency and emotional pacing – especially important when working with parents reflecting on challenging life events.

## Sample size and rationale

Rather than seeking broad generalisability, the focus of the empirical study was on generating rich, situated insights into parents' engagement with a novel, creative method. Consistent with qualitative principles, the aim was to explore meaning and experience in depth rather than to reach saturation in a conventional sense (Braun & Clarke, 2022; Tracy, 2010). The sample size aligned with the practical and emotional demands of the method, which required participants to reflect on potentially sensitive experiences within a single session. In this context, the sample size attained allowed for detailed, reflexive analysis and close attention to nuance, supporting the integrity of the interpretive process (Braun & Clarke, 2022).

## Reflexive practice and supervision

Reflexivity is a core element of reflexive thematic analysis (Braun & Clarke, 2019, 2022) and is particularly relevant within a critical realist approach, where knowledge is understood as shaped by both participants' accounts and the researcher's interpretative lens. In the empirical study, reflexivity was used to examine how my own assumptions, clinical background, and interactions with participants influenced the research process and the meanings I constructed from the data. Engaging in reflexive practice also contributed to the trustworthiness and rigour of the analysis by making these influences visible and open to critical scrutiny. Reflexive practice was embedded throughout, supported by a structured reflexive journal and regular supervision. These provided spaces to interrogate my interpretations, remain open to alternative explanations, and attend to the interpersonal and contextual dynamics that shaped the storytelling process.

A structured reflexive journal was kept throughout the research process, providing space to record observations, uncertainties, and shifts in thinking. Early in the process, I reflected on my discomfort with how the *Wool & Stones* approach was introduced during initial study visits. Watching the videos back, I noted: *"[Researcher] gives them minimal guidance, and then expects them to do something with the wool and stones while she sits there watching. It's seems like too personal an ask to expect someone to do this honestly on such short notice."* I wondered whether participants had been given enough support to engage with the materials meaningfully, or whether the awkwardness of the task might inhibit honest expression.

As I familiarised myself with the data, however, I became increasingly interested in how parents responded to the invitation to use the materials. Some engaged straightaway, building symbolic or structured representations of their journeys. Others interacted more tentatively or only when prompted, and some avoided the materials entirely after creating an initial arrangement. Reflecting on this, I wrote: *"Parents respond to [Researcher]. If [Researcher] asks or refocuses them, then the parent reattends… Otherwise tend to focus on talking."* This helped me notice how much the process was shaped by interpersonal dynamics and how important it was to consider not only what was created but how and when materials were used or not used.

Supervision offered a space to think critically about these dynamics and how my clinical lens might shape the way I interpreted participants' stories and silences. My journal became a tool for working through interpretative uncertainties. In one entry, I wrote: *"She's clearly telling a story about grief and disconnection, but she keeps swerving away from it. Is this a subtheme about avoidance? Or emotional pacing? Or maybe something about what's unsayable?"* These reflections helped me stay open to ambiguity and contributed to the development of the theme *Leaning in or holding back.*

Later, when reviewing the dataset as a whole, I noticed that even minimal or hesitant engagement with the materials sometimes seemed to coincide with emotional intensity: *"The emotion of the CYP's ABI gets transferred onto the materials. To point where the materials* *are avoided in some cases and wholeheartedly embraced in others."* This helped me approach both use and non-use of the materials as potentially meaningful, shaped by comfort, timing, and emotional readiness rather than willingness alone. These kinds of reflexive insights helped ensure that the analysis remained transparent, critically informed, and attentive to the relational and emotional contexts shaping parents' storytelling, thereby strengthening the credibility and depth of the study's findings.

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# Chapter Six: Extended Discussion and Critical Evaluation

# Extended discussion and critical evaluation

## Overview

This chapter integrates the systematic review and empirical paper presented in this portfolio. It considers their contributions to research and practice, examines methodological strengths and limitations, and explores how they extend current understandings of family-centred psychological support following paediatric Acquired Brain Injury (ABI). The chapter concludes with implications and directions for future research, practice, and intervention development.

The two papers were designed to address key gaps in how families are supported following ABI in childhood and adolescence. The systematic review synthesised parents'/carers' perspectives on a range of interventions, identifying what families found helpful, accessible, or burdensome during recovery. The empirical paper explored a creative materials-based storytelling approach, focusing on how parents engaged with this process and the meanings they constructed through it.

Although the studies were developed concurrently, insights from each informed the interpretation of the other. For instance, the empirical paper provided a lived experience-based illustration of several key features identified as important in the review – such as flexibility, family-centredness, and emotional pacing. Taken together, the two papers offer a more holistic understanding of family recovery and support needs. Both draw on qualitative methods to centre lived experience and shift focus away from biomedical models towards the relational, psychological, and developmental dimensions of neurorehabilitation. This combined contribution supports the development of person- and family-centred approaches within health psychology and paediatric neuropsychology.

## Co-production and lived experience: shaping family-centred research

This portfolio was shaped by values aligned with co-production – including collaboration, relationality, and power sharing. These values informed both the choice of research focus and the design of the two studies. Co-production has gained increasing recognition as an ethical and methodological imperative in healthcare research, particularly in the context of long-term, life-altering conditions such as ABI (Whiffin & Ellis-Hill, 2021; Whiffin et al., 2021). This is especially salient when working with individuals and families whose lives have been disrupted by ABI, where traditional service models have often prioritised the injured individual while overlooking the relational, narrative, and emotional dimensions of recovery (Drake et al., 2024; Rixon, 2022; Tyerman et al., 2017). Involving families in shaping interventions not only supports ethical engagement but also increases the relevance, accessibility, and emotional resonance of support (Hickey et al., 2016; Miley et al., 2022).

The systematic review focused on studies in which parents/carers were active contributors to intervention design, rather than passive recipients or evaluators. Although not all included studies explicitly used the language of co-production, they shared a commitment to eliciting families' views on what support should look like (e.g., Bennett et al., 2023; Svendsen et al., 2023). Parent/carer participants in these studies were asked to help identify priority content areas, shape the structure and tone of sessions, or give feedback on materials prior to delivery (Drake et al., 2024; Gan et al., 2010). For example, in the development of the HOPE video-based resource, families co-led the design process and shared their own stories to ensure the material felt relatable and supportive to other families (Drake et al., 2024). In another study, parents worked collaboratively with clinicians to adapt intervention goals to their child's needs and preferences, helping to avoid a 'done to them' approach (Svendsen et al., 2023). Through this focus, the review advanced methodological alignment with participatory and humanising values. Synthesising the findings across studies offered important insights into how collaborative processes can enhance the design of family-centred interventions post ABI, improving their relevance, accessibility, and emotional impact (Drake et al., 2024; Gan et al., 2010).

Although the empirical paper was not co-produced, it was shaped by closely-aligned values, including participant autonomy, openness, and reflexivity. The creative materials-based approach used in Davies (2024) invited participants to share stories on their own terms, with no expectation that they use the materials in any particular way. The aim of Davies (2024) was to elicit different/richer narratives, while the empirical study in this portfolio engaged participants in reflecting on and feeding back on the process of using the *Wool & Stones* approach – i.e., gathering their perspectives on the use of the materials and their potential to be used supportively outside of a research setting. This 'soft-entry' design supported emotional pacing and autonomy, enabling participants to feel safe and in control of the storytelling process (Drake et al., 2024). These design choices were informed by a relational ethics that prioritises respect, responsiveness, and shared ownership of the research encounter, consistent with approaches that centre the lived experiences and preferences of families affected by ABI (Tyerman et al., 2017; Whiffin & Ellis-Hill, 2021). As Rixon (2022) argues, embedding opportunities for meaningful connection and story sharing can help disrupt isolating clinical narratives and create space for emotional truth. In this sense, the empirical paper represented a small but meaningful step toward co-creation and power sharing in research aimed at developing or improving interventions/support. (Drake et al., 2024; Tyerman et al., 2017).

Together, the two studies contribute to wider debates in health psychology and neuropsychology about participatory approaches to knowledge production and the ethics of working alongside people with lived experience. These questions are particularly salient when working with families affected by ABI, whose voices are often marginalised in clinical and academic spaces. By recognising families as experts in their own lives, and by centring their perspectives in both intervention development and storytelling, this portfolio supports the move toward more inclusive, lifeworld-led, and context-sensitive research practices (Ellis-Hill et al., 2021; Holloway & Ellis-Hill, 2022). The systematic review highlighted how participatory approaches, such as those described in Svendsen et al. (2023) and Drake et al. (2024), can enhance the relevance and emotional resonance of family-centred interventions. In parallel, the empirical paper illustrated how creative, participant-led methods can make space for individual meaning-making and emotional pacing, in line with lifeworld-led principles.

## Methodological reflections on creative and narrative approaches

This section reflects on two interconnected aspects of the empirical paper: first, the use of creative and narrative tools to support participant engagement and meaning-making; and second, the balance between structure and openness in storytelling-based approaches.

### *Using creative and narrative tools*

Part 1 of the *Wool & Stones* study adopted a creative materials-based approach to storytelling to elicit richer or different narratives from parents (Davies, 2024). Part 2 – the empirical study in this portfolio – explored parents' experiences of using the method and its potential applications beyond a research setting. This approach offered participants flexible and open-ended ways to engage with their experiences and was influenced by broader movements in health psychology and rehabilitation research towards narrative, creative, relational, and phenomenological approaches (Drake et al., 2024; Galvin & Todres, 2013; Whiffin & Ellis-Hill, 2021). Galvin and Todres' lifeworld-led framework emphasises the importance of recognising individuals' embodied, emotional, and temporal experiences in healthcare encounters, advocating for approaches that honour people's own ways of making sense of their lives. This was evident in parents' use of the materials to explore shifting identities, map temporal transitions, and re-establish a sense of belonging – for example, through reflecting on "before and after" their child's injury, or asserting ownership over how their story was told (Tyerman et al., 2017). By inviting parents to select and use materials in whatever way felt meaningful, the study aimed to support personal agency, emotional safety, and reflective meaning-making (Drake et al., 2024; Rixon, 2022).

The creative materials used in the study – a selection of wool and stones varying in colour, texture, size, and shape – were chosen for their symbolic, tactile, and interpretive possibilities. Participants were not instructed how to use them, but were instead invited to engage "in whatever way feels right for you." This open-ended invitation supported a 'soft-entry' approach, allowing participants to begin gently, pause or redirect the process, and engage on their own terms. Such flexibility was particularly important given the emotional and relational complexity of sharing experiences after paediatric ABI, where vulnerability, uncertainty, and loss of control are common (Drake et al., 2024; Tyerman et al., 2017). The materials offered a non-verbal, metaphor-rich medium through which participants could express layered and sometimes difficult experiences, while retaining ownership over how and when to share.

The *Wool & Stones* approach is underpinned by lifeworld-led and humanising care principles (Ellis-Hill et al., 2021; Holloway & Ellis-Hill, 2022), aligning with practices that centre the embodied, relational, and temporal dimensions of meaning-making. By recognising the participant as expert in their own experience, this approach supported a way of working that values emotional pacing, presence, and shared understanding. Rather than following a structured set of prompts, the researcher adopted a responsive stance, seeking to enable rather than direct participants' storytelling – an approach consistent with the phenomenological, lifeworld-led and humanising frameworks developed by Ellis-Hill and colleagues (Ellis-Hill et al., 2008; Ellis-Hill et al., 2021; Galvin et al., 2020; Holloway & Ellis-Hill, 2022), as well as with relational ethics and trauma-informed research practice (Drake et al., 2024; Tyerman et al., 2017). Participants appeared to value this flexibility, with several commenting on how the open format made it easier to share difficult or unexpected aspects of their story – a process captured in the subtheme *Feeling safe enough to share*.

These reflections raise important questions about the balance between structured guidance and flexible engagement, and about how different creative formats may meet different therapeutic needs. As highlighted in the subtheme *Leaning in or holding back*, participants varied in how actively and emotionally they engaged with the storytelling process, suggesting that one size may not fit all. Future work could explore how offering a range of materials, levels of structure, and relational entry points may enhance accessibility, resonance, and emotional safety for families affected by ABI (Bedell et al., 2017; Drake et al., 2024).

### ***Structure versus openness in storytelling-based approaches***

The empirical paper formed part of a broader programme of research exploring creative, narrative-based approaches to supporting families following ABI, providing an opportunity to reflect on the distinct models emerging across different strands of inquiry. Among these, the *Life Threads* approach (Ellis-Hill et al., 2008; Whiffin et al., 2025; Whiffin et al., 2024) represents a more structured method of supporting identity reconstruction following ABI. Although the *Life Threads* and *Wool & Stones* approaches were developed independently and with different populations in mind, both are grounded in lifeworld-led care and embodied meaning-making (Ellis-Hill et al., 2021; Galvin & Todres, 2013).

The *Life Threads* approach uses themed prompts, symbolic materials, and curated creative media to support people in making sense of their lives after ABI. The approach is paced to build relational safety, explore key life experiences (e.g., family, achievements, adversity), and integrate these into a coherent personal narrative. It was developed as a potentially therapeutic tool, rooted in narrative sense-making, for use with adult family members of people who have sustained a traumatic brain injury. While guided, the approach retains flexibility – for example, in the *Life Threads* study, participants were given the materials to use as and when they chose over a four-week period, with no restrictions on whether they used the materials alone or involved friends or other family members, including the injured relative (Whiffin et al., 2025). The approach shares lifeworld-led and trauma-informed principles, including emotional pacing, relational attunement, and psychological safety (Holloway & Ellis-Hill, 2022; Whiffin et al., 2024). This challenges the assumption that openness alone ensures resonance or readiness, showing that structure – when sensitively delivered – can also support agency and containment.

By contrast, the *Wool & Stones* approach was originally developed and used as a participatory research method rooted in phenomenological and embodied principles, rather than as a therapeutic tool. In the current study, it was used to explore parents' experiences of the method and its potential value as a supportive tool beyond research. The materials were introduced in a single interview, offering less flexibility, compared to the *Life Threads* approach, in when or with whom they might be used. The approach has no fixed structure or expectation that participants use the materials at all – they are offered as symbolic resources, with stories invited entirely on the participant's terms. This openness may better support agency, emotional pacing, and autonomy, particularly in contexts where power, trust, and vulnerability are particularly relevant (Ellis-Hill et al., 2021; Whiffin & Ellis-Hill, 2021). This ‘soft-entry’ design aligns with key themes from the empirical paper, such as *Feeling safe enough to share* and *Leaning in or holding back*, and reflects the flexible, non-prescriptive ethos of Drake et al.’s (2024) video-based resource for parents of children with ABI.

From a lifeworld-led perspective, both the *Life Threads* and the *Wool & Stones* approaches aim to humanise healthcare by reconnecting people with their values, relationships, and sense of self (Galvin & Todres, 2013; Holloway & Ellis-Hill, 2022). However, they take different routes – one more structured and explicitly therapeutic, the other more emergent and participatory in origin. The *Life Threads* approach offers a defined narrative process and a longer engagement period, potentially supporting coherence, emotional containment, and therapeutic focus. The *Wool & Stones* approach offers immediacy, choice, and minimal direction, which may foster autonomy and exploratory engagement within the safety of a single encounter. These differences reflect a wider dilemma in psychological care: how to support meaning-making without constraint, and emotional safety without overstepping. Importantly, this is not a binary choice. There is value in offering a continuum of creative and narrative formats, enabling individuals to engage in ways that suit their readiness, preferences, and needs. At present, both the *Wool & Stones* and *Life Threads* approaches represent initial explorations of this potential, with findings centred on participants’ feedback and experiences. In this sense, they can be viewed as a ‘phase one’ in the development of family-centred creative approaches, providing foundations for future refinement and adaptation in line with co-production principles.

### Methodological strengths and limitations

Both the systematic review and empirical paper were underpinned by qualitative methodologies that prioritise lived experience, participant voice, and in-depth exploration. This was appropriate given the relational and emotional complexity of the research topic, and the exploratory nature of the research aims. The review was strengthened by the use of thematic synthesis, which enabled findings across studies to be integrated while preserving the nuance of each individual paper (Thomas & Harden, 2008). By including only studies in which parents/carers were actively involved in shaping interventions, the review centred family knowledge and aligned with participatory and humanising values. Methodological quality was assessed using the CASP checklist, supporting critical engagement and ensuring transparency and rigour.

The empirical paper drew on Reflexive Thematic Analysis (RTA), which allowed for flexible interpretation while attending to the co-constructed nature of meaning-making (Braun & Clarke, 2019, 2022). The decision to combine RTA with a creative materials-based storytelling method was partly informed by the systematic review's emphasis on emotional safety, agency, and responsiveness to family needs. In keeping with RTA principles, theme development was guided by deep engagement with the data, critical reflexivity, and contextual sensitivity. This included iterative re-reading of transcripts and materials, reflective supervision, and ongoing dialogue between researchers to consider the influence of power, positionality, and emotional resonance (Nowell et al., 2017).

Across both studies, several limitations must be acknowledged. Although attention was given to heterogeneity, participants were predominantly white, cisgender, and from relatively high-income backgrounds. This reflects broader access and equity issues within paediatric neurorehabilitation research (Miley et al., 2022; Tyerman et al., 2017) and limits the transferability of findings. In the empirical paper, the single-site design constrains opportunity to capture diversity in demographics and contexts, and limits the scope of transferability. The flexible nature of the creative method also posed interpretive challenges, as participants' use of materials varied and sometimes resisted thematic categorisation. These ambiguities were embraced as part of working with open-ended, lifeworld-led methods, though they did increase the complexity of interpretation and presentation.

## Exploring implications and future directions

Together, the systematic review and empirical paper offer a richer understanding of how to support families after ABI in childhood and adolescence. Several implications for research, practice, and future intervention design can be drawn.

### *Research and intervention design*

The systematic review highlighted the value of involving parents/carers in the co-design of interventions, while the empirical paper offered deeper insight into how parents engaged with a flexible, emotionally paced, and participatory approach. Across both studies, the relevance of co-production principles, emotional safety, and meaning-making emerged consistently. These findings support the continued development of creative and narrative approaches that enable families to reflect, connect, and make sense of their experiences (Galvin & Todres, 2013; Holloway & Ellis-Hill, 2022). A key recommendation is to offer a continuum of approaches that vary in structure, delivery mode, and materials, enabling families to choose formats that feel manageable, emotionally resonant, and appropriate to their stage of recovery (Drake et al., 2024; Whiffin & Ellis-Hill, 2021). This continuum would also benefit from considering delivery format. While the systematic review highlighted the value families placed on group- and peer-based interventions, the *Wool & Stones* approach was delivered in an individual format, with parents engaging one-to-one with the researcher. In contrast, the *Life Threads* approach provided opportunities for collective engagement, allowing materials to be used with friends, relatives, or peers. This suggests that peer connection can provide an important complement to individual reflection, and that different delivery formats may meet different needs at different stages of recovery.

Future research could explore how to tailor creative and narrative approaches to different populations, contexts, and preferences. Comparative work might examine the distinctive features of structured versus open-ended models – such as the *Life Threads* and *Wool & Stones* approaches, respectively – and how these influence engagement, emotional safety, and therapeutic impact. A future conceptual paper could build on this thesis portfolio to examine how varying levels of structure and openness align with different contexts and aims, thereby strengthening psychologically informed and person-centred care following ABI. Further attention to cultural and linguistic relevance, emotional pacing, and researcher-clinician positionality will also be important for enhancing inclusivity and responsiveness (Miley et al., 2022; Tyerman et al., 2017).

### ***Clinical and systemic practice***

Both papers underscore the importance of centring family knowledge in how services are delivered and evaluated. This includes recognising families' emotional needs, contextualising support within everyday life, and attending to the relational and developmental aspects of recovery (Miley et al., 2022; Tyerman et al., 2017). Findings also support the use of methods that create space for emotional expression, shared reflection, and narrative meaning-making – particularly in contexts where families feel unheard, overwhelmed, or disconnected (Galvin & Todres, 2013).

System-level changes will be needed to integrate creative, narrative, and co-produced approaches into routine support for families – whether within clinical services or less formal contexts such as social care and the voluntary sector. This may involve training practitioners in participatory methods, resourcing protected time for relational work, and embedding humanising principles into service design (Ellis-Hill et al., 2021; Holloway & Ellis-Hill, 2022). While these approaches are not new, they often remain marginalised within dominant biomedical systems. Alternatively, they may be better situated outside clinical settings, forming part of community-focused provision – for example, within asset-based community development or community psychology approaches – or aligning more closely with public health and social care frameworks that emphasise health promotion and prevention rather than treatment and rehabilitation. This portfolio contributes to the growing evidence base for humanising, psychologically-informed, and co-developed models of family support following paediatric ABI.

## Research reflexivity

My role as a trainee clinical psychologist and member of the wider research team inevitably shaped how I approached this work. I came to both the systematic review and the empirical paper with a strong commitment to emotional safety, inclusion, and co-production – values that informed how I made decisions about which studies to prioritise, how to engage with families, and what to attend to in the data. At times, these values aligned easily with the findings; at other times, they prompted me to question my assumptions and stay open to discomfort or ambiguity. Working closely with co-researchers, participants, and supervisors offered space for reflection, challenge, and growth. I see this thesis not only as a contribution to the literature, but also as part of my own ongoing process of learning how to listen well, to stay with complexity, and to approach research in a way that feels both ethical and human.

## Conclusion

This thesis portfolio set out to explore how families can be more effectively supported following childhood ABI. Drawing on two interlinked qualitative studies, it examined the support families say they want and need (systematic review), and how one creative, narrative approach may help parents reflect on their experiences and tell their stories (empirical paper). Together, the two papers contribute to a broader movement toward psychologically-informed, humanising, and family-centred approaches within paediatric neuropsychology and health psychology.

The systematic review synthesised parents'/carers' views across studies that either actively involved families in shaping interventions or explicitly sought their input to guide future support. Across this body of work, families highlighted the importance of principles associated with co-production, relational attunement, contextual relevance, and the need for flexible, emotionally safe interventions. The empirical paper built on these priorities by exploring a creative materials-based storytelling approach grounded in openness, emotional pacing, and meaning-making. These principles were brought into focus through the rich narratives shared by participants, who engaged with the method in ways that reflected their agency, values, and individual journeys.

By highlighting the relational and emotional dimensions of post-ABI care, this portfolio advocates for a more humane, inclusive, and responsive model of support – one that elevates and honours the voices, stories, and strengths of families navigating life after brain injury. In doing so, it adds to the evidence base for psychologically-informed, co-developed, and lifeworld-led approaches. Future research could build on this foundation by refining and comparing creative interventions, extending participatory practices with a wider range of families, and designing supports that align more closely with families' lived experiences. In all of this, the goal remains the same: to create space for stories to be shared, meanings to be made, and support to feel truly supportive.

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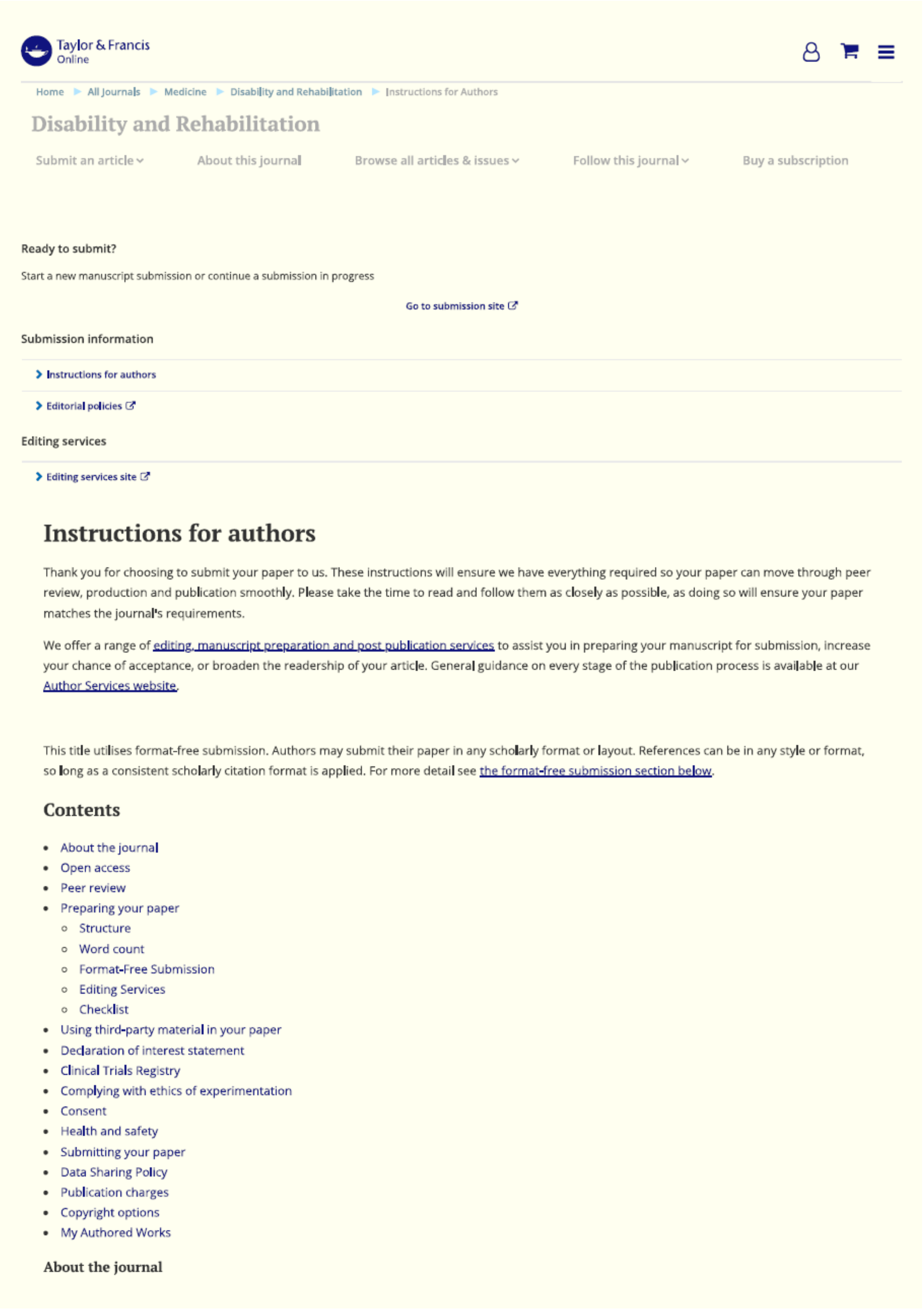
# Appendices

**Appendix A.** *Author Guidelines for Disability and Rehabilitation*



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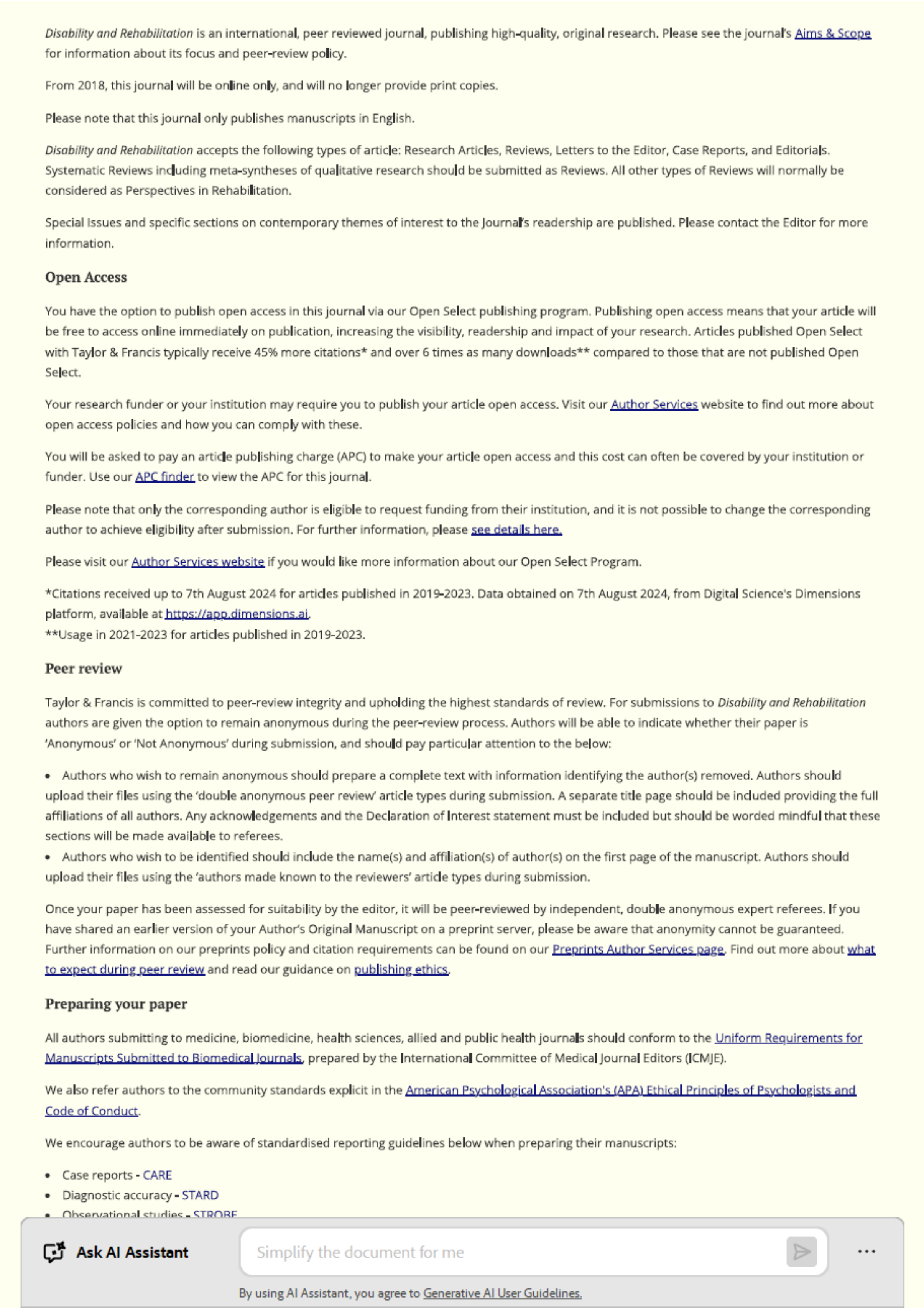

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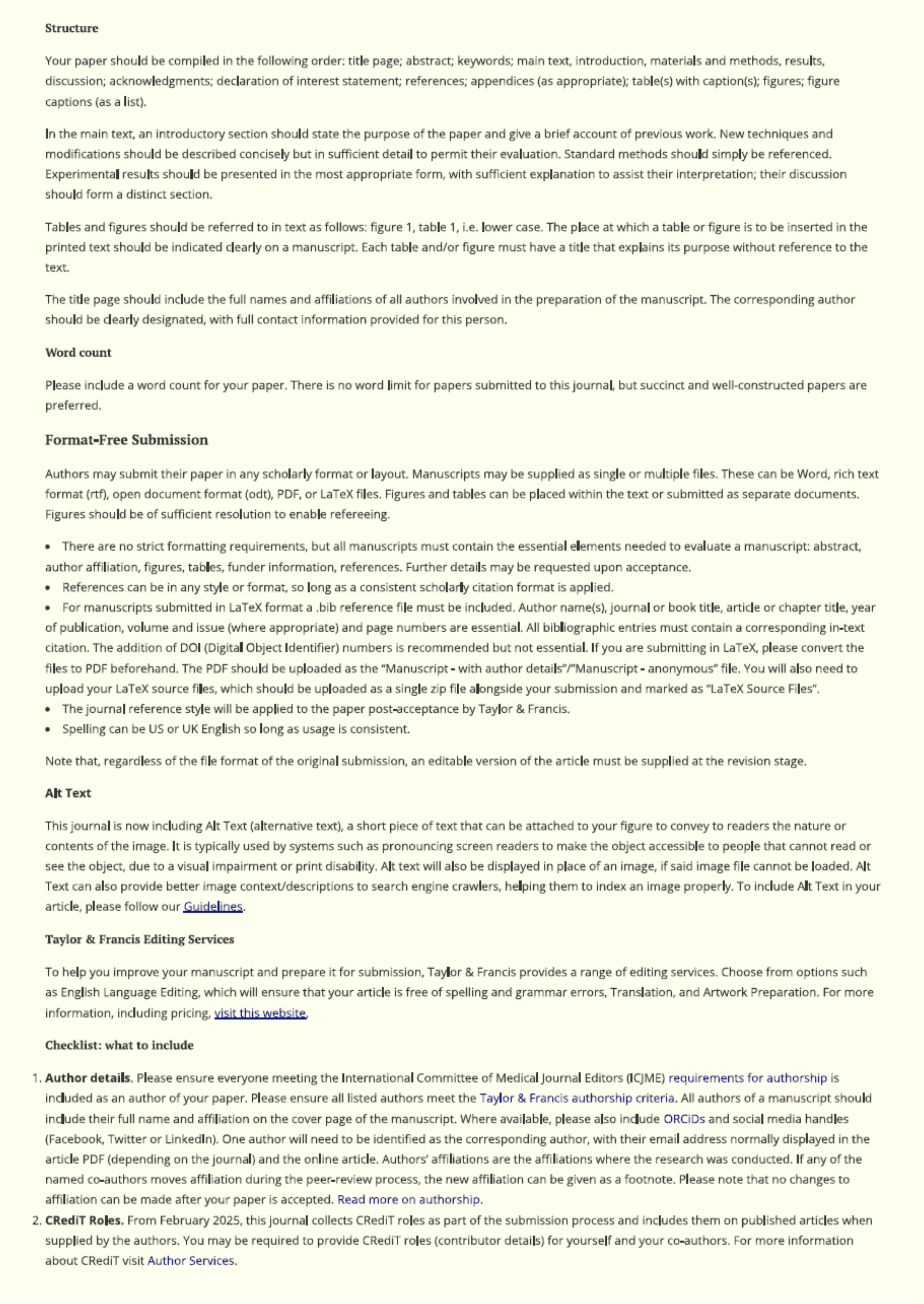

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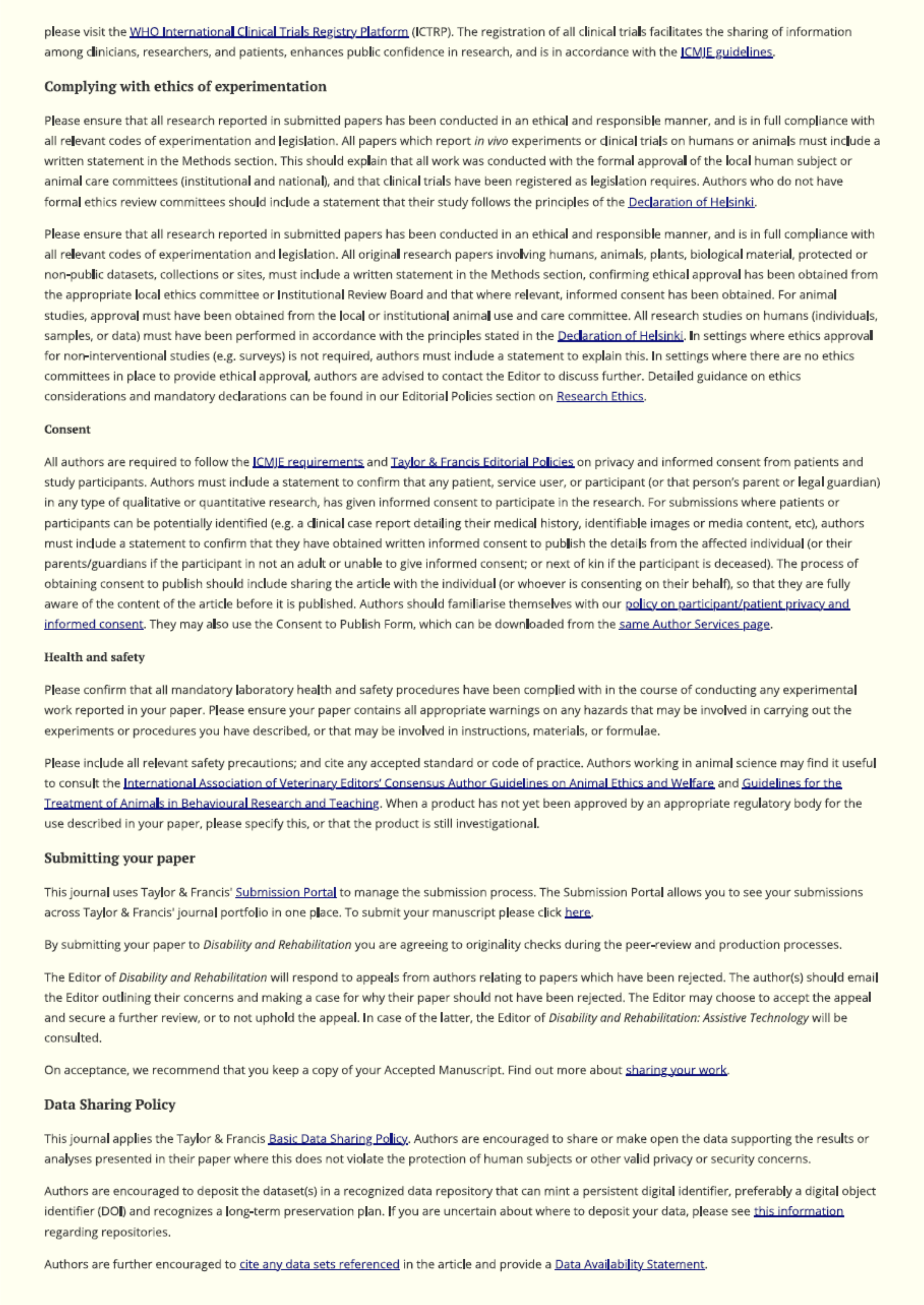

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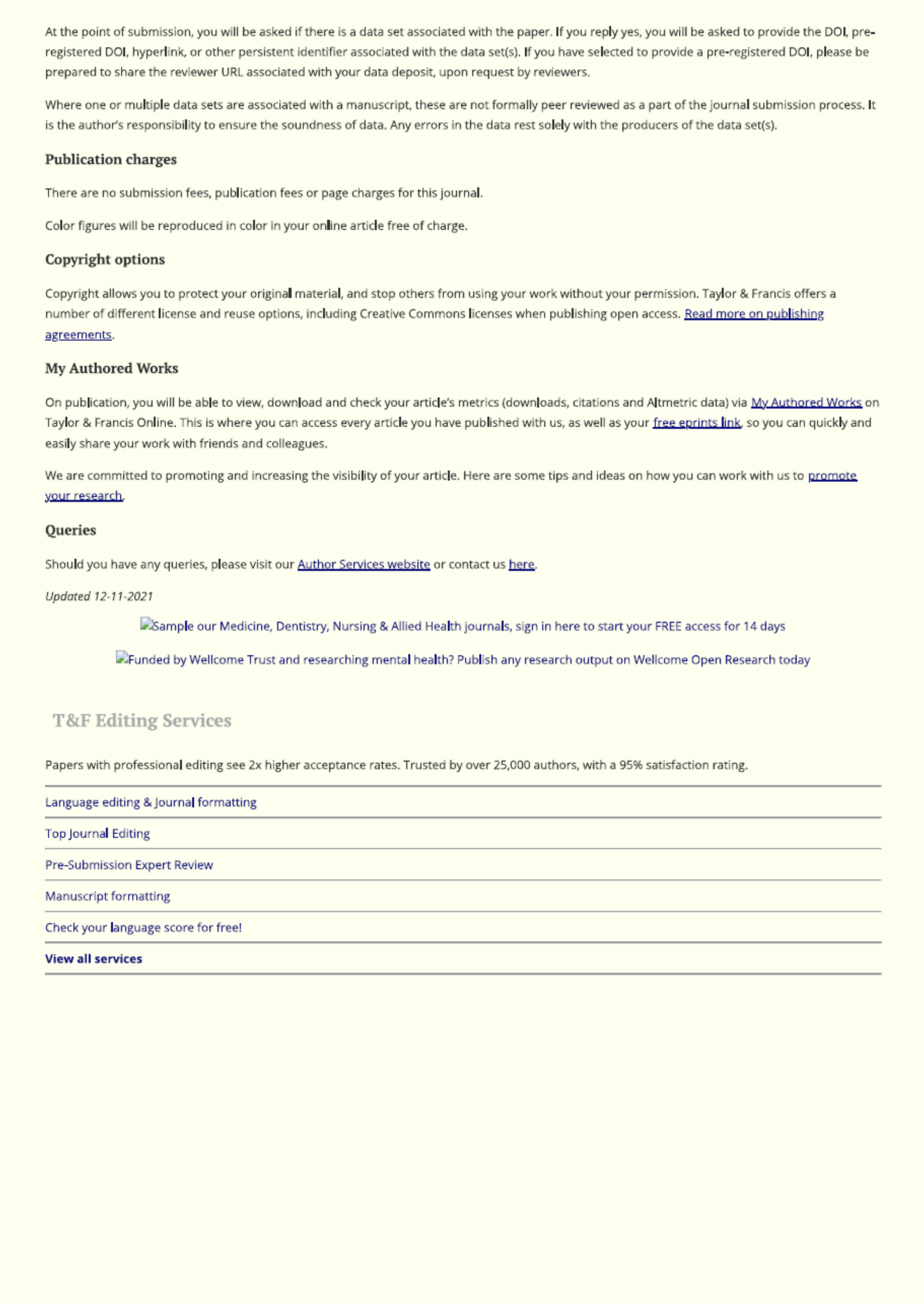

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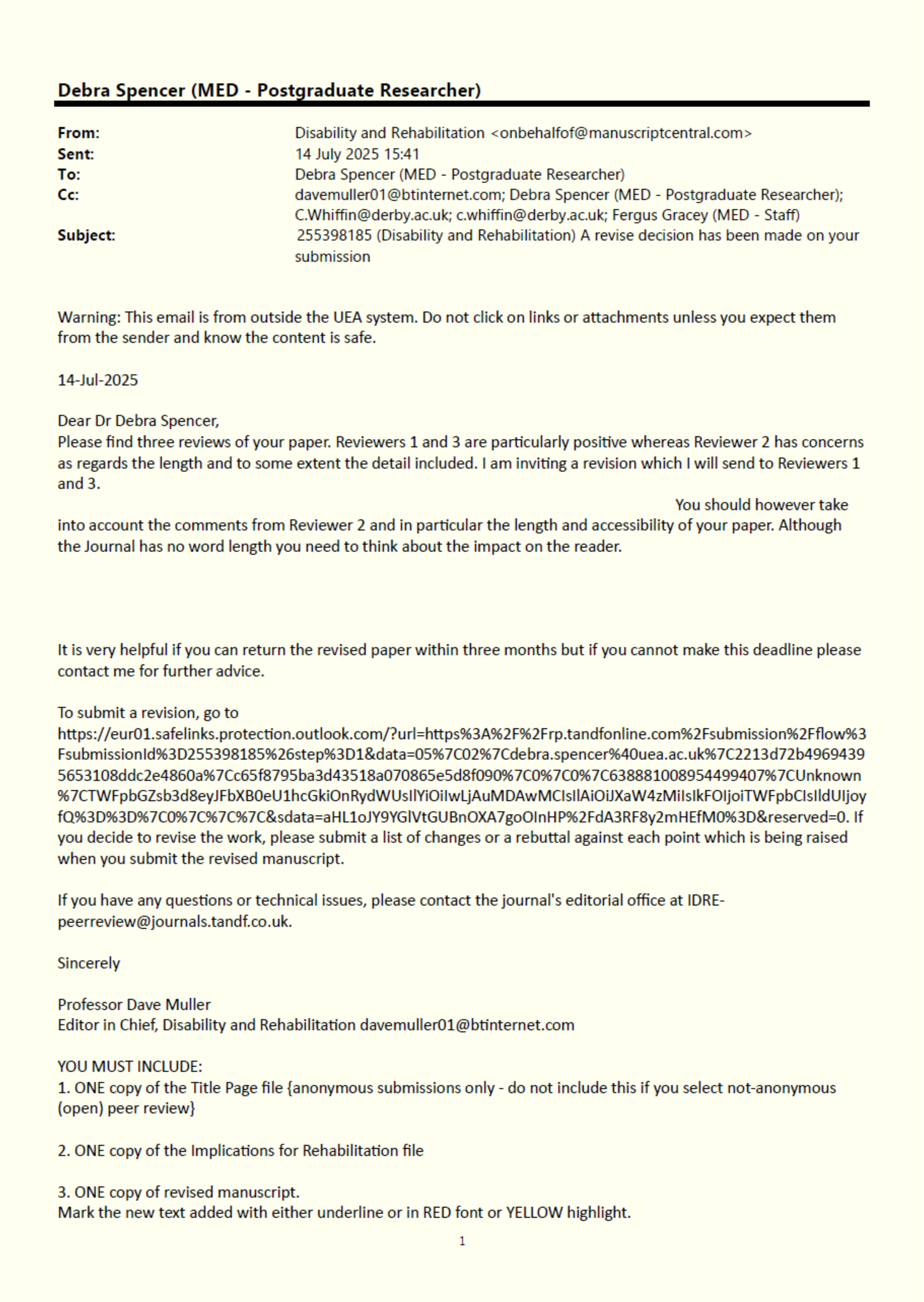
*Updated 12-11-2021*

## **Appendix B.** *Editor's Decision and Reviewers' Feedback on Manuscript Submission*



**Debra Spencer (MED - Postgraduate Researcher)**

**From:** Disability and Rehabilitation <onbehalfof@manuscriptcentral.com>
**Sent:** 14 July 2025 15:41
**To:** Debra Spencer (MED - Postgraduate Researcher)
**Cc:** davemuller01@btinternet.com; Debra Spencer (MED - Postgraduate Researcher); C.Whiffin@derby.ac.uk; c.whiffin@derby.ac.uk; Fergus Gracey (MED - Staff)
**Subject:** 255398185 (Disability and Rehabilitation) A revise decision has been made on your submission

Warning: This email is from outside the UEA system. Do not click on links or attachments unless you expect them from the sender and know the content is safe.

14-Jul-2025

Dear Dr Debra Spencer,
Please find three reviews of your paper. Reviewers 1 and 3 are particularly positive whereas Reviewer 2 has concerns as regards the length and to some extent the detail included. I am inviting a revision which I will send to Reviewers 1 and 3.

You should however take into account the comments from Reviewer 2 and in particular the length and accessibility of your paper. Although the Journal has no word length you need to think about the impact on the reader.

It is very helpful if you can return the revised paper within three months but if you cannot make this deadline please contact me for further advice.

To submit a revision, go to
https://eur01.safelinks.protection.outlook.com/?url=https%3A%2F%2Frp.tandfonline.com%2Fsubmission%2Fflow%3FsubmissionId%3D255398185%26step%3D1&data=05%7C02%7Cdebra.spencer%40uea.ac.uk%7C2213d72b49694395653108ddc2e4860a%7Cc65f8795ba3d43518a070865e5d8f090%7C0%7C0%7C638881008954499407%7CUnknown%7CTWFpbGZsb3d8eyJFbXB0eU1hcGkiOnRydWUsIlYiOiIwLjAuMDAwMCIsIlAiOiJXaW4zMiIsIkFOIjoiTWFpbCIsIldUIjoyfQ%3D%3D%7C0%7C%7C%7C&sdata=aHL1oJY9YGlVtGUBnOXA7goOInHP%2FdA3RF8y2mHEfM0%3D&reserved=0. If you decide to revise the work, please submit a list of changes or a rebuttal against each point which is being raised when you submit the revised manuscript.

If you have any questions or technical issues, please contact the journal's editorial office at IDRE-peerreview@journals.tandf.co.uk.

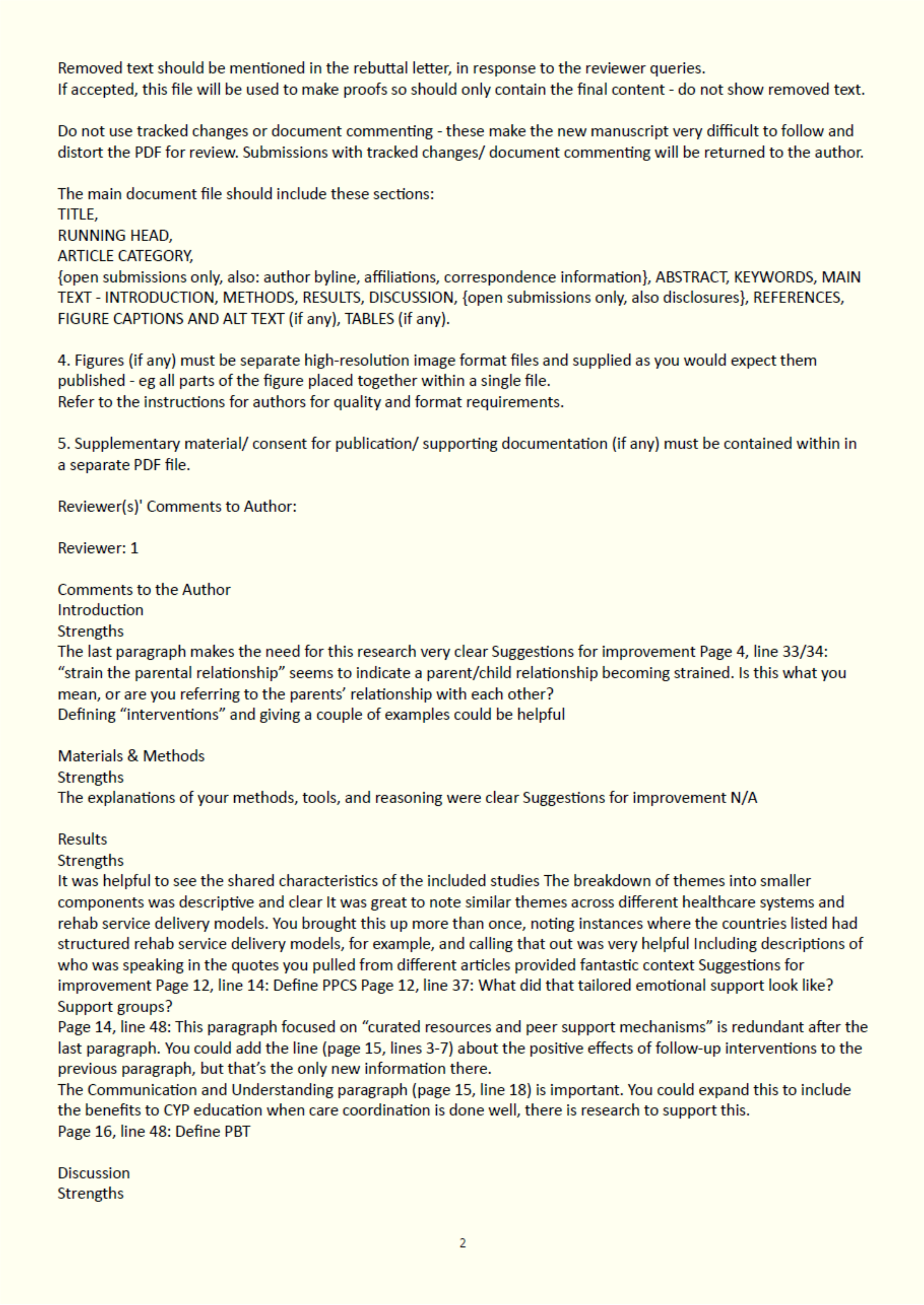
Sincerely

Professor Dave Muller
Editor in Chief, Disability and Rehabilitation davemuller01@btinternet.com

YOU MUST INCLUDE:
1. ONE copy of the Title Page file {anonymous submissions only - do not include this if you select not-anonymous (open) peer review}

2. ONE copy of the Implications for Rehabilitation file

3. ONE copy of revised manuscript.
Mark the new text added with either underline or in RED font or YELLOW highlight.



Removed text should be mentioned in the rebuttal letter, in response to the reviewer queries.
If accepted, this file will be used to make proofs so should only contain the final content - do not show removed text.

Do not use tracked changes or document commenting - these make the new manuscript very difficult to follow and distort the PDF for review. Submissions with tracked changes/ document commenting will be returned to the author.

The main document file should include these sections:
TITLE,
RUNNING HEAD,
ARTICLE CATEGORY,
{open submissions only, also: author byline, affiliations, correspondence information}, ABSTRACT, KEYWORDS, MAIN TEXT - INTRODUCTION, METHODS, RESULTS, DISCUSSION, {open submissions only, also disclosures}, REFERENCES, FIGURE CAPTIONS AND ALT TEXT (if any), TABLES (if any).

4. Figures (if any) must be separate high-resolution image format files and supplied as you would expect them published - eg all parts of the figure placed together within a single file.
Refer to the instructions for authors for quality and format requirements.

5. Supplementary material/ consent for publication/ supporting documentation (if any) must be contained within in a separate PDF file.

Reviewer(s)' Comments to Author:

Reviewer: 1

Comments to the Author
Introduction
Strengths
The last paragraph makes the need for this research very clear Suggestions for improvement Page 4, line 33/34: “strain the parental relationship” seems to indicate a parent/child relationship becoming strained. Is this what you mean, or are you referring to the parents’ relationship with each other?
Defining “interventions” and giving a couple of examples could be helpful

Materials & Methods
Strengths
The explanations of your methods, tools, and reasoning were clear Suggestions for improvement N/A

Results
Strengths
It was helpful to see the shared characteristics of the included studies The breakdown of themes into smaller components was descriptive and clear It was great to note similar themes across different healthcare systems and rehab service delivery models. You brought this up more than once, noting instances where the countries listed had structured rehab service delivery models, for example, and calling that out was very helpful Including descriptions of who was speaking in the quotes you pulled from different articles provided fantastic context Suggestions for improvement Page 12, line 14: Define PPCS Page 12, line 37: What did that tailored emotional support look like? Support groups?
Page 14, line 48: This paragraph focused on “curated resources and peer support mechanisms” is redundant after the last paragraph. You could add the line (page 15, lines 3-7) about the positive effects of follow-up interventions to the previous paragraph, but that’s the only new information there.
The Communication and Understanding paragraph (page 15, line 18) is important. You could expand this to include the benefits to CYP education when care coordination is done well, there is research to support this.
Page 16, line 48: Define PBT

Discussion
Strengths

Expanding on the importance of culturally responsive interventions was good Your limitations were well thought through Suggestions for improvement N/A

Reviewer: 2

Comments to the Author
The topic of this manuscript fits well within the scope of Disability and Rehabilitation. Although this is a comprehensive manuscript with an apparently comprehensive methodology, I believe it requires substantial revisions to improve its readability. At over 12,000 words, the manuscript is overly lengthy, which significantly compromises clarity.

The introduction could more clearly articulate the knowledge gap. The methods section is mostly clear, and the study demonstrates a thorough approach. But I believe it is a missed opportunity to include only studies whose aims focused on developing an intervention aimed at supporting children and young people (CYP) with ABI and/or their families post-injury. This approach excludes studies that do provide valuable insights into parental perspectives on service provision for ABI across different phases and settings (e.g., studies by Jenkin et al., Sullivan et al., Gmelig Meyling et al., Bennet et al.). It is unclear to me why these studies were not included, especially given that the discussion states the current study “offers insights into what parents/carers want from future interventions and what they found valuable about existing ones.” The connection between this statement and the eligibility criteria for included studies is not logically consistent or easy to follow.

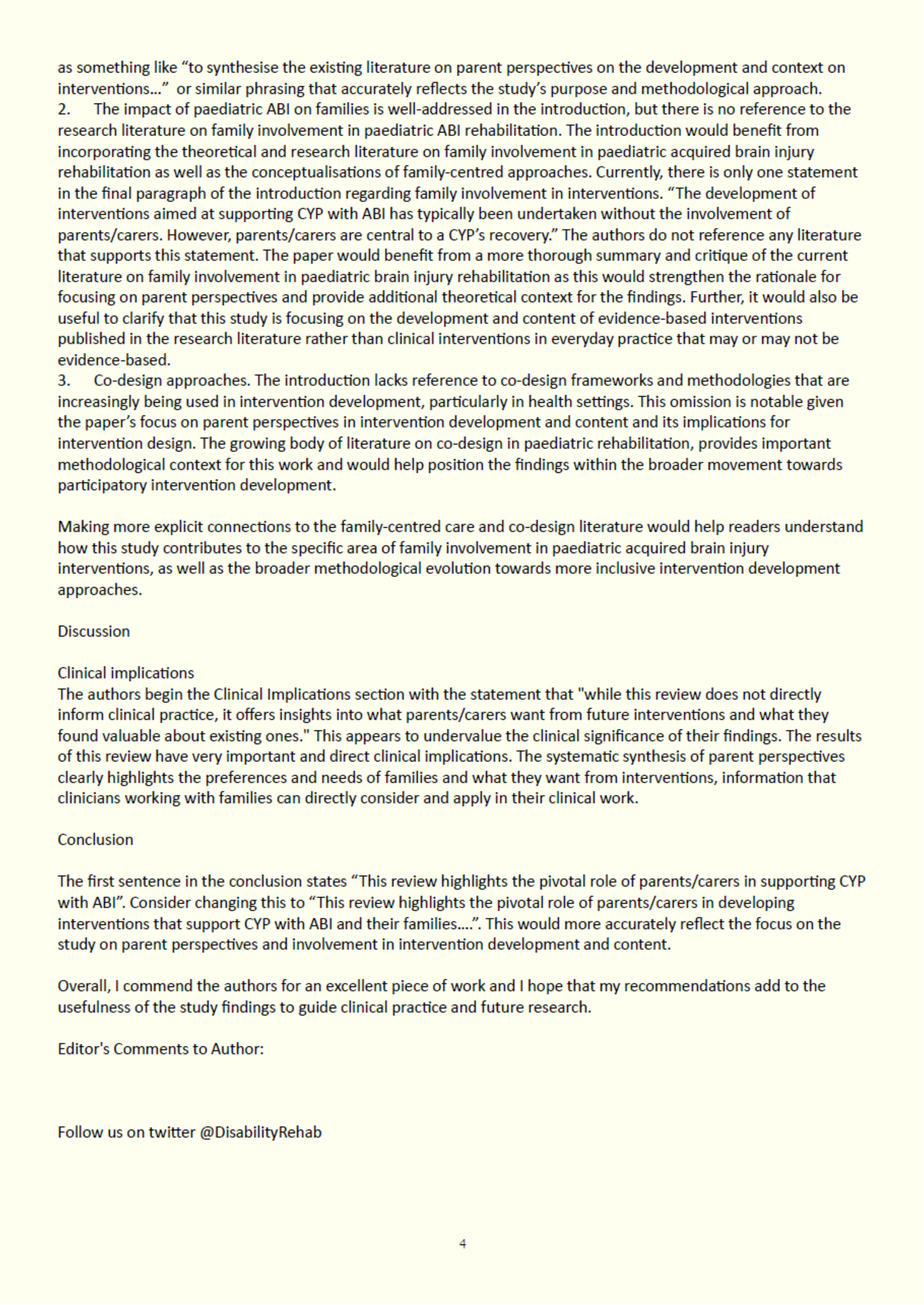
Results: It remains unclear how the final results or themes were derived. I would recommend including a schematic overview of the main themes and how subthemes relate to them to provide insight into the coding process. The themes are currently described in too much detail and are often already interpreted within the results section. For instance, reporting in which country each result was found and including quotes both in the text and in tables contributes to redundancy. To enhance readability, the results section should be presented more concisely. Including eight tables does not seem feasible from a readability perspective.

I would advise the authors to make a clearer distinction between main and supporting findings and to focus more directly on answering the research question.

Reviewer: 3

Comments to the Author
This qualitative scoping review makes a valuable contribution to the literature by systematically examining parent/carer perspectives on the development and content of interventions designed to support children with brain injury and their families. The paper addresses an important gap in understanding what parents want and need from such interventions by providing a synthesis of the existing literature that has valued parent perspectives in intervention development. This paper will provide important insights to inform future intervention design and implementation. Overall, the manuscript is exceptionally well-written and clear, and the methodological approach is thorough and clearly described and justified. However, overall, the paper would benefit from improved clarity on the purpose and focus of the research throughout. I have classified my recommendations as requiring minor revisions as my suggestions focus on a change to the positioning of the work within the broader research context and greater clarity on the purpose of the research rather than a major change to the project methodology and results. I am expecting that this would not be too onerous but would greatly improve the relevance and usability of findings in both clinical practice and future research. These are the areas where minor revisions would strengthen the work:

1. Clarity of study aim. The aim of the study could be more precisely articulated in the introduction. Currently, the authors state that the aim is “Through a process of distilling parents’/carers’ perspectives into actionable recommendations, this review aims to provide clear guidance to healthcare professionals, schools, and policymakers for developing effective interventions aimed at supporting CYP with ABI and their families”. This appears to be more of an intended impact of the study rather than the study’s actual aim. The study’s aim should be more clearly stated



as something like “to synthesise the existing literature on parent perspectives on the development and context on interventions…” or similar phrasing that accurately reflects the study’s purpose and methodological approach.

2. The impact of paediatric ABI on families is well-addressed in the introduction, but there is no reference to the research literature on family involvement in paediatric ABI rehabilitation. The introduction would benefit from incorporating the theoretical and research literature on family involvement in paediatric acquired brain injury rehabilitation as well as the conceptualisations of family-centred approaches. Currently, there is only one statement in the final paragraph of the introduction regarding family involvement in interventions. “The development of interventions aimed at supporting CYP with ABI has typically been undertaken without the involvement of parents/carers. However, parents/carers are central to a CYP’s recovery.” The authors do not reference any literature that supports this statement. The paper would benefit from a more thorough summary and critique of the current literature on family involvement in paediatric brain injury rehabilitation as this would strengthen the rationale for focusing on parent perspectives and provide additional theoretical context for the findings. Further, it would also be useful to clarify that this study is focusing on the development and content of evidence-based interventions published in the research literature rather than clinical interventions in everyday practice that may or may not be evidence-based.
3. Co-design approaches. The introduction lacks reference to co-design frameworks and methodologies that are increasingly being used in intervention development, particularly in health settings. This omission is notable given the paper’s focus on parent perspectives in intervention development and content and its implications for intervention design. The growing body of literature on co-design in paediatric rehabilitation, provides important methodological context for this work and would help position the findings within the broader movement towards participatory intervention development.

Making more explicit connections to the family-centred care and co-design literature would help readers understand how this study contributes to the specific area of family involvement in paediatric acquired brain injury interventions, as well as the broader methodological evolution towards more inclusive intervention development approaches.

## Discussion

### Clinical implications

The authors begin the Clinical Implications section with the statement that "while this review does not directly inform clinical practice, it offers insights into what parents/carers want from future interventions and what they found valuable about existing ones." This appears to undervalue the clinical significance of their findings. The results of this review have very important and direct clinical implications. The systematic synthesis of parent perspectives clearly highlights the preferences and needs of families and what they want from interventions, information that clinicians working with families can directly consider and apply in their clinical work.

## Conclusion

The first sentence in the conclusion states “This review highlights the pivotal role of parents/carers in supporting CYP with ABI”. Consider changing this to “This review highlights the pivotal role of parents/carers in developing interventions that support CYP with ABI and their families….”. This would more accurately reflect the focus on the study on parent perspectives and involvement in intervention development and content.

Overall, I commend the authors for an excellent piece of work and I hope that my recommendations add to the usefulness of the study findings to guide clinical practice and future research.

Editor's Comments to Author:

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## **Appendix C.** *Search Terms Used for MEDLINE Searches*

**Table A1.** *Search Terms Used for MEDLINE Searches*

| Search ID# | Search Terms |
|---|---|
| S1 | TI famil* OR AB famil* |
| S2 | TI relative OR AB relative |
| S3 | TI parent OR AB parent |
| S4 | TI mother OR AB mother |
| S5 | TI father OR AB father |
| S6 | TI carer OR AB carer |
| S7 | TI caregiver OR AB caregiver |
| S8 | (MM “Family”) OR (MM “Parents+”) OR (MM “Caregivers”) |
| S9 | S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 |
| S10 | TI child* OR AB child* |
| S11 | TI adolescent OR AB adolescent |
| S12 | TI youth OR AB youth |
| S13 | TI teen OR AB teen |
| S14 | TI “young person” OR AB “young person” |
| S15 | TI “young people” OR AB “young people” |
| S16 | TI “young adult” OR AB “young adult” |
| S17 | TI toddler OR AB toddler |
| S18 | TI infant OR AB infant |
| S19 | TI preschool* OR AB preschool* |
| S20 | (MM “Infant+”) OR (MM “Child+”) OR (MM “Young Adult”) OR (MM “Adolescent”) |
| S21 | S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 |

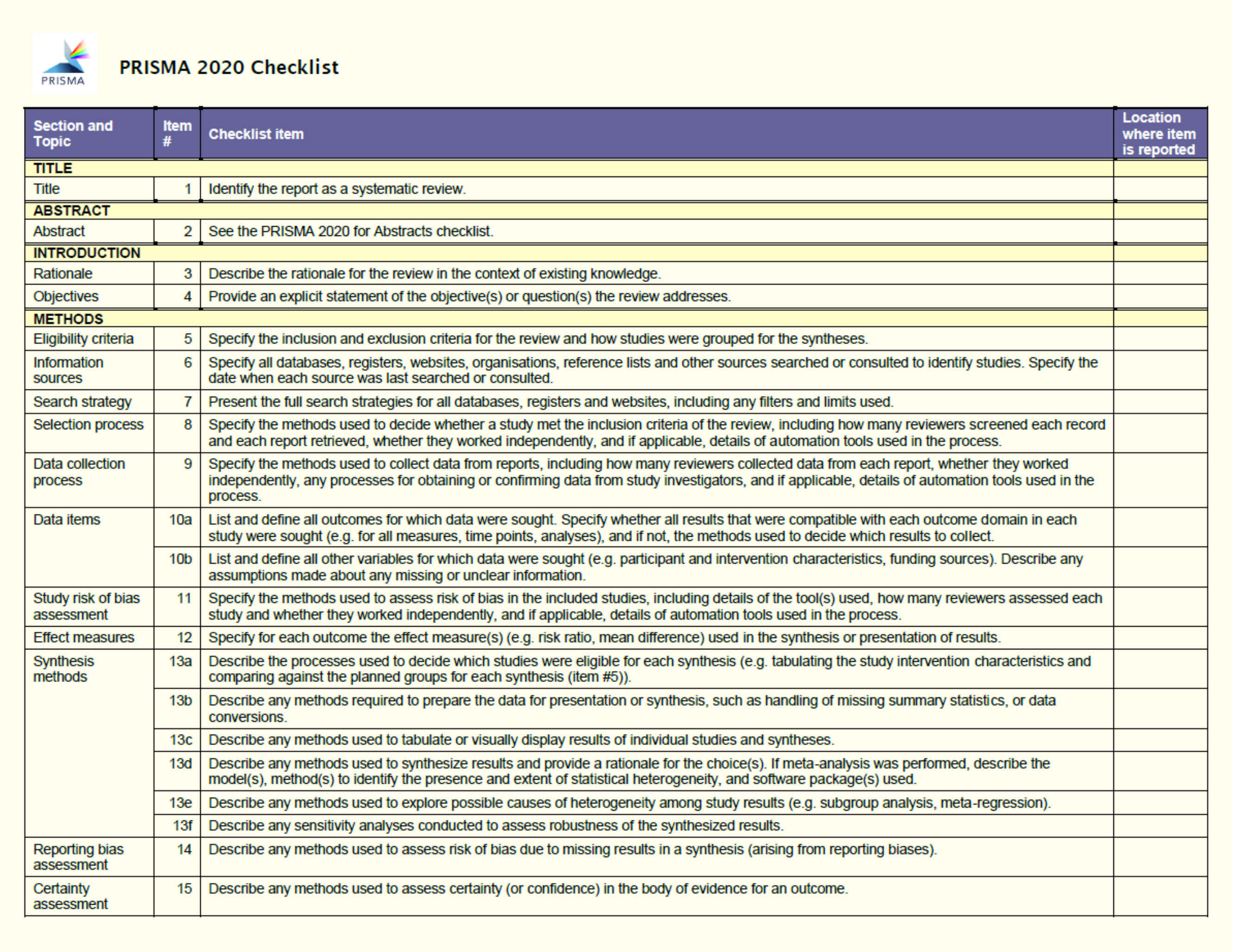
| | |
|---|---|
| S22 | TI “brain injur*” OR AB “brain injur*” |
| S23 | TI “head injur*” OR AB “head injur*” |
| S24 | (MM “Brain Injuries”) OR (MM “Brain Injuries, Traumatic”) OR (MM “Head Injuries, Penetrating”) OR (MM “Brain Injuries, Diffuse”) OR (MM “Head Injuries, Closed”) OR (MM “Craniocerebral Trauma”) |
| S25 | S22 OR S23 OR S24 |
| S26 | TI feasibility OR AB feasibility |
| S27 | TI acceptability OR AB acceptability |
| S28 | TI “case stud*” OR AB “case stud*” |
| S29 | TI ethnograph* OR AB ethnograph* |
| S30 | TI phenomenolog* OR AB phenomenolog* |
| S31 | TI narrative OR AB narrative |
| S32 | TI “grounded theor*” OR AB “grounded theor*” |
| S33 | TI “discourse analys*” OR AB “discourse analys*” |
| S34 | TI “content analys*” OR AB “content analys*” |
| S35 | TI “thematic analys*” OR AB “thematic analys*” |
| S36 | TI “lived experience” OR AB “lived experience” |
| S37 | TI “focus group” OR AB “focus group” |
| S38 | TI questionnaire OR AB questionnaire |
| S39 | TI survey OR AB survey |
| S40 | TI interview OR AB interview |
| S41 | TI observ* OR AB observ* |
| S42 | (MM “Grounded Theory”) OR (MM “Focus Groups”) OR (MM “Feasibility Studies”) OR (MM “Patient Acceptance of Health Care”) |
| S43 | S26 OR S27 OR S28 OR S29 OR S30 OR S31 OR S32 OR S33 OR S34 OR S35 OR S36 OR S37 OR S38 OR S39 OR S40 OR S41 OR S42 |
| S44 | TI qualitative OR AB qualitative |
| S45 | TI mixed method OR AB mixed method |

| | |
|---|---|
| S46 | (MM "Qualitative Research") OR (MM "Hermeneutics") |
| S47 | S44 OR S45 OR S46 |
| S48 | S9 AND S21 AND S25 |
| S49 | S9 AND S21 AND S25 AND S43 |
| S50 | S9 AND S21 AND S25 AND S47 |

*Note*. TI = title; AB = abstract; MM = MeSH term.

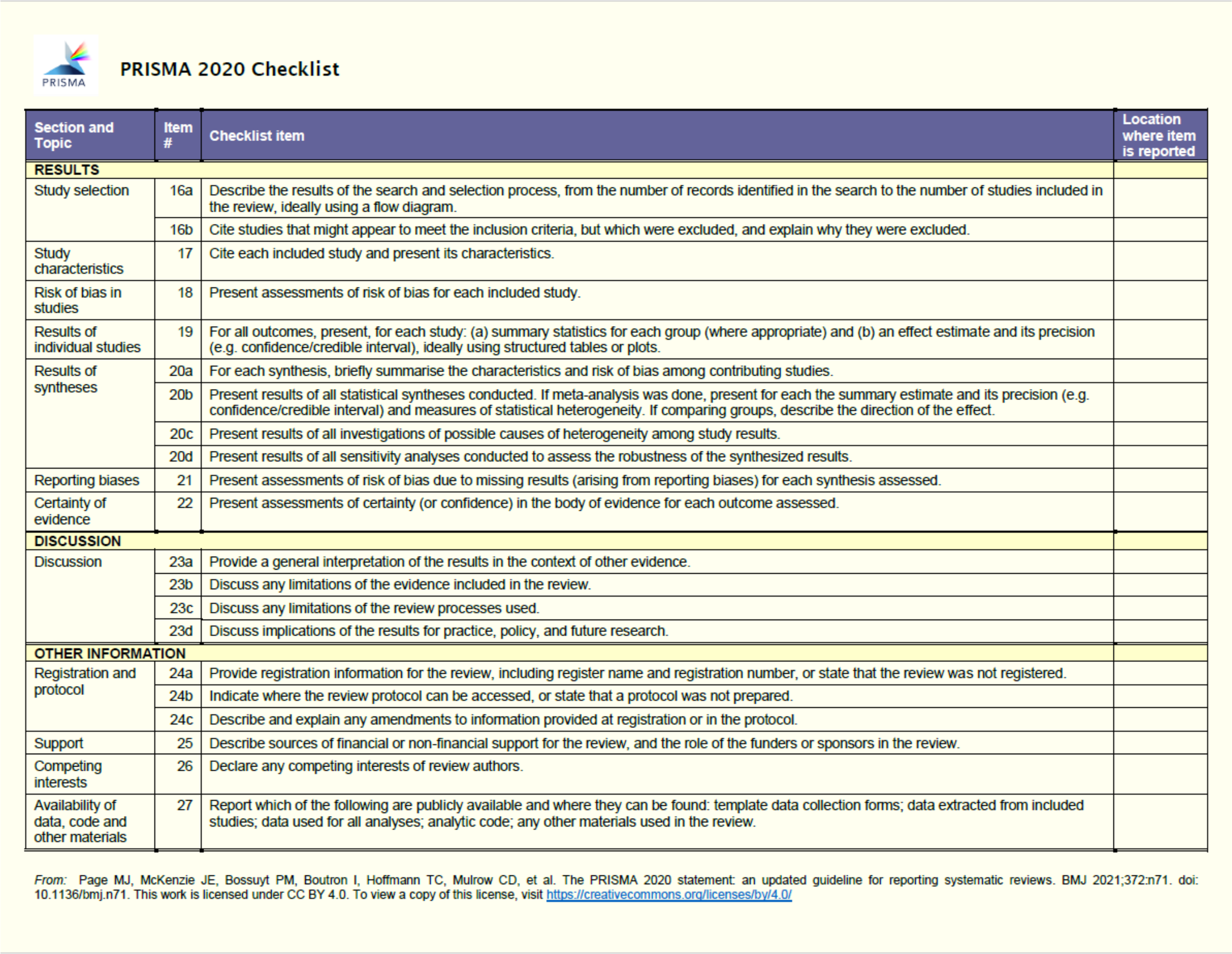
## **Appendix D.** *PRISMA 2020 Checklist*

**Table A2.** *PRISMA 2020 Checklist*



PRISMA 2020 Checklist

| Section and Topic | Item # | Checklist item | Location where item is reported |
|---|---|---|---|
| **TITLE** | | | |
| Title | 1 | Identify the report as a systematic review. | |
| **ABSTRACT** | | | |
| Abstract | 2 | See the PRISMA 2020 for Abstracts checklist. | |
| **INTRODUCTION** | | | |
| Rationale | 3 | Describe the rationale for the review in the context of existing knowledge. | |
| Objectives | 4 | Provide an explicit statement of the objective(s) or question(s) the review addresses. | |
| **METHODS** | | | |
| Eligibility criteria | 5 | Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses. | |
| Information sources | 6 | Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted. | |
| Search strategy | 7 | Present the full search strategies for all databases, registers and websites, including any filters and limits used. | |
| Selection process | 8 | Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process. | |
| Data collection process | 9 | Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process. | |
| Data items | 10a | List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect. | |
| | 10b | List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information. | |
| Study risk of bias assessment | 11 | Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process. | |
| Effect measures | 12 | Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results. | |
| Synthesis methods | 13a | Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)). | |
| | 13b | Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions. | |
| | 13c | Describe any methods used to tabulate or visually display results of individual studies and syntheses. | |
| | 13d | Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used. | |
| | 13e | Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression). | |
| | 13f | Describe any sensitivity analyses conducted to assess robustness of the synthesized results. | |
| Reporting bias assessment | 14 | Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases). | |
| Certainty assessment | 15 | Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome. | |



PRISMA

## PRISMA 2020 Checklist

| Section and Topic | Item # | Checklist item | Location where item is reported |
|---|---|---|---|
| **RESULTS** | | | |
| Study selection | 16a | Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram. | |
| | 16b | Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded. | |
| Study characteristics | 17 | Cite each included study and present its characteristics. | |
| Risk of bias in studies | 18 | Present assessments of risk of bias for each included study. | |
| Results of individual studies | 19 | For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots. | |
| Results of syntheses | 20a | For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies. | |
| | 20b | Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect. | |
| | 20c | Present results of all investigations of possible causes of heterogeneity among study results. | |
| | 20d | Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results. | |
| Reporting biases | 21 | Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed. | |
| Certainty of evidence | 22 | Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed. | |
| **DISCUSSION** | | | |
| Discussion | 23a | Provide a general interpretation of the results in the context of other evidence. | |
| | 23b | Discuss any limitations of the evidence included in the review. | |
| | 23c | Discuss any limitations of the review processes used. | |
| | 23d | Discuss implications of the results for practice, policy, and future research. | |
| **OTHER INFORMATION** | | | |
| Registration and protocol | 24a | Provide registration information for the review, including register name and registration number, or state that the review was not registered. | |
| | 24b | Indicate where the review protocol can be accessed, or state that a protocol was not prepared. | |
| | 24c | Describe and explain any amendments to information provided at registration or in the protocol. | |
| Support | 25 | Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review. | |
| Competing interests | 26 | Declare any competing interests of review authors. | |
| Availability of data, code and other materials | 27 | Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review. | |

*From:* Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71.

## **Appendix E.** *Quality Assessment Criteria*

CASP
Critical Appraisal
Skills Programme

www.casp-uk.net
info@casp-uk.net
Summertown Pavilion, Middle
Way Oxford OX2 7LG

**CASP Checklist:** 10 questions to help you make sense of a **Qualitative** research

**How to use this appraisal tool:** Three broad issues need to be considered when appraising a qualitative study:

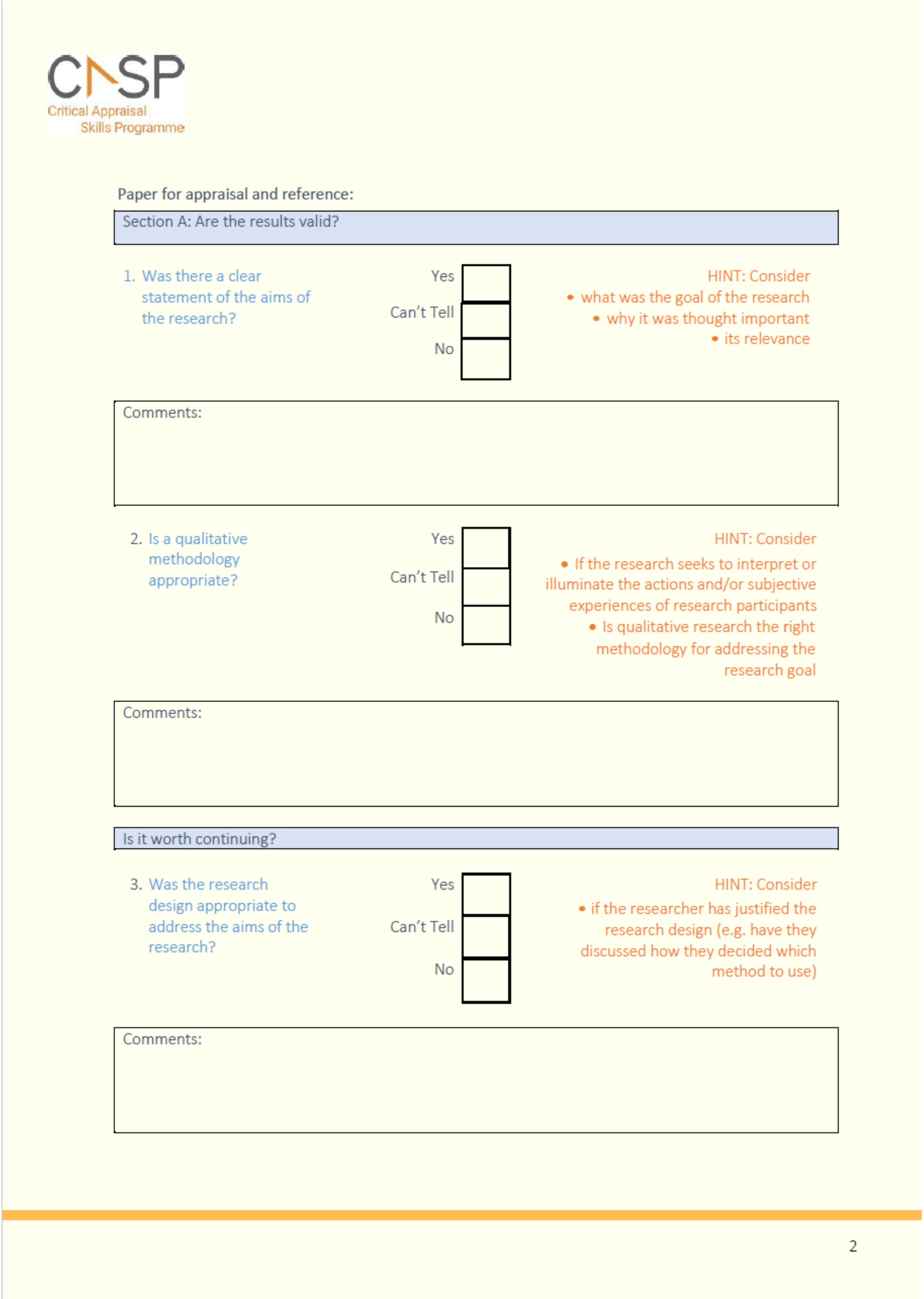
- Are the results of the study valid? (Section A)
- What are the results? (Section B)
- Will the results help locally? (Section C)

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is "yes", it is worth proceeding with the remaining questions. There is some degree of overlap between the questions, you are asked to record a "yes", "no" or "can't tell" to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

**About:** These checklists were designed to be used as educational pedagogic tools, as part of a workshop setting, therefore we do not suggest a scoring system. The core CASP checklists (randomised controlled trial & systematic review) were based on JAMA 'Users' guides to the medical literature 1994 (adapted from Guyatt GH, Sackett DL, and Cook DJ), and piloted with health care practitioners.

For each new checklist, a group of experts were assembled to develop and pilot the checklist and the workshop format with which it would be used. Over the years overall adjustments have been made to the format, but a recent survey of checklist users reiterated that the basic format continues to be useful and appropriate.

**Referencing:** we recommend using the Harvard style citation, i.e.: *Critical Appraisal Skills Programme (2018). CASP (insert name of checklist i.e. Qualitative) Checklist. [online] Available at: URL. Accessed: Date Accessed.*



CASP
Critical Appraisal
Skills Programme

Paper for appraisal and reference:

**Section A: Are the results valid?**

1. Was there a clear statement of the aims of the research?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- what was the goal of the research
- why it was thought important
- its relevance

Comments:

2. Is a qualitative methodology appropriate?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
- Is qualitative research the right methodology for addressing the research goal

Comments:

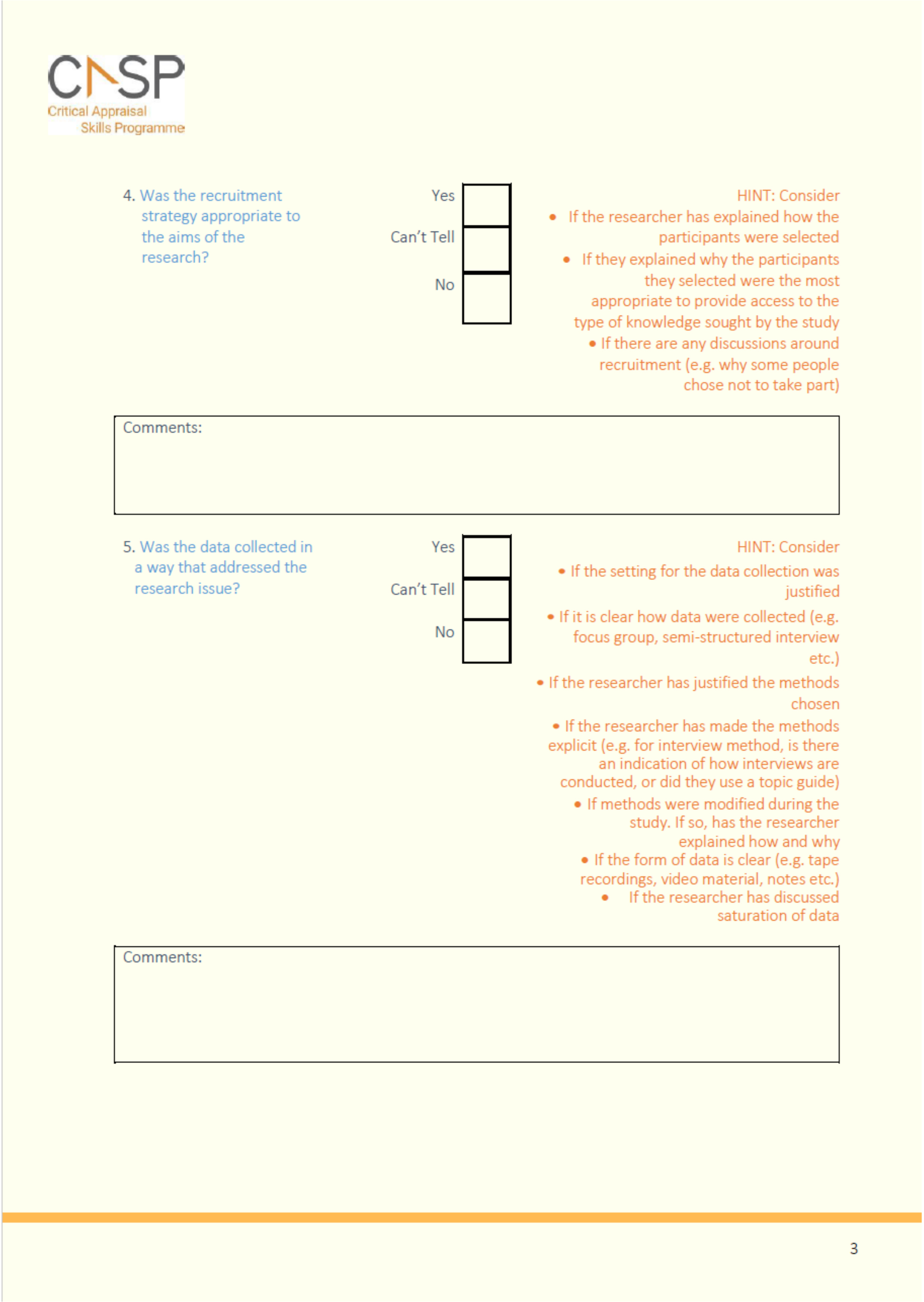
**Is it worth continuing?**

3. Was the research design appropriate to address the aims of the research?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- if the researcher has justified the research design (e.g. have they discussed how they decided which method to use)

Comments:



CASP
Critical Appraisal
Skills Programme

4. Was the recruitment strategy appropriate to the aims of the research?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g. why some people chose not to take part)

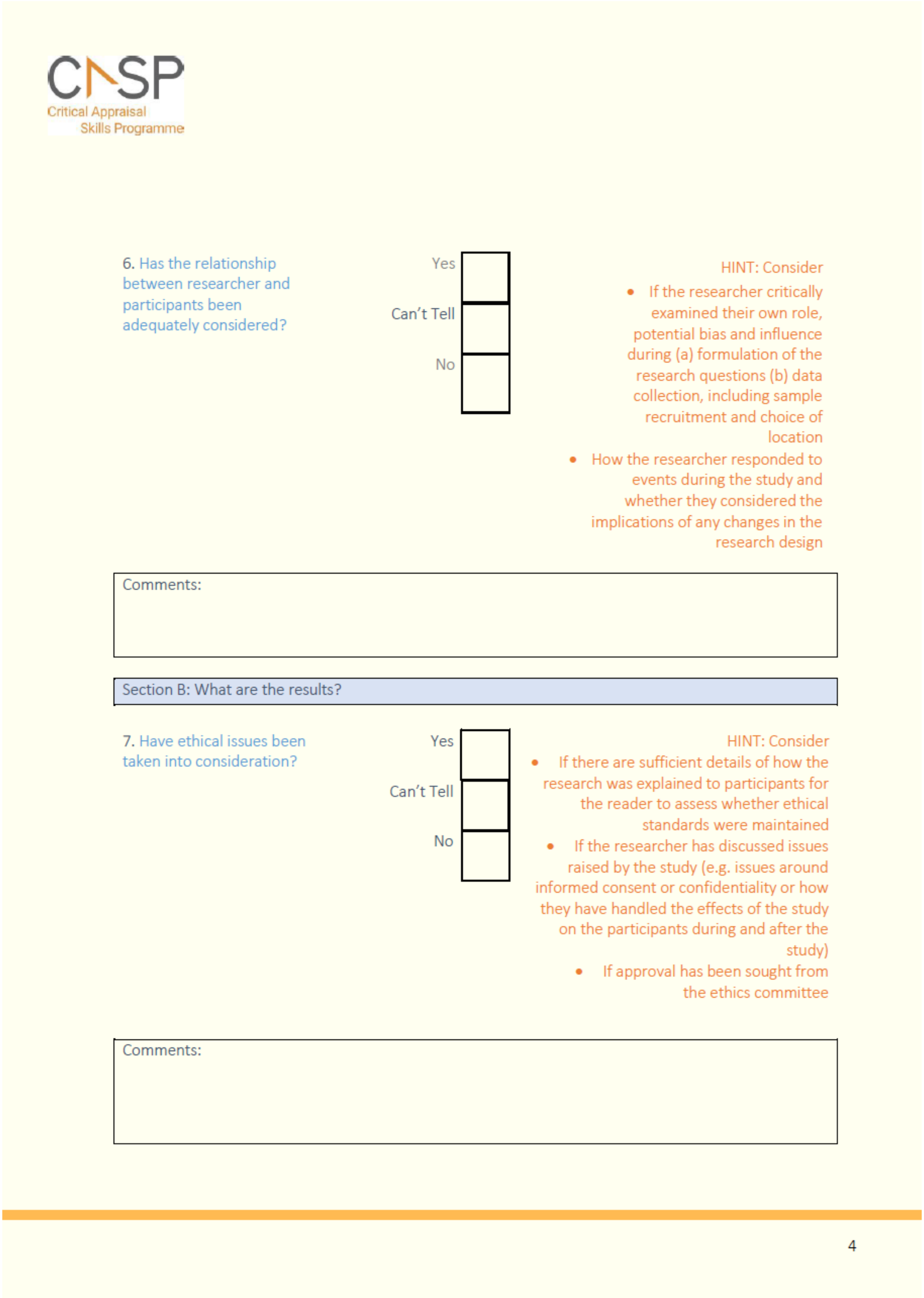
Comments:

5. Was the data collected in a way that addressed the research issue?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the setting for the data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)
- If methods were modified during the study. If so, has the researcher explained how and why
- If the form of data is clear (e.g. tape recordings, video material, notes etc.)
- If the researcher has discussed saturation of data

Comments:



CASP
Critical Appraisal
Skills Programme

6. Has the relationship between researcher and participants been adequately considered?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

Comments:

Section B: What are the results?

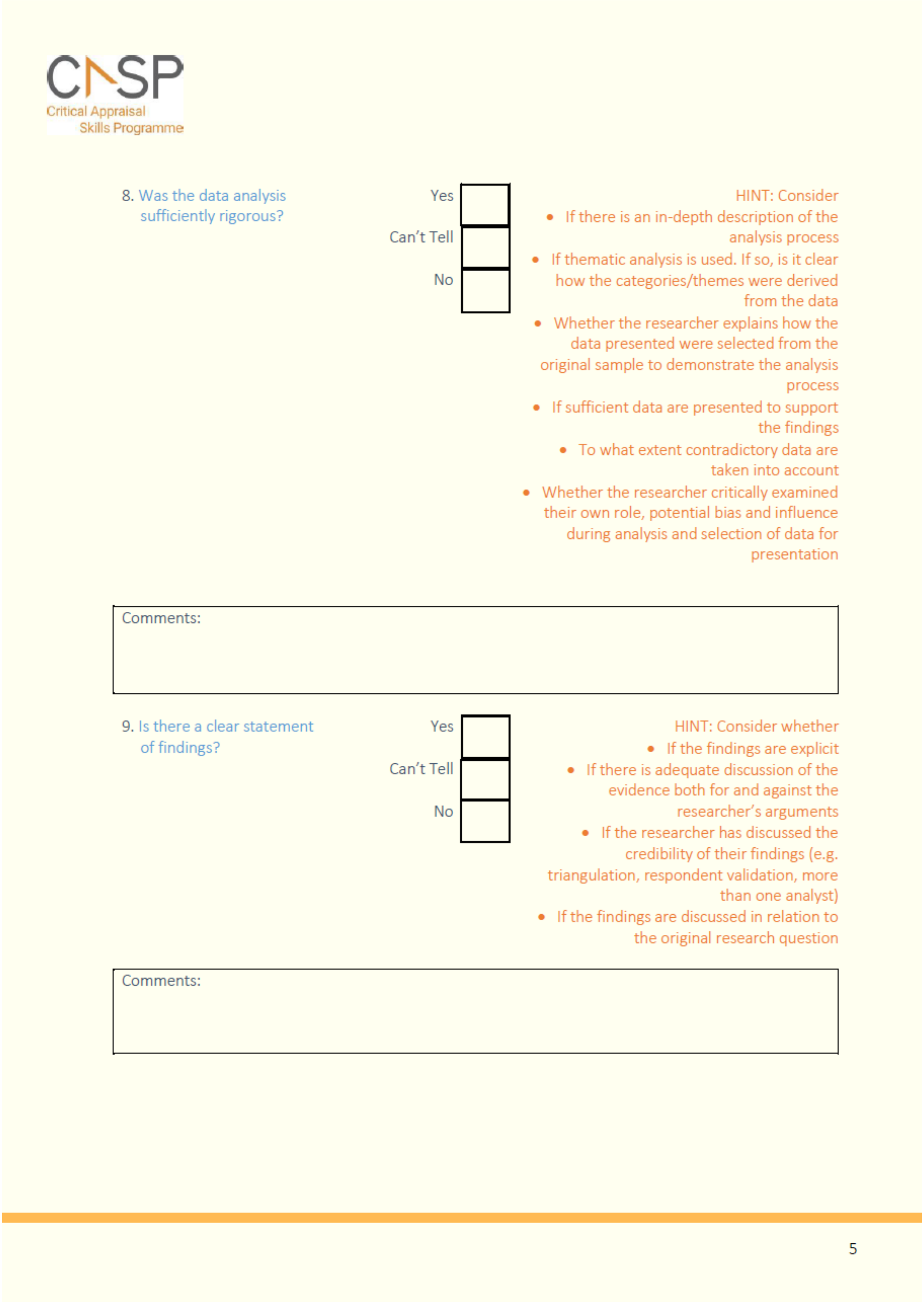
7. Have ethical issues been taken into consideration?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

Comments:

4



CASP
Critical Appraisal
Skills Programme

8. Was the data analysis sufficiently rigorous?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

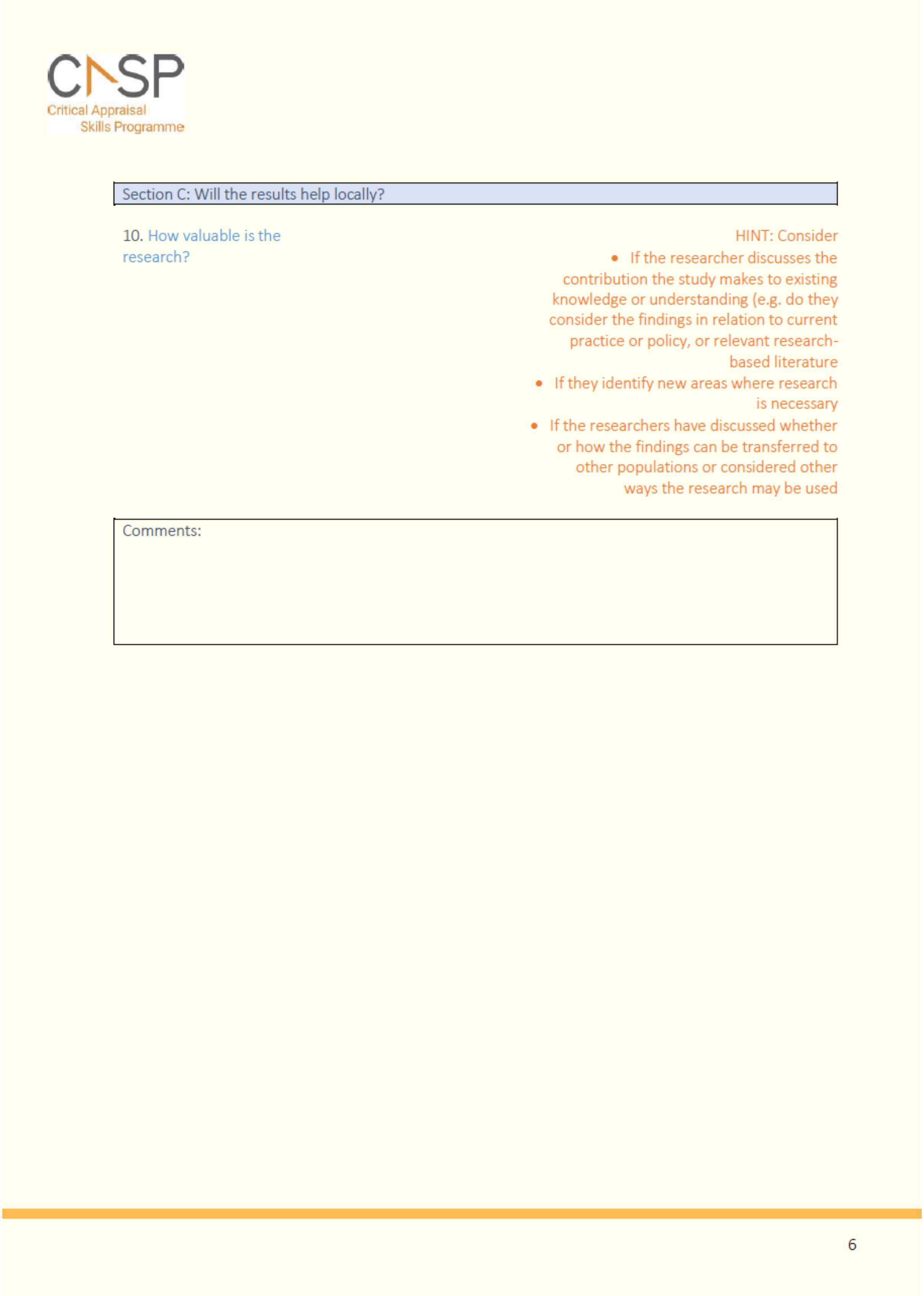
Comments:

9. Is there a clear statement of findings?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider whether
- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researcher's arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

Comments:



CASP
Critical Appraisal
Skills Programme

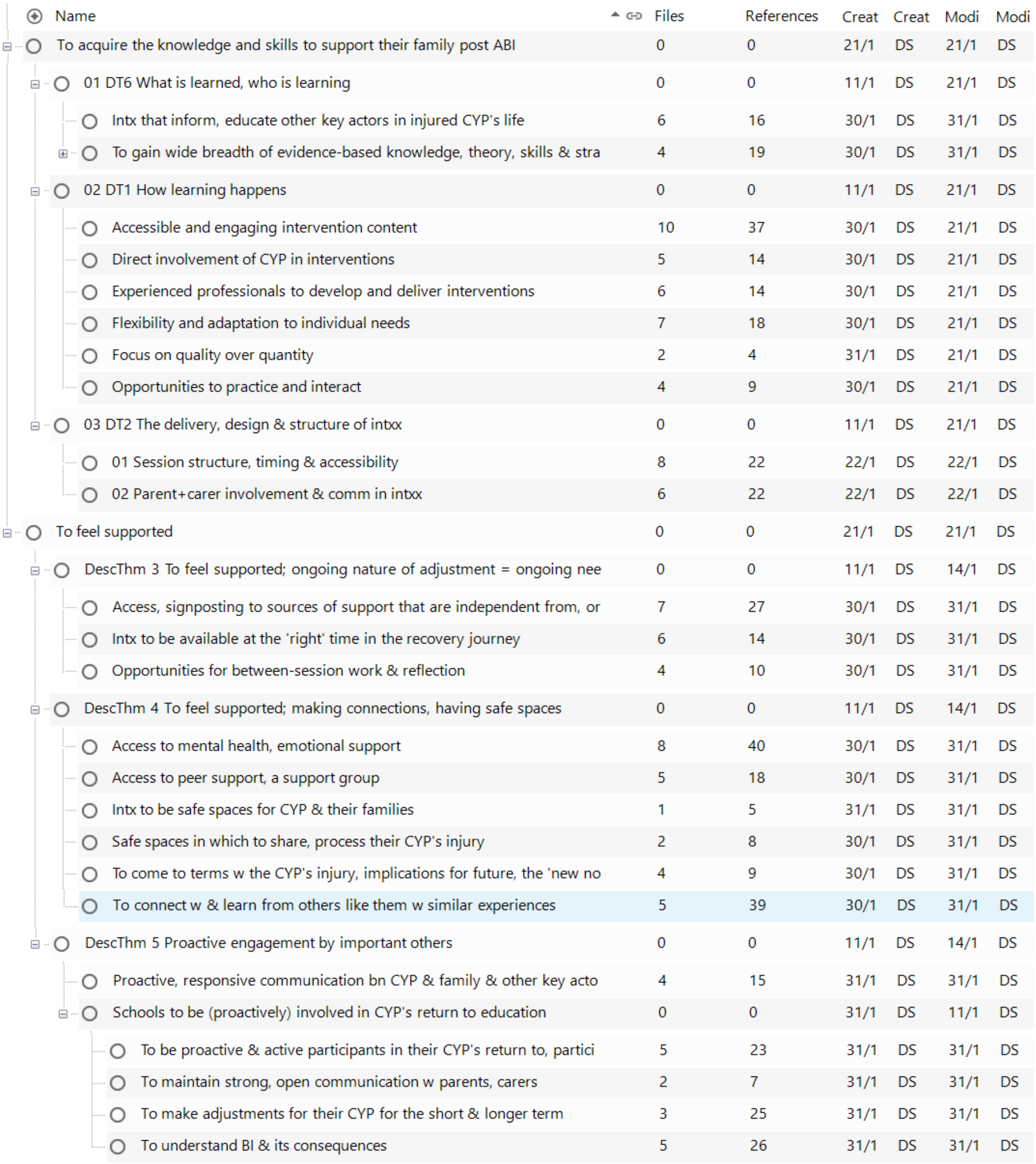
## Section C: Will the results help locally?

10. How valuable is the research?

HINT: Consider
- If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Comments:

## **Appendix F.** *Snapshot of NVivo Codebook during Stage 3 of Analysis*



| Name | Files | References | Creat | Creat | Modi | Modi |
|---|---|---|---|---|---|---|
| To acquire the knowledge and skills to support their family post ABI | 0 | 0 | 21/1 | DS | 21/1 | DS |
| 01 DT6 What is learned, who is learning | 0 | 0 | 11/1 | DS | 21/1 | DS |
| Intx that inform, educate other key actors in injured CYP's life | 6 | 16 | 30/1 | DS | 31/1 | DS |
| To gain wide breadth of evidence-based knowledge, theory, skills & stra | 4 | 19 | 30/1 | DS | 31/1 | DS |
| 02 DT1 How learning happens | 0 | 0 | 11/1 | DS | 21/1 | DS |
| Accessible and engaging intervention content | 10 | 37 | 30/1 | DS | 21/1 | DS |
| Direct involvement of CYP in interventions | 5 | 14 | 30/1 | DS | 21/1 | DS |
| Experienced professionals to develop and deliver interventions | 6 | 14 | 30/1 | DS | 21/1 | DS |
| Flexibility and adaptation to individual needs | 7 | 18 | 30/1 | DS | 21/1 | DS |
| Focus on quality over quantity | 2 | 4 | 31/1 | DS | 21/1 | DS |
| Opportunities to practice and interact | 4 | 9 | 30/1 | DS | 21/1 | DS |
| 03 DT2 The delivery, design & structure of intxx | 0 | 0 | 11/1 | DS | 21/1 | DS |
| 01 Session structure, timing & accessibility | 8 | 22 | 22/1 | DS | 22/1 | DS |
| 02 Parent+carer involvement & comm in intxx | 6 | 22 | 22/1 | DS | 22/1 | DS |
| To feel supported | 0 | 0 | 21/1 | DS | 21/1 | DS |
| DescThm 3 To feel supported; ongoing nature of adjustment = ongoing nee | 0 | 0 | 11/1 | DS | 14/1 | DS |
| Access, signposting to sources of support that are independent from, or | 7 | 27 | 30/1 | DS | 31/1 | DS |
| Intx to be available at the 'right' time in the recovery journey | 6 | 14 | 30/1 | DS | 31/1 | DS |
| Opportunities for between-session work & reflection | 4 | 10 | 30/1 | DS | 31/1 | DS |
| DescThm 4 To feel supported; making connections, having safe spaces | 0 | 0 | 11/1 | DS | 14/1 | DS |
| Access to mental health, emotional support | 8 | 40 | 30/1 | DS | 31/1 | DS |
| Access to peer support, a support group | 5 | 18 | 30/1 | DS | 31/1 | DS |
| Intx to be safe spaces for CYP & their families | 1 | 5 | 31/1 | DS | 31/1 | DS |
| Safe spaces in which to share, process their CYP's injury | 2 | 8 | 30/1 | DS | 31/1 | DS |
| To come to terms w the CYP's injury, implications for future, the 'new no | 4 | 9 | 30/1 | DS | 31/1 | DS |
| To connect w & learn from others like them w similar experiences | 5 | 39 | 30/1 | DS | 31/1 | DS |
| DescThm 5 Proactive engagement by important others | 0 | 0 | 11/1 | DS | 14/1 | DS |
| Proactive, responsive communication bn CYP & family & other key acto | 4 | 15 | 31/1 | DS | 31/1 | DS |
| Schools to be (proactively) involved in CYP's return to education | 0 | 0 | 31/1 | DS | 11/1 | DS |
| To be proactive & active participants in their CYP's return to, partici | 5 | 23 | 31/1 | DS | 31/1 | DS |
| To maintain strong, open communication w parents, carers | 2 | 7 | 31/1 | DS | 31/1 | DS |
| To make adjustments for their CYP for the short & longer term | 3 | 25 | 31/1 | DS | 31/1 | DS |
| To understand BI & its consequences | 5 | 26 | 31/1 | DS | 31/1 | DS |

## **Appendix G.** *Strategies to improve understanding, communication, and support for families of CYP with ABI*

**Table A3.** *Strategies to improve understanding, communication, and support for families of CYP with ABI*

| Key strategy | Description | Illustrative quotes |
|---|---|---|
| Proactive and responsive communication | Consistent, open dialogue with healthcare providers and educators to address CYP's evolving needs, particularly during transitions such as returning to school | "*There should have been some direct communication between hospital and school. School knew nothing about what had happened or what should be in place*" (parent of CYP with ABI; Bennett et al., 2023, p. 633). |
| Tailored educational support | Adjustments such as reduced hours, regular breaks, counselling, and exam accommodations to meet the unique academic and emotional needs of CYP with ABI | "*I would've liked teachers to follow the advice of the clinical psychologist report, by giving [CYP] time to process the subject matter... and understand how fatigued he would be*" (parent of CYP with ABI; Bennett et al., 2023, p. 631). |
| Sustained long-term adjustments | Ensuring schools maintain accommodations over time rather than reverting to pre-injury expectations | "*Take note and implement recommendations from the [Brain Injury Specialist] and parents, and… maintain these over the long term… [don't] forget them after the first few weeks*" (parent of CYP with ABI; Bennett et al., 2023, p. 629). |
| Recognising hidden challenges | Raising awareness among educators and peers about the invisible nature of ABI and its cognitive, emotional, and physical impacts | "*The tumor was just the tip of the iceberg… [late effects were] a lot harder to deal with as you're fighting something that's invisible*" (parent of PBT survivor; Raj et al., 2018, p. 191). |
| Investing in training and awareness | Providing educators with training to better understand ABI and its long-term effects on CYP | "*Until the brain injury specialist went into school, they were clueless... I think it's easy for them to forget that because he looks ok doesn't mean the ABI isn't there*" (parent of CYP with ABI; Bennett et al., 2023, p. 634). |

## **Appendix H.** *Knowledge and skills parents/carers seek to support family functioning and educate others*

**Table A4.** *Knowledge and skills parents/carers seek to support family functioning and educate others*

| Focus area | Key knowledge and skills | Illustrative quotes |
|---|---|---|
| Supporting family functioning | Tools for managing conflict and navigating shifting family dynamics; strategies to improve communication and address trauma or grief | "*As a family we had zero support… we all were traumatised with it, but there was no one that came to us. We had to go and pay people to assist us as [a] family, because it made an impact on our lives as well*" (mother of teenage boy with TBI; Jacobs-Nzuzi Khuabi et al., 2019, p. 9). |
| Empowering parents/carers | Advocacy strategies for navigating systems (e.g., education, healthcare); positive parenting techniques that balance independence with discipline; self-care strategies to manage stress, build resilience, and sustain ability to support CYP | "*We've got [a] common language when we try and talk to her about social situations*" (female caregiver of 12-year-old girl with ABI; Gilmore et al., 2023, p. 4). |
| Educating others about ABI | Raising awareness of ABI's invisible challenges to reduce stigma; providing structured resources for teachers, peers, and extended family | "*Our biggest problem has been getting people to take my child's challenges seriously, because she does not look disabled*" (parent of PBT survivor; Raj et al., 2018, p. 191). |

## **Appendix I.** *Key components of effective learning and engagement in interventions*

**Table A5.** *Key components of effective learning and engagement in interventions*

| Key component | Description | Examples with illustrative quotes |
|---|---|---|
| Knowledgeable professionals | Clinicians who are empathetic, knowledgeable, and skilled at building trust, offering clear guidance, and tailoring interventions to family needs | Clinicians skilled at addressing family concerns: "*I think, afterwards, you'll have a lot of questions, and having somebody to be able to ask those questions to and give you the comfort that there is support…*" (mother of 15-year-old stroke survivor; Drake et al., 2024, p. 10). |
| Parent/carer involvement in intervention design | Opportunities for parents/carers to participate in developing and shaping interventions to meet family needs | Collaborative design process: "*I found it exciting to be a part of it. And when we've mentioned something, it's been taken care of, so it's worked out well*" (father of teenage girl with ABI; Svendsen et al., 2023, p. 6). |
| Flexible delivery | Interventions that accommodate individual family needs, allowing participants to engage at their own pace | Self-paced design enabling flexibility: "*You could have as much or as little... you can pick up where you left off. So you can consume it all at once in large chunks, or you can consume it in small chunks*" (mother of 16-year-old with TBI; Drake et al., 2024, p. 8). |
| Engaging and accessible content | Use of tools such as visual aids, interactive apps, and personalised activities to ensure clarity and relevance to CYP and families | Annotated slides and personalised activities: "*I love a slideshow, haha, especially with the annotating in it … when you see your ideas written down you feel more engaged*" (Al-Hakeem et al., 2024, p. 222). |
| Practical learning opportunities | Approaches that combine theory with hands-on application during sessions and at home, such as role-plays and interactive exercises | Role-plays to apply theory: "*I think it's important to have like the theory and then try to apply it … briefly in the moment and then… [during] the week, I think that's a good model to use*" (mother of 13-year-old girl with PPCS; Al-Hakeem et al., 2024, p. 223). |
| Active CYP involvement | Including CYP in planning and goal-setting to ensure interventions are meaningful and encourage participation | Collaborative planning with CYP: "*It was very important to us… to include [CYP] in the team… it [was] important to focus on something… important to him*" (father of teenage boy with ABI; Svendsen et al., 2023, p. 7). |

**Appendix J.** *Author Guidelines for Journal of Health Psychology*

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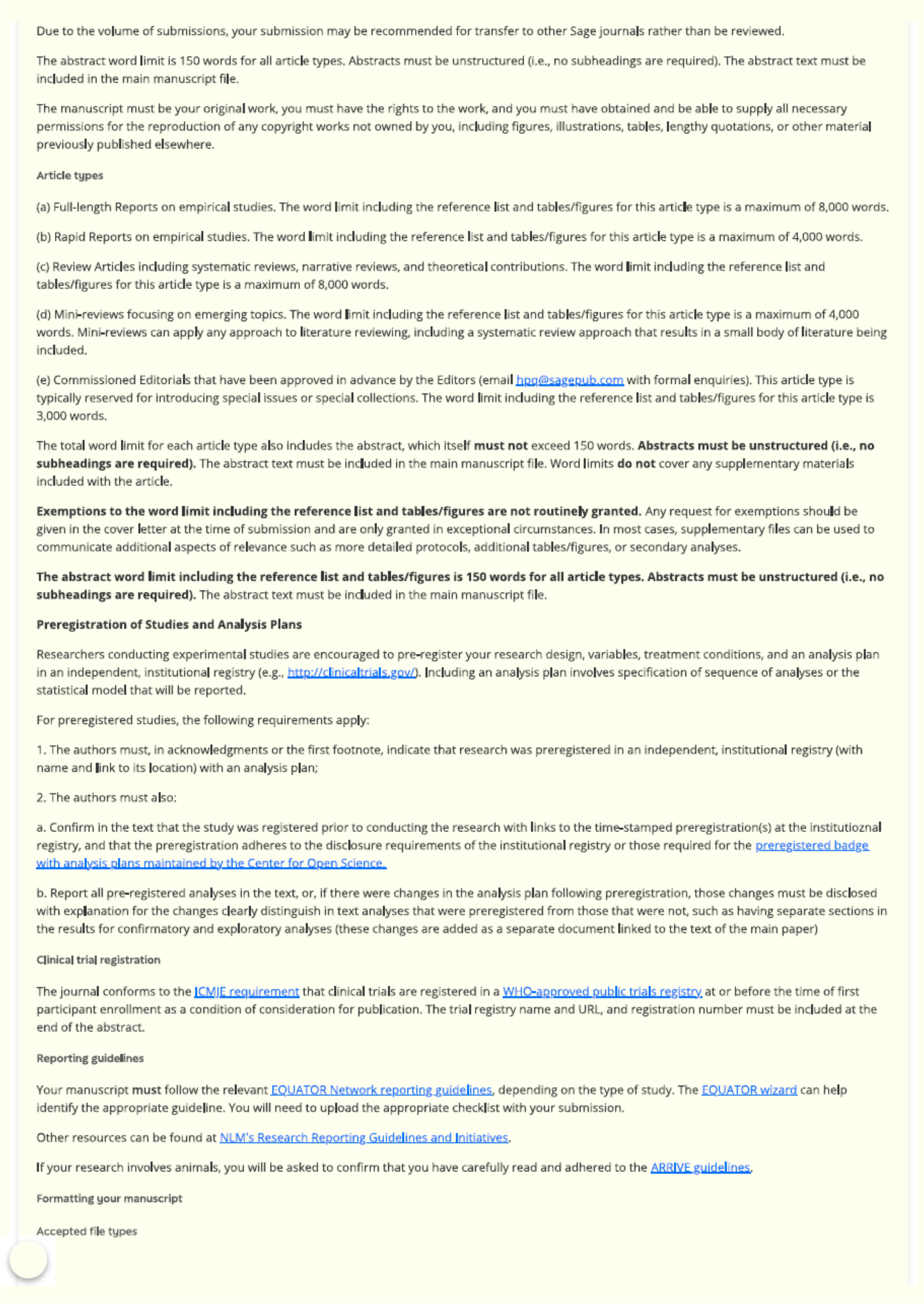

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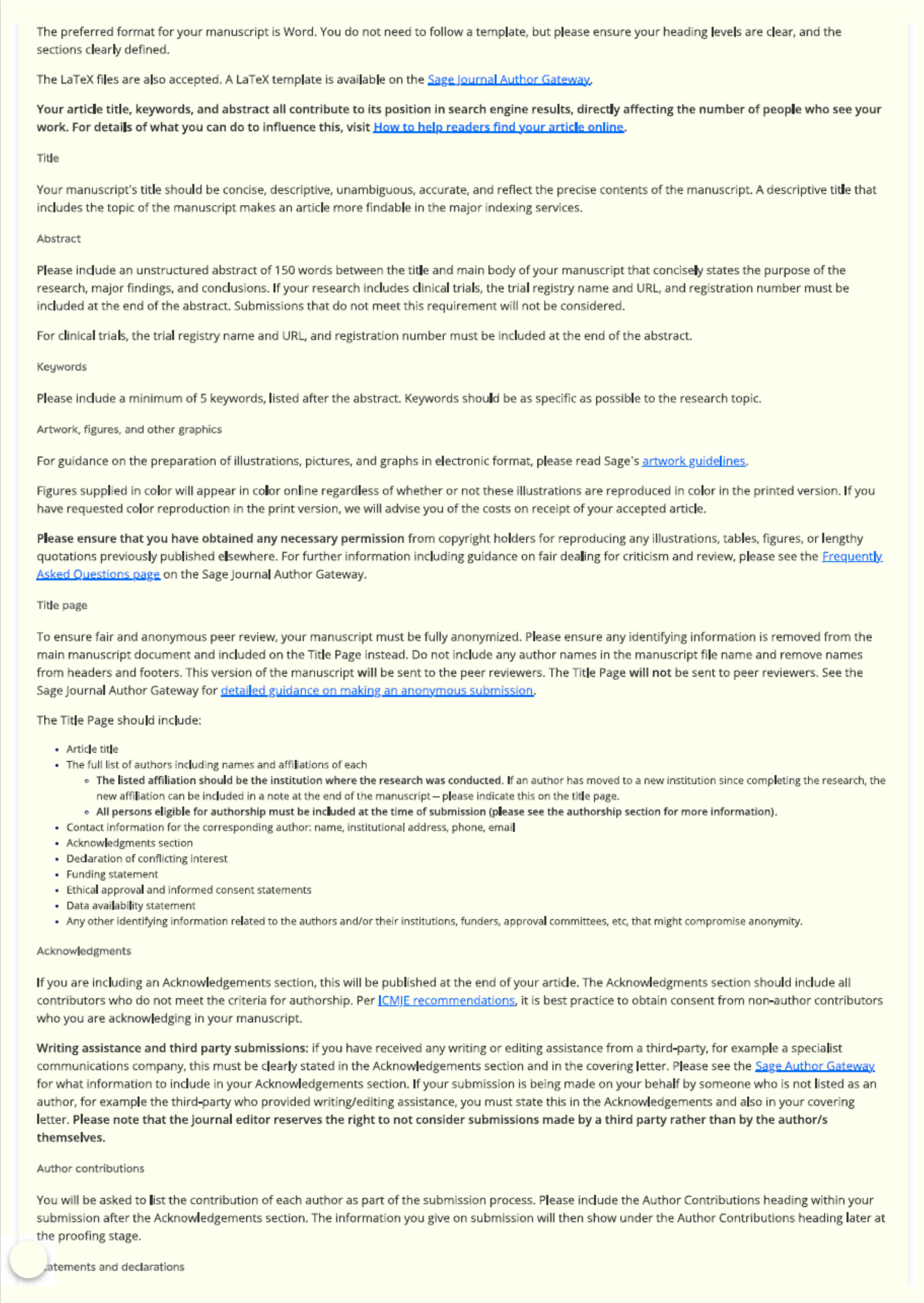

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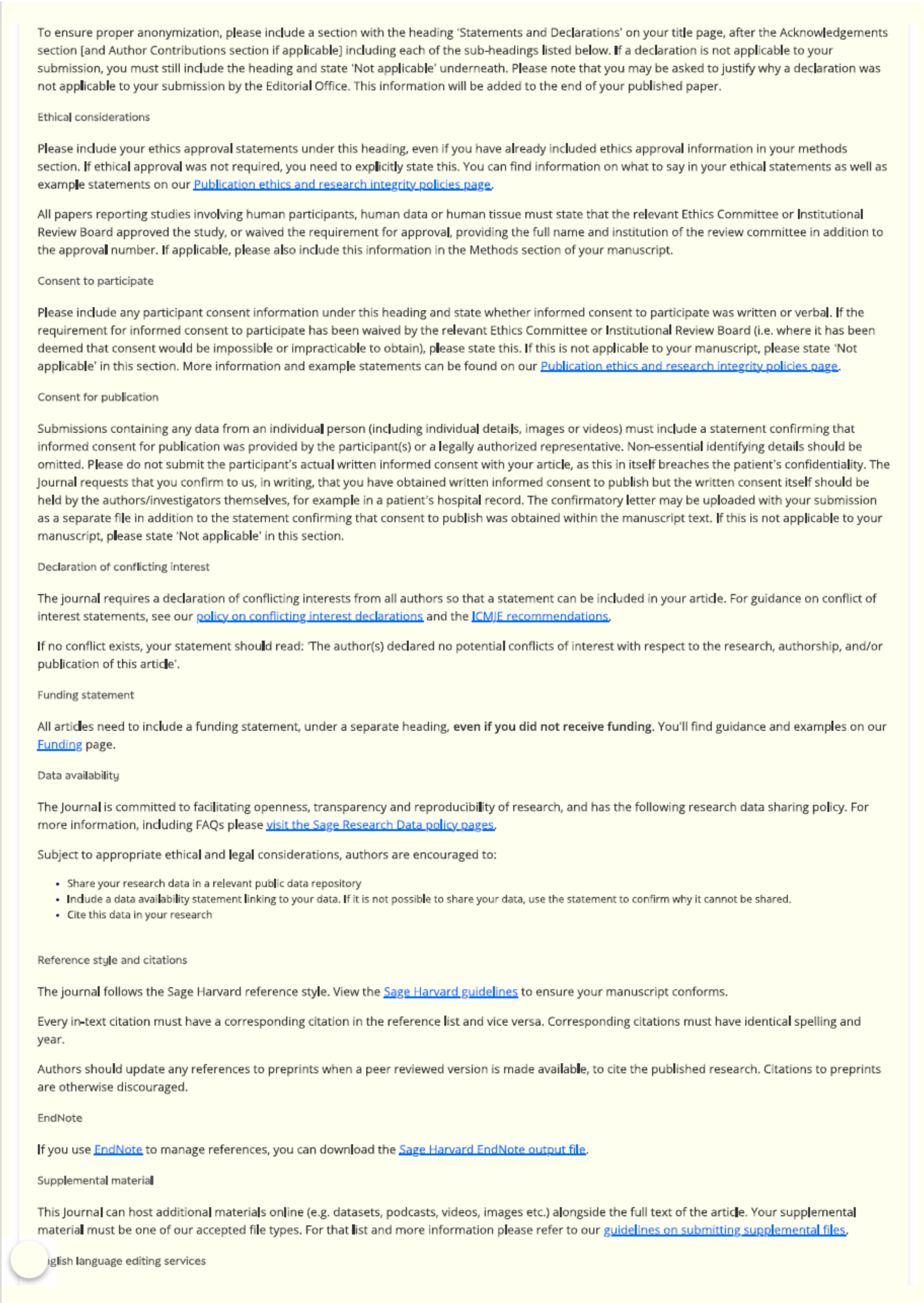

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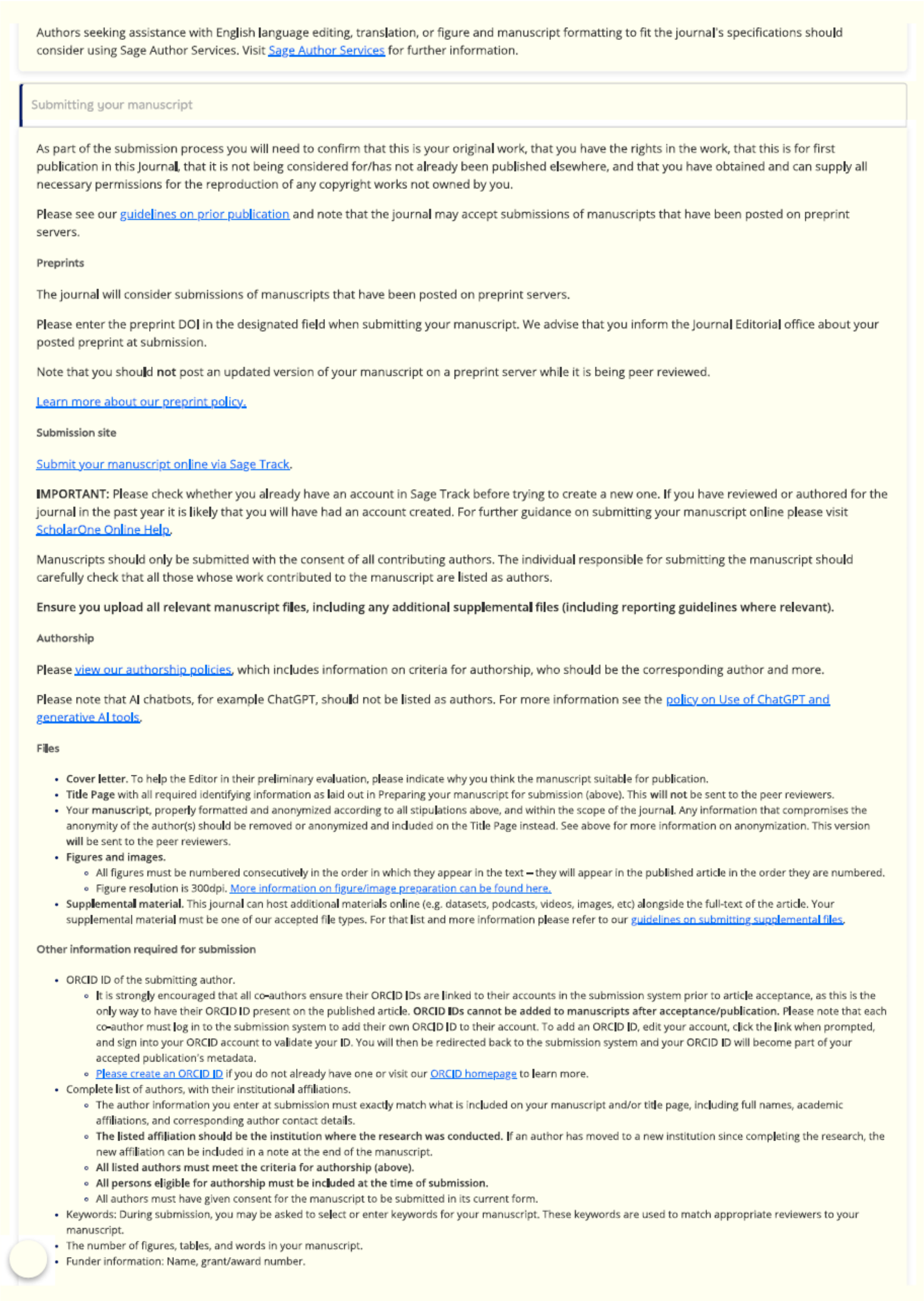

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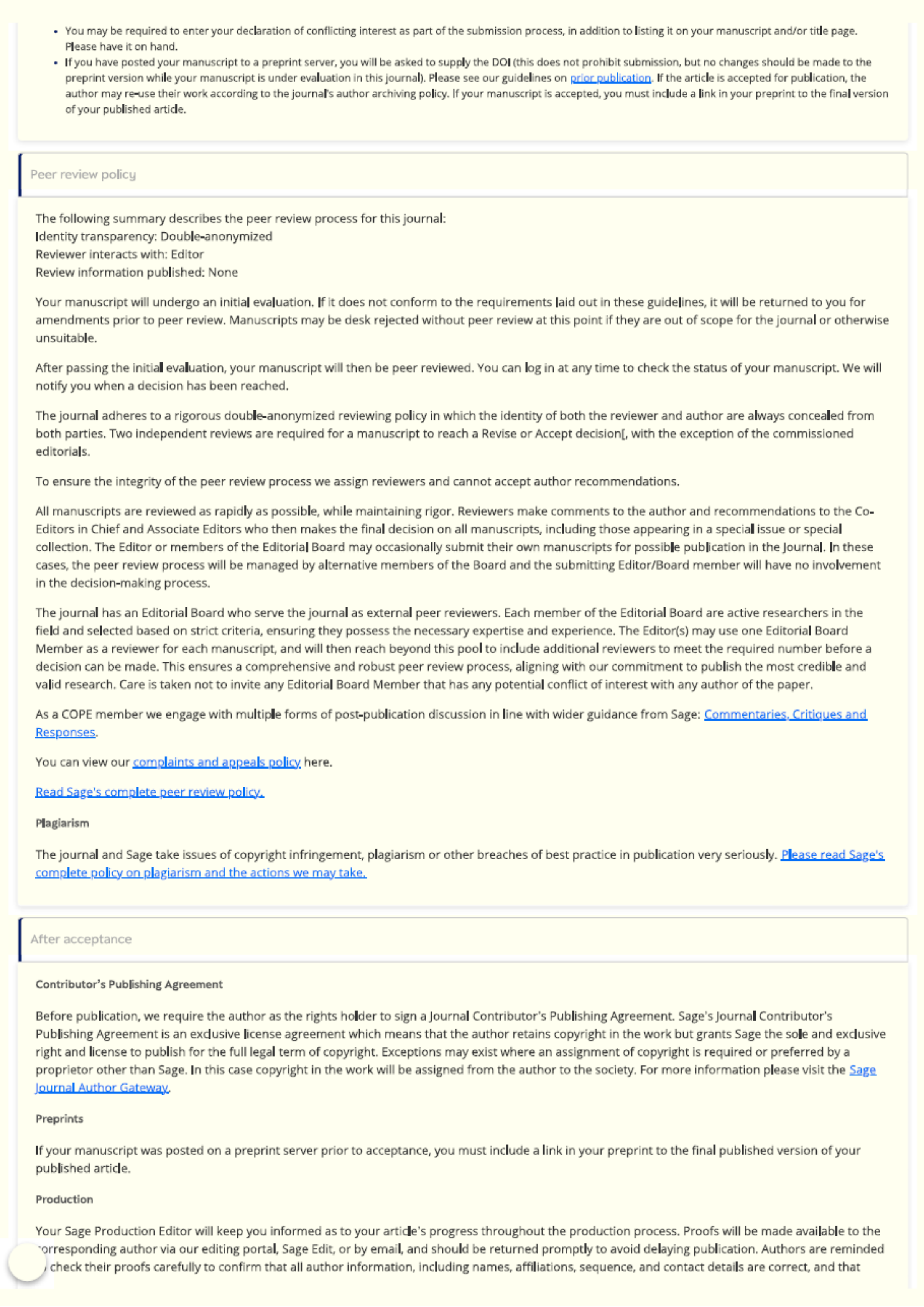
    - It is strongly encouraged that all co-authors ensure their ORCID IDs are linked to their accounts in the submission system prior to article acceptance, as this is the only way to have their ORCID ID present on the published article. **ORCID IDs cannot be added to manuscripts after acceptance/publication.** Please note that each co-author must log in to the submission system to add their own ORCID ID to their account. To add an ORCID ID, edit your account, click the link when prompted, and sign into your ORCID account to validate your ID. You will then be redirected back to the submission system and your ORCID ID will become part of your accepted publication's metadata.
    - Please create an ORCID ID if you do not already have one or visit our ORCID homepage to learn more.
- Complete list of authors, with their institutional affiliations.
    - The author information you enter at submission must exactly match what is included on your manuscript and/or title page, including full names, academic affiliations, and corresponding author contact details.
    - **The listed affiliation should be the institution where the research was conducted.** If an author has moved to a new institution since completing the research, the new affiliation can be included in a note at the end of the manuscript.
    - **All listed authors must meet the criteria for authorship (above).**
    - **All persons eligible for authorship must be included at the time of submission.**
    - All authors must have given consent for the manuscript to be submitted in its current form.
- Keywords: During submission, you may be asked to select or enter keywords for your manuscript. These keywords are used to match appropriate reviewers to your manuscript.
- The number of figures, tables, and words in your manuscript.
- Funder information: Name, grant/award number.



- You may be required to enter your declaration of conflicting interest as part of the submission process, in addition to listing it on your manuscript and/or title page. Please have it on hand.
- If you have posted your manuscript to a preprint server, you will be asked to supply the DOI (this does not prohibit submission, but no changes should be made to the preprint version while your manuscript is under evaluation in this journal). Please see our guidelines on prior publication. If the article is accepted for publication, the author may re-use their work according to the journal's author archiving policy. If your manuscript is accepted, you must include a link in your preprint to the final version of your published article.

Peer review policy

The following summary describes the peer review process for this journal:
Identity transparency: Double-anonymized
Reviewer interacts with: Editor
Review information published: None

Your manuscript will undergo an initial evaluation. If it does not conform to the requirements laid out in these guidelines, it will be returned to you for amendments prior to peer review. Manuscripts may be desk rejected without peer review at this point if they are out of scope for the journal or otherwise unsuitable.

After passing the initial evaluation, your manuscript will then be peer reviewed. You can log in at any time to check the status of your manuscript. We will notify you when a decision has been reached.

The journal adheres to a rigorous double-anonymized reviewing policy in which the identity of both the reviewer and author are always concealed from both parties. Two independent reviews are required for a manuscript to reach a Revise or Accept decision[, with the exception of the commissioned editorials.

To ensure the integrity of the peer review process we assign reviewers and cannot accept author recommendations.

All manuscripts are reviewed as rapidly as possible, while maintaining rigor. Reviewers make comments to the author and recommendations to the Co-Editors in Chief and Associate Editors who then makes the final decision on all manuscripts, including those appearing in a special issue or special collection. The Editor or members of the Editorial Board may occasionally submit their own manuscripts for possible publication in the Journal. In these cases, the peer review process will be managed by alternative members of the Board and the submitting Editor/Board member will have no involvement in the decision-making process.

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Read Sage's complete peer review policy.

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After acceptance

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**Preprints**

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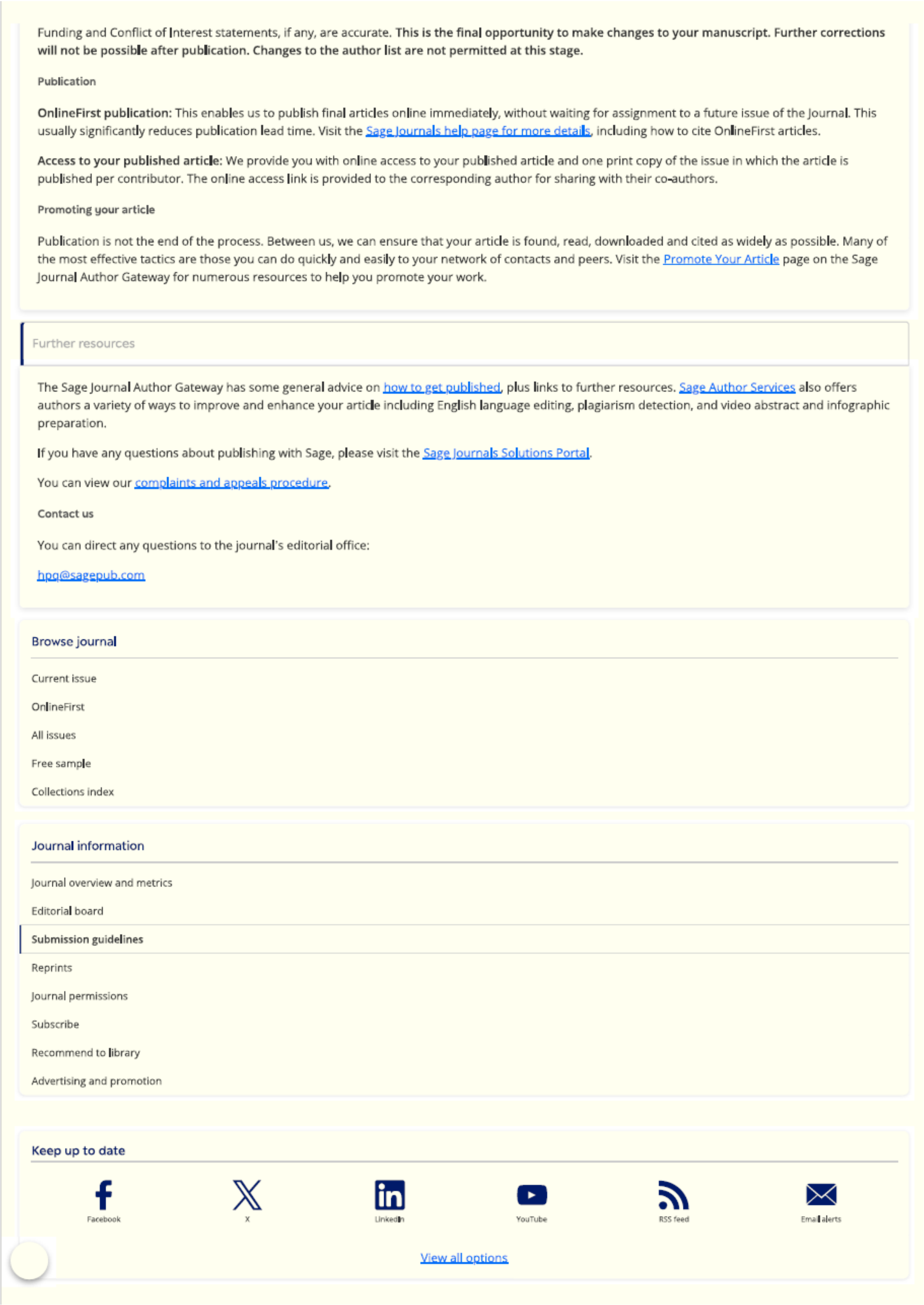
Your Sage Production Editor will keep you informed as to your article's progress throughout the production process. Proofs will be made available to the orresponding author via our editing portal, Sage Edit, or by email, and should be returned promptly to avoid delaying publication. Authors are reminded check their proofs carefully to confirm that all author information, including names, affiliations, sequence, and contact details are correct, and that



Funding and Conflict of Interest statements, if any, are accurate. **This is the final opportunity to make changes to your manuscript. Further corrections will not be possible after publication. Changes to the author list are not permitted at this stage.**

**Publication**

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Further resources

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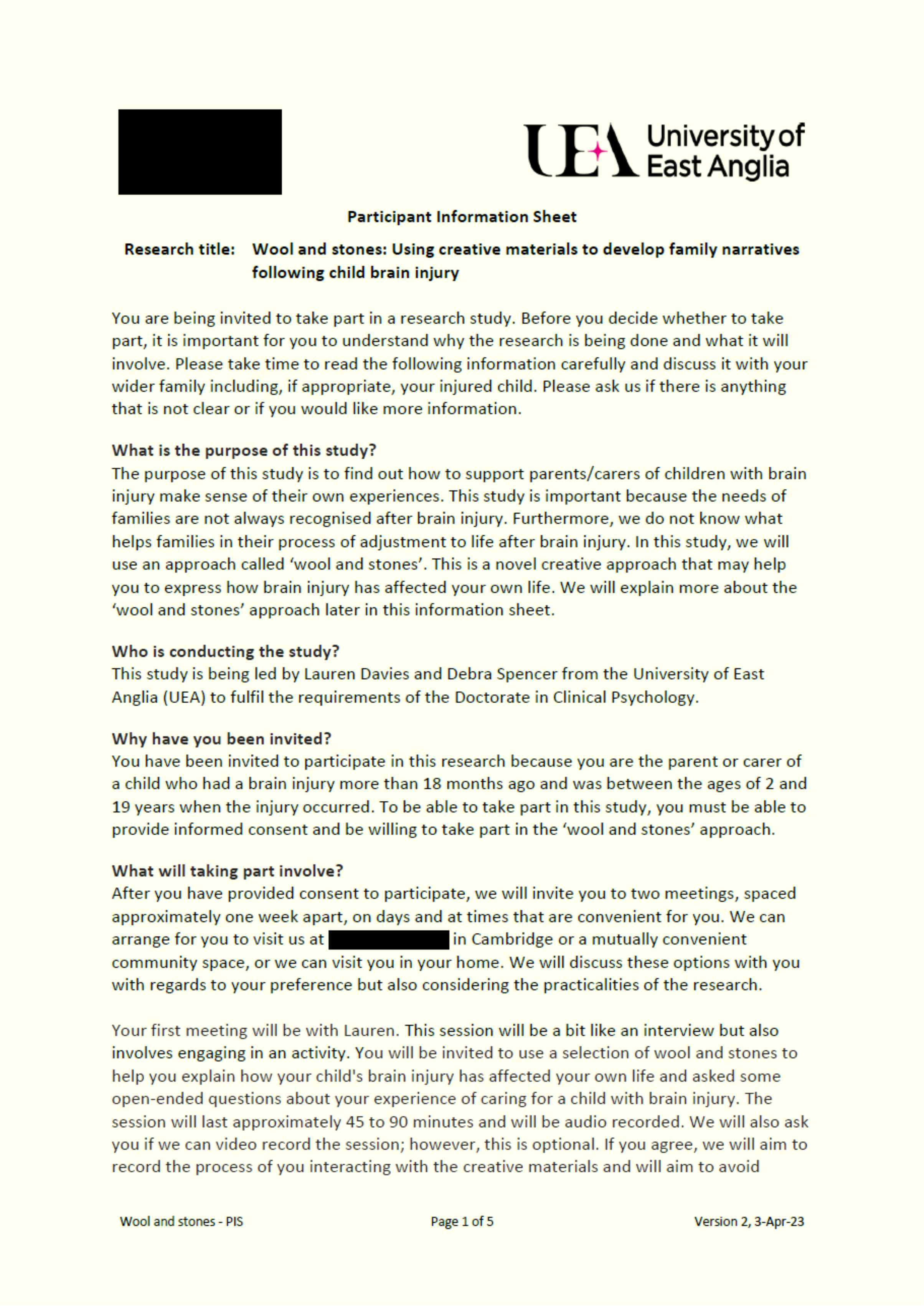
## **Appendix K.** *Participant Information Sheet*



[redacted]

University of East Anglia

**Participant Information Sheet**

**Research title: Wool and stones: Using creative materials to develop family narratives following child brain injury**

You are being invited to take part in a research study. Before you decide whether to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with your wider family including, if appropriate, your injured child. Please ask us if there is anything that is not clear or if you would like more information.

**What is the purpose of this study?**
The purpose of this study is to find out how to support parents/carers of children with brain injury make sense of their own experiences. This study is important because the needs of families are not always recognised after brain injury. Furthermore, we do not know what helps families in their process of adjustment to life after brain injury. In this study, we will use an approach called 'wool and stones'. This is a novel creative approach that may help you to express how brain injury has affected your own life. We will explain more about the 'wool and stones' approach later in this information sheet.

**Who is conducting the study?**
This study is being led by Lauren Davies and Debra Spencer from the University of East Anglia (UEA) to fulfil the requirements of the Doctorate in Clinical Psychology.

**Why have you been invited?**
You have been invited to participate in this research because you are the parent or carer of a child who had a brain injury more than 18 months ago and was between the ages of 2 and 19 years when the injury occurred. To be able to take part in this study, you must be able to provide informed consent and be willing to take part in the 'wool and stones' approach.

**What will taking part involve?**
After you have provided consent to participate, we will invite you to two meetings, spaced approximately one week apart, on days and at times that are convenient for you. We can arrange for you to visit us at [redacted] in Cambridge or a mutually convenient community space, or we can visit you in your home. We will discuss these options with you with regards to your preference but also considering the practicalities of the research.

Your first meeting will be with Lauren. This session will be a bit like an interview but also involves engaging in an activity. You will be invited to use a selection of wool and stones to help you explain how your child's brain injury has affected your own life and asked some open-ended questions about your experience of caring for a child with brain injury. The session will last approximately 45 to 90 minutes and will be audio recorded. We will also ask you if we can video record the session; however, this is optional. If you agree, we will aim to record the process of you interacting with the creative materials and will aim to avoid

recording identifiable features such as your face. At the end of the session Lauren will take a photograph of your ‘wool and stones’ creation. You are also welcome to take your own photograph and/or take your creation home with you along with some of the remaining materials.

The second meeting will be with Debra and will take place approximately one week after the first. This second meeting will be an interview about how you felt using the ‘wool and stones’ approach, whether you feel this approach may be helpful for others and what improvements could be made to make it more helpful. This interview will also take approximately 45 to 90 minutes and be audio recorded. At the end of the interview, Debra will invite you to keep the box of ‘wool and stones’ materials if you would like to and give you a £20 shopping voucher as a token of gratitude.

**What is the ‘wool and stones’ approach and what will you be asked to do?**
You will be given a selection of wool and stones that vary in colour, texture and size and will be invited to use them to help you share your experiences. Lauren will support and guide you through the process of using the wool and stones to tell your story of how life has been for you following your child’s brain injury. There is no right or wrong way to engage with the materials. A similar approach has been used with stroke patients and their carers and was found to be helpful.

**Do you have to take part?**
No, it is up to you to decide. Your decision will not affect the care you or your child receives in any way. If you do decide to take part, you will be asked to sign a consent form to show that you have agreed to take part. However, you are free to withdraw from the study at any time without giving a reason.

**How will we use information about you?**
We will need to use information from you for this research project. This information will include your name, contact details and demographic information such as your gender and ethnic background. 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 name or contact details. Your data will be linked to 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.
- If you agree to take part in this study, you will have the option to take part in future research using your data saved from this study.

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

You can find out more about how we use your information:

- At www.hra.nhs.uk/information-about-patients/
- By asking one of the research team
- By sending an email to the sponsor's data protection team on dataprotection@uea.ac.uk

**Who will have access to the research data?**

The recordings from the study will be stored on a secure server at the University of East Anglia and will be managed by Lauren and Debra. The recordings will be transcribed by Lauren and Debra using General Data Protection Regulation (GDPR)-compliant transcription software and the resulting transcriptions stored on a secure server at the University of East Anglia. Information that might identify you or your family (e.g., names of people or places) will be removed from the transcriptions. Research data, including personal information such as your name and contact details, will be accessed by Lauren and Debra and by their primary and secondary supervisors, Dr Fergus Gracey and Dr Kiki Mastroyannopoulou, respectively, both of whom are based at the University of East Anglia. Anonymised research data will be shared with the wider research team, including Lauren and Debra's external supervisor, Dr Charlie Whiffin, who is based at the University of Derby. Identifiable information about you will be kept for ten years after the study has finished.

**What will you do with the research findings?**

The research findings will be reported in two doctoral theses, which will be accessible to the public through the library at the University of East Anglia. Some of the findings may be published in peer-reviewed journals or presented at scientific meetings or in talks at academic institutions. We also will share a summary of our results with you and the other participants in this study. Anonymised quotations and photos of 'wool and stones' creations will be included in these publications or presentations.

**Are there any benefits to taking part?**

There is no direct therapeutic benefit to taking part in this study. However, we know from past research that participating in this type of study and/or having an opportunity to share one's story can be a positive experience for some people. Also, we hope that this study will provide us with information about innovative ways to support the needs of parents and carers after brain injury.

**Are there any potential risks in taking part?**

We do not anticipate any significant risks in taking part in this study. However, it is possible that you may find talking about your experiences emotionally difficult. If at any time you feel upset, we can pause for a few minutes, or you may wish to stop altogether or withdraw from the study. Lauren and Debra are experienced mental health professionals and therefore will be able to provide sensitive support as needed. Please note that, if you say anything that makes us concerned for your safety or the safety of others, we may be obligated to inform the appropriate authorities and/or follow local safeguarding procedures. If this is the case, we will discuss it with you at the time.

**Where can you go for further support?**
The organisations listed overleaf provide help, advice and support to individuals in distress. You can also reach out to your GP and/or self-refer for support with your local wellbeing service www.wellbeingnands.co.uk/norfolk/get-support/register-with-our-services/.

**Child Brain Injury Trust**
*A charity for families and professionals supporting children affected by brain injury*
T: 0303 303 2248
W: www.childbraininjurytrust.org.uk

**Headway**
*Supporting people with a brain injury and those who care about them*
T: 01223 576550
E: info@headway-cambs.org.uk
W: www.headway-cambs.org.uk

**Mind**
*A mental health charity*
T: 0300 123 3393
E: info@mind.org.uk
W: www.mind.org.uk

**Samaritans**
*Mental wellbeing support help line*
T: 116 123
E: jo@samaritans.org
W: www.samaritans.org

**Participation in future, related research**
If you are interested in participating in future research on this or related topics, you can indicate this on the consent form. If you consent to being contacted, we will store your name and contact details (e.g., mobile number, email address) on a password-protected spreadsheet. This information will be retained for a maximum of ten years. During this time, it will be securely stored on an encrypted network drive at UEA. The person responsible for looking after these data will be Lauren and Debra's primary supervisor, Dr Fergus Gracey.

**Who has reviewed the study?**
All research in the NHS is looked at by an independent group of people, in the form of a Research Ethics Committee, to protect your rights and to ensure your safety, wellbeing, and dignity. This study was reviewed and given a favourable opinion by the South Central – Berkshire Research Ethics Committee (reference number 23/SC/0068).

**Who is sponsoring this study?**
The University of East Anglia is sponsoring this study. The study is being hosted by [redacted].

**What if you have a concern or complaint?**
If you have a concern about any aspect of the study, please contact Lauren or Debra in the first instance. If you do not wish to speak with them, please contact Dr Fergus Gracey using the details below. If you continue to have concerns or wish to make a formal complaint about the research team or any aspect of the conduct of this study, please contact the Head of the Department of Clinical Psychology and Psychological Therapies at UEA, Professor Niall Broomfield (n.broomfield@uea.ac.uk). If you wish to raise concerns or make a formal complaint about how your data is stored or used, please contact the Data Protection team at UEA (dataprotection@uea.ac.uk).

Thank you for considering taking part in this study. Research depends on the goodwill and generosity of potential participants such as you. If you require further information, we will be pleased to help you in any way we can. You can contact us using the details below:

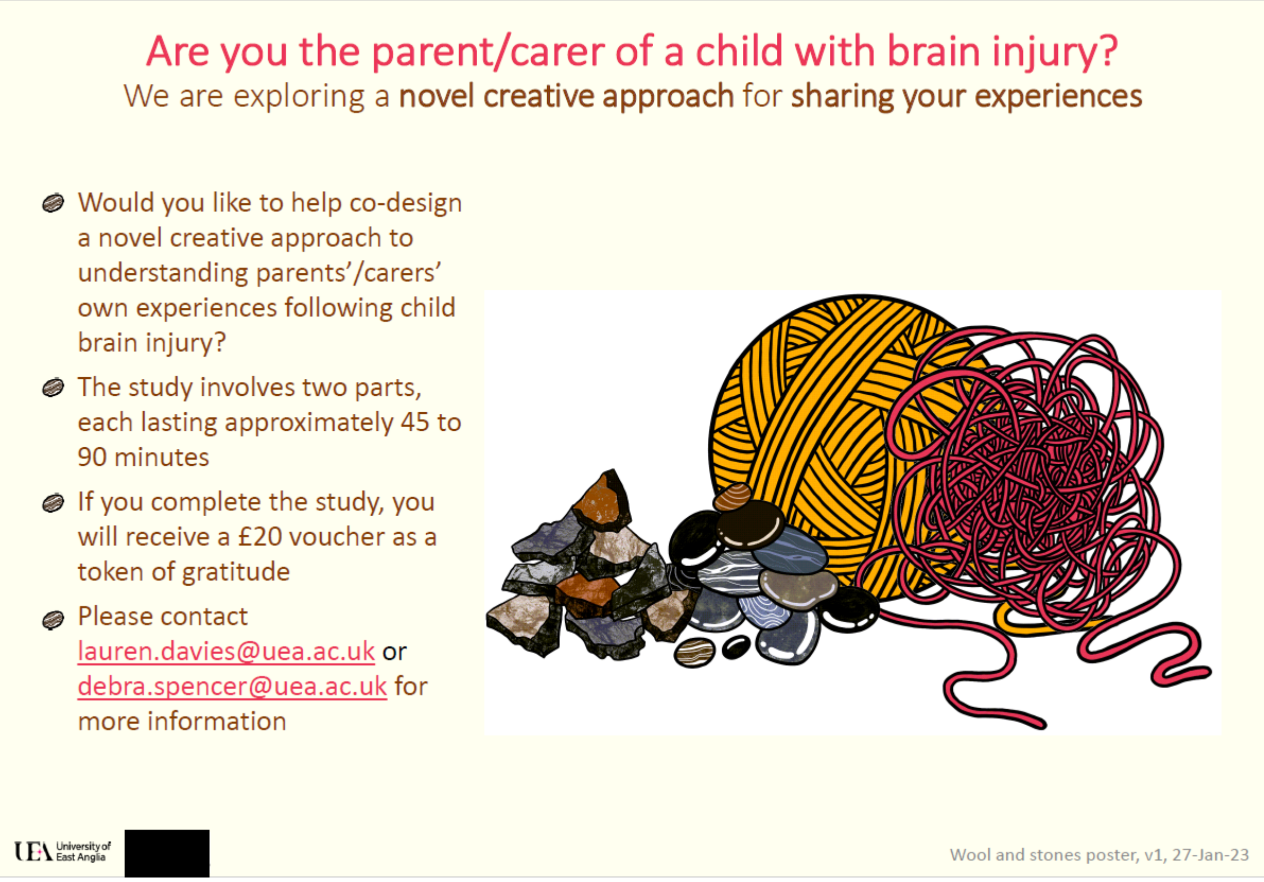
Lauren Davies
Trainee Clinical Psychologist
Department of Clinical Psychology and Psychological Therapies
University of East Anglia
Norwich Research Park
Norwich, NR4 7TJ
T:
E: lauren.davies@uea.ac.uk

Debra Spencer
Trainee Clinical Psychologist
Department of Clinical Psychology and Psychological Therapies
University of East Anglia
Norwich Research Park
Norwich, NR4 7TJ
T:
E: debra.spencer@uea.ac.uk

Dr Fergus Gracey
Clinical Associate Professor in Clinical Psychology
Department of Clinical Psychology and Psychological Therapies
University of East Anglia
Norwich Research Park
Norwich, NR4 7TJ
E: f.gracey@uea.ac.uk

## **Appendix L.** *Recruitment Materials*

### Recruitment poster



## Are you the parent/carer of a child with brain injury?

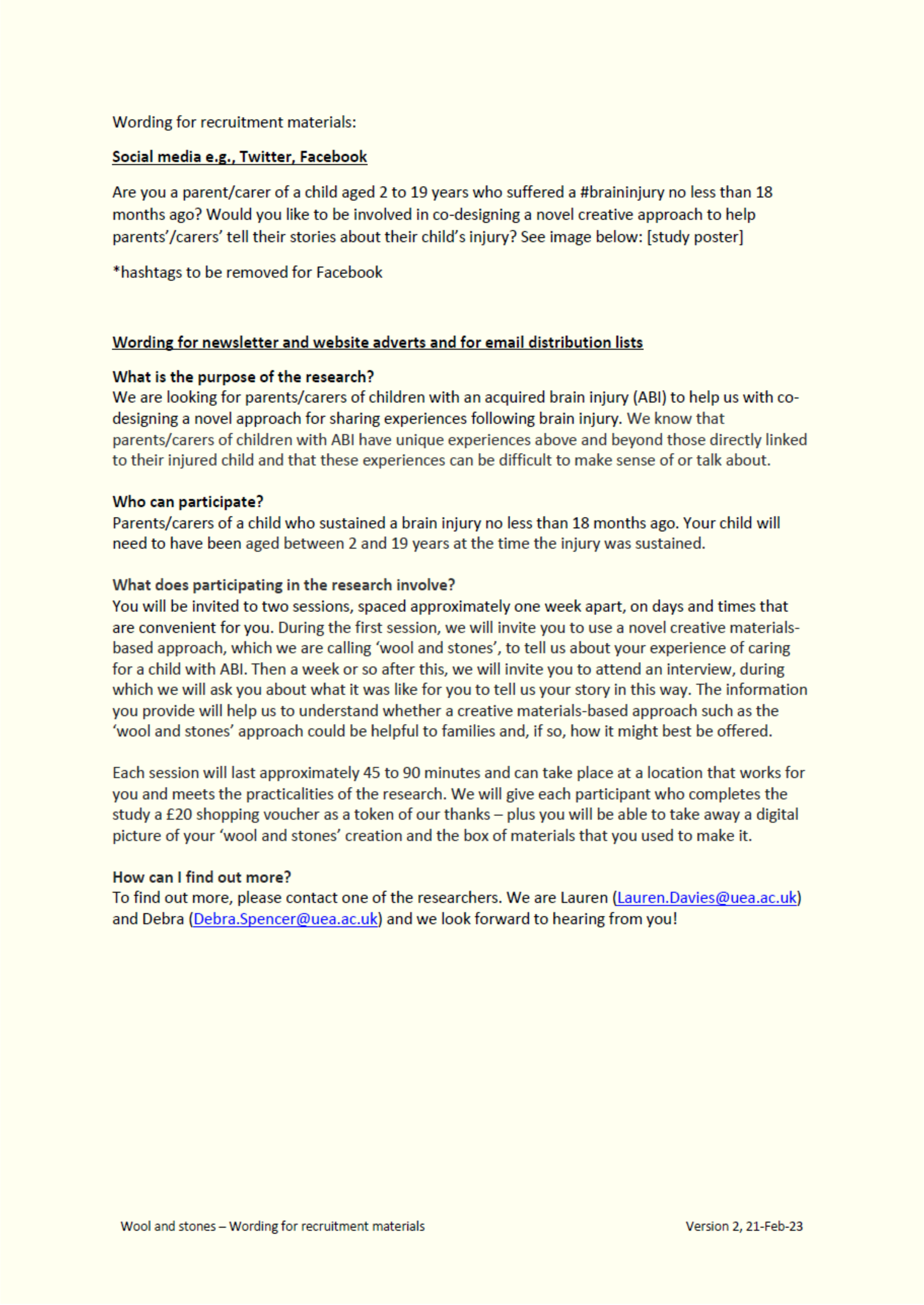
We are exploring a **novel creative approach** for **sharing your experiences**

- Would you like to help co-design a novel creative approach to understanding parents'/carers' own experiences following child brain injury?
- The study involves two parts, each lasting approximately 45 to 90 minutes
- If you complete the study, you will receive a £20 voucher as a token of gratitude
- Please contact lauren.davies@uea.ac.uk or debra.spencer@uea.ac.uk for more information

[redacted]

Wool and stones poster, v1, 27-Jan-23

## Wording used for recruitment



Wording for recruitment materials:

**Social media e.g., Twitter, Facebook**

Are you a parent/carer of a child aged 2 to 19 years who suffered a #braininjury no less than 18 months ago? Would you like to be involved in co-designing a novel creative approach to help parents'/carers' tell their stories about their child's injury? See image below: [study poster]

*hashtags to be removed for Facebook

**Wording for newsletter and website adverts and for email distribution lists**

**What is the purpose of the research?**
We are looking for parents/carers of children with an acquired brain injury (ABI) to help us with co-designing a novel approach for sharing experiences following brain injury. We know that parents/carers of children with ABI have unique experiences above and beyond those directly linked to their injured child and that these experiences can be difficult to make sense of or talk about.

**Who can participate?**
Parents/carers of a child who sustained a brain injury no less than 18 months ago. Your child will need to have been aged between 2 and 19 years at the time the injury was sustained.

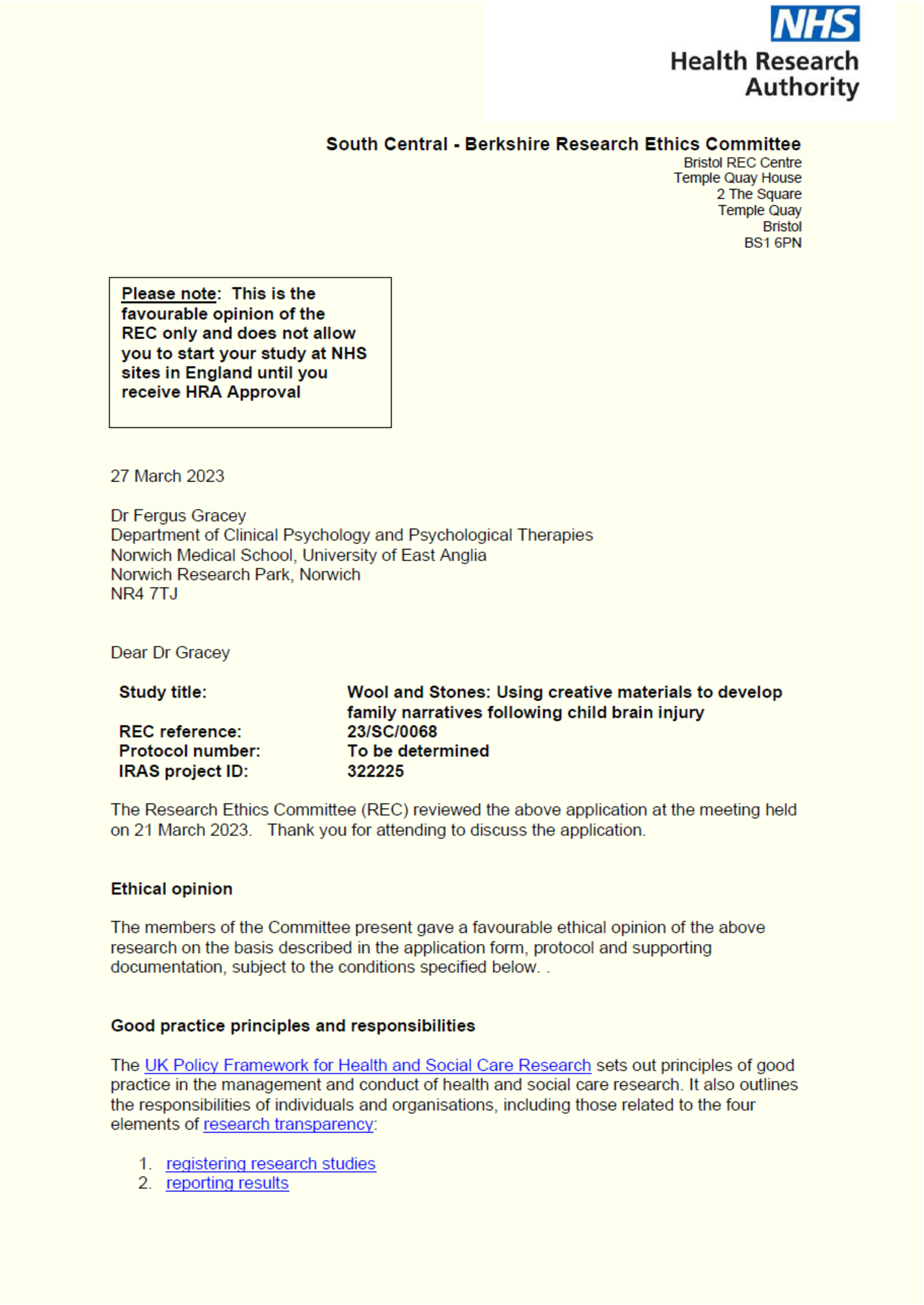
**What does participating in the research involve?**
You will be invited to two sessions, spaced approximately one week apart, on days and times that are convenient for you. During the first session, we will invite you to use a novel creative materials-based approach, which we are calling 'wool and stones', to tell us about your experience of caring for a child with ABI. Then a week or so after this, we will invite you to attend an interview, during which we will ask you about what it was like for you to tell us your story in this way. The information you provide will help us to understand whether a creative materials-based approach such as the 'wool and stones' approach could be helpful to families and, if so, how it might best be offered.

Each session will last approximately 45 to 90 minutes and can take place at a location that works for you and meets the practicalities of the research. We will give each participant who completes the study a £20 shopping voucher as a token of our thanks – plus you will be able to take away a digital picture of your 'wool and stones' creation and the box of materials that you used to make it.

**How can I find out more?**
To find out more, please contact one of the researchers. We are Lauren (Lauren.Davies@uea.ac.uk) and Debra (Debra.Spencer@uea.ac.uk) and we look forward to hearing from you!

# **Appendix M.** *Ethical Approvals for Empirical Study*

## NHS REC approval for empirical study



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**South Central - Berkshire Research Ethics Committee**
Bristol REC Centre
Temple Quay House
2 The Square
Temple Quay
Bristol
BS1 6PN

**<u>Please note</u>: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval**

27 March 2023

Dr Fergus Gracey
Department of Clinical Psychology and Psychological Therapies
Norwich Medical School, University of East Anglia
Norwich Research Park, Norwich
NR4 7TJ

Dear Dr Gracey

| | |
|---|---|
| **Study title:** | **Wool and Stones: Using creative materials to develop family narratives following child brain injury** |
| **REC reference:** | **23/SC/0068** |
| **Protocol number:** | **To be determined** |
| **IRAS project ID:** | **322225** |

The Research Ethics Committee (REC) reviewed the above application at the meeting held on 21 March 2023. Thank you for attending to discuss the application.

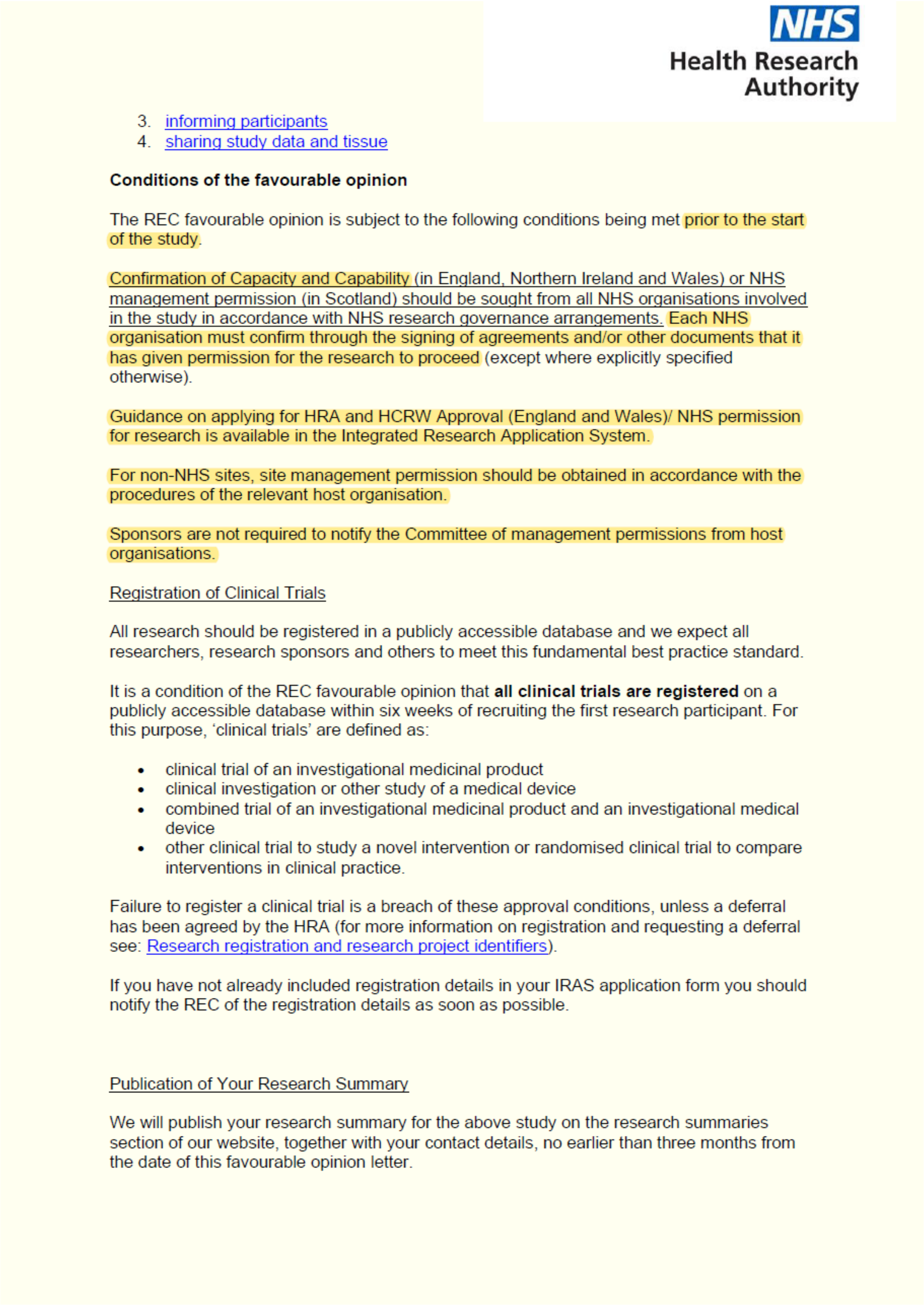
### Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below. .

### Good practice principles and responsibilities

The UK Policy Framework for Health and Social Care Research sets out principles of good practice in the management and conduct of health and social care research. It also outlines the responsibilities of individuals and organisations, including those related to the four elements of research transparency:

1. registering research studies
2. reporting results



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3. informing participants
4. sharing study data and tissue

**Conditions of the favourable opinion**

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

All research should be registered in a publicly accessible database and we expect all researchers, research sponsors and others to meet this fundamental best practice standard.

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a publicly accessible database within six weeks of recruiting the first research participant. For this purpose, ‘clinical trials’ are defined as:

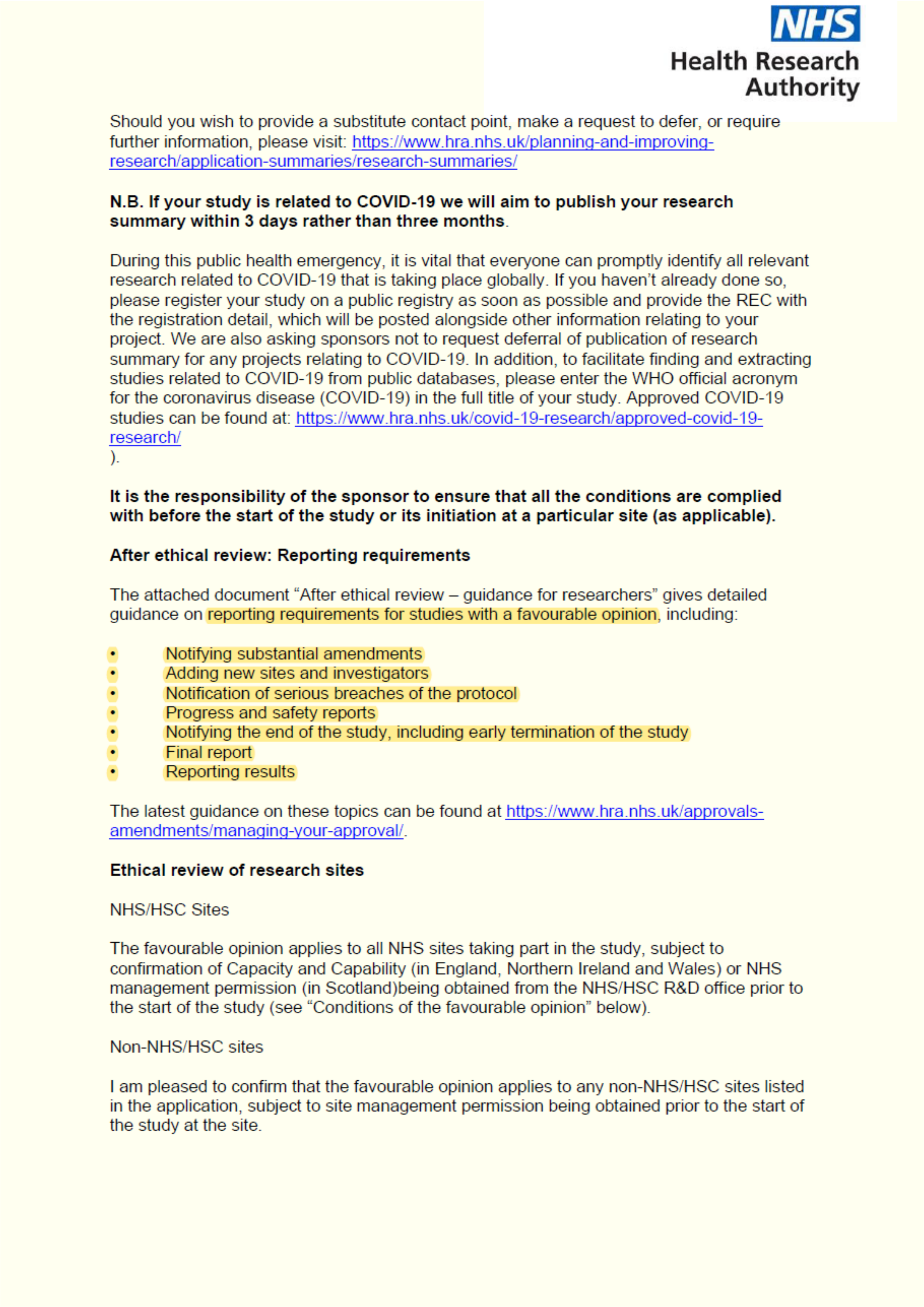
- clinical trial of an investigational medicinal product
- clinical investigation or other study of a medical device
- combined trial of an investigational medicinal product and an investigational medical device
- other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice.

Failure to register a clinical trial is a breach of these approval conditions, unless a deferral has been agreed by the HRA (for more information on registration and requesting a deferral see: Research registration and research project identifiers).

If you have not already included registration details in your IRAS application form you should notify the REC of the registration details as soon as possible.

Publication of Your Research Summary

We will publish your research summary for the above study on the research summaries section of our website, together with your contact details, no earlier than three months from the date of this favourable opinion letter.



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Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit: https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/research-summaries/

**N.B. If your study is related to COVID-19 we will aim to publish your research summary within 3 days rather than three months**.

During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you haven't already done so, please register your study on a public registry as soon as possible and provide the REC with the registration detail, which will be posted alongside other information relating to your project. We are also asking sponsors not to request deferral of publication of research summary for any projects relating to COVID-19. In addition, to facilitate finding and extracting studies related to COVID-19 from public databases, please enter the WHO official acronym for the coronavirus disease (COVID-19) in the full title of your study. Approved COVID-19 studies can be found at: https://www.hra.nhs.uk/covid-19-research/approved-covid-19-research/
).

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

**After ethical review: Reporting requirements**

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, including early termination of the study
- Final report
- Reporting results

The latest guidance on these topics can be found at https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/.

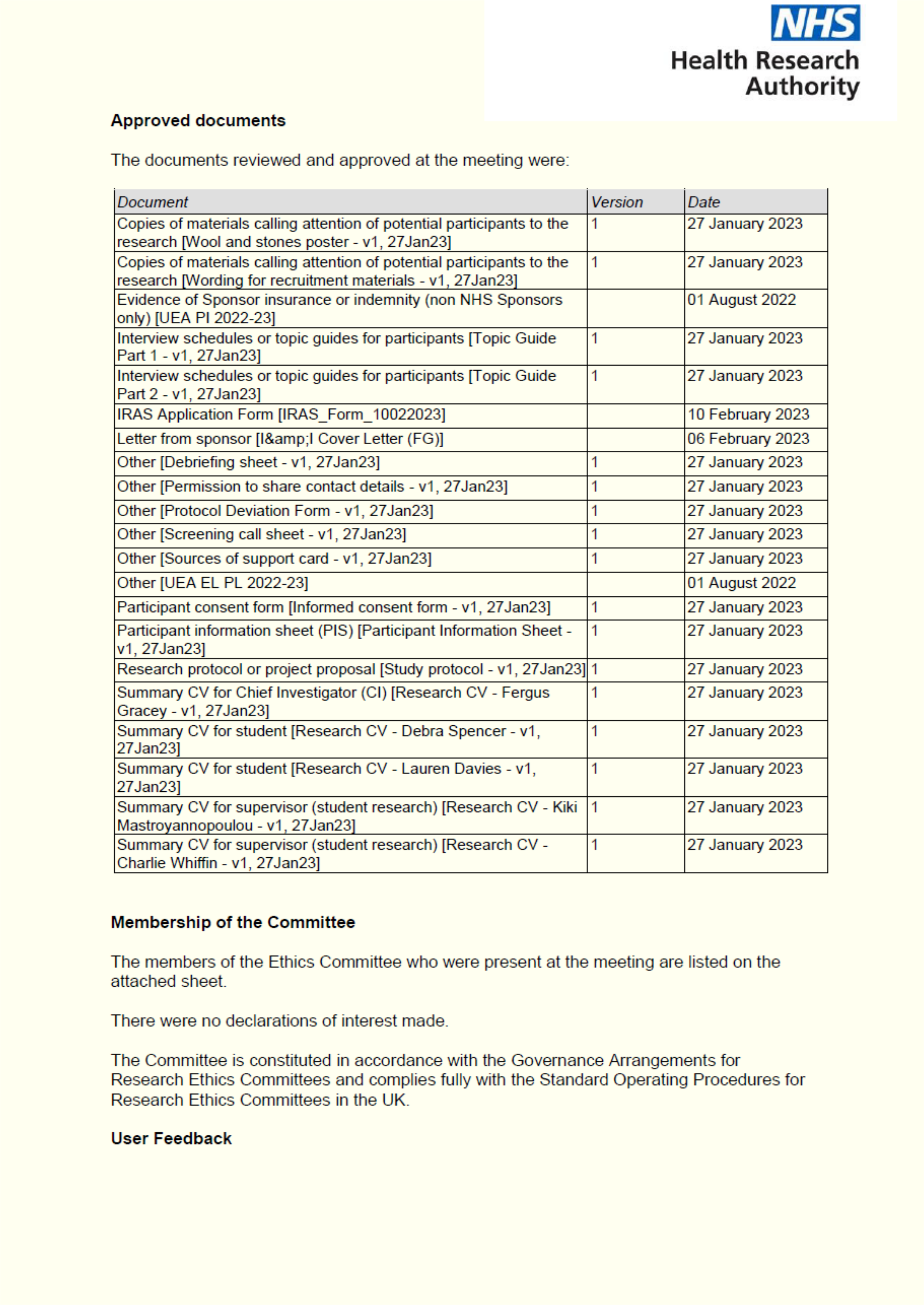
**Ethical review of research sites**

NHS/HSC Sites

The favourable opinion applies to all NHS sites taking part in the study, subject to confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland)being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS/HSC sites

I am pleased to confirm that the favourable opinion applies to any non-NHS/HSC sites listed in the application, subject to site management permission being obtained prior to the start of the study at the site.



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**Approved documents**

The documents reviewed and approved at the meeting were:

| *Document* | *Version* | *Date* |
|---|---|---|
| Copies of materials calling attention of potential participants to the research [Wool and stones poster - v1, 27Jan23] | 1 | 27 January 2023 |
| Copies of materials calling attention of potential participants to the research [Wording for recruitment materials - v1, 27Jan23] | 1 | 27 January 2023 |
| Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [UEA PI 2022-23] | | 01 August 2022 |
| Interview schedules or topic guides for participants [Topic Guide Part 1 - v1, 27Jan23] | 1 | 27 January 2023 |
| Interview schedules or topic guides for participants [Topic Guide Part 2 - v1, 27Jan23] | 1 | 27 January 2023 |
| IRAS Application Form [IRAS_Form_10022023] | | 10 February 2023 |
| Letter from sponsor [I&amp;I Cover Letter (FG)] | | 06 February 2023 |
| Other [Debriefing sheet - v1, 27Jan23] | 1 | 27 January 2023 |
| Other [Permission to share contact details - v1, 27Jan23] | 1 | 27 January 2023 |
| Other [Protocol Deviation Form - v1, 27Jan23] | 1 | 27 January 2023 |
| Other [Screening call sheet - v1, 27Jan23] | 1 | 27 January 2023 |
| Other [Sources of support card - v1, 27Jan23] | 1 | 27 January 2023 |
| Other [UEA EL PL 2022-23] | | 01 August 2022 |
| Participant consent form [Informed consent form - v1, 27Jan23] | 1 | 27 January 2023 |
| Participant information sheet (PIS) [Participant Information Sheet - v1, 27Jan23] | 1 | 27 January 2023 |
| Research protocol or project proposal [Study protocol - v1, 27Jan23] | 1 | 27 January 2023 |
| Summary CV for Chief Investigator (CI) [Research CV - Fergus Gracey - v1, 27Jan23] | 1 | 27 January 2023 |
| Summary CV for student [Research CV - Debra Spencer - v1, 27Jan23] | 1 | 27 January 2023 |
| Summary CV for student [Research CV - Lauren Davies - v1, 27Jan23] | 1 | 27 January 2023 |
| Summary CV for supervisor (student research) [Research CV - Kiki Mastroyannopoulou - v1, 27Jan23] | 1 | 27 January 2023 |
| Summary CV for supervisor (student research) [Research CV - Charlie Whiffin - v1, 27Jan23] | 1 | 27 January 2023 |

**Membership of the Committee**

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

There were no declarations of interest made.

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

**User Feedback**

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

**HRA Learning**

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: https://www.hra.nhs.uk/planning-and-improving-research/learning/

| | |
|---|---|
| **IRAS project ID: 322225** | **Please quote this number on all correspondence** |

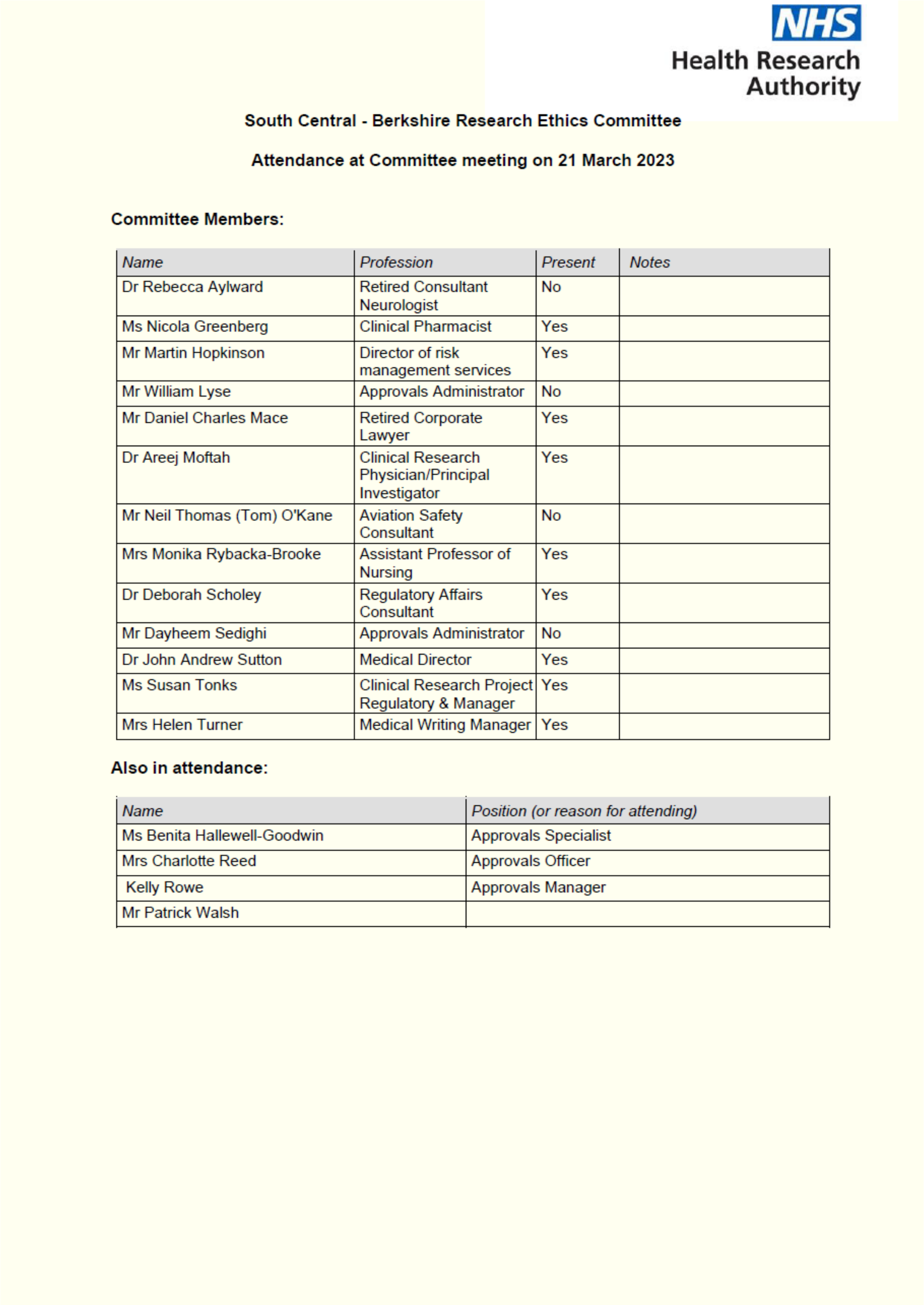
With the Committee's best wishes for the success of this project.

Yours sincerely

Pp
**Ms Susan Tonks**
**Chair**

E-mail: berkshire.rec@hra.nhs.uk

| | |
|---|---|
| Enclosures: | List of names and professions of members who were present at the meeting and those who submitted written comments<br>"After ethical review – guidance for researchers"<br>**After ethical review guidance for sponsors and investigators – Non CTIMP Standard Conditions of Approval]** |
| Copy to: | Ms Tracy Moulton<br>Lead Nation approvals@hra.nhs.uk |



NHS
Health Research
Authority

**South Central - Berkshire Research Ethics Committee**

**Attendance at Committee meeting on 21 March 2023**

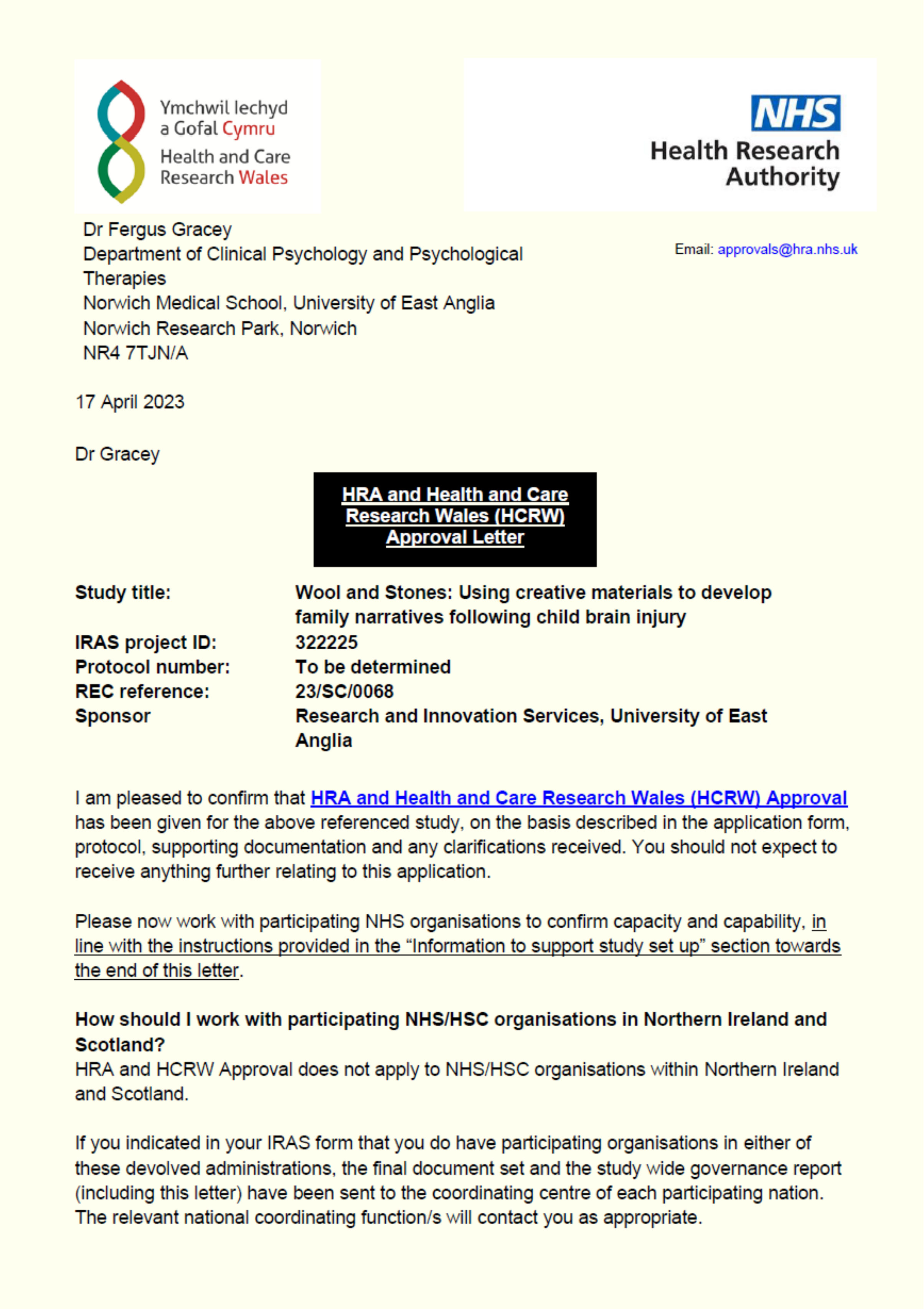
**Committee Members:**

| *Name* | *Profession* | *Present* | *Notes* |
|---|---|---|---|
| Dr Rebecca Aylward | Retired Consultant Neurologist | No | |
| Ms Nicola Greenberg | Clinical Pharmacist | Yes | |
| Mr Martin Hopkinson | Director of risk management services | Yes | |
| Mr William Lyse | Approvals Administrator | No | |
| Mr Daniel Charles Mace | Retired Corporate Lawyer | Yes | |
| Dr Areej Moftah | Clinical Research Physician/Principal Investigator | Yes | |
| Mr Neil Thomas (Tom) O'Kane | Aviation Safety Consultant | No | |
| Mrs Monika Rybacka-Brooke | Assistant Professor of Nursing | Yes | |
| Dr Deborah Scholey | Regulatory Affairs Consultant | Yes | |
| Mr Dayheem Sedighi | Approvals Administrator | No | |
| Dr John Andrew Sutton | Medical Director | Yes | |
| Ms Susan Tonks | Clinical Research Project Regulatory & Manager | Yes | |
| Mrs Helen Turner | Medical Writing Manager | Yes | |

**Also in attendance:**

| *Name* | *Position (or reason for attending)* |
|---|---|
| Ms Benita Hallewell-Goodwin | Approvals Specialist |
| Mrs Charlotte Reed | Approvals Officer |
| Kelly Rowe | Approvals Manager |
| Mr Patrick Walsh | |

## NHS HRA approval for empirical study



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Dr Fergus Gracey
Department of Clinical Psychology and Psychological Therapies
Norwich Medical School, University of East Anglia
Norwich Research Park, Norwich
NR4 7TJN/A

Email: approvals@hra.nhs.uk

17 April 2023

Dr Gracey

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

| | |
|---|---|
| **Study title:** | **Wool and Stones: Using creative materials to develop family narratives following child brain injury** |
| **IRAS project ID:** | **322225** |
| **Protocol number:** | **To be determined** |
| **REC reference:** | **23/SC/0068** |
| **Sponsor** | **Research and Innovation Services, University of East Anglia** |

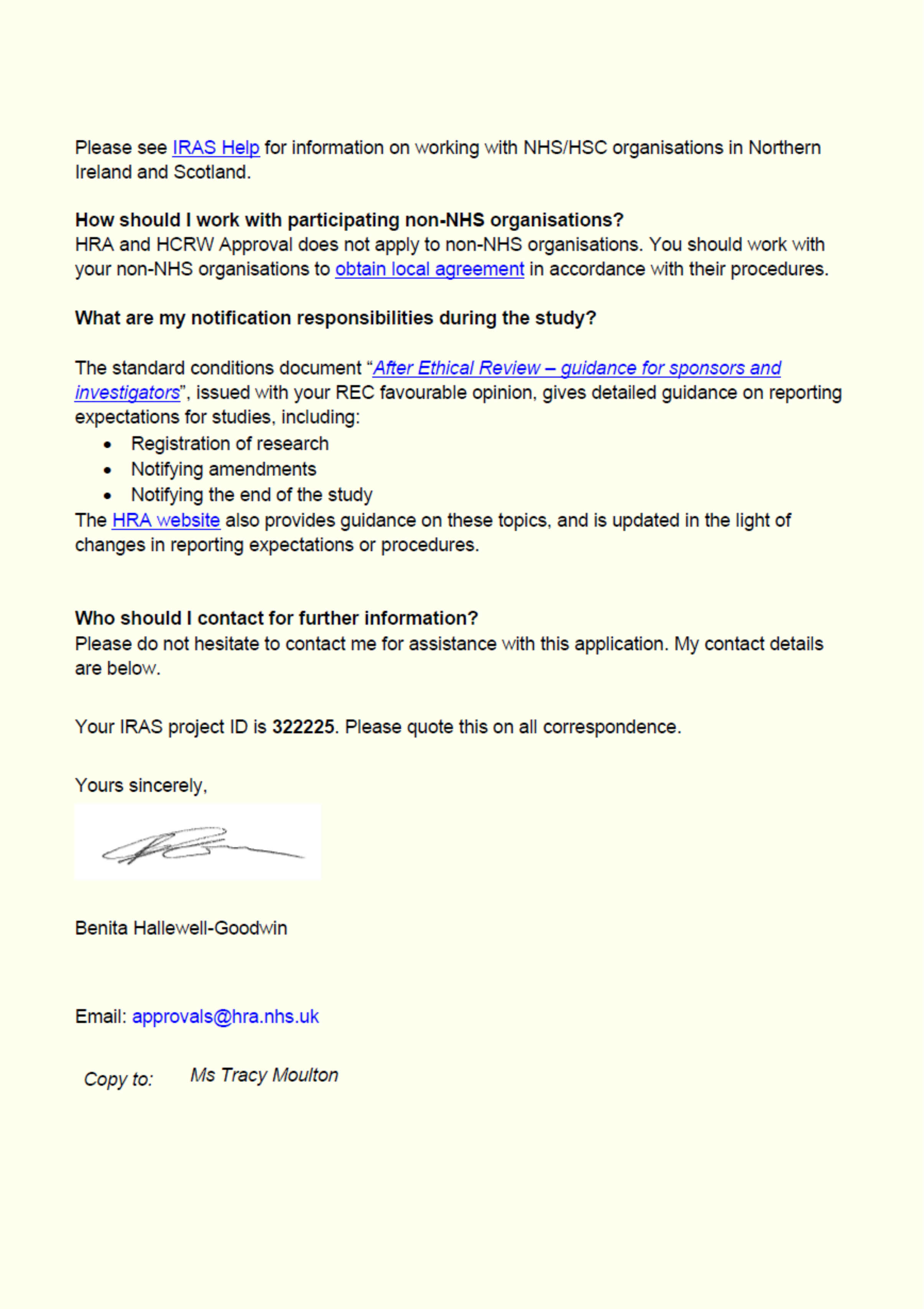
I am pleased to confirm that HRA and Health and Care Research Wales (HCRW) Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating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

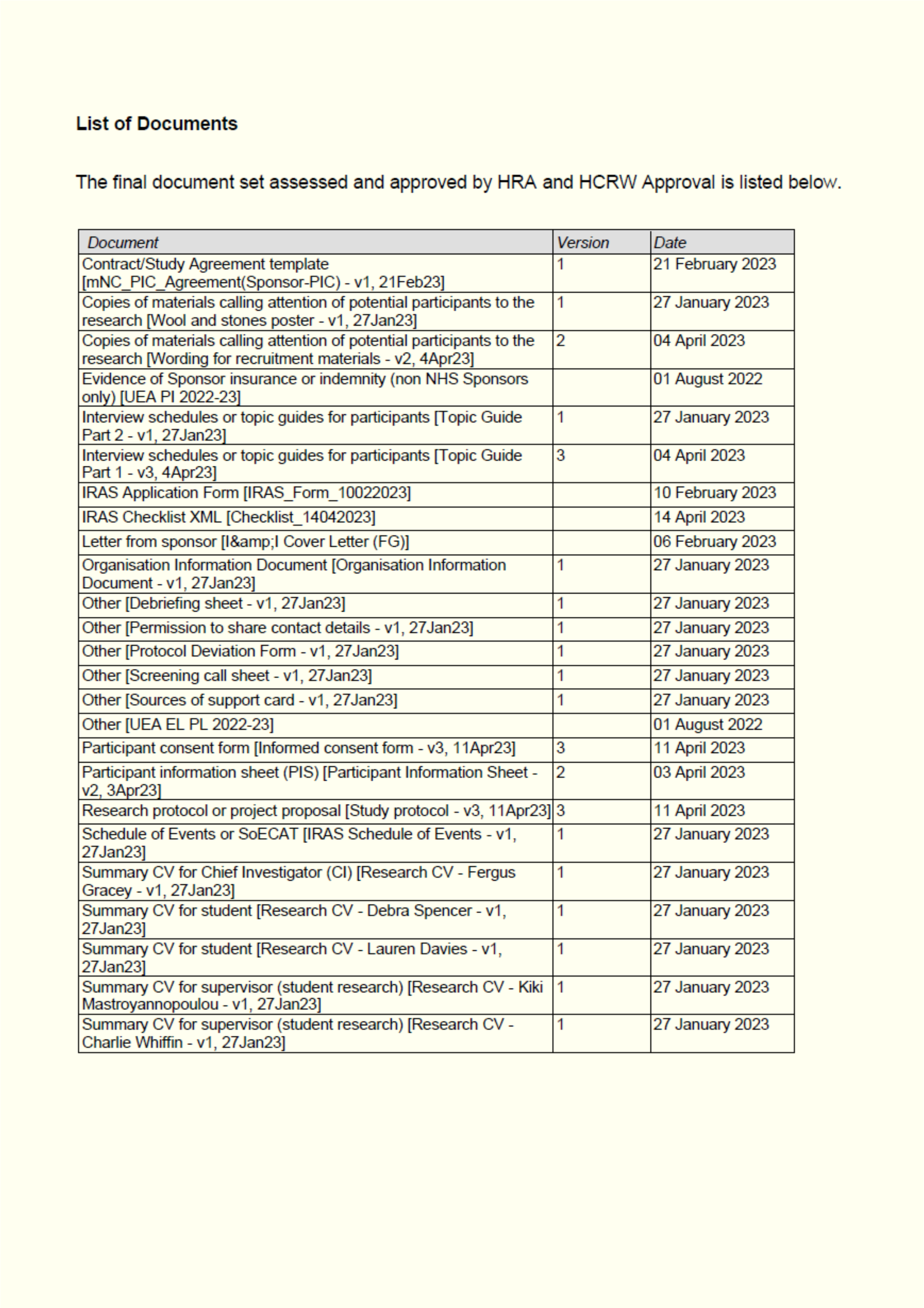
Your IRAS project ID is **322225**. Please quote this on all correspondence.

Yours sincerely,

Benita Hallewell-Goodwin

Email: approvals@hra.nhs.uk

*Copy to:* *Ms Tracy Moulton*

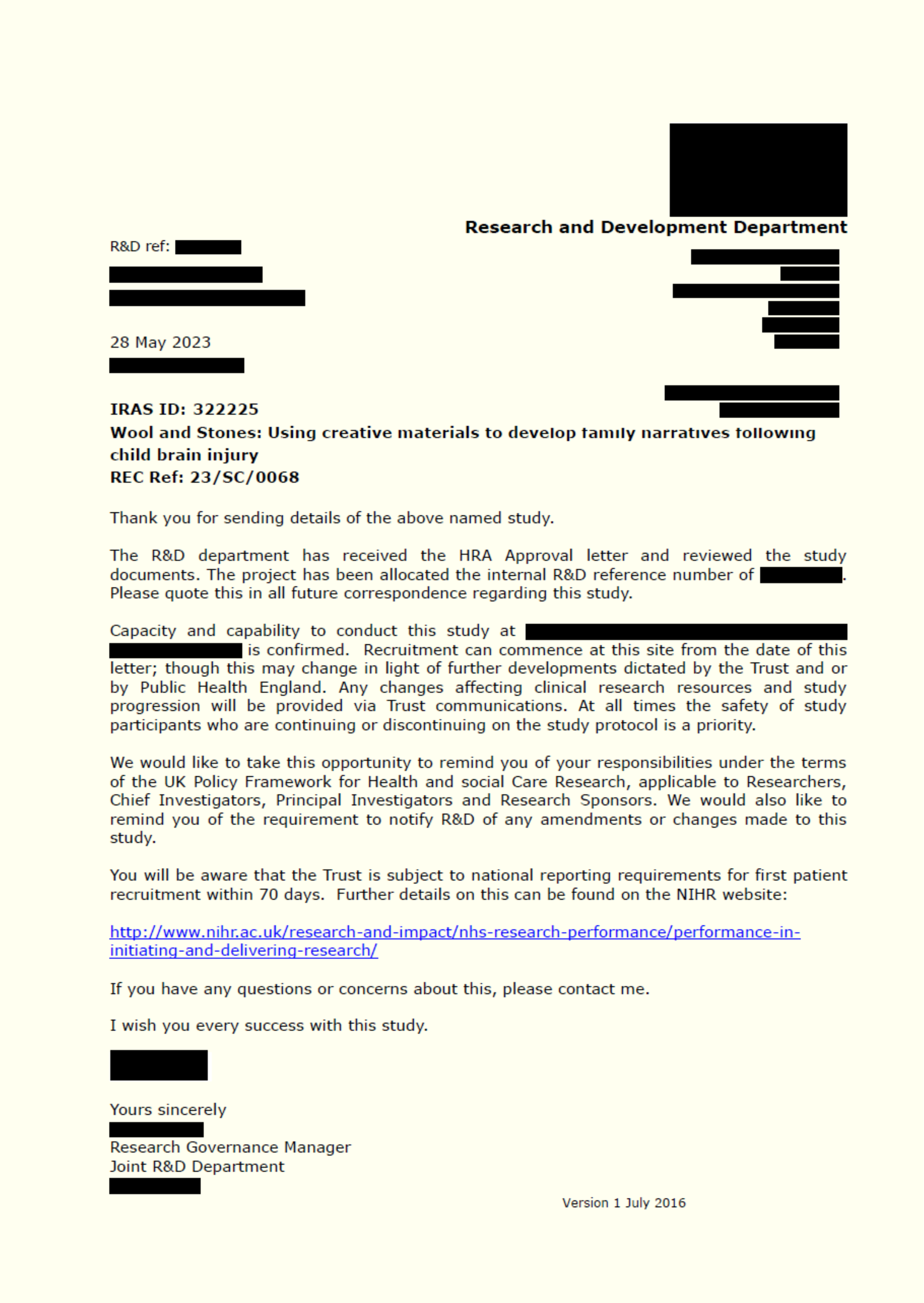


**List of Documents**

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

| *Document* | *Version* | *Date* |
|---|---|---|
| Contract/Study Agreement template [mNC_PIC_Agreement(Sponsor-PIC) - v1, 21Feb23] | 1 | 21 February 2023 |
| Copies of materials calling attention of potential participants to the research [Wool and stones poster - v1, 27Jan23] | 1 | 27 January 2023 |
| Copies of materials calling attention of potential participants to the research [Wording for recruitment materials - v2, 4Apr23] | 2 | 04 April 2023 |
| Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [UEA PI 2022-23] | | 01 August 2022 |
| Interview schedules or topic guides for participants [Topic Guide Part 2 - v1, 27Jan23] | 1 | 27 January 2023 |
| Interview schedules or topic guides for participants [Topic Guide Part 1 - v3, 4Apr23] | 3 | 04 April 2023 |
| IRAS Application Form [IRAS_Form_10022023] | | 10 February 2023 |
| IRAS Checklist XML [Checklist_14042023] | | 14 April 2023 |
| Letter from sponsor [I&amp;I Cover Letter (FG)] | | 06 February 2023 |
| Organisation Information Document [Organisation Information Document - v1, 27Jan23] | 1 | 27 January 2023 |
| Other [Debriefing sheet - v1, 27Jan23] | 1 | 27 January 2023 |
| Other [Permission to share contact details - v1, 27Jan23] | 1 | 27 January 2023 |
| Other [Protocol Deviation Form - v1, 27Jan23] | 1 | 27 January 2023 |
| Other [Screening call sheet - v1, 27Jan23] | 1 | 27 January 2023 |
| Other [Sources of support card - v1, 27Jan23] | 1 | 27 January 2023 |
| Other [UEA EL PL 2022-23] | | 01 August 2022 |
| Participant consent form [Informed consent form - v3, 11Apr23] | 3 | 11 April 2023 |
| Participant information sheet (PIS) [Participant Information Sheet - v2, 3Apr23] | 2 | 03 April 2023 |
| Research protocol or project proposal [Study protocol - v3, 11Apr23] | 3 | 11 April 2023 |
| Schedule of Events or SoECAT [IRAS Schedule of Events - v1, 27Jan23] | 1 | 27 January 2023 |
| Summary CV for Chief Investigator (CI) [Research CV - Fergus Gracey - v1, 27Jan23] | 1 | 27 January 2023 |
| Summary CV for student [Research CV - Debra Spencer - v1, 27Jan23] | 1 | 27 January 2023 |
| Summary CV for student [Research CV - Lauren Davies - v1, 27Jan23] | 1 | 27 January 2023 |
| Summary CV for supervisor (student research) [Research CV - Kiki Mastroyannopoulou - v1, 27Jan23] | 1 | 27 January 2023 |
| Summary CV for supervisor (student research) [Research CV - Charlie Whiffin - v1, 27Jan23] | 1 | 27 January 2023 |

## Research site’s confirmation of capacity and capability (C&C) to support study



[redacted]

**Research and Development Department**

[redacted]

R&D ref: [redacted]

[redacted]

28 May 2023

[redacted]

[redacted]

**IRAS ID: 322225**
**Wool and Stones: Using creative materials to develop family narratives following child brain injury**
**REC Ref: 23/SC/0068**

Thank you for sending details of the above named study.

The R&D department has received the HRA Approval letter and reviewed the study documents. The project has been allocated the internal R&D reference number of [redacted]. Please quote this in all future correspondence regarding this study.

Capacity and capability to conduct this study at [redacted] is confirmed. Recruitment can commence at this site from the date of this letter; though this may change in light of further developments dictated by the Trust and or by Public Health England. Any changes affecting clinical research resources and study progression will be provided via Trust communications. At all times the safety of study participants who are continuing or discontinuing on the study protocol is a priority.

We would like to take this opportunity to remind you of your responsibilities under the terms of the UK Policy Framework for Health and social Care Research, applicable to Researchers, Chief Investigators, Principal Investigators and Research Sponsors. We would also like to remind you of the requirement to notify R&D of any amendments or changes made to this study.

You will be aware that the Trust is subject to national reporting requirements for first patient recruitment within 70 days. Further details on this can be found on the NIHR website:

http://www.nihr.ac.uk/research-and-impact/nhs-research-performance/performance-in-initiating-and-delivering-research/

If you have any questions or concerns about this, please contact me.

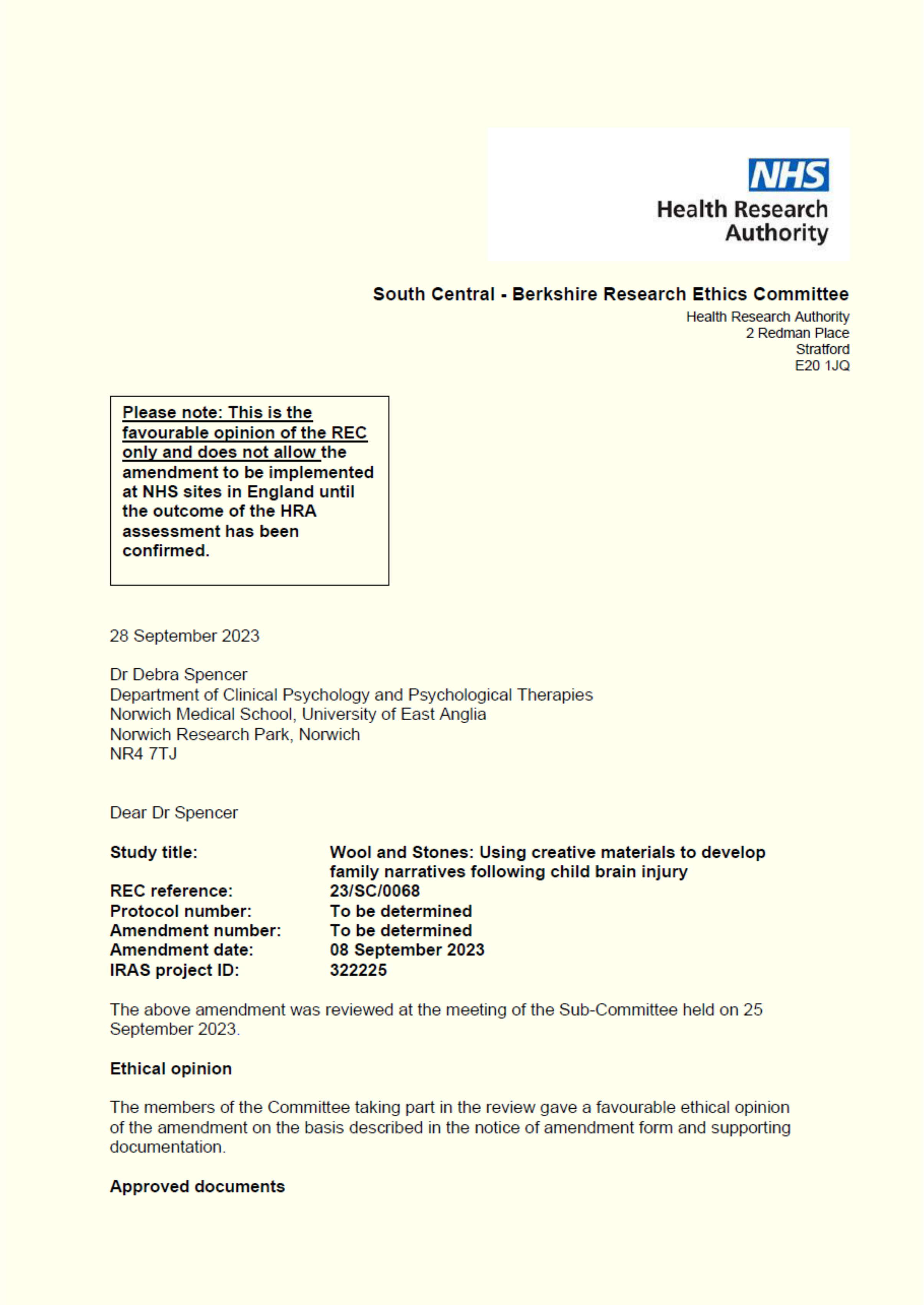
I wish you every success with this study.

[redacted]

Yours sincerely
[redacted]
Research Governance Manager
Joint R&D Department
[redacted]

Version 1 July 2016

## NHS REC approval for substantial amendment to study



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**South Central - Berkshire Research Ethics Committee**
Health Research Authority
2 Redman Place
Stratford
E20 1JQ

**Please note: This is the favourable opinion of the REC only and does not allow the amendment to be implemented at NHS sites in England until the outcome of the HRA assessment has been confirmed.**

28 September 2023

Dr Debra Spencer
Department of Clinical Psychology and Psychological Therapies
Norwich Medical School, University of East Anglia
Norwich Research Park, Norwich
NR4 7TJ

Dear Dr Spencer

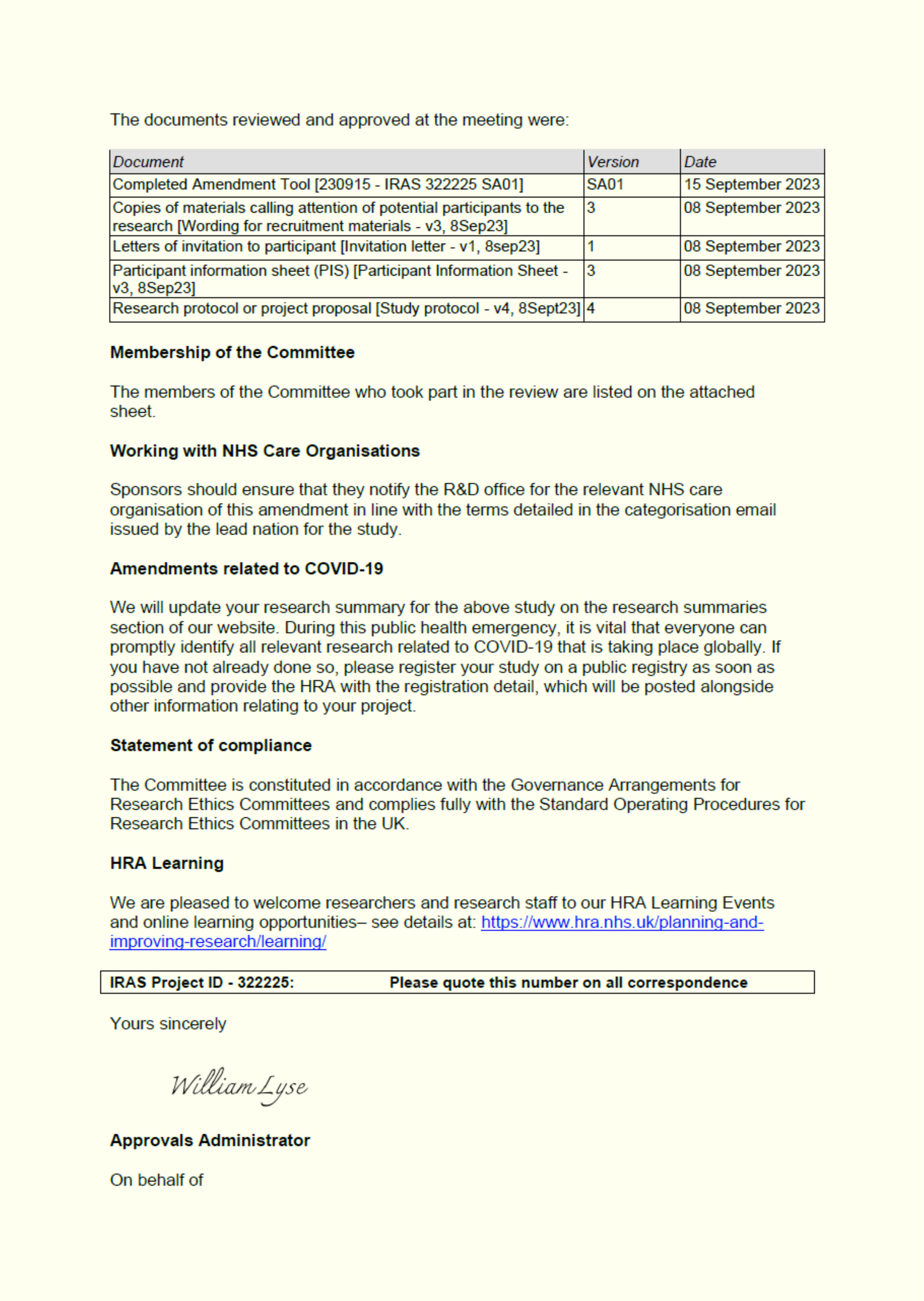
| | |
|---|---|
| **Study title:** | **Wool and Stones: Using creative materials to develop family narratives following child brain injury** |
| **REC reference:** | **23/SC/0068** |
| **Protocol number:** | **To be determined** |
| **Amendment number:** | **To be determined** |
| **Amendment date:** | **08 September 2023** |
| **IRAS project ID:** | **322225** |

The above amendment was reviewed at the meeting of the Sub-Committee held on 25 September 2023.

**Ethical opinion**

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

**Approved documents**



The documents reviewed and approved at the meeting were:

| *Document* | *Version* | *Date* |
|---|---|---|
| Completed Amendment Tool [230915 - IRAS 322225 SA01] | SA01 | 15 September 2023 |
| Copies of materials calling attention of potential participants to the research [Wording for recruitment materials - v3, 8Sep23] | 3 | 08 September 2023 |
| Letters of invitation to participant [Invitation letter - v1, 8sep23] | 1 | 08 September 2023 |
| Participant information sheet (PIS) [Participant Information Sheet - v3, 8Sep23] | 3 | 08 September 2023 |
| Research protocol or project proposal [Study protocol - v4, 8Sept23] | 4 | 08 September 2023 |

**Membership of the Committee**

The members of the Committee who took part in the review are listed on the attached sheet.

**Working with NHS Care Organisations**

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

**Amendments related to COVID-19**

We will update your research summary for the above study on the research summaries section of our website. During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you have not already done so, please register your study on a public registry as soon as possible and provide the HRA with the registration detail, which will be posted alongside other information relating to your project.

**Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

**HRA Learning**

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: https://www.hra.nhs.uk/planning-and-improving-research/learning/

**IRAS Project ID - 322225:** **Please quote this number on all correspondence**

Yours sincerely

William Lyse

**Approvals Administrator**

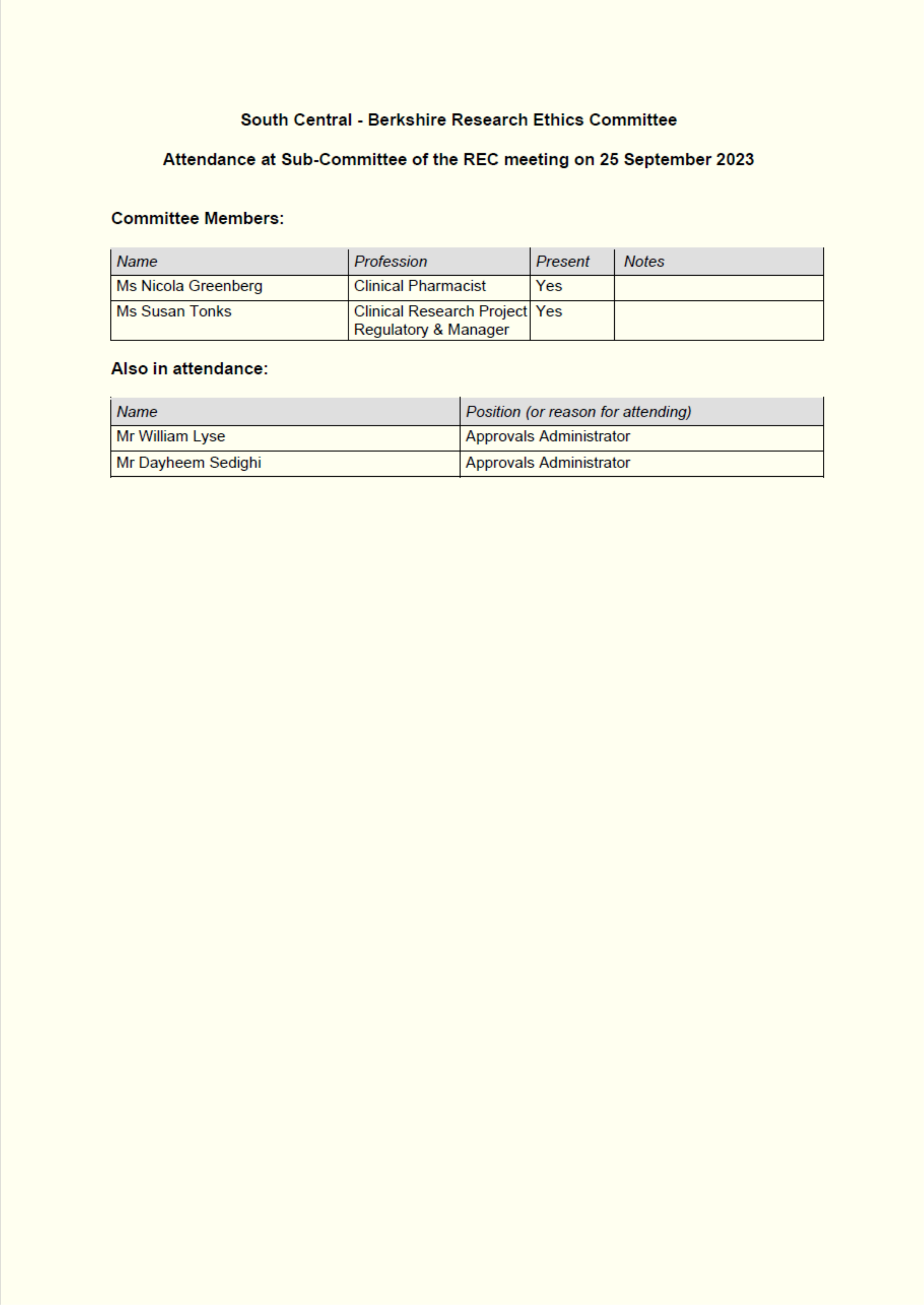
On behalf of

**Ms Susan Tonks**
**Chair**

E-mail: berkshire.rec@hra.nhs.uk

*Enclosures:* *List of names and professions of members who took part in the review*

*Copy to:* *Dr Debra Spencer*



**South Central - Berkshire Research Ethics Committee**

**Attendance at Sub-Committee of the REC meeting on 25 September 2023**

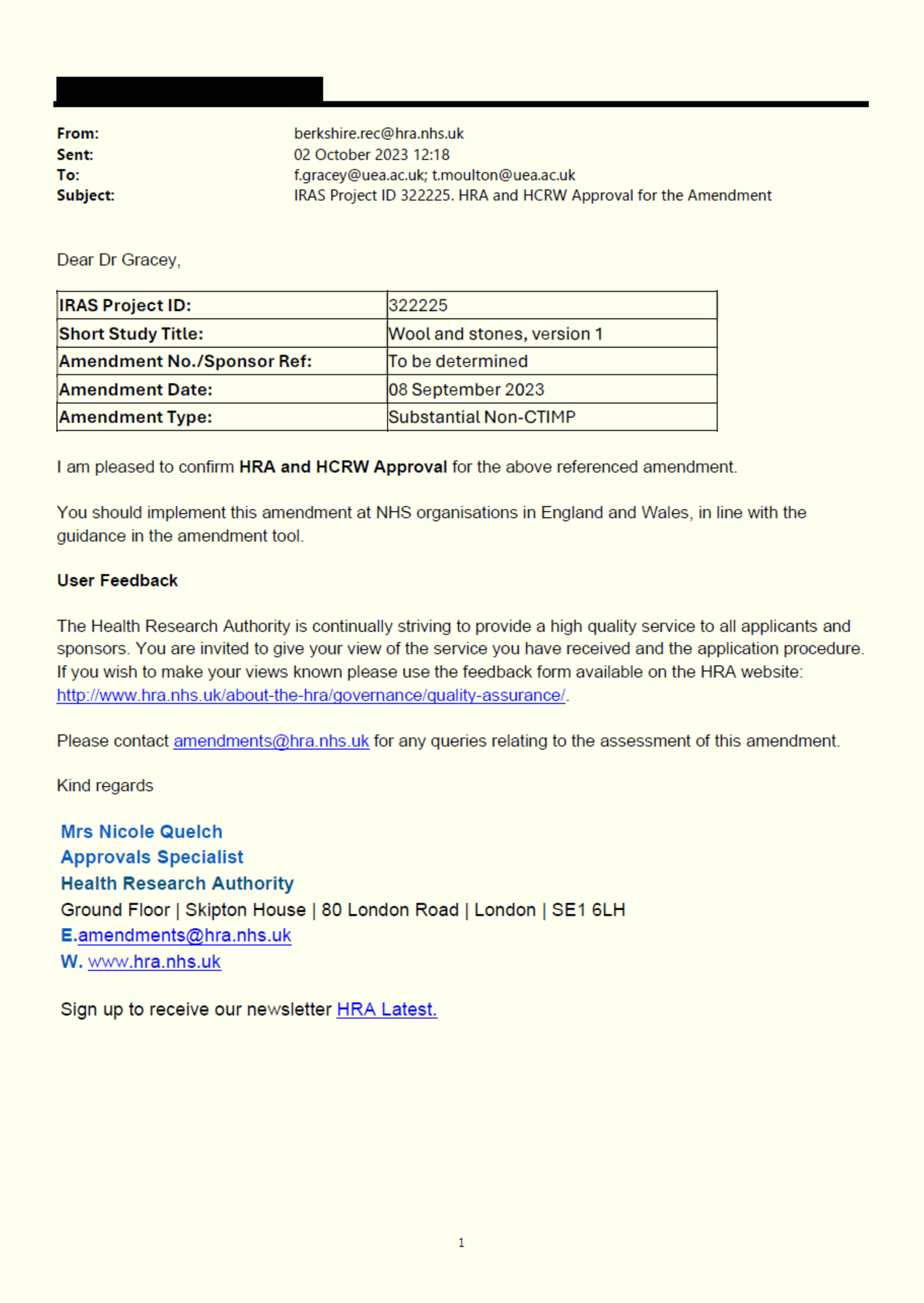
**Committee Members:**

| *Name* | *Profession* | *Present* | *Notes* |
|---|---|---|---|
| Ms Nicola Greenberg | Clinical Pharmacist | Yes | |
| Ms Susan Tonks | Clinical Research Project Regulatory & Manager | Yes | |

**Also in attendance:**

| *Name* | *Position (or reason for attending)* |
|---|---|
| Mr William Lyse | Approvals Administrator |
| Mr Dayheem Sedighi | Approvals Administrator |

## NHS HRA approval for substantial amendment to study



[redacted]

**From:** berkshire.rec@hra.nhs.uk
**Sent:** 02 October 2023 12:18
**To:** f.gracey@uea.ac.uk; t.moulton@uea.ac.uk
**Subject:** IRAS Project ID 322225. HRA and HCRW Approval for the Amendment

Dear Dr Gracey,

| | |
|---|---|
| **IRAS Project ID:** | 322225 |
| **Short Study Title:** | Wool and stones, version 1 |
| **Amendment No./Sponsor Ref:** | To be determined |
| **Amendment Date:** | 08 September 2023 |
| **Amendment Type:** | Substantial Non-CTIMP |

I am pleased to confirm **HRA and HCRW Approval** for the above referenced amendment.

You should implement this amendment at NHS organisations in England and Wales, in line with the guidance in the amendment tool.

**User Feedback**

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/.

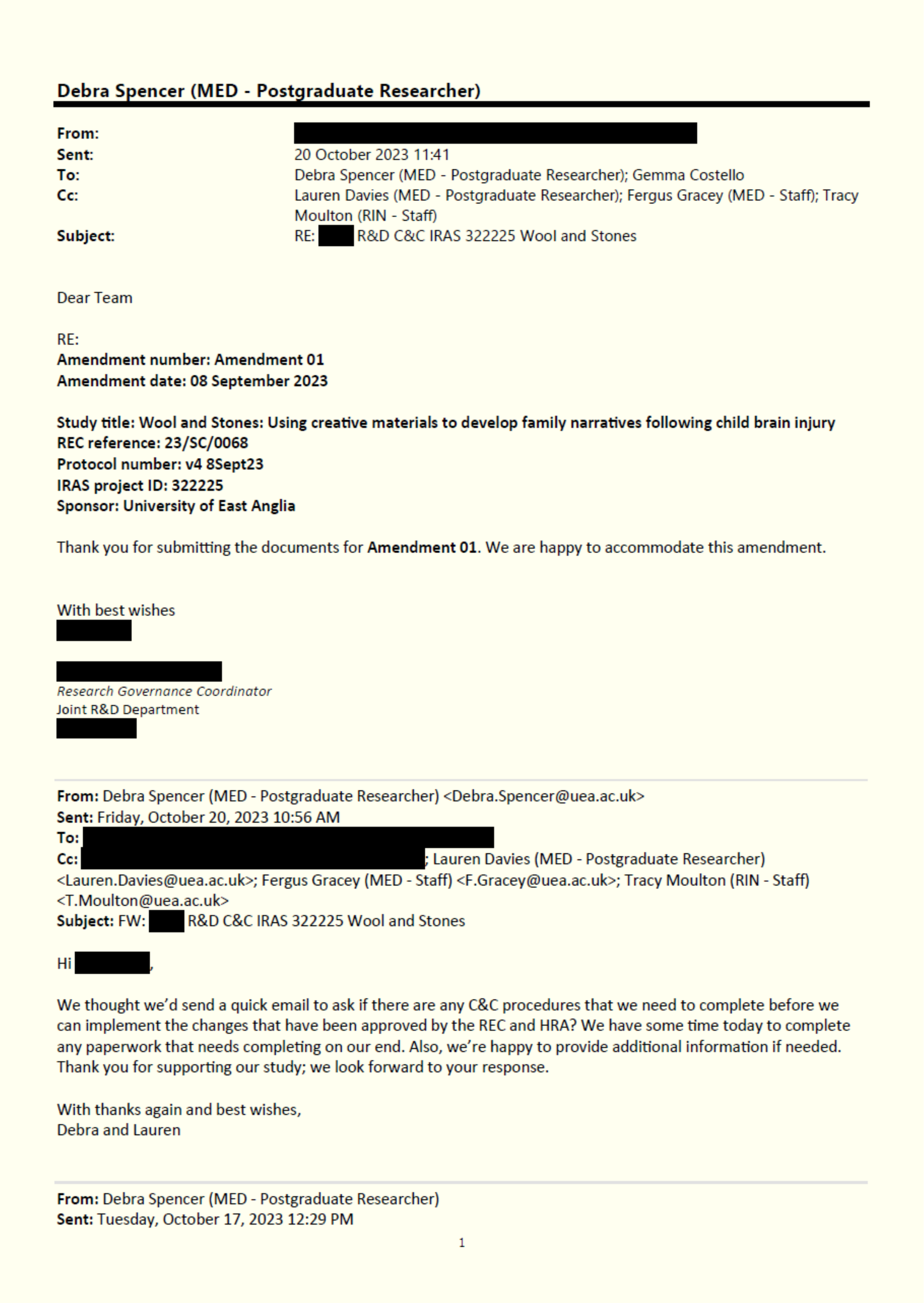
Please contact amendments@hra.nhs.uk for any queries relating to the assessment of this amendment.

Kind regards

**Mrs Nicole Quelch**
**Approvals Specialist**
**Health Research Authority**
Ground Floor | Skipton House | 80 London Road | London | SE1 6LH
**E.**amendments@hra.nhs.uk
**W.** www.hra.nhs.uk

Sign up to receive our newsletter HRA Latest.

## Research site's confirmation of continued C&C following substantial amendment



**Debra Spencer (MED - Postgraduate Researcher)**

**From:** [redacted]
**Sent:** 20 October 2023 11:41
**To:** Debra Spencer (MED - Postgraduate Researcher); Gemma Costello
**Cc:** Lauren Davies (MED - Postgraduate Researcher); Fergus Gracey (MED - Staff); Tracy Moulton (RIN - Staff)
**Subject:** RE: [redacted] R&D C&C IRAS 322225 Wool and Stones

Dear Team

RE:
**Amendment number: Amendment 01**
**Amendment date: 08 September 2023**

**Study title: Wool and Stones: Using creative materials to develop family narratives following child brain injury**
**REC reference: 23/SC/0068**
**Protocol number: v4 8Sept23**
**IRAS project ID: 322225**
**Sponsor: University of East Anglia**

Thank you for submitting the documents for **Amendment 01**. We are happy to accommodate this amendment.

With best wishes
[redacted]

[redacted]
*Research Governance Coordinator*
Joint R&D Department
[redacted]

---

**From:** Debra Spencer (MED - Postgraduate Researcher) <Debra.Spencer@uea.ac.uk>
**Sent:** Friday, October 20, 2023 10:56 AM
**To:** [redacted]
**Cc:** [redacted]; Lauren Davies (MED - Postgraduate Researcher) <Lauren.Davies@uea.ac.uk>; Fergus Gracey (MED - Staff) <F.Gracey@uea.ac.uk>; Tracy Moulton (RIN - Staff) <T.Moulton@uea.ac.uk>
**Subject:** FW: [redacted] R&D C&C IRAS 322225 Wool and Stones

Hi [redacted],

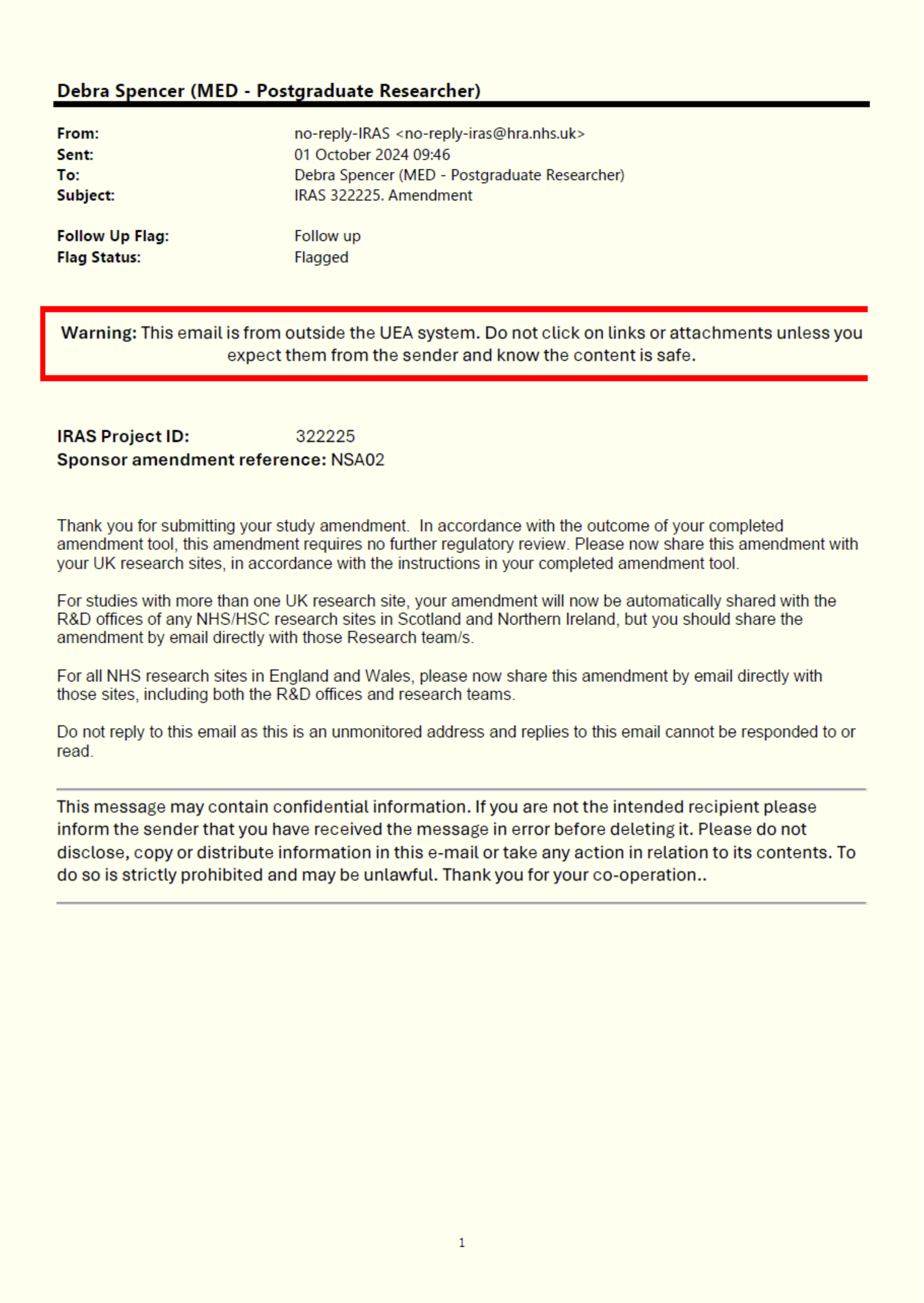
We thought we'd send a quick email to ask if there are any C&C procedures that we need to complete before we can implement the changes that have been approved by the REC and HRA? We have some time today to complete any paperwork that needs completing on our end. Also, we're happy to provide additional information if needed. Thank you for supporting our study; we look forward to your response.

With thanks again and best wishes,
Debra and Lauren

---

**From:** Debra Spencer (MED - Postgraduate Researcher)
**Sent:** Tuesday, October 17, 2023 12:29 PM

## NHS HRA approval for non-substantial amendment to study



**Debra Spencer (MED - Postgraduate Researcher)**

**From:** no-reply-IRAS <no-reply-iras@hra.nhs.uk>
**Sent:** 01 October 2024 09:46
**To:** Debra Spencer (MED - Postgraduate Researcher)
**Subject:** IRAS 322225. Amendment

**Follow Up Flag:** Follow up
**Flag Status:** Flagged

**IRAS Project ID:** 322225
**Sponsor amendment reference:** NSA02

Thank you for submitting your study amendment. In accordance with the outcome of your completed amendment tool, this amendment requires no further regulatory review. Please now share this amendment with your UK research sites, in accordance with the instructions in your completed amendment tool.

For studies with more than one UK research site, your amendment will now be automatically shared with the R&D offices of any NHS/HSC research sites in Scotland and Northern Ireland, but you should share the amendment by email directly with those Research team/s.

For all NHS research sites in England and Wales, please now share this amendment by email directly with those sites, including both the R&D offices and research teams.

Do not reply to this email as this is an unmonitored address and replies to this email cannot be responded to or read.

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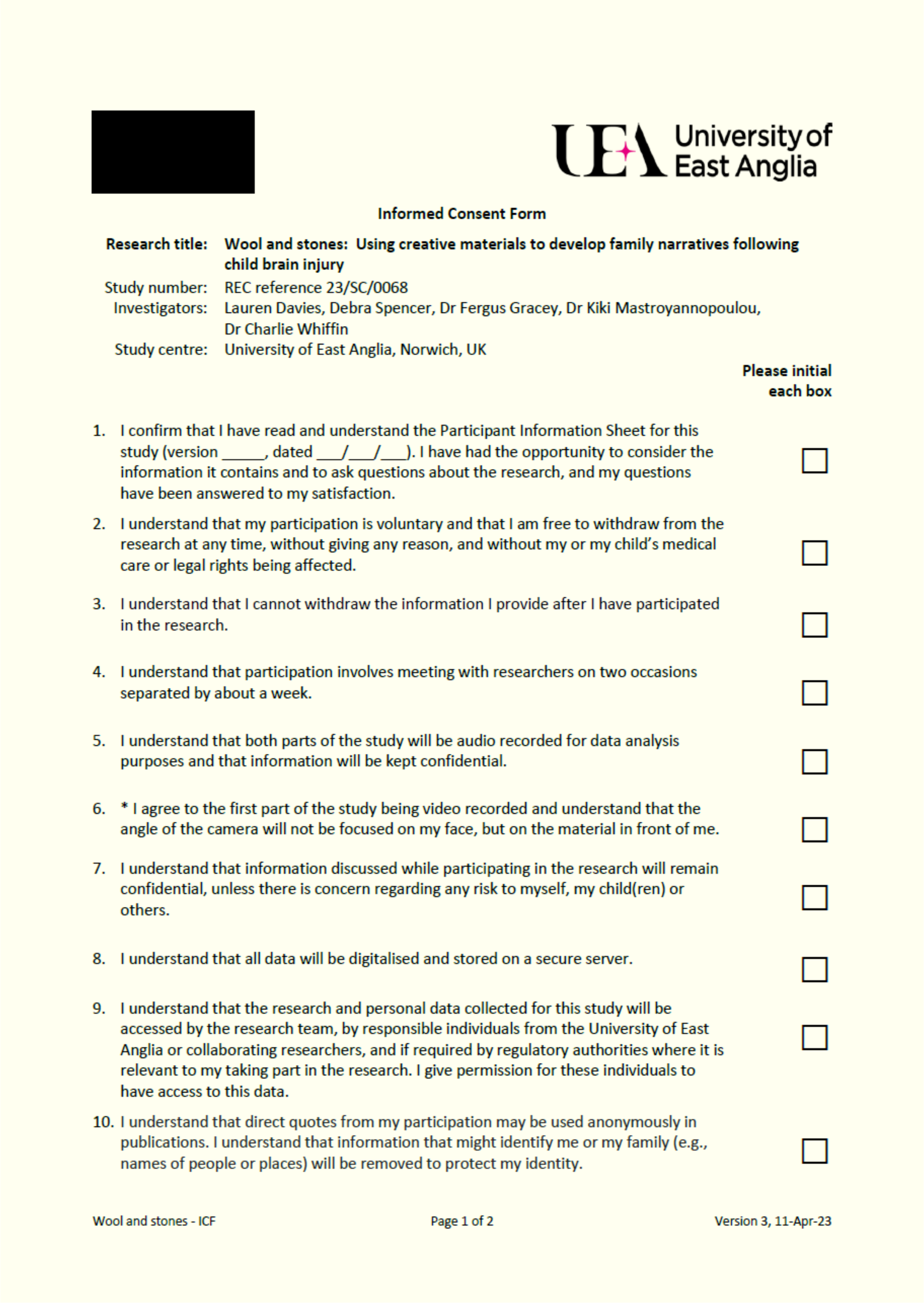
## **Appendix N.** *Informed Consent Form*



[redacted]

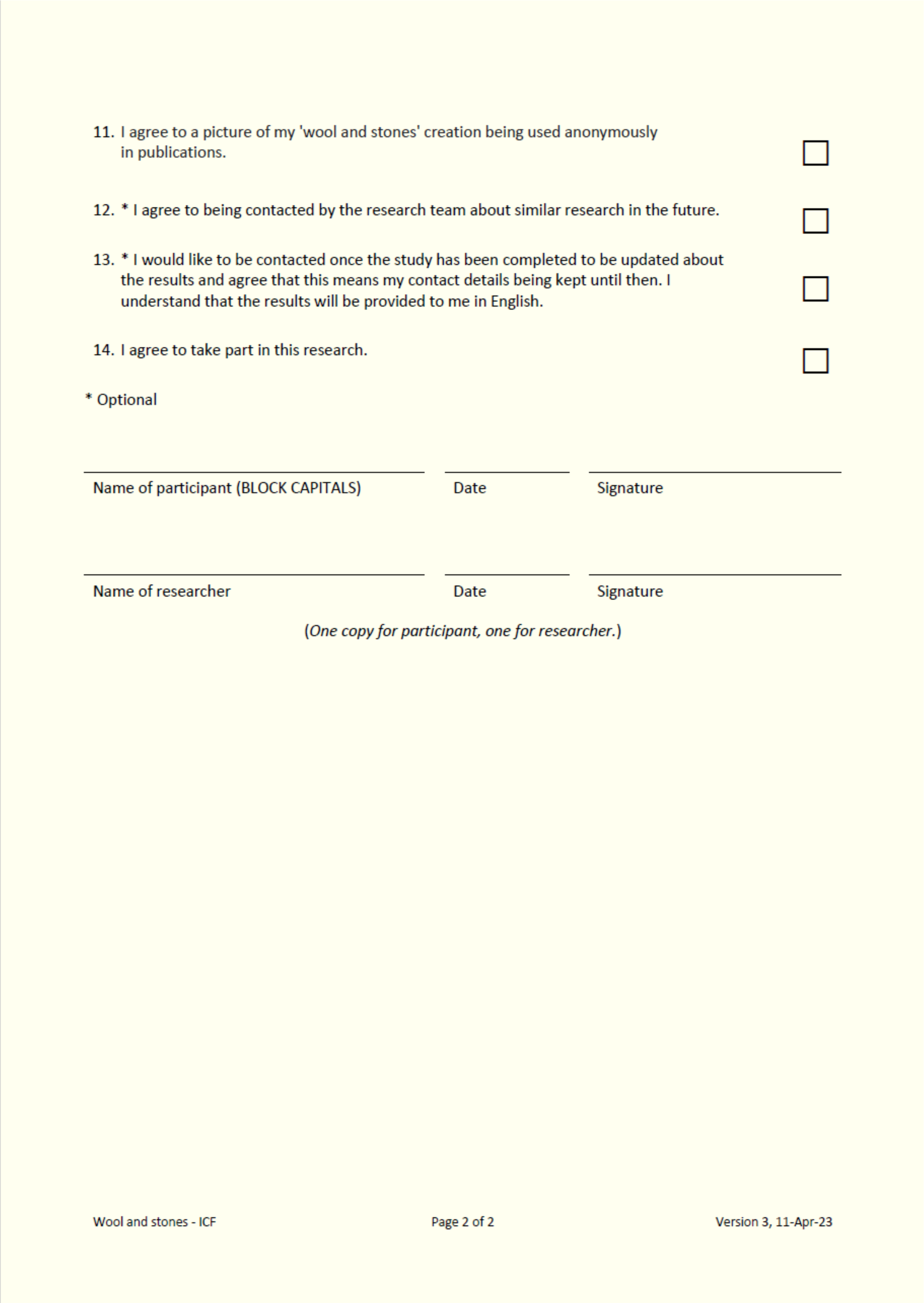
University of East Anglia

### Informed Consent Form

**Research title:** **Wool and stones: Using creative materials to develop family narratives following child brain injury**
Study number: REC reference 23/SC/0068
Investigators: Lauren Davies, Debra Spencer, Dr Fergus Gracey, Dr Kiki Mastroyannopoulou, Dr Charlie Whiffin
Study centre: University of East Anglia, Norwich, UK

**Please initial each box**

1. I confirm that I have read and understand the Participant Information Sheet for this study (version _____, dated ___/___/___). I have had the opportunity to consider the information it contains and to ask questions about the research, and my questions have been answered to my satisfaction. ☐
2. I understand that my participation is voluntary and that I am free to withdraw from the research at any time, without giving any reason, and without my or my child's medical care or legal rights being affected. ☐
3. I understand that I cannot withdraw the information I provide after I have participated in the research. ☐
4. I understand that participation involves meeting with researchers on two occasions separated by about a week. ☐
5. I understand that both parts of the study will be audio recorded for data analysis purposes and that information will be kept confidential. ☐
6. * I agree to the first part of the study being video recorded and understand that the angle of the camera will not be focused on my face, but on the material in front of me. ☐
7. I understand that information discussed while participating in the research will remain confidential, unless there is concern regarding any risk to myself, my child(ren) or others. ☐
8. I understand that all data will be digitalised and stored on a secure server. ☐
9. I understand that the research and personal data collected for this study will be accessed by the research team, by responsible individuals from the University of East Anglia or collaborating researchers, and if required by regulatory authorities where it is relevant to my taking part in the research. I give permission for these individuals to have access to this data. ☐
10. I understand that direct quotes from my participation may be used anonymously in publications. I understand that information that might identify me or my family (e.g., names of people or places) will be removed to protect my identity. ☐



11. I agree to a picture of my 'wool and stones' creation being used anonymously in publications. ☐

12. * I agree to being contacted by the research team about similar research in the future. ☐

13. * I would like to be contacted once the study has been completed to be updated about the results and agree that this means my contact details being kept until then. I understand that the results will be provided to me in English. ☐

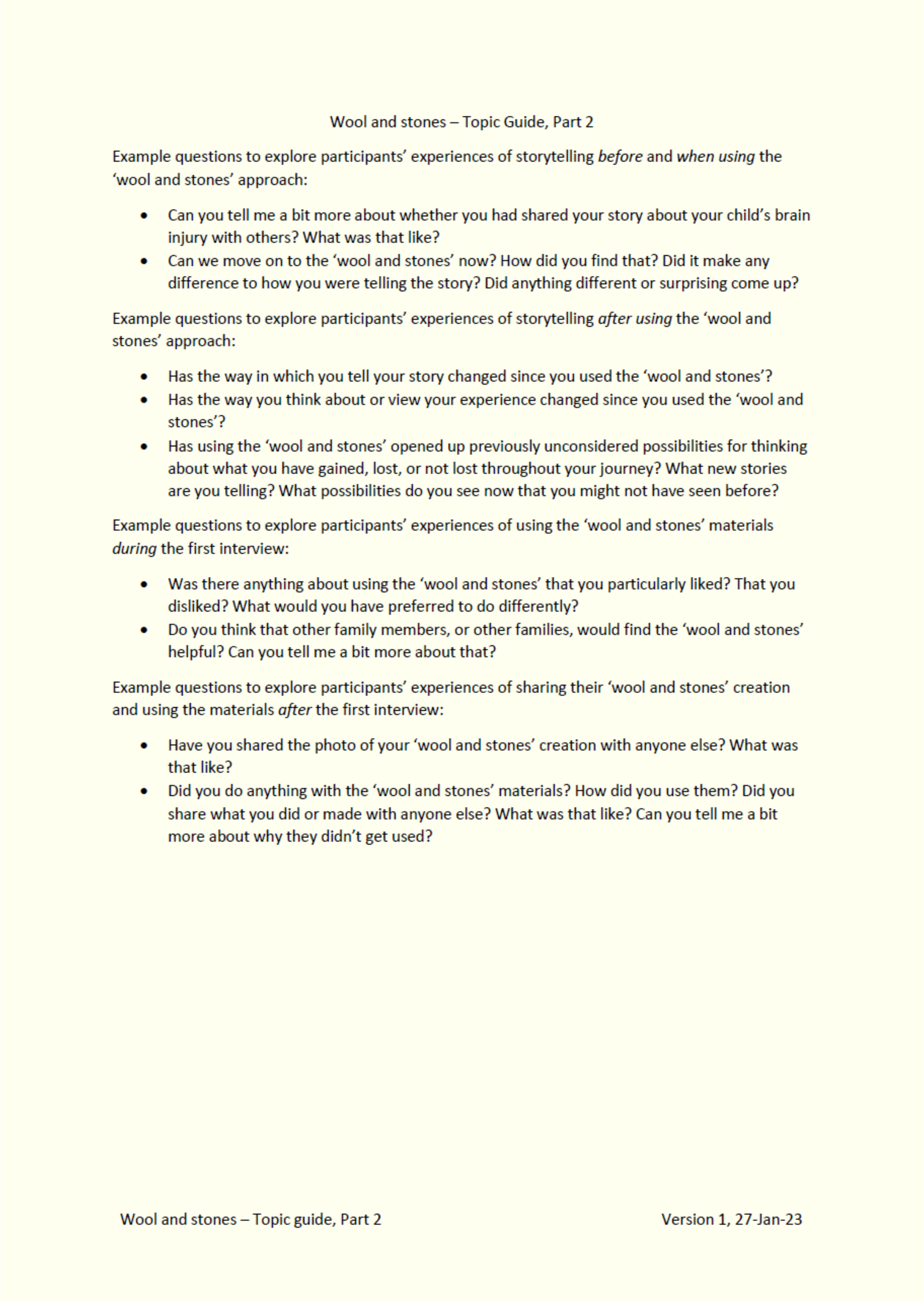
14. I agree to take part in this research. ☐

* Optional

| | | |
|---|---|---|
| Name of participant (BLOCK CAPITALS) | Date | Signature |
| Name of researcher | Date | Signature |

(*One copy for participant, one for researcher.*)

## **Appendix O.** *Part 2 Topic Guide*



### Wool and stones – Topic Guide, Part 2

Example questions to explore participants' experiences of storytelling *before* and *when using* the 'wool and stones' approach:

- Can you tell me a bit more about whether you had shared your story about your child's brain injury with others? What was that like?
- Can we move on to the 'wool and stones' now? How did you find that? Did it make any difference to how you were telling the story? Did anything different or surprising come up?

Example questions to explore participants' experiences of storytelling *after using* the 'wool and stones' approach:

- Has the way in which you tell your story changed since you used the 'wool and stones'?
- Has the way you think about or view your experience changed since you used the 'wool and stones'?
- Has using the 'wool and stones' opened up previously unconsidered possibilities for thinking about what you have gained, lost, or not lost throughout your journey? What new stories are you telling? What possibilities do you see now that you might not have seen before?

Example questions to explore participants' experiences of using the 'wool and stones' materials *during* the first interview:

- Was there anything about using the 'wool and stones' that you particularly liked? That you disliked? What would you have preferred to do differently?
- Do you think that other family members, or other families, would find the 'wool and stones' helpful? Can you tell me a bit more about that?

Example questions to explore participants' experiences of sharing their 'wool and stones' creation and using the materials *after* the first interview:

- Have you shared the photo of your 'wool and stones' creation with anyone else? What was that like?
- Did you do anything with the 'wool and stones' materials? How did you use them? Did you share what you did or made with anyone else? What was that like? Can you tell me a bit more about why they didn't get used?

Wool and stones – Topic guide, Part 2 Version 1, 27-Jan-23

## **Appendix P.** *Debriefing Sheet*

[redacted]

University of East Anglia

### Debriefing Sheet

**Research title:** **Wool and stones: Using creative materials to develop family narratives following child brain injury**
Study number: [TBD]
Investigators: Lauren Davies, Debra Spencer, Dr Fergus Gracey, Dr Kiki Mastroyannopoulou, Dr Charlie Whiffin
Study centre: University of East Anglia, Norwich, UK

Thank you for taking part in our research. We know that people who are hospitalised recover better when all of their needs – psychological, social and medical – are looked after, not just their medical needs. We also know that parents/carers of children with brain injury have unique experiences above and beyond those directly linked to their injured child and that these experiences can be difficult to make sense of or talk about.

The purpose of this study is to find out whether using a novel creative approach, 'wool and stones', might be helpful to parents/carer to tell their experiences of caring for a child with Acquired Brain Injury. To do this, we carried out two interviews with you which have been recorded and will be analysed. The information you have given will help us to understand whether using an approach like this could be helpful to families and, if so, where and how it might best be offered. We hope this study will provide us with information about innovative ways to support the needs of parents and carers after brain injury.

We are very grateful for your time, thank you. Please find below a list of support avenues should you like any further support. You can also reach out to your GP and/or self-refer for support with your local wellbeing service [redacted]

**Child Brain Injury Trust**
*A charity for families and professionals supporting children affected by brain injury*
T: 0303 303 2248
W: www.childbraininjurytrust.org.uk

**Headway**
*Supporting people with a brain injury and those who care about them*
T: 01223 576550
E: info@headway-cambs.org.uk
W: www.headway-cambs.org.uk

**Mind**
*A mental health charity*
T: 0300 123 3393
E: info@mind.org.uk
W: www.mind.org.uk

**Samaritans**
*Mental wellbeing support help line*
T: 116 123
E: jo@samaritans.org
W: www.samaritans.org

## **Appendix Q.** *Illustrative participant quotations by theme and subtheme*

**Table A6.** *Illustrative participant quotations by theme and subtheme*

| Theme 1: Piecing together the story | |
|---|---|
| Subtheme 1.1: Mapping the journey | |
| Participant | Quotation |
| P6 | "So mine was more the journey … this bit was the start, when it first happened. It's all kind of chaotic. And then, you know, we came out of hospital. And it kind of got much worse. And then as we kind of found [support] here … and then the stones were … us now … plodding along." |
| P2 | "For me, like the red was the anger. And the frustrations of what had happened, because you do feel angry in some ways about it." |
| P4 | "This one reminded me of when … when my daughter was suicidal and I was terrified she was going to … I think it was just the texture that brought that to my mind." |
| P1 | "I was able to kind of tie it up. That's what happened. It happened. We survived. That's where I am now." |
| P4 | "Once I started moving things around, I realised I was actually telling a story." |
| P6 | "I think it's just kind of to show the kind of plodding that it's now… we seem to just plod on now. And it's a bit more settled." |
| P1 | "I could put things into order. And that was really handy. And that's why I think it came out in a line." |
| P1 | "I felt like I tidied it all up and pushed it to one side." |

| | |
|---|---|
| P7 | “From where we were, to where we are, is completely and utterly different.” |
| Subtheme 1.2: Owning the narrative | |
| Participant | Quotation |
| P2 | “There’s no right or wrong to it. That’s my interpretation.” |
| P1 | “I kept it really quite private. But that was really nice.” |
| P7 | “It would have come to surface sometime. And I think it was my choice that it come to surface last week. So I’m in control of it.” |
| P1 | “It was in perspective, and then move it away. It’s control. I’m a control freak.” |
| P1 | “No, no, no, because that’s a real personal thing… You’re talking about something that’s so personal to you… It was nice just to be told, you can do it your own way. There’s no right or wrong to it.” |
| P1 | “It’s the first time I’ve done something like that, where I haven’t talked about everyone else… it was about me.” |
| P2 | “The reassurance that there’s no right or wrong as well… it’s very much an individual thing.” |
| P7 | “No, because this is my experience. This is my time. This is for me.” |
| P7 | “Anybody looking at that picture would just think it’s wool and stones with a pair of scissors. But actually, there’s a story behind it.” |
| P1 | “No. I kept it quite private… it was just about me.” |
| Theme 2: Engaging with the process | |
| Subtheme 2.1: Feeling safe enough to share | |

| Participant | Quotation |
|---|---|
| P4 | “It was really nice to talk about the journey with someone that doesn’t know me … there’s no judgement.” |
| P2 | “So yeah, it’s been hard to talk about things and unpick everything – but positive as well. I don’t regret it in the slightest.” |
| P7 | “It was the right time to do it. I was too afraid before. I was concentrating on how we were going to manage.” |
| P2 | “It makes you address those emotions that are quite buried, and that was really hard. Really draining. I was exhausted.” |
| P1 | “It’s the first time I’ve done something like that, where I haven’t talked about everyone else. It was about me.” |
| P2 | “Not being asked, ‘How are you?’ That’s a big thing.” |
| P5 | “Yeah. Because we were able to talk about it a bit more. It gave you the, um, the green light to talk about things.” |
| P4 | “When I left here, my husband was sort of like, you know, are you sure you should be doing this, because I don’t want it to drag you down. And I was like actually, it was really good to talk. I felt just a little bit of a lift because it was… I could talk to [father], don’t get me wrong… Whereas it just felt, [researcher]… you understood?” |
| P2 | “And I said, that was so hard… I found it really tiring. But I actually found it helpful. It is helpful.” |
| P2 | “So, yeah… I can talk about it. I can let go a little. And I’ll be all right. I was all right.” |
| P6 | “I don’t think I would have wanted to have done it any sooner… I think probably about the year stage is, yeah, it’s about right.” |

Subtheme 2.2: Leaning in or holding back

| Participant | Quotation |
|---|---|
| P7 | “I didn’t look at the time. I could have sat there for six and a half hours. It was very… free.” |

| | |
|---|---|
| P2 | “You don’t realise how much comes out until you start talking through what each bit means.” |
| P7 | “You’re using your brain as well as the materials… you’ve got that sensitivity on your fingers… and I think it just flew.” |
| P1 | “I felt like I was wrapping it up… even in my messy, scrappy world in my head, I still liked things completed.” |
| P6 | “It didn’t really bring up anything new, I don’t think.” |
| P5 | “She got all the stuff out … and started explaining to me how she felt after her injury.” |
| P4 | “I did keep looking at the bag, but in my head, I was like, I don’t know what to do with it.” |
| P5 | “I did think about them a few times, yeah… but I didn’t really get them out to look at it.” |
| P6 | “It’s in a box.” [Laughs] |
| P6 | “It’s, it’s in a cupboard.” |
| P7 | “It’s in my bedroom.” |
| P7 | “Yeah, because you could explain how you’re actually feeling with… you’ve started and where you’ve ended up, which is a very good idea.” |