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Exploring the road to and from surgery: Cognitive prehabilitation and long-term neuropsychological and psychosocial outcomes in resective epilepsy surgery

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Submitted in partial fulfilment of the requirements for the degree of Doctorate in Clinical Psychology

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Table of Contents

List of Tables **4**

List of Figures **5**

Acknowledgements **6**

1. Chapter 1: Systematic Review **8**

Abstract *9*

Introduction *11*

Methods *13*

Results *18*

Discussion *48*

References *55*

2. Chapter 2: Major Research Project **59**

Patient Experiences of Cognitive Prehabilitation on the Epilepsy Surgery Pathway **59**

MRP Plain Language Summary *60*

Background 60

Aim 60

Research Questions 60

Methods 60

Findings 60

Conclusions 61

Abstract *62*

Introduction *64*

Methods *67*

Results *72*

Discussion *87*

References *97*

Appendices **100**

3. Systematic Review Appendix **100**

Appendix 1.1: PRISMA Checklist *100*

Appendix 1.2: Search Terms *104*

4. Major Research Project Appendix **109**

Appendix 2.1: COREQ Checklist 109

Appendix 2.2: Final MRP Proposal 112

Appendix 2.3: Ethic Approval Letter 113

Appendix 2.4: Amendments 120

Appendix 2.5: Management Approval Letters 122
Appendix 2.6: Participant Information Sheet 135
Appendix 2.7: Privacy Notice 136
Appendix 2.8: Consent Form Template 137
Appendix 2.9: Topic Guide 138
Appendix 2.10: Detailed Data-Analysis Plan 139
Appendix 2.11: Record of Data Analysis Process 140
Appendix 2.12: Data Availability Statement 141
Appendix 2.13: Researcher Reflexivity Statement 142
Appendix 2.14: Participant Recruitment Procedure 143
Appendix 2.15: Final Thematic Map 144
Appendix 2.15: A 15-point checklist of Criteria for Good Thematic Analysis Process (Braun and Clarke 2006) 145

List of Tables

Chapter 1: Systematic Review
Table 1.1: Study Characteristics Table 21
Table 1.2: JBI Cohort Checklist Tool Table 26
Table 1.3: JBI Assessment of Risk of Bias for Analytical Cross-sectional Studies Table ... 29
Table 1.4: Table of Meta-analyses 45

Chapter 2: Major Research Project
Table 2.1: Summary of Main Themes 72

Systematic Review Appendices
Table 3.1: PRISMA Checklist 100
Table 3.2: Search Terms (Ran on 2nd April 2026) 104

Major Research Project Appendices
Table 4.1: COREQ Checklist 109
Table 4.2: A 15-point checklist of Criteria for Good Thematic Analysis Process (Braun and Clarke 2006) 145

List of Figures

Chapter 1: Systematic Review

Figure 1.1: Prisma Flow Diagram 19
Figure 1.2: LTLE Immediate Verbal Memory Forest Plot 33
Figure 1.3: LTLE Delayed Verbal Memory Forest Plot 33
Figure 1.4: LTLE Immediate Visual Memory Forest Plot 34
Figure 1.5: LTLE Delayed Visual Memory Forest Plot 34
Figure 1.6: LTLE VIQ Forest Plot 35
Figure 1.7: LTLE PIQ Forest Plot 35
Figure 1.8: LTLE Confrontational Naming Forest Plot 36
Figure 1.9: LTLE Phonemic Fluency Forest Plot 36
Figure 1.10: LTLE Semantic Fluency Forest Plot 37
Figure 1.11: RTLE Immediate Verbal Memory Forest Plot 37
Figure 1.12: RTLE Delayed Verbal Memory Forest Plot 38
Figure 1.13: RTLE Immediate Visual Memory Forest Plot 38
Figure 1.14: RTLE Delayed Visual Memory Forest Plot 39
Figure 1.15: RTLE VIQ Forest Plot 39
Figure 1.16: RTLE PIQ Forest Plot 40
Figure 1.17: RTLE Confrontational Naming Forest Plot 40
Figure 1.18: RTLE Phonemic Fluency Forest Plot 41
Figure 1.19: RTLE Semantic Fluency Forest Plot 41
Figure 1.20: Non-Lateralised Immediate Verbal Memory Forest Plot 42
Figure 1.21: Non-Lateralised Delayed Verbal Memory Forest Plot 42
Figure 1.22: Non-Lateralised FSIQ Forest Plot 43
Figure 1.23: Total QOLIE QOL Forest Plot 44

Major Research Project Appendices

Figure 4.1: Thematic Map from MindMup 144

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1. Chapter 1: Systematic Review

Long-term neuropsychological and psychosocial wellbeing outcomes post resective epilepsy surgery.

Prepared in accordance with the author requirements for *Epilepsy & Behavior* (Elsevier) https://www.sciencedirect.com/journal/epilepsy-and-behavior/publish/guide-for-authors

Abstract

Background: This review examined the long-term neuropsychological, quality of life and mood-based outcomes of resective epilepsy surgery.

Methods: Eligible studies included original research involving adults undergoing resective epilepsy surgery that reported standardised neuropsychological, mood, or quality-of-life outcomes at least five years postoperatively. The study followed the PRISMA guidelines. The databases searched were Medline (OVID), PsycINFO (EBSCO), Embase (OVID), and PubMed on 2nd April 2026. Study quality was assessed using the JBI Critical Appraisal Checklist for Cohort studies. The present study used both narrative synthesis and meta-analysis to examine outcomes.

Results: A total of 23 eligible studies were included in the analysis. Participants had a weighted mean age of 35.5 years at the time of surgery or baseline testing. Most studies focused on temporal lobe epilepsy, and anterior temporal lobe resection (ATLR) surgery was the most common surgical procedure. The methodological quality of the included studies was generally high. Neuropsychological outcomes appeared mixed, with deterioration noted in memory outcomes and some improvements noted in language domains. Quality of life outcomes showed improvement narratively and in meta-analysis. Both neuropsychological and quality of life outcomes were influenced by other factors, such as side of surgery and seizure freedom. Mood outcomes were largely cross-sectional and varied across studies.

Discussion: Overall, findings indicate that outcomes following resective epilepsy surgery were mixed. Neuropsychological outcomes showed changes in both memory and language domains compared with baseline performance, but the included papers also showed significant heterogeneity. The findings support the role of neuropsychological assessment throughout the epilepsy surgery pathway and the importance of longitudinal, long-term evaluation of outcomes to provide accurate information to patients considering resective surgery. Future epilepsy research should focus on larger, multi-centre studies to reduce variability and enable more effective subgroup analyses.

Keywords: Epilepsy, treatment-resistant epilepsy, resective epilepsy surgery, neurosurgery, neuropsychology, cognitive outcomes, quality of life outcomes, mood outcomes, anxiety, depression, long-term outcomes.

Funding: No funding was received for this project

Disclosure Statement: There are no competing interests to declare.

Introduction

Neurosurgery is an evidence-based treatment of choice for drug-resistant epilepsy and has been associated with better seizure, psychiatric and Quality-of-Life (QOL) outcomes compared with non-surgical medical management (National Guideline Centre, 2022; SIGN, 2018). Several types of surgery have been developed to reduce the number and severity of seizures in drug-resistant epilepsy. The neurosurgical intervention with the strongest evidence base for focal drug-resistant epilepsy is currently resective surgery, which involves removing abnormal brain tissue (focal tissue) that is likely responsible for seizure activity (National Institute for Health and Care Excellence [NICE], 2025). Types of resective surgery include lesionectomy, lobectomy, multilobar resection and amygdalohippocampectomy, with the most common being temporal lobe resective surgery.

While surgery can effectively reduce seizure frequency, it often carries a cognitive cost (Baxendale & Thompson, 2018). The cognitive cost of a treatment refers to the cognitive consequences of the proposed treatment (Baxendale & Thompson, 2018). Neuropsychological changes are commonly observed following surgery, with changes in verbal memory after left temporal lobe surgery and visual memory following right temporal surgery (Lee et al., 2002; McDermid Vaz, 2004)

Wallerian degeneration is a process that occurs following nerve fiber damage, in which the axon distal to the site of injury degenerates. This phenomenon is particularly relevant in the context of epilepsy surgery, such as temporal lobe resective surgery. During such procedures, surgical intervention can intentionally or unintentionally damage neural pathways, leading to Wallerian degeneration (Concha et al., 2007). While the primary goal of epilepsy surgery is to remove or alter the epileptogenic zone to reduce or eliminate seizures, understanding the implications of Wallerian degeneration is crucial for postoperative management and patient prognosis.

Up to 40% of temporal lobe epilepsy surgery patients experience a decline in cognition, regardless of seizure control, 1-10 patients experience a significant decline in memory function and are also not seizure-free following surgery (Baxendale, 2008; Baxendale & Thompson, 2018). Previous research has estimated that the weighted proportion of long-

term seizure-free patients in 40 studies of temporal lobe surgery was 66% (Téllez-Zenteno et al., 2005). Previous research has also examined the association between cognitive changes following epilepsy surgery and QOL, and found that whilst QOL improves following surgery, those who experienced more widespread cognitive decline across cognitive measures showed less improvement in QOL post-operatively (Janecek et al., 2023).

Previous systematic reviews have examined long-term seizure reduction following resective/non-resective surgery (Téllez-Zenteno et al., 2005). They have also examined post-surgical neuropsychological outcomes (Sherman et al., 2011). Sherman and colleagues' systematic review provided information largely focused on short-to medium-term cognitive changes following epilepsy. Alexandratou and colleagues (2021) published a structured literature review that provided an update on neuropsychological outcomes following temporal lobe epilepsy surgery, including 11 studies with >5-year follow-up.

Given that most studies focus on short- to medium-term outcomes, a systematic review of long-term neuropsychological effects may help to clarify whether early cognitive changes persist, improve, or worsen over time and to better inform clinical decision-making. By examining longer-term neuropsychological and psychosocial well-being outcomes, the present study aims to provide more context for informed consent to individuals who are candidates for surgery.

Review Questions

Primary: What are the long-term neuropsychological outcomes for resective epilepsy surgery patients?

Secondary: What are the long-term psychosocial well-being outcomes for resective epilepsy surgery patients?

Methods

Registration

The study followed the PRISMA guidelines for reporting systematic reviews and Meta-Analyses, with a completed checklist provided in *Appendix 1.1* (Page et al., 2021). The protocol for this systematic review was registered with the International Prospective Register of Systematic Reviews (PROSPERO) on 30th March 2026 (CRD420251119339).

Search Strategy

Data Sources

A pre-planned systematic search with no date restrictions was conducted on 2nd April 2026. The following electronic databases were searched: Medline (OVID), PsycINFO (EBSCO), Embase (OVID), and PubMed. Databases were searched individually rather than a multiple-database search to reduce the chance of papers being missed due to index term conflicts within each database. Reference lists of identified articles were hand-searched for additional papers, as were those of systematic reviews and meta-analyses on similar topics. Limitations were set for these databases to include studies focused on human populations, including adults (18+), and English-language publications.

Search Terms Eligibility/ Criteria

Search terms were formulated using the PICO framework. Boolean logic was used to increase the sensitivity and specificity of the search. Support for developing the strategy was sought from a specialist librarian from the University of Glasgow.

The following key search categories were searched:

- Post-resective epilepsy surgery patients
- Resective Surgery
- Long-term cognitive, mood-based and QOL outcomes.

A detailed account of search terms and a full electronic search strategy can be found in *Appendix 1.2*.

Eligibility Criteria

Inclusion Criteria

- Studies reporting outcomes of resective surgical procedures for the treatment of epilepsy e.g. lesionectomy, corticectomy, lobectomy.
- Studies where the mean age of participants is in the adult range (n= 18+).
- Original research article, or review/book chapter containing original data.
- Pre-post design with neuropsychological data.
- Clearly articulated neuropsychological outcomes in the form of standardised tests.
- Includes comparisons with baseline measures of psychometric tools assessing mood or QOL.
- Studies investigating neuropsychological/cognitive changes following surgical intervention for epilepsy.
- Studies investigating mood and QOL following surgical intervention for epilepsy.
- Studies reporting outcomes at least 5 years following resective surgery.

Exclusion Criteria

- Studies reporting on non-epilepsy-based seizure disorders.
- Studies where the majority of/mean age of participants are children (<18 years).
- Studies focused on non-surgical interventions for the treatment of Epilepsy.
- Surgeries reporting outcomes of non-resective procedures for the treatment of epilepsy e.g. multiple subpial transactions, callostomy).
- Studies focused on non-human surgical treatments for refractory epilepsy.
- Non-English language publication.
- Studies which use a literature review, systematic review, or case study format.
- Studies reporting outcomes less than 5 years after surgery.

Review Process

Study Screening

Database searches were completed by the lead researcher, and citations were stored on Rayyan. Duplicates were identified and removed electronically and manually. The search results were screened by title and abstract in line with the inclusion and exclusion criteria. When it was unclear whether an article should be included, it was included and reviewed at the full-text screening stage.

Where abstracts met the inclusion criteria, the full text was retrieved. References and full-text articles were uploaded to Rayyan and reviewed in detail to assess their relevance; any irrelevant papers were excluded. All full-text exclusions were reported in sufficient detail to meet PRISMA standards. 10% of retrieved articles were checked at both the title and abstract screening and the full-text screening stages by a second reviewer, JL, using Rayyan software to ensure they met the inclusion and exclusion criteria. Any disagreements were resolved through discussion until consensus was reached

Data Extraction

Information was extracted from the included papers by hand and electronically using Microsoft Excel by the researcher, with JL performing a check to ensure accurate extraction on five consecutive papers. Authors were contacted when the data were partially incomplete. Relevant data included pre-surgical and long-term post-surgical outcomes; neuropsychological outcomes from cognitive assessments; outcomes from Quality of Life In Epilepsy (QOLIE) form QOLIE-31, QOLIE-10, QOLIE-8; or mood-based outcomes (mean and standard deviation or median and interquartile range). Where data were provided on multiple outcomes e.g., verbal and visual memory, all appropriate outcomes were extracted.

Data Extracted included:

- Study characteristics: study title, authors, year of publication, research design, data collection method, assessments used, and follow-up period.
- Study sample: number of participants, gender, age at baseline testing, and type of epilepsy.

- Study Findings: seizure freedom, neuropsychological outcomes in the form of means and standard deviations, QOLIE and/or psychometric mood outcomes.

The accuracy of the extracted data was verified by a second reviewer for 10% of the included studies.

Quality Assessment Tool

Study quality was assessed using either the *JBI Critical Appraisal Checklist for Cohort studies* (JBI, 2020) or the JBI Assessment of Risk of Bias for Analytical Cross-sectional studies (JBI, 2026). This second tool was used when outcomes from the papers identified were only taken at a single time-point. Reviewers SB and JL independently reviewed the quality of five studies before meeting to address any discrepancies. As these tools do not provide an overall risk of bias score, classifications were determined by the pattern of responses across applicable items. In addition to the individual criterion-level judgements, risk of bias judgments were based on an overall assessment of the nature, number and likely importance of the methodological limitations identified within each study. Specific attention was given to limitations that were identified as likely to influence the validity of the study findings. This included the identification and management of confounding factors, the completeness of follow-up, the handling of attrition, and the appropriateness of statistical analyses. Studies with concerns across multiple key domains were classified as high risk of bias, whereas studies with isolated methodological limitations but otherwise robust methodology were classified as low or moderate risk.

Statistical analyses- effect measures and synthesis

Key information from the included studies was presented narratively in text and tables. Where sufficient data were available, a meta-analysis was conducted to quantitatively synthesise the effects of the intervention on neuropsychological and psychosocial outcomes. Given the expected clinical and methodological heterogeneity across studies, including differences in participant characteristics, intervention protocols, and outcome measures, random-effects meta-analyses were conducted using JASP Version 0.98.0 (JASP, 2026) using the Restricted Maximum Likelihood (REML) estimator for between-

study variance (τ^2). Confidence intervals were calculated using the standard Wald method without Hartung-Knapp adjustment.

As the included studies employed a pre-post observational cohort study design, effect sizes were calculated as within-group changes from baseline to follow-up. Standardised mean change was calculated as Hedges' g using means and standard deviations extracted from each study and computed using JASP Version 0.98.0 (JASP, 2026).

Where required data were unavailable, study authors were contacted for additional information. Studies for which sufficient data could not be obtained were included in the narrative synthesis but excluded from the quantitative analysis.

Meta-analyses were conducted separately for clinically meaningful outcome domains (e.g., verbal/visual memory, naming, fluency, mood), rather than combining conceptually distinct neuropsychological constructs into a single pooled estimate. Where studies reported multiple measures within the same outcome domain, a single effect size was selected according to a pre-specified hierarchy to ensure that each study contributed only one independent effect size to each meta-analysis.

Statistical heterogeneity was assessed using Cochran's Q statistic and the I^2 statistic. I^2 values of approximately 25%, 50%, and 75% were interpreted as indicating low, moderate, and high heterogeneity, respectively. Given the limited number of studies contributing to several analyses, pooled effect estimates and measures of heterogeneity were interpreted cautiously. Publication bias was not assessed because fewer than ten studies contributed to each meta-analysis.

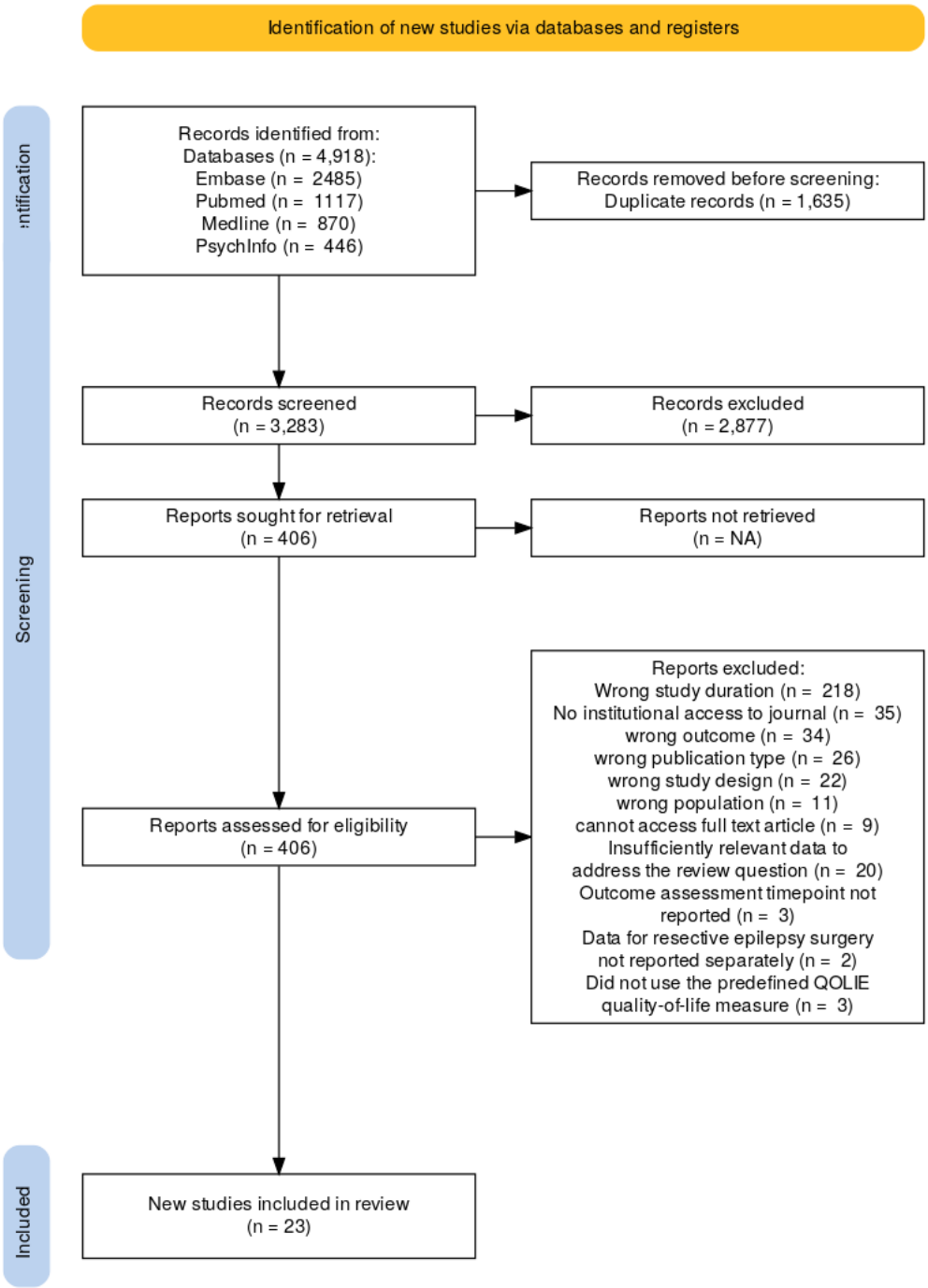
Most neuropsychological outcomes show that higher positive scores are associated with greater improvement in the resective epilepsy surgery group.

Results

Study Selection/Data Screening

A total of 4,918 records were identified, and 1,635 were identified as duplicates. 2,877 papers were excluded at the title and abstract screening stage as they did not meet the inclusion criteria. A second reviewer independently screened 10% of the titles and abstracts, resulting in an inter-reviewer agreement of 87.8%. Disagreements were resolved through discussion prior to full-text screening. 406 papers were then examined in full text. A second reviewer independently screened 10% of the titles and abstracts, resulting in an inter-reviewer agreement of 80.5%. All disagreements were resolved through discussion. Following full-text review, 51 papers appeared to meet the inclusion criteria. These papers were checked to determine if they had enough information to be included, and authors were contacted where possible for additional information. Of the 51 full-text reports assessed for eligibility, 28 were excluded: not relevant to the review question (n = 20), outcome assessment timepoint not reported (n = 3), data for resective epilepsy surgery not reported separately (n = 2), did not use the predefined QOLIE outcome measure (n = 3) and two studies reported outcomes from the same participant sample. Two studies reported outcomes from the same participant sample. However, because each study contributed different outcome data and was not entered into the same meta-analysis, participant data were not double-counted within pooled estimates. Both studies were therefore retained for analysis. This led to the inclusion of 23 papers in total; this process is also depicted in the PRISMA flow diagram in *Figure 1.1.*

Figure 1.1: Prisma Flow Diagram



Study Characteristics

Table 1 summarises the study characteristics. A random 10% sample of the extracted data was independently checked by a second reviewer, and no discrepancies were identified between reviewers. Studies were published between 2001-2025. Studies took place in 15 countries (Austria n=1, Brazil n=2, Canada n=2, Czech Republic n=1,

Germany n=1, Indonesia n=1, Italy n=2, Japan n=1, Norway n=1, South Africa n=1, Sweden n=1, Thailand n=1, U.K. n=4, U.S.A. n=3, Uganda n=1). Study designs were mostly longitudinal cohort studies (n=17), including both prospective (n=10) and retrospective (n=7), while the remainder were single-time-point cross-sectional studies of retrospective surgical cohorts (n=6). Surgical sample sizes varied significantly, ranging from 10 to 375 participants who were included in the final analyses, with several studies reporting attrition between baseline and follow-up assessments.

There were 2,010 participants in total across all 23 studies, with a weighted mean age of 35.5 years at the time of surgery or baseline testing. Most studies focused on temporal lobe epilepsy/mesial temporal lobe epilepsy (n=17), with the remaining studies included mixed temporal/extratemporal or insular epilepsy samples (n=6). ATLR surgery was the most common surgical procedure, whilst studies also reported selective amygdalohippocampectomy (SAH), corticoamygdalohippocapectomy (CAH), lesionectomy and extratemporal resections. 18 studies reported left/right laterality, while two reported dominant versus non-dominant hemisphere instead. One study reported the percentage of left-sided participants, and two studies did not report laterality. In studies that reported laterality, there was no clear pattern of resections: some were balanced between left and right-sided surgery, whereas others had nearly twice as many on one side. Duration of follow-up ranged from 5 to 16.6 years, and postoperative seizure freedom rates varied widely (approximately 25%- 92%), reflecting heterogeneity in surgical populations, aetiology, and outcome definitions.

12 studies reported neuropsychological outcomes, 11 studies reported QOL outcomes using some form of the QOLIE-81, QOLIE-30, or QOLIE-10, and five studies reported mood outcomes. Studies with an asterisk indicate that studies recruited from the same participant pool.

Table 1.1: Study Characteristics Table

Author (Year)	**Country**	**Study Design**	**Sample Size**	**Age (at baseline/surgery)** Mean/median Years	**Epilepsy Type** TLE / extratemporal / mixed	**Type of Surgery** (ATL / SAH / extratemporal resection)	**Laterality** Left/Right	**Duration/ Follow-up** (mean/median)	**Seizure Freedom** (% seizure free)	**Neuropsy-chological Outcomes** (Yes/No)	**Mood Outcomes** (Yes/No)	**QOL Outcomes** (Yes/No)
(Sablik et al., 2025)*	U.K.	Prospective longitudinal cohort study	N= 24	Median= LTLE: 37.5, RTLE:	TLE	ATLR	Left n= 12; Right n= 12	9 years	83%	Yes	No	No
(Fleury et al., 2025)*	U.K.	Longitudinal observational cohort design	Surgical n= 25	Median: LATL 38, RATL Median: 38	TLE	ATLR	Right ATLR (n = 13), Left ATLR (n = 12	9 years	LTLE= 83%, RTLE= 92%	Yes	No	No
(Baxendale et al., 2012)	U.K.	Retrospective longitudinal cohort study	N= 70, 68 with completed measures	RTLE= 34.5 , LTLE= 33.1	TLE	ATLR	LTLE n= 33, RTLE n= 37,	9.3 years	RTLE= 40%; LTLE= 45%	Yes	No	No
(Fernandes et al., 2014)	Brazil	prospective longitudinal cohort study.	N= 47	surgical=44.7	Mesial TLE	Mixed: selective transsylvian amygdalohippocampectomy (SelAH, n= 24) or ATLR (n= 23)	23 right-sided HS n= 23; left-sided HS n= 24	8.7 years	80%	Yes	No	No
(Helmstaedter et al., 2018)	Germany	Retrospective longitudinal cohort study	Surgical N= 161	29.00	TLE	ATLR	RTLE n=77, LTLE n=84	8 years	41%	Yes	No	No
(Engman et al., 2006)	Sweden	Prospective longitudinal cohort study	Surgical n=25	Surgical= 30	TLE	ATLR	Dominant TL n=10; Non-dominant temporal lobe n=15.	9.8 years	58%	Yes	No	No
(Salvato et al., 2016)	Italy	Retrospective longitudinal cohort study	N= 151	33.95	Mesial TLE	Equivalent anteromesial temporal lobectomy	LTLE (n = 75) RTLE (n = 76)	5 years	71.2% (only reported 1 year post surgery)	Yes	No	No
(Simcik et al., 2026)	Czech Republic	Prospective longitudinal cohort study	N= 24	37	Mesial TLE	ATLR	LTLE= 15, RTLE= 9	11.6 years	83.3%	Yes	No	No
(Giovagnoli et al., 2016)	Italy	Prospective longitudinal cohort study	Baseline n= 106; Last F/U n= 60;	LTLE= 36.85 (11.10) RTLE= 34.33 (10.59)	TLE	ATLR	LTLE n = 54 RTLE= n = 52	5 year years	LTLE= 81%; RTLE= 87%	Yes	No	No

(Jud et al., 2024)	Austria	Retrospective longitudinal cohort study	N=171	36.9±10.1	Mesial TLE	selective amygdalohippocampectomy (SAHE)	Side of resection Left= 95, Right n= 76	12.3 years	67.9%	Yes	No	No
(Usami et al., 2016)	Japan	Prospective longitudinal cohort study	Baseline n= 24; Last F/U n= 12	35.5	Mesial TLE	Mixed: multiple subpial transection or lesionectomy (MHT + MST/L).	Left n= 16; Right n= 8	WMS-R and WAIS III m= 6.1 years, WPMR m= 5.9	67%	Yes	No	No
(Rausch et al., 2001)	U.S.A.	Longitudinal observational cohort study	N= 44	LTLE= 27.7; RLTE=27.3	TLE	En bloc ATLR	left= 21 (47.7%), right= 23 (52.3%)	12.8 years	79.5%	Yes	No	No
(Benevides et al., 2021)	Brazil	Prospective observational cohort study	N=77, 72 included in analysis	34.3	Mesial TLE	ATLR	Did not report	7.75 years	44.4%	No	Yes	Yes
(Thaweeboksomboon et al., 2016)	Thailand	Cross-sectional observational study	N=37	38.6	TLE (62.2%; Neocortical epilepsy (37.8%)	Mixed: ATLR n= 20 (54.1%), Lesionectomy n= 6 (16.2%); focal cortical resection n= 11 (29.7%)	mTLE: Left n= 13; Right n= 10 Neocortical epilepsy: Left n= 7; Right n= 7	6.4 years	51.4%	No	Yes	No
(Kansu et al., 2020)	U.K.	Cross-sectional observational study of a retrospective surgical cohort	N=57, 30 with complete responses	34	Mixed	ATLR n= 40; SAH n=7; Lesionectomy n=10	Left (n = 28); Right (n = 14)	7 years	49%	No	No	Yes
(Gravel et al., 2021)	Canada	Retrospective observational cohort study	N= 65	Means: insular: 41.3 TLE: 39.6	Insular surgery; TLE	Mixed: Insular n=27; TLE n=38	% Left= 44% Insular, 55.3% TLE	Insular m= 5.4 years TLE m=5.5 years	insular: 77.8%; TLE: 72.7%	No	Yes	Yes
(Fletcher et al., 2015)	Uganda	Cross-sectional study of a retrospective epilepsy surgery cohort	Total n= 19; Surgical n=10, Non-surgical n=9	23.67	TLE	Corticoamygdalohippocampectomy (CAH)	Left n= 7; Right n=3	8 years	70%	No	No	Yes
(Asukile et al., 2025)	South Africa	Retrospective cohort study with cross-sectional patient-reported outcome assessment	N=375	37	Mixed	ATLR n= 281; Extra-temporal surgery n = 94	Not reported	16.6 years	51%	No	No	Yes
(Bakhtiar et al., 2021)	Indonesia	Retrospective cohort study with cross-	N= 40	27.6	TLE	Mixed: ATLR n= 22 (55.0 %);	Right n=18 (45%) Left n= 22 (55%)	7.1 years	55.0 %	No	Yes	Yes

		sectional patient-reported outcome assessment				SAH n= 18 (45.0 %)						
(Hamid et al., 2014)	U.S.A.	Prospective longitudinal cohort study	N= 373	37.7	Mixed	Mixed: ATLR (n= 325); Extratemporal lobe resection (n= 48)	Right n=191; Left n= 182	5 years	35.2%	No	Yes	Yes
(Tanriverdi et al., 2008)	Canada	Prospective longitudinal cohort study	Baseline= 68, F/U n= 48	34.4	TLE	Mixed: SAH; CAH; Temporal lobe lesionectomy	Right n= 29; Left= 34	12.3 years	70.8%	No	No	Yes
(Stavem et al., 2008)	Norway	Retrospective matched cohort study	Surgical n=35	37	Mixed	Mixed: ATLR= 75%;Frontal resections= 13%	Not reported	15 years	48%	No	No	Yes
(Langfitt et al., 2007)	U.S.A.	Prospective longitudinal cohort study	initial: 348, 138 patients at last follow up	39.5 years	TLE	Mixed: ATLR= (n= 131); Lesionectomies (n=6); neocortical resection= 1	Left/right not reported dominant hemisphere (41%); non dominant hemisphere 59%	5 years	56%	No	No	Yes

*= Studies with an asterisk indicate that studies recruited from the same participant pool.

Risk of Bias and Quality Appraisal in Studies

Critical appraisal using the JBI Cohort Checklist indicated that the methodological quality of the included studies was generally high (*Table 1.2*). Most of these studies met most applicable appraisal criteria and were judged to be at low risk of bias.

Two cohort studies were judged to be at moderate risk of bias. In each case, concerns related to at least one key methodological domain, typically regarding the identification and management of confounding variables, the completeness of follow-up, or the handling of attrition. A second reviewer independently appraised four of the 23 included studies. Minor differences in ratings (e.g., 'No' versus 'Unclear' on individual JBI items) were identified and resolved through discussion, with consensus reached on all quality appraisal ratings. Four studies met the criteria for an appropriate control group, however this was not considered a significant confounding factor when considering the quality of papers, as the focus of this review was on within-subject outcomes. Common limitations related to inadequate reporting of strategies used to address incomplete follow-up and occasional concerns regarding confounding factors or group comparability. It is also worth noting that whilst most studies scored yes for appropriate statistical analysis, there were seven studies whose limited sample sizes may have affected their statistical power (Engman et al., 2006; Fletcher et al., 2015; Fleury et al., 2025; Sablik et al., 2025; Simcik et al., 2026; Usami et al., 2016).

When assessing whether the outcomes were measured validly and reliably, one factor considered was how practice effects may have affected participants' performance on repeat tests. Four studies reported using parallel/alternative neuropsychological forms where possible(Baxendale et al., 2012; Engman et al., 2006; Helmstaedter et al., 2018; Salvato et al., 2016). Three studies did not use alternative forms but reported calculating reliable change indices to attempt to control for practice effects (Fleury et al., 2025; Giovagnoli et al., 2016; Sablik et al., 2025). Five studies did not report using alternative forms or reliable change indices to account for practice effects (Fernandes et al., 2014; Jud et al., 2024; Rausch et al., 2001; Simcik et al., 2026; Usami et al., 2016). This felt appropriate to highlight as this approach represents a methodological strength that may help minimise practice effects in repeated assessments and is consistent with

guidance emphasising appropriate administration of psychometric measures and consideration of test–retest issues when interpreting repeated assessments. However, given the minimum five-year interval between pre- and post-operative assessments, it is unlikely that practice effects substantially influenced the observed changes in neuropsychological test performance. Therefore, the absence of alternative test forms was not considered indicative of lower study quality or increased risk of bias.

When assessing the quality of the studies that provided cross-sectional outcomes for this review, the included studies demonstrated generally good methodological quality, with most studies meeting the majority of the quality appraisal criteria (*Table 1.3)*. Two studies met seven of the eight criteria, with the only unmet criterion relating to whether strategies for addressing confounding factors were stated(Kansu et al., 2020; Thaweepoksomboon et al., 2016). Asukile and colleagues (2025) met all eight criteria and therefore demonstrated the strongest methodological quality within the included studies. Bakhtiar and colleagues (2021) also met seven of the eight criteria, with the only unmet criterion relating to whether the study subjects and setting were described in sufficient detail. Fletcher and colleagues (2015) met five criteria, did not meet two criteria, and had one criterion assessed as unclear, indicating comparatively greater methodological limitations. Overall, the appraisal indicated that most studies were of good methodological quality, although limitations relating to confounding and reporting of study characteristics were identified.

Table 1.2: JBI Cohort Checklist Tool Table

Study Name	Were the two groups similar and recruited from the same population?	Were the exposures measured similarly to assign people to both exposed and unexposed groups?	Was the exposure measured in a valid and reliable way?	Were confounding factors identified?	Were strategies to deal with confounding factors stated?	Were the groups/participants free of the outcome at the start of the study (or at the moment of exposure)?	Were the outcomes measured in a valid and reliable way?	Was the follow up time reported and sufficient to be long enough for outcomes to occur?	Was follow up complete, and if not, were the reasons to loss to follow up described and explored?	Were strategies to address incomplete follow up utilized?	Was appropriate statistical analysis used?	**Overall Risk of Bias/ Quality**
(Benevides et al., 2021)	N/A	N/A	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	**Low risk / High quality**
(Sablik et al., 2025)	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	**Low risk / High quality**
(Fleury et al., 2025)	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	**Low risk / High quality**
(Baxendale et al., 2012)	N/A	N/A	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	**Low risk / High quality**
(Fernandes et al., 2014)	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	No	Yes	**Low risk / High quality**
(Helmstaedter et al., 2018)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	**Low risk / High quality**

(Engman et al., 2006)	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	**Low risk / High quality**
(Gravel et al., 2021)	Yes	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	No	Yes	**Low risk / High quality**
(Salvato et al., 2016)	N/A	N/A	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	**Low risk / High quality**
(Simcik et al., 2026)	N/A	N/A	Yes	Yes	Yes	Yes	Yes	yes	Unclear	Yes	Yes	**Low risk / High quality**
(Giovagnoli et al., 2016)	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	**Low risk / High quality**
(Hamid et al., 2014)	N/A	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	Yes	**Low risk / High quality**
(Jud et al., 2024)	N/A	N/A	Yes	Yes	Yes	yes	Yes	Yes	Yes	No	Yes	**Low risk / High quality**
(Usami et al., 2016)	N/A	N/A	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	**Low risk / High quality**
(Stavem et al., 2008)	Yes	Yes	Yes	Yes	Yes	Unclear	yes	yes	Yes	Yes	Yes	**Low risk / High quality**
(Tanriverdi et al., 2008)	N/A	N/A	Yes	Yes	No	Yes	Yes	Yes	Yes	No	Yes	**Moderate Risk/Moderate Quality**

(Rausch et al., 2001)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	**Low risk / High quality**
(Langfitt et al., 2007)	N/A	N/A	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	**Low risk / High quality**

Table 1.3: JBI Assessment of Risk of Bias for Analytical Cross-sectional Studies Table

Study Name	Were the criteria for inclusion in the sample clearly defined	Were the objective, standard criteria used for the measurement of the condition?	Was the exposure measured in a valid and reliable way	Were the outcomes measures in a valid and reliable way	Were confounding factors identified	Were strategies to deal with confounding factors stated?	Was appropriate statistical analysis used	Were the study subject and the setting described in detail?	Overall
(Asukile et al., 2025)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	**Low Risk of Bias/High Quality**
(Bakhtiar et al., 2021)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	**Low Risk/High Quality**
(Fletcher et al., 2015)	No	Yes	Yes	Yes	No	No	Yes	Unclear	**Moderate Risk/Quality**
(Kansu et al., 2020)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	**Low Risk/High Quality**
(JASP, 2026; Thaweepoksomboon et al., 2016)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	**Low Risk/High Quality**

Results of Synthesis

Given the large number of outcomes and meta-analyses conducted across neuropsychological and QOL domains, full meta-analytical results are reported in *Table 1.4* rather than in full in the text. The narrative results below focus on the primary outcomes of interest and notable findings from the meta-analyses.

Narrative Synthesis

Neuropsychological Outcomes

General trends regarding neuropsychological outcomes were mixed, with overall evidence suggesting many cognitive functions remained stable or recovered following surgery, but that there was also a subset of patients who experienced continuous and progressive decline. Memory outcomes were most frequently observed and showed the greatest variability across studies. Persistent difficulties or declines in verbal memory outcomes were observed following surgery, although some individual studies reported improvement or stabilisation over long-term follow-up. Visual memory outcomes demonstrated variability, with pooled findings suggesting small-to-moderate declines, particularly following left-sided surgery. Other studies reported persistent memory impairment, with more than half of participants remaining below normative expectations at long-term follow-up. Improvements in language domains over time were also observed at long-term follow-up, though patients continued to perform below healthy controls on some language measures when healthy controls were included in studies. Progressive declines in verbal and visual memory, as well as some small decline in IQ and facial perception, were also reported in some cohorts, especially following left-sided surgery. Only one study examined social cognition, and found that scores on emotional recognition tests remained relatively stable over time. Outcomes on Theory of Mind, measured using the faux pas test, declined gradually, with later epilepsy onset initially predicting higher FPT scores but a faster decline (Simcik et al., 2026). Only one study examined verbal memory with regards to story recall and paired associate learning (Salvato et al., 2016). They found that, following surgery, patients with RTLE showed gradual memory improvement, while those with LTLE experienced a temporary

decline in verbal memory that returned to baseline within five years (Salvato et al., 2016).

All studies examined factors influencing cognitive performance. Laterality was the most studied in longitudinal neuropsychological change after temporal lobe epilepsy surgery, with most finding an association with cognitive change. Patients with left-sided resections typically had greater verbal memory or language decline than right-sided ones. Seizure outcome was analysed in many of these studies, with over half reporting significant associations, with seizure-freedom being correlated with better cognitive trajectories or recovery, though some studies did not find seizure outcome to be an independent predictor. One study specifically grouped their participants by seizure-free versus continued seizure and found that verbal memory decline after temporal lobe surgery was less common in patients who achieved seizure freedom than in those whose seizures persisted at long-term follow-up (Helmstaedter et al., 2018). They also noted that when long-term cognitive changes were compared with a non-operated control group, operated patients showed no overall disadvantage, suggesting that successful seizure control is an important factor in preserving verbal memory over time. Unfortunately, this study's outcome data was reported in a format that was not comparable with those used in the other studies, preventing inclusion in the meta-analysis. Cognitive reserve factors such as IQ, education, and baseline abilities were assessed in several studies, with most showing significant associations where higher baseline ability predicted better preservation and recovery. In studies that examined anti-seizure medication burden, most found lower medication burden or reductions associated with better recovery and cognitive outcomes, a consistent finding. Overall, laterality, seizure freedom, cognitive reserve, and ASM burden are most consistently linked to neuropsychological change. Age, epilepsy duration, pathology, and sex are less consistent predictors.

Twelve studies focused on neuropsychological outcomes were included in the narrative synthesis, with nine included in the meta-analysis and three not suitable for meta-analysis. Two of these studies could not be meta-analysed because they were the only ones examining these specific outcomes (Salvato et al., 2016; Simcik et al., 2026). The outcome data from the remaining study were reported in a format that was not

comparable with those used in the other studies, preventing inclusion in the meta-analysis (Helmstaedter et al., 2018). Recalculation of effect sizes from the supplementary participant-level dataset was undertaken for one paper due to inconsistencies between the published summary statistics and the underlying source data (Fleury et al., 2025). The recalculated effect sizes were subsequently entered into the meta-analysis.

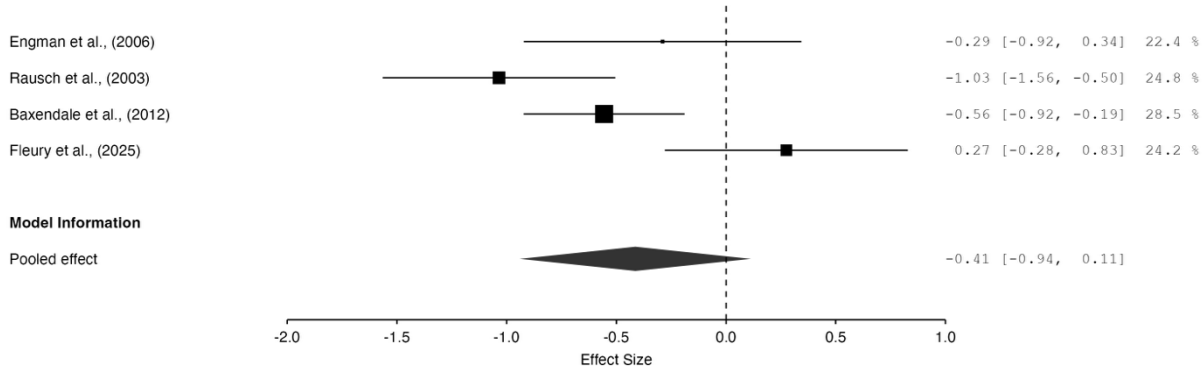
Meta-analyses

21 random-effects meta-analyses were conducted examining neuropsychological outcomes. Meta-analyses were run separately for distinct cognitive domains and, where possible, by the laterality of surgery, due to potential confounding effects. 18 meta-analyses examined left- or right-sided surgery, and 4 assessed neuropsychological outcomes without differentiating the side of surgery. Heterogeneity varied in left-sided surgery meta-analyses. Most intelligence and fluency outcomes demonstrated little or no observed heterogeneity, whereas immediate verbal memory showed considerable heterogeneity. Similarly, heterogeneity ranged from absent to very high in right-sided surgery meta-analyses. Delayed verbal memory, delayed visual memory, PIQ and semantic fluency showed little or no heterogeneity, whereas immediate verbal memory, confrontational naming and phonemic fluency exhibited considerable heterogeneity. In laterality-unspecified meta-analyses, considerable heterogeneity was observed for immediate verbal memory, and delayed verbal memory, whereas no heterogeneity was detected for full-scale IQ. These results may be influenced by the low number of studies in each meta-analysis. Forest plots are included to visually summarise the effect estimates and confidence intervals from individual studies, allowing readers to assess the overall effect, precision, and consistency of the evidence.

Left-Sided Surgery

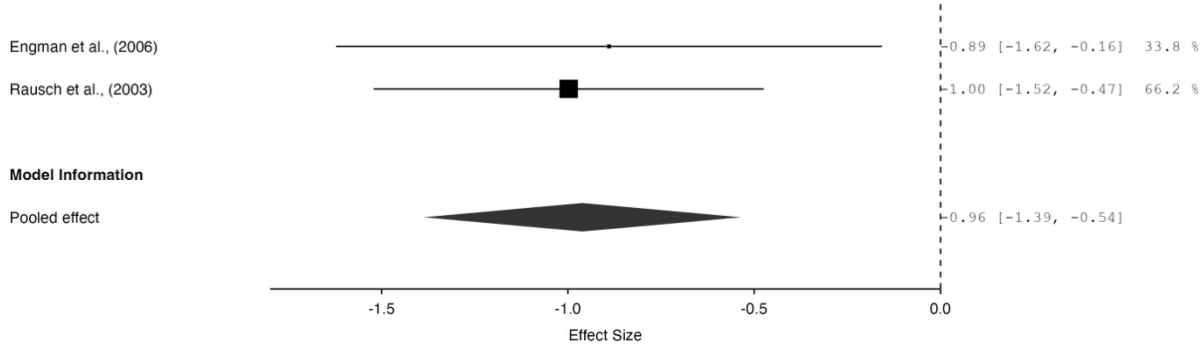
A meta-analysis examining immediate verbal memory showed that left-sided resective surgery was associated with a non-significant small-to-moderately negative effect size (Hedge's G = -0.41, 95% CI [(-0.94), 0.11], p = 0.124, I^2 = 76.56%), indicating small-to-moderately poorer performance on immediate verbal memory outcomes when compared to baseline (*Figure 1.2*).

Figure 1.2: LTLE Immediate Verbal Memory Forest Plot



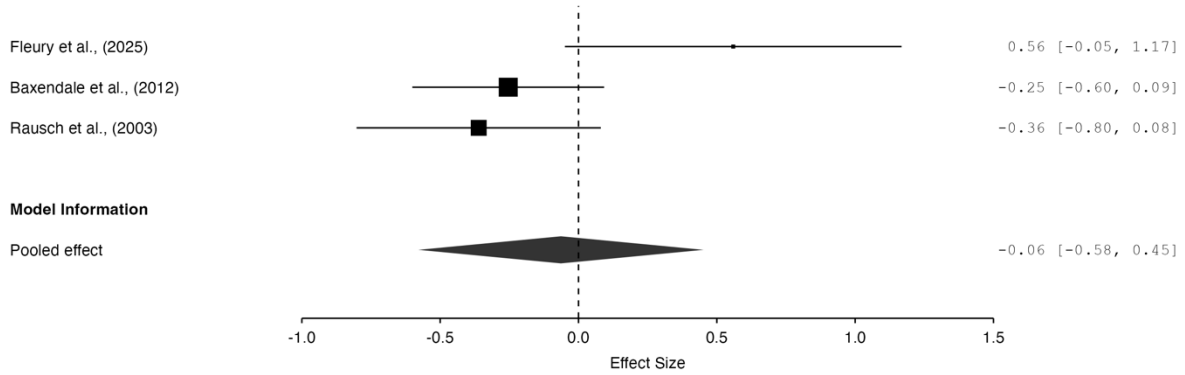
A meta-analysis examining delayed verbal memory showed that left-sided resective surgery was associated with a significant large negative effect size (Hedge's G = -0.96, 95% CI [(-1.39), (-0.54)], $p < .001$, $I^2 = 0.00\%$), indicating considerably poorer performance on delayed verbal memory outcomes when compared to baseline *(Figure 1.3*).

Figure 1.3: LTLE Delayed Verbal Memory Forest Plot



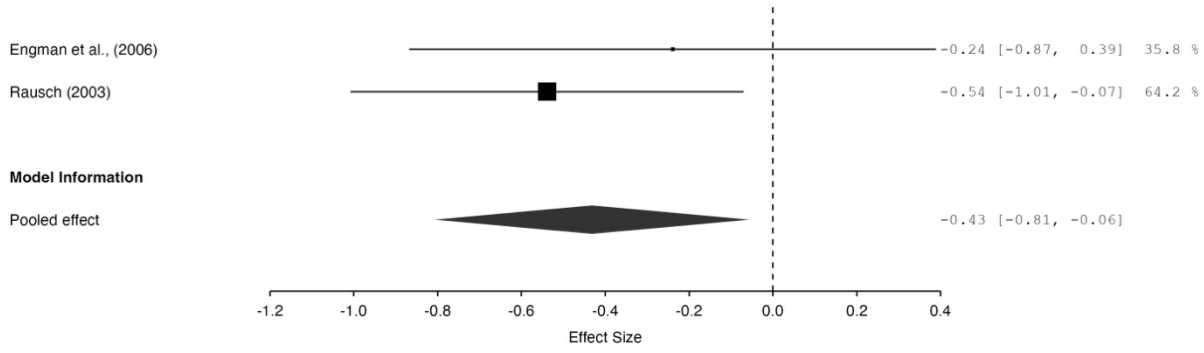
A meta-analysis demonstrated no meaningful difference in left-sided resective surgery immediate visual memory outcomes (Hedge's G= -0.06, 95% CI [(-0.58), 0.45]. p= 0.809, $I^2 = 74.01\%$), indicating no meaningful change with regard to performance on immediate visual memory outcomes compared to baseline (*Figure 1.4*)

Figure 1.4: LTLE Immediate Visual Memory Forest Plot



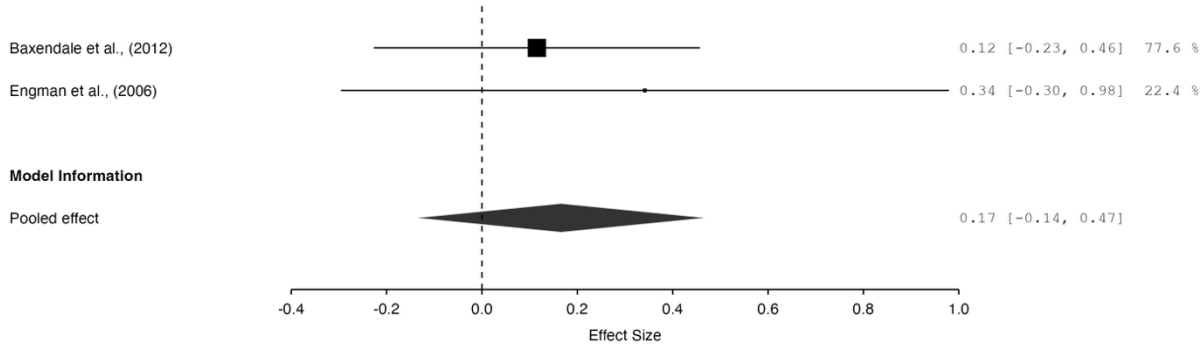
A meta-analysis examining delayed visual memory showed that left-sided resective surgery was associated with a significant small-to-moderately negative effect size (Hedge's G = -0.43, 95% CI [(-0.81), (-0.06)], p= 0.024, I^2 = 0%), indicating small-to-moderately poorer performance on delayed visual memory outcomes when compared to baseline (*Figure 1.5*).

Figure 1.5: LTLE Delayed Visual Memory Forest Plot



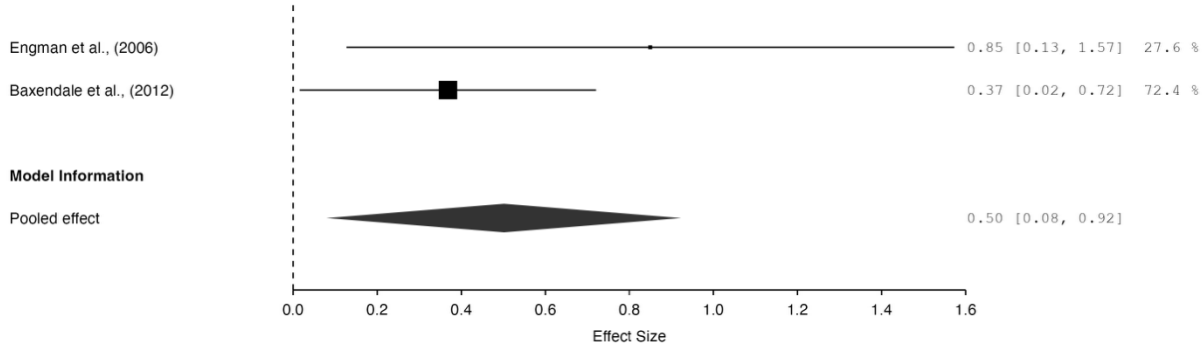
A meta-analysis examining overall performance in the VIQ domain (WAIS-III) showed that left-sided resective surgery was associated with a non-significant small positive effect size (Hedge's G = 0.17, 95% CI [(-0.14), 0.47], p= 0.281, I^2 = 0 %), indicating small improvements in VIQ scores when compared to baseline (*Figure 1.6*).

Figure 1.6: LTLE VIQ Forest Plot



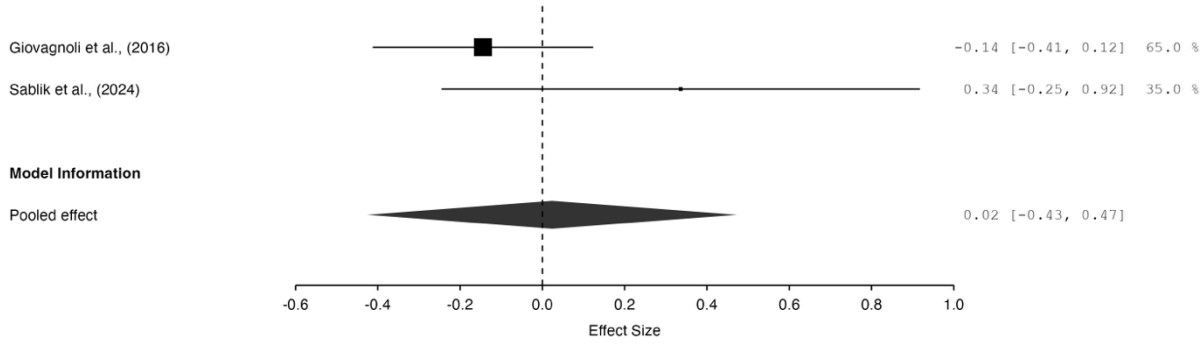
A meta-analysis examining overall performance in the PIQ domain (WAIS-III) showed that left-sided resective surgery was associated with a significant moderately positive effect size (Hedge's G = 0.50, 95% CI [0.08, 0.92], p= 0.020, I^2= 27.41%), indicating improved PIQ scores when compared to baseline (*Figure 1.7*).

Figure 1.7: LTLE PIQ Forest Plot



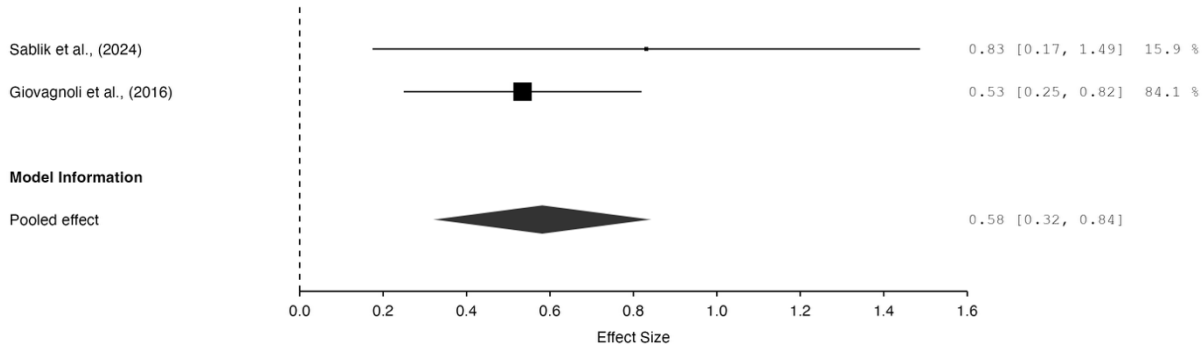
A meta-analysis demonstrated no meaningful difference in left-sided resective surgery confrontational naming outcomes (Hedge's G= 0.02, 95% CI [(-0.43), 0.47]. p=918, I^2 = 53.78%), indicating no meaningful change with regard to performance on confrontational naming outcomes compared to baseline (*Figure 1.8*)

Figure 1.8: LTLE Confrontational Naming Forest Plot



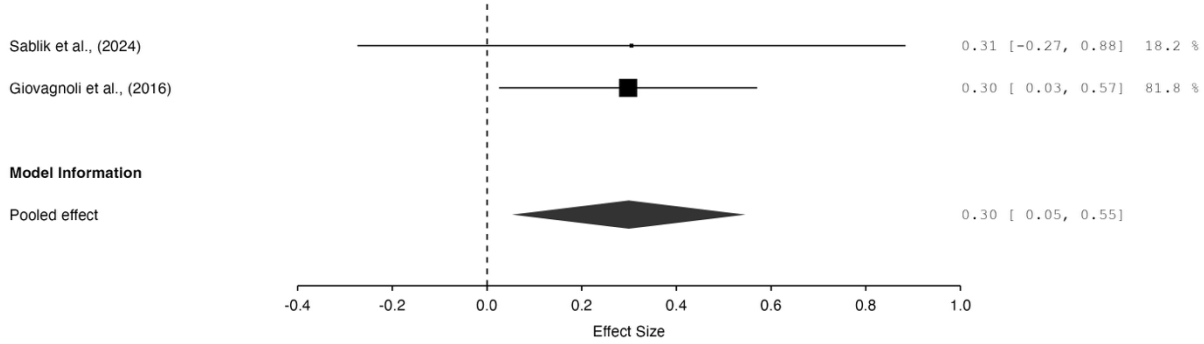
A meta-analysis examining phonemic fluency showed that left-sided resective surgery was associated with a significant moderately positive effect size (Hedge's G = 0.58, 95% CI [0.32-0.84], $p < .001$, $I^2 = 0.00\%$), indicating moderately improved performance on phonemic fluency outcomes when compared to baseline (*Figure 1.9*).

Figure 1.9: LTLE Phonemic Fluency Forest Plot



A meta-analysis examining semantic fluency showed that left-sided resective surgery was associated with a significant small positive effect size (Hedge's G = 0.30, 95% CI [0.05, 0.55], p= 0.017, $I^2 = 0.00\%$), indicating a slight improvement in performance on semantic fluency outcomes when compared to baseline (*Figure 1.10*).

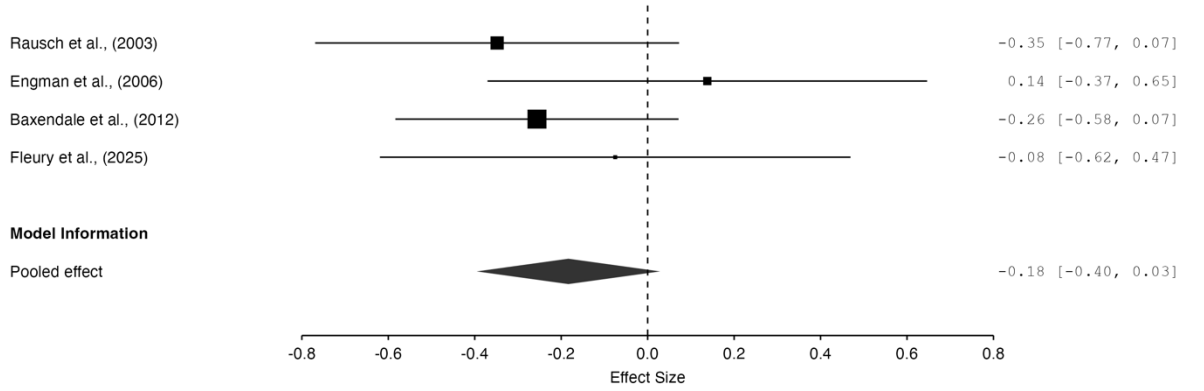
Figure 1.10: LTLE Semantic Fluency Forest Plot



Right-Sided Surgery

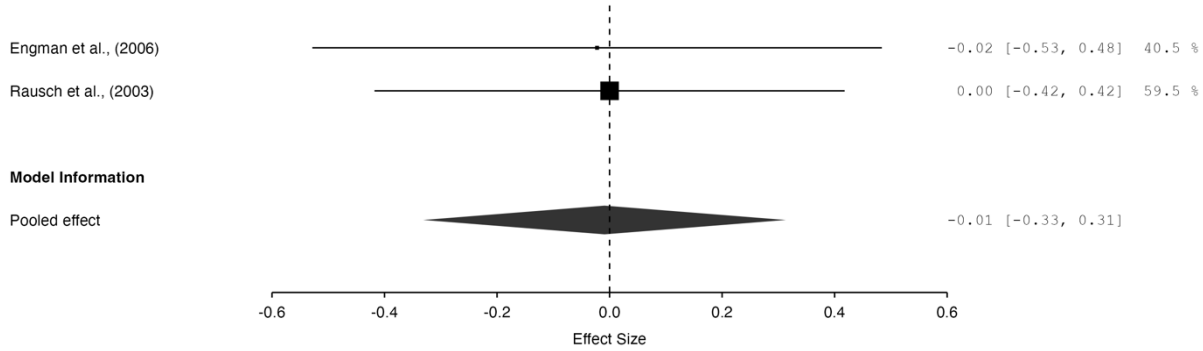
A meta-analysis examining immediate verbal memory showed that right-sided resective surgery was associated with a non-significant small negative effect size (Hedge's G = -0.18, 95% CI [(-0.40), 0.03], p =0.090, I^2 = 0.00%), indicating small poorer performance on verbal memory outcomes when compared to baseline (*Figure 1.11*).

Figure 1.11: RTLE Immediate Verbal Memory Forest Plot



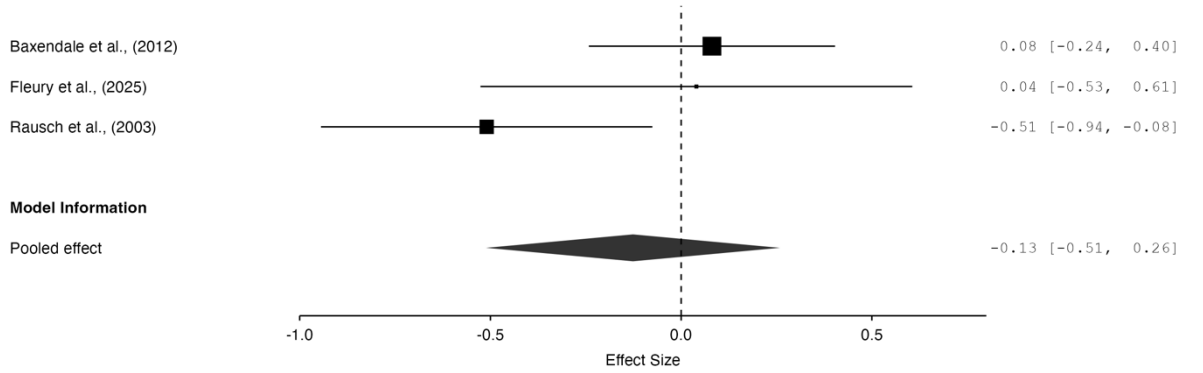
A meta-analysis demonstrated no meaningful difference in right-sided resective surgery delayed verbal memory outcomes (Hedge's G= -0.01, 95% CI [(-0.33), 0.31], p= 0.956, I^2 = 0.00%), indicating no meaningful change with regard to performance on delayed verbal memory outcomes compared to baseline (*Figure 1.12*)

Figure 1.12: RTLE Delayed Verbal Memory Forest Plot



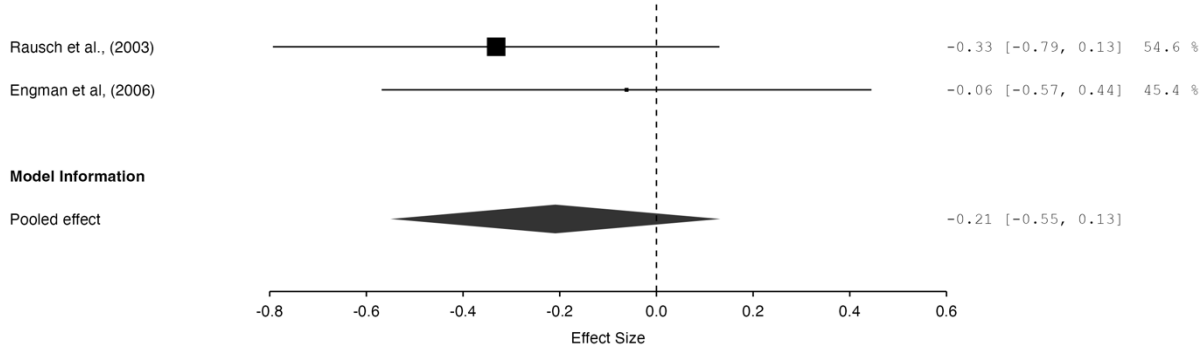
A meta-analysis examining immediate visual memory showed that right-sided resective surgery was associated with a non-significant small negative effect size (Hedge's G = -0.13, 95% CI [(-0.51), 0.26], p = 0.521, I^2 = 58.2%), indicating small poorer performance on visual memory outcomes when compared to baseline (*Figure 1.13*).

Figure 1.13: RTLE Immediate Visual Memory Forest Plot



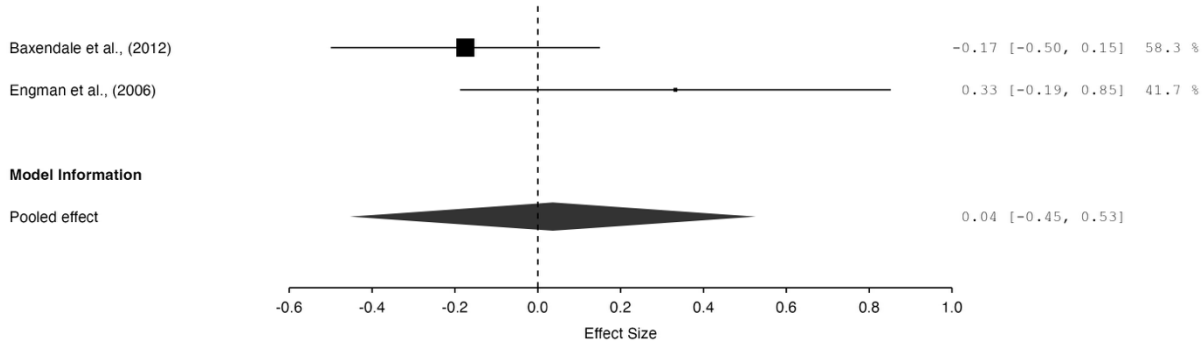
A meta-analysis examining delayed visual memory showed that right-sided resective surgery was associated with a non-significant small negative effect size (Hedge's G = -0.21, 95% CI [(-0.55), 0.13], p = 0.230, I^2 = 0.00%), indicating small poorer performance on visual memory outcomes when compared to baseline (*Figure 1.14*).

Figure 1.14: RTLE Delayed Visual Memory Forest Plot



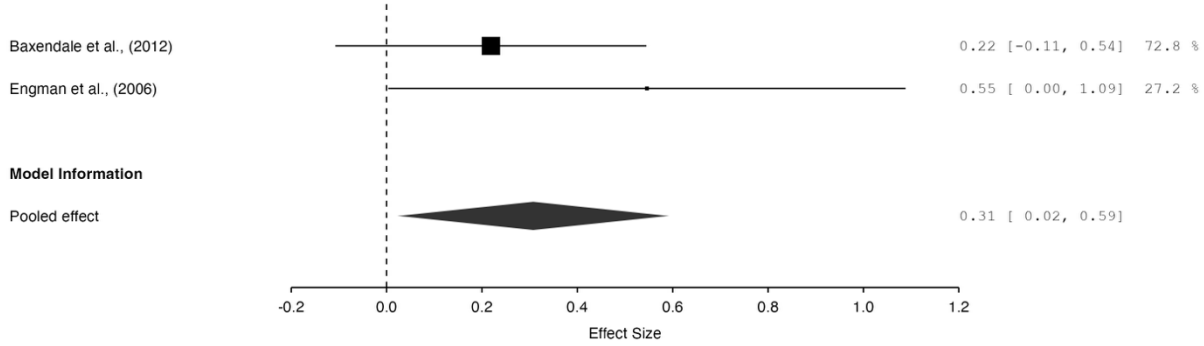
A meta-analysis demonstrated no meaningful difference in right-sided resective surgery delayed VIQ outcomes (Hedge's G= 0.04, 95% CI [(-0.45), 0.53], p= 0.884, I^2 = 61.96%), indicating no meaningful change with regard to performance on VIQ outcomes compared to baseline (*Figure 1.15*)

Figure 1.15: RTLE VIQ Forest Plot



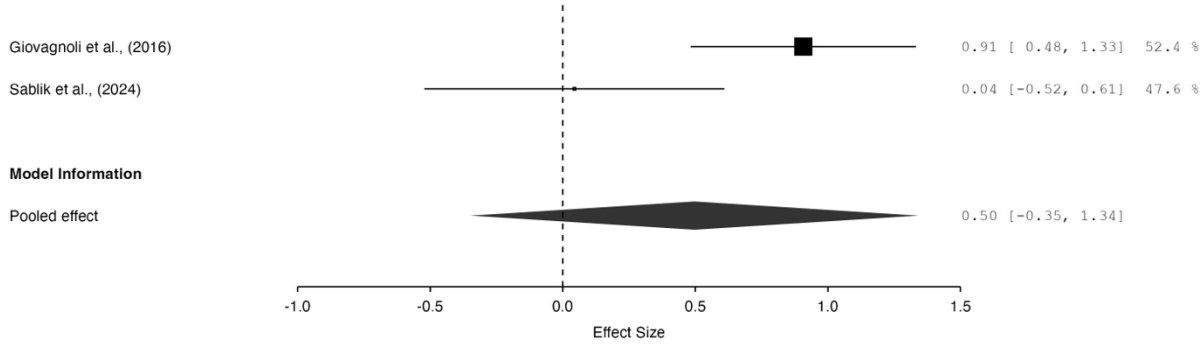
A meta-analysis examining overall performance in the PIQ domain (WAIS-III) showed that right-sided resective surgery was associated with a statistically significant small effect size (Hedge's G = 0.31, 95% CI [0.02, 0.59], p = 0.035, I^2 = 2.62%), indicating a small improvement in performance on the PIQ domain of the WAIS-III when compared to baseline (*Figure 1.16*).

Figure 1.16: RTLE PIQ Forest Plot



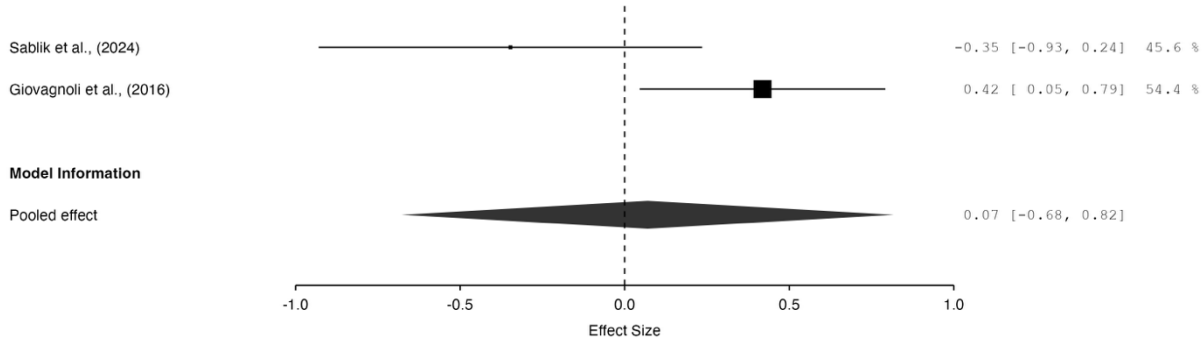
A meta-analysis examining confrontational naming showed that right-sided resective surgery was associated with a non-significant moderate positive effect size (Hedge's G = 0.50, 95% CI [(-0.35), 1.34], p = 0.249, I^2 = 82.50%), indicating moderate improvements in performance on confrontational naming outcomes when compared to baseline performance (*Figure 1.17*).

Figure 1.17: RTLE Confrontational Naming Forest Plot



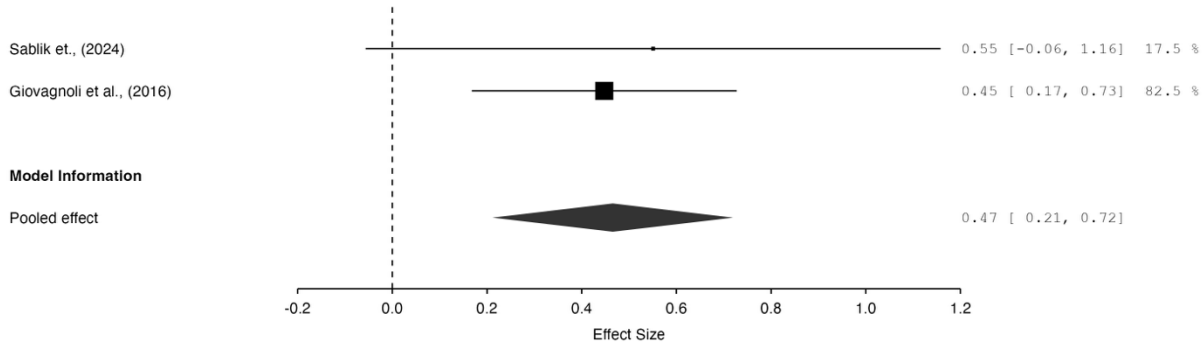
A meta-analysis demonstrated no meaningful difference in right-sided resective surgery phonemic fluency outcomes (Hedge's G= 0.07, 95% CI [(-0.68), 0.82], p= 0.855, I^2 = 78.76%), indicating no meaningful change with regard to performance on verbal phonemic fluency outcomes compared to baseline (*Figure 1.18*)

Figure 1.18: RTLE Phonemic Fluency Forest Plot



A meta-analysis examining semantic fluency showed that right-sided resective surgery was associated with a significant small-to-moderate positive effect size (Hedge's G = 0.47, 95% CI [0.21, 0.72], p <.001, I^2 = 0.00%), indicating small-to-moderate improvements in performance on semantic fluency outcomes when compared to baseline (*Figure 1.19*).

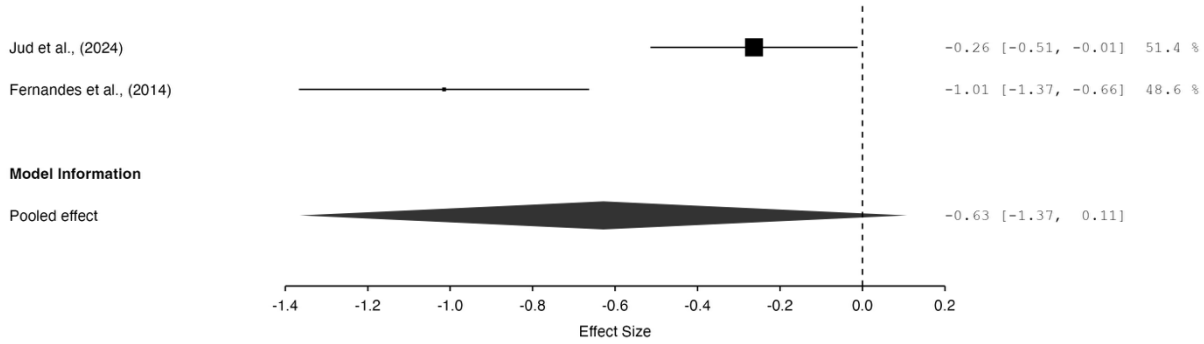
Figure 1.19: RTLE Semantic Fluency Forest Plot



Laterality Unspecified

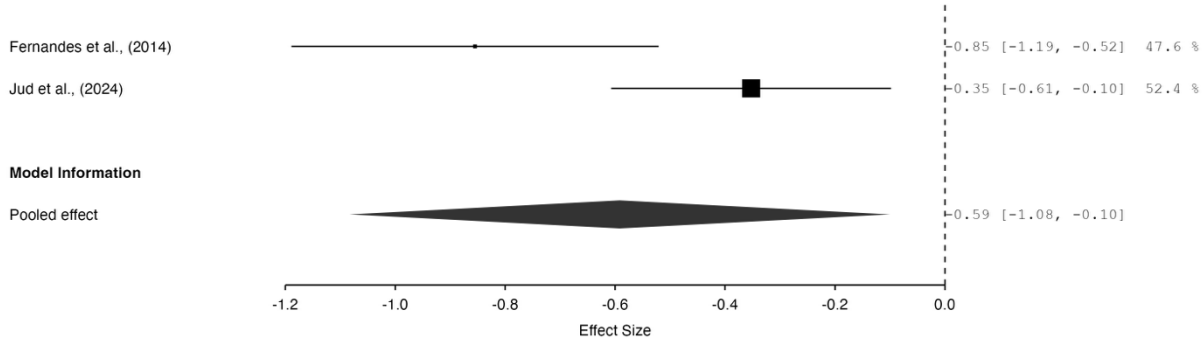
A meta-analysis examining immediate verbal memory showed that resective surgery was associated with a non-significant moderate negative effect size (Hedge's G = -0.63, 95% CI [(-1.37), 0.11], p = 0.094, I^2 = 91.39%), indicating poorer performance on immediate verbal memory outcomes when compared to baseline performance (*Figure 1.20*).

Figure 1.20: Non-Lateralised Immediate Verbal Memory Forest Plot



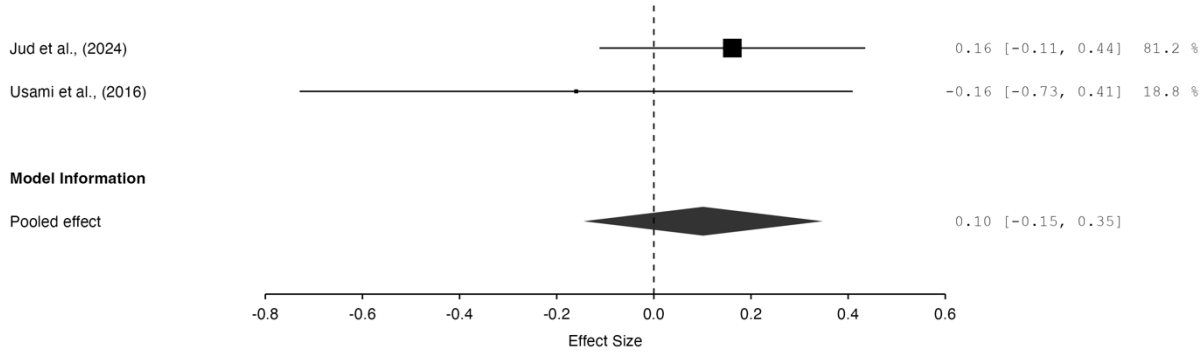
A meta-analysis examining delayed verbal memory showed that resective surgery was associated with a statistically significant moderate negative effect size (Hedge's G = -0.59, 95% CI[(-1.08)(-0.10)], p = 0.018, I^2 = 81.81%), indicating poorer performance on delayed verbal memory outcomes when compared to baseline performance (*Figure 1.21*).

Figure 1.21: Non-Lateralised Delayed Verbal Memory Forest Plot



A meta-analysis demonstrated no meaningful difference in non-lateralised resective surgery FSIQ outcomes (Hedge's G= 0.10, 95% CI [(-0.15), 0.35], p= 0.421, I^2 = 0.00%), indicating no meaningful change with regard to performance on FSIQ outcomes compared to baseline (*Figure 1.22*)

Figure 1.22: Non-Lateralised FSIQ Forest Plot



Quality of Life

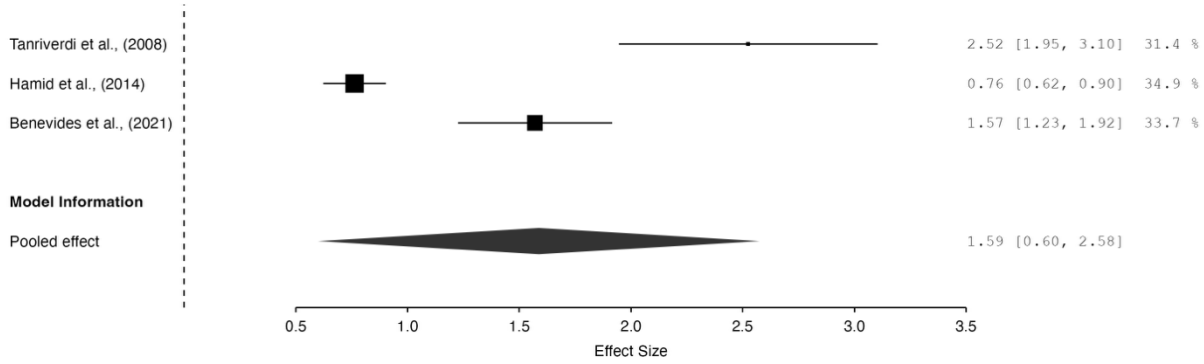
11 studies assessed QOL outcomes using variations of the QOLIE assessment. Four out of 11 studies utilised a longitudinal model to assess QOL outcomes following surgery. Of the longitudinal studies, only one study found significant overall improvements in QOL across the entire cohort and did not identify seizure freedom as an independent predictor of higher QOL. However, it noted that lower depressive symptoms were significantly associated with better QOL outcomes (Benevides et al., 2021). This association was also observed in Hamid and colleagues (2014), where anxiety and depressive symptoms were reported as independent predictors of QOL, though seizure freedom was also associated with improved QOL. The remaining two longitudinal studies highlighted that seizure freedom was associated with improved QOL, whilst poorer outcomes were associated with stable or declining QOL.

Findings from cross-sectional studies were more consistent, with seven of the eight studies reporting associations between seizure freedom and better-reported QOL outcomes. Seizure control and employment status were the most consistent predictors of QOL when formally tested, whereas laterality was not.

A random-effects meta-analysis examining QOL using the total overall QOLIE scores included 3 studies. Effect size direction was reversed for the Tanriverdi and colleagues' paper (2008) as lower scores indicated better quality of life. Results showed a significant positive effect size when comparing long-term scores to baseline (Hedge's G

= 1.59, 95% CI [0.60, 2.58], p = .002, I^2 = 96.42%). High heterogeneity was also observed between studies (*Figure 1.23*), though this may be due to the limited number of studies in the meta-analysis, and all individual effect sizes were observed to be positive.

Figure 1.23: Total QOLIE QOL Forest Plot



Mood outcomes

Five studies used mood outcome assessments, e.g., HADS-A, HADS-D, BDI-II, STAI-T, Zung-SAS, BAI. Across the studies examined, depression and anxiety symptoms generally appeared to be in the mild-moderate ranges, with most patients free of clinically significant symptoms at follow-up. Four out of five studies did not assess mood outcomes longitudinally, instead using a cross-sectional approach in which participants were contacted at a single time point following surgery, thereby limiting the ability to conduct a meta-analysis and draw conclusions regarding the trajectory and stability of mood outcomes.

The impact of seizure control on mood-based outcomes varied across studies. One study found a significant association between seizure freedom and anxiety levels, but not depressive symptoms (Bakhtiar et al., 2021), whilst another found that sustained seizure control was associated with significantly lower depression and anxiety scores over repeated assessments (Benevides et al., 2021). Findings were consistent regarding the laterality of surgery, suggesting that mood outcomes may generalise across surgical subtypes.

Table 1.4: Table of Meta-analyses

	Outcome	K	Total N	Effect Size (Hedge's g/SMD)	95% CI	Z	P value (two tailed)	I^2	τ^2	Direction of Effect
Left Sided Surgery										
1.	Immediate Verbal Memory	4	77	-0.41	(-0.94)-0.11	-1.54	0.124	76.56%	0.22	A non-significant small-to-moderate negative effect was observed. Substantial heterogeneity indicates considerable variation in effects across studies.
2.	Delayed Verbal Memory	2	31	-0.96	(-1.39)-(-0.54)	-4.43	p < .001	0.00%	0.00	Statistically significant large negative effect observed. No statistical heterogeneity was detected, interpret cautiously as k=2.
3.	Immediate Visual Memory	3	66	-0.06	(-0.58)-(0.45)	-0.24	0.809	74.01%	0.15	No meaningful difference detected, with significant heterogeneity
4.	Delayed Visual Memory	2	30	-0.43	(-0.81)-(-0.06)	-2.25	0.024	0.00%	0.00	Statistically significant small-to-moderate negative effect observed. No statistical heterogeneity was detected, interpret cautiously as k=2.
5.	VIQ	2	43	0.17	(-0.14)-0.47	1.08	0.281	0.00%	0.00	Non-significant small positive effect observed. No statistical heterogeneity was detected, interpret cautiously as k=2.
6.	PIQ	2	43	0.50	0.08-0.92	2.33	0.020	27.41%	0.03	Statistically significant moderate positive effect observed. Low-to-moderate heterogeneity, and wide confidence interval.

7.	Confrontational Naming	2	66	0.02	(-0.43)-0.47	0.10	0.918	53.78%	0.06	No meaningful difference detected, with moderate heterogeneity
8.	Verbal Phonemic Fluency	2	66	0.58	0.32-0.84	4.36	p < .001	0.00%	0.00	Statistically significant moderate positive effect observed. No statistical heterogeneity was detected, interpret cautiously as k=2.
9.	Verbal Semantic Fluency	2	66	0.2994	0.05-0.55	2.38	0.017	0.00%	0.00	Statistically significant small positive effect observed. No statistical heterogeneity was detected, interpret cautiously as k=2.
Right Sided Surgery										
10.	Immediate Verbal Memory	4	88	-0.18	(-0.40)-0.03	-1.69	0.090	0.00	0.00	Non-significant small negative effect observed. No statistical heterogeneity was detected, interpret cautiously as k=4.
11.	Delayed Verbal Memory	2	37	-0.01	(-0.33)-0.31	-0.05	0.956	0.00%	0.00	No meaningful difference detected.
12.	Immediate Visual Memory	3	72	-0.13	(-0.51)-0.26	-0.64	0.521	58.2%	0.07	A small non-significant negative pooled effect was observed. Moderate heterogeneity and a confidence interval spanning both benefit and decline indicate uncertainty in the pooled estimate.
13.	Delayed Visual Memory	2	34	-0.21	(-0.55)-0.13	-1.20	0.230	0.00%	0.00	Non-significant small negative effect observed. No statistical heterogeneity was detected, interpret cautiously as k=2.
14.	VIQ	2	52	0.04	(-0.45)-0.53	0.15	0.884	61.96%	0.08	No meaningful difference detected. Wide confidence intervals and substantial heterogeneity indicate variation between studies.

15.	PIQ	2	52	0.31	0.02-0.59	2.11	0.035	2.62%	0.00	Statistically significant small positive effect observed. Low Heterogeneity, interpret cautiously as k=2.
16.	Confrontational Naming	2	42	0.50	(-0.35)-1.34	1.15	0.249	82.50%	0.31	Non-significant moderate positive effect observed. Wide confidence intervals and substantial heterogeneity indicate variation between studies
17.	Verbal Phonemic Fluency	2	42	0.07	(-0.68)-0.82	0.18	0.855	78.76%	0.23	No meaningful difference detected. Wide confidence intervals and substantial heterogeneity indicate variation between studies.
18.	Verbal Semantic Fluency	2	66	0.47	0.21-0.72	3.59	$p < .001$	0.00%	0.00	Statistically significant small-to-moderate positive effect observed. No statistical heterogeneity was detected, interpret cautiously as k=2.
Laterality Unspecified										
19.	Immediate Verbal Memory	2	110	-0.63	(-1.37)-0.11	-1.67	0.094	91.39%	0.26	Non-significant moderate negative effect observed. Wide confidence intervals and substantial heterogeneity indicate variation between studies.
20.	Delayed Verbal Memory	2	110	-0.59	(-1.08)-(-0.10)	-2.36	0.018	81.81%	0.10	Statistically significant moderate negative effect observed with high heterogeneity between studies.
21.	Full Scale IQ	2	64	0.10	(-0.15)-0.35	0.81	0.421	0.00%	0.00	No meaningful difference detected.
22.	QOL	3	374	1.59	0.60-2.58	3.15	0.002	96.42%	0.72	Significant large positive effect size observed with substantial heterogeneity observed between studies.

Discussion

Overview of Findings

This review examined long-term outcomes following resective surgery for treatment-resistant epilepsy, focusing on neuropsychological, mood, and QOL outcomes. Results suggest that long-term outcomes following epilepsy surgery differ across outcome domains.

Studies that utilised a longitudinal design and were suitable for meta-analysis identified a significant long-term improvement in QOL outcomes. Although marked variability was observed in individual studies' effect sizes in the quality of life meta-analysis, all studies reported effects in a positive direction, indicating improvements in quality of life over time. They found depressive symptoms to be a predictor of QOL scores. Studies that used a cross-sectional design identified seizure control as a significant predictor of higher QOLIE scores. An important finding of this review is the limited evidence regarding long-term mood outcomes. Although depressive and anxiety symptoms were frequently identified as predictors of QOL, few studies directly examined longitudinal changes in mood following surgery, and it was difficult to make inferences regarding mood at long-term follow-up, representing an important gap in the literature. Similar results have also been reported in recent literature reviews, noting the association between seizure freedom and the absence of mood disorders when assessing QOL following epilepsy surgery, and highlighting the significance of addressing mental health alongside surgical management (Deleo et al., 2020; Hamid et al., 2014; Shakhatreh et al., 2023). Janecek and colleagues' (2023) study found that individuals with cognitive decline on more cognitive measures showed less improvement in QOL, highlighting the importance of understanding the relationship between these two areas.

When considering outcomes in the present study, meta-analyses including studies that didn't differentiate lateralisation reported a moderate decline in delayed verbal memory and a similarly sized but non-significant decline in immediate verbal memory, and no meaningful difference in FSIQ scores. An overall

performance estimate showed improvement in PIQ scores at least five years after surgery, observed in both right- and left-sided surgeries (small and moderate positive changes, respectively), similar to results reported in a previous systematic review examining short-term neuropsychological outcomes after surgery (Sherman et al., 2011). Meta-analyses most often reported changes in memory domains, consistent with previous research (Lee et al., 2002).

Meta-analyses focused on left-sided surgery reported poorer performance in both immediate and delayed verbal memory, with moderate and large negative pooled effect sizes, respectively, although evidence was stronger for delayed verbal memory decline than for immediate verbal memory decline. These findings were also observed in previous research evaluating shorter-term neuropsychological outcomes following surgery (Sherman et al., 2011). Left-sided surgery was also associated with a small-to-moderate decline in delayed visual memory outcomes, and right-sided surgery was associated with a small negative effect on visual memory outcomes; however, these findings did not reach statistical significance. Meta-analyses on right-sided surgery, however, did not find similar results regarding poorer verbal memory, with immediate verbal memory demonstrating a small, non-significant positive effect and delayed verbal memory showing virtually no overall change at long-term assessment.

Meta-analyses for left-sided surgeries identified changes in some language domains, including moderately improved phonemic performance and a smaller improvement in semantic fluency, but did not report any meaningful differences on confrontational naming assessments. These language results regarding verbal fluency are similar to those in a previous review of neuropsychological outcomes but differ in naming, which showed reduced naming in patients with left-sided surgery (Sherman et al., 2011). Studies included in Sherman and colleagues' review comprised larger sample sizes than those included in the current review and were not specifically focused on long-term outcomes. Therefore, differences in sample size and follow-up duration may contribute to the discrepant findings. Meta-analyses examining language performance among participants undergoing right-sided surgery found a significant improvement in semantic fluency. Although

the pooled estimate for confrontational naming suggested a moderate positive effect, this finding was not statistically significant and was characterised by considerable heterogeneity but no meaningful difference in phonemic fluency. Interpretation of several pooled estimates should be made cautiously, as a number of analyses demonstrated substantial to considerable heterogeneity, indicating important variability in findings across studies.

Given that most of these studies examined temporal lobe surgery, the results are consistent with current models of memory organisation in temporal lobe epilepsy. The decline in verbal memory after left-sided surgery may reflect disruption of the dominant medial temporal memory system, particularly hippocampal mechanisms involved in encoding and consolidation (Helmstaedter et al., 1997; Squire & Zola-Morgan, 1991). Preservation of the left temporal lobe after right-sided surgery may contribute to the stability of verbal memory, reflecting greater functional reserve within remaining medial temporal structures (Chelune, 1995). This may also be facilitated by improved seizure control and reductions in antiseizure medication burden following surgery (Helmstaedter et al., 1997) The smaller and more variable effects observed for visual memory may reflect differences in the lateralisation of memory processes, with verbal memory typically showing stronger left-hemisphere dominance, whereas visual/non-verbal memory has traditionally been associated more strongly with right medial temporal structures but may also rely on broader bilateral memory networks (Bonelli et al., 2010; Milner, 1972) These findings support the theory that postoperative cognitive outcomes depend not only on laterality but also on preoperative hippocampal integrity, contralateral reserve, and network-level reorganisation (Bonelli et al., 2010; Chelune, 1995).

Given the significant heterogeneity observed across studies included in meta-analyses, it is crucial to consider methodological aetiological factors associated with resective surgery and how these may have influenced the present study's findings. Narrative synthesis of factors that may influence neuropsychological performance included seizure freedom, baseline cognitive function, educational attainment, the side of surgery, epilepsy duration, and age at onset. Postoperative seizures and the resulting continued anti-epileptic medication use due to ongoing

epileptic activity were most consistently reported after lateralisation as a factor predicting poorer cognitive outcomes, suggesting that ongoing epileptic activity may limit the brain's capacity for functional reorganisation and recovery, and that medication may also impact cognitive function (Alexandratou et al., 2021). The synthesis also suggested that cognitive reserve is associated with better preservation of cognitive function and more favourable long-term recovery, which lends further weight to the hypothesis that greater cognitive reserve may enhance resilience to cognitive decline and serve as a predictor of successful surgical outcomes (Baxendale & Thompson, 2018). Study heterogeneity may also have been influenced by variation in the year of surgery. Improvements in surgical techniques, presurgical evaluation, and candidate selection over time may mean that patients operated on more recently are not fully comparable to those who underwent surgery in earlier periods. Given the small number of studies available for most analyses, it was not possible to investigate the influence of year of surgery as a potential moderator of outcome.

Strengths and Limitations

A major strength of this study is that it is the first to systematically review long-term neuropsychological, QOL, and mood outcomes after resective surgery. While previous research has examined these outcomes in both short- and medium-term contexts, the observed changes in seizure recurrence over extended follow-up periods highlight the importance of also assessing neuropsychological, QOL, and mood outcomes at these later stages to better understand how they evolve over the lifespan following surgery. This review also has several methodological strengths, including the adherence to PRISMA guidelines and the involvement of a specialist librarian when developing the search strategy. The inclusion of studies from different geographical locations improved the external validity by reflecting different populations and healthcare systems. The review also covered multiple cognitive domains, enabling a more comprehensive evaluation of cognitive outcomes.

It is worth considering the specific methodological limitations of quantitative synthesis via meta-analysis. One limitation is that many pooled analyses included

only two or three studies. Consequently, estimates of heterogeneity may be unreliable, and the absence of observed heterogeneity for several outcomes should not be interpreted as evidence that studies were truly homogeneous. Another methodological limitation of the meta-analyses is the substantial variance in study effect sizes and the limited number of papers per cognitive domain. Whilst this is a methodological limitation of the present study, it also highlights the limitations of adopting a broad-lens review approach in this research, as noted in previous systematic reviews (Sherman et al., 2011). Whilst it can provide a valuable overview of neuropsychological and QOL outcomes following epilepsy surgery, it may also limit the accuracy and clinical relevance of conclusions when substantial heterogeneity within the epilepsy population is not adequately considered. Epilepsy surgery outcomes appear to be shaped by the complex, interactive factors mentioned earlier, and meaningful differences can be obscured when these are not considered or given appropriate weight. It may be beneficial to view heterogeneity within the present study not as 'statistical noise' but as clinically meaningful information that may help explain why outcomes differ so significantly between studies and their participants. Subgroup analyses could provide more precise insights into long-term outcomes. Some studies in this review identified confounding factors, but limited sample sizes restricted robust subgroup analyses. Alongside this, variability in neuropsychological outcomes may not always be captured by small samples, leading to findings that are influenced by participant characteristics and to increased heterogeneity. Future epilepsy research should focus on larger, multi-centre studies to reduce variability and enable more effective subgroup analyses.

Implications for practise, policy and future research

NICE guidelines recommend discussing the process of resective epilepsy surgery assessment, including the potential benefits and risks of surgery, and referring eligible patients to a tertiary epilepsy service for multidisciplinary assessment, which may include neuropsychological evaluation (NICE, 2022). The present study also demonstrates the importance of neuropsychological input throughout the surgical pathway to establish baseline cognitive functioning and to provide realistic estimates of postoperative cognitive risk (NICE, 2022). It also aligns with

research by Baxendale & Thompson (2018), which identifies the relationship between baseline cognitive functioning and surgical decision-making, suggesting that baseline cognitive functioning may be a predictor of surgical outcomes when evaluating predictors of double loss following epilepsy surgery (Baxendale & Thompson, 2018). Beyond informing individual clinical decision-making, the present findings suggest that long-term neuropsychological outcomes should be considered alongside seizure freedom when evaluating the effectiveness of epilepsy surgery services. The findings support the provision of neuropsychological input as a core component of epilepsy surgery pathways, including access to longer-term follow-up where cognitive difficulties may emerge or persist beyond the immediate postoperative period

The NICE evidence review reported that surgery led to much greater improvements in QOL than medical care; however, it included only studies examining this outcome for up to two years (National Guideline Centre, 2022). Given the possibility of seizure recurrence over longer-term follow-up, it is also important to consider how this may affect QOL during longer-term follow-up after surgery. The present study identified a significant long-term improvement in QOL. Future research examining long-term QOL outcomes would ideally strengthen the evidence base regarding the durability of surgical benefits and inform future clinical guidelines. The findings also support the routine collection of long-term neuropsychological and quality-of-life outcomes within epilepsy surgery services, enabling service evaluation, informing resource allocation, and supporting policy development. Cognitive and functional outcomes should be considered alongside seizure control when evaluating surgical success.

Conclusions

Overall, this review synthesised findings from 23 studies to examine the long-term neuropsychological, QOL, and mood-based outcomes of individuals who had undergone resective surgery at least five years earlier, using both narrative synthesis and meta-analyses where possible. Overall, findings related to neuropsychological outcomes highlighted changes in both memory and language domains compared with baseline performance, but also revealed significant heterogeneity among the included papers, so these results should be interpreted with caution. One likely contributor to this heterogeneity was the side of surgery and seizure recurrence. This highlighted the need for research to account for these contributors where possible and provides recommendations for how best to facilitate this. The present study also examined long-term QOL outcomes using QOLIE measures and found evidence of improved QOL at long-term follow-up, with both the narrative synthesis and meta-analysis indicating positive postoperative outcomes**.** Many of these studies were single-time-point cross-sectional, which are not suitable for meta-analysis and limit inferences about change over time. It also highlighted the limited number of studies examining mood over time. The findings support the role of neuropsychological assessment throughout the epilepsy surgery pathway and the importance of longitudinal long-term evaluation of outcomes to provide accurate information to patients who are considering resective surgery. Given the frequency and variability of post-operative memory changes, memory may represent an important target for prehabilitation approaches. Future research may also benefit from **e**xamining whether the earlier implementation of compensatory memory strategies may mitigate functional postoperative memory decline**.**

References

Alexandratou, I., Patrikelis, P., Messinis, L., Alexoudi, A., Verentzioti, A., Stefanatou, M., Nasios, G., Panagiotopoulos, V., & Gatzonis, S. (2021). Long-term neuropsychological outcomes following temporal lobe epilepsy surgery: An update of the literature. *Healthcare (Switzerland)*, *9*(9). https://doi.org/10.3390/healthcare9091156

Asukile, M., Soni, A., Gule, M., Mendelow, E., Mngxitam, N., Eastman, R., Pan, E. L., Ives-Delliperi, V., Melvill, R., Butler, J., & Tucker, L. (2025). Long-term seizure and quality of life outcomes of an epilepsy surgery program in Cape Town, South Africa. *Epilepsy and Behavior*, *168*. https://doi.org/10.1016/j.yebeh.2025.110430

Bakhtiar, Y., Pratama Brilliantika, S., Bunyamin, J., Arifin, M. T., Hardian, H., Bintoro, A. C., & Muttaqin, Z. (2021). Postoperative Evaluation of the Quality of Life, Depression, and Anxiety of Temporal Lobe Epilepsy Cohort: A Single Institute Experience in Indonesia. *Frontiers in Neurology*, *12*. https://doi.org/10.3389/fneur.2021.708064.

Baxendale, S. (2008). The impact of epilepsy surgery on cognition and behavior. *Epilepsy and Behavior*, *12*(4), 592–599. https://doi.org/10.1016/j.yebeh.2007.12.015

Baxendale, S., & Thompson, P. (2018). Red flags in epilepsy surgery: Identifying the patients who pay a high cognitive price for an unsuccessful surgical outcome. *Epilepsy and Behavior*, *78*, 269–272. https://doi.org/10.1016/j.yebeh.2017.08.003

Baxendale, S., Thompson, P. J., & Duncan, J. S. (2012). Neuropsychological function in patients who have had epilepsy surgery: A long-term follow-up. *Epilepsy and Behavior*, *23*(1), 24–29. https://doi.org/10.1016/j.yebeh.2011.10.021

Benevides, M. L., Costa Nunes, J., Guarnieri, R., Pauli, C., Wolf, P., Lunardi, M., Kondageski, C., Neves Linhares, M., Lin, K., & Walz, R. (2021). Quality of life long after temporal lobe epilepsy surgery. *Acta Neurologica Scandinavica*, *143*(6), 629–636. https://doi.org/10.1111/ane.13406

Bonelli, S. B., Powell, R. H. W., Yogarajah, M., Samson, R. S., Symms, M. R., Thompson, P. J., Koepp, M. J., & Duncan, J. S. (2010). Imaging memory in temporal lobe epilepsy: Predicting the effects of temporal lobe resection. *Brain*, *133*(4), 1186–1199. https://doi.org/10.1093/brain/awq006

Chelune, G. J. (1995). Hippocampal adequacy versus functional reserve: Predicting memory functions following temporal lobectomy. Archives of Clinical Neuropsychology, 10(5), 413–432. https://doi.org/10.1093/arclin/10.5.413

Concha, L., Beaulieu, C., Wheatley, B. M., & Gross, D. W. (2007). Bilateral white matter diffusion changes persist after epilepsy surgery. *Epilepsia*, *48*(5), 931–940. https://doi.org/10.1111/j.1528-1167.2007.01006.x

Deleo, F., Quintas, R., Pastori, C., Pappalardo, I., Didato, G., Di Giacomo, R., de Curtis, M., & Villani, F. (2020). Quality of life, psychiatric symptoms, and stigma perception in three groups of persons with epilepsy. *Epilepsy and Behavior*, *110*. https://doi.org/10.1016/j.yebeh.2020.107170

Engman, E., Andersson-Roswall, L., Samuelsson, H., & Malmgren, K. (2006). Serial cognitive change patterns across time after temporal lobe resection for epilepsy. *Epilepsy and Behavior*, *8*(4), 765–772. https://doi.org/10.1016/j.yebeh.2006.02.013

Fernandes, D. A., Yasuda, C. L., Lopes, T. M., Enrico, G., Alessio, A., Tedeschi, H., de Oliveira, E., & Cendes, F. (2014). Long-term postoperative atrophy of contralateral hippocampus and cognitive function in unilateral refractory MTLE with unilateral

hippocampal sclerosis. *Epilepsy and Behavior*, *36*, 108–114. https://doi.org/10.1016/j.yebeh.2014.04.028
Fletcher, A., Sims-Williams, H., Wabulya, A., & Boling, W. (2015). Stigma and quality of life at long-term follow-up after surgery for epilepsy in Uganda. *Epilepsy and Behavior*, *52*, 128–131. https://doi.org/10.1016/j.yebeh.2015.09.002
Fleury, M. N., Binding, L. P., Taylor, P., Xiao, F., Giampiccolo, D., Buck, S., Winston, G. P., Thompson, P. J., Baxendale, S., McEvoy, A. W., Koepp, M. J., Duncan, J. S., & Sidhu, M. K. (2025). Long-term memory plasticity in a decade-long connectivity study post anterior temporal lobe resection. *Nature Communications* , *16*(1). https://doi.org/10.1038/s41467-024-55704-x
Giovagnoli, A. R., Parente, A., Didato, G., Manfredi, V., Deleo, F., Tringali, G., & Villani, F. (2016). The course of language functions after temporal lobe epilepsy surgery: a prospective study. *European Journal of Neurology*, *23*(12), 1713–1721. https://doi.org/10.1111/ene.13113
Gravel, V., Boucher, O., Citherlet, D., Hébert-Seropian, B., Bouthillier, A., & Nguyen, D. K. (2021). Psychological status after insulo-opercular resection in patients with epilepsy: Depression, anxiety, and quality of life. *Epilepsy and Behavior*, *118*. https://doi.org/10.1016/j.yebeh.2021.107919
Hamid, H., Blackmon, K., Cong, X., Dziura, J., Atlas, L. Y., Vickrey, B. G., Berg, A. T., Bazil, C. W., Langfitt, J. T., Walczak, T. S., Sperling, M. R., Shinnar, S., & Devinsky, O. (2014). Mood, anxiety, and incomplete seizure control affect quality of life after epilepsy surgery. *Neurology*, *82*(10), 887–894. https://doi.org/10.1212/WNL.0000000000000183
Helmstaedter, C., Elger, C. E., & Vogt, V. L. (2018). Cognitive outcomes more than 5 years after temporal lobe epilepsy surgery: Remarkable functional recovery when seizures are controlled. *Seizure*, *62*, 116–123. https://doi.org/10.1016/j.seizure.2018.09.023
Helmstaedter, C., Gleißner, U., Di Perna, M., & Elger, C. E. (1997). Relational verbal memory processing in patients with temporal lobe epilepsy. *Cortex*, *33*(4), 667–678. https://doi.org/10.1016/S0010-9452(08)70724-X
Janecek, J. K., Brett, B. L., Pillay, S., Murphy, H., Binder, J. R., & Swanson, S. J. (2023). Cognitive decline and quality of life after resective epilepsy surgery. *Epilepsy and Behavior*, *138*. https://doi.org/10.1016/j.yebeh.2022.109005
JASP Team. (2026). JASP (Version 0.98.0) [Computer software]. https://jasp-stats.org/
Joanna Briggs Institute. (2020). JBI critical appraisal checklist for cohort studies. https://jbi.global/sites/default/files/2020-08/Checklist_for_Cohort_Studies.pdf
Joanna Briggs Institute. (2020). JBI critical appraisal checklist for analytical cross sectional studies. https://jbi.global/sites/default/files/2020-08/Checklist_for_Analytical_Cross_Sectional_Studies.pdf
Jud, J., Stefanits, H., Gelpi, E., Quinot, V., Aull-Watschinger, S., Czech, T., Dorfer, C., Rössler, K., Baumgartner, C., Kasprian, G., Watschinger, C., Moser, D., Brugger, J., & Pataraia, E. (2024). Which parameters influence cognitive, psychiatric and long-term seizure outcome in mesial temporal lobe epilepsy after selective amygdalohippocampectomy? *Journal of Neurology*, *271*(7), 4249–4257. https://doi.org/10.1007/s00415-024-12343-y
Kansu, B., Pickrell, W. O., Lacey, A. S., Edwards, F., Samolia, G., Rees, M. I., Elwes, R., Hatfield, R., Gray, W., & Hamandi, K. (2020). Long-term outcomes after epilepsy surgery, a retrospective cohort study linking patient-reported outcomes and

routine healthcare data. *Epilepsy and Behavior*, *111*. https://doi.org/10.1016/j.yebeh.2020.107196
Langfitt, J. T., Westerveld, M., Hamberger, M. J., Walczak, T. S., Cicchetti, D. V., Berg, A. T., Vickrey, B. G., Barr, W. B., Sperling, M. R., Masur, D., & Spencer, S. S. (2007). Worsening of quality of life after epilepsy surgery. *Neurology*, *68*(23), 1988–1994. https://doi.org/10.1212/01.wnl.0000264000.11511.30
Lee, T. M. C., Yip, J. T. H., & Jones-Gotman, M. (2002). Memory deficits after resection from left or right anterior temporal lobe in humans: A meta-analytic review. *Epilepsia*, *43*(3), 283–291. https://doi.org/10.1046/j.1528-1157.2002.09901.x
McDermid Vaz, S. A. (2004). Nonverbal memory functioning following right anterior temporal lobectomy: A meta-analytic review. *Seizure*, *13*(7), 446–452. https://doi.org/10.1016/j.seizure.2003.12.004
Milner, B. (1972). Disorders of learning and memory after temporal lobe lesions in man. Clinical Neurosurgery, 19, 421–446. https://doi.org/10.1093/neurosurgery/19.cn_suppl_1.421
National Guideline Centre. (2022). Evidence reviews for surgery: Referral and surgical interventions. In Epilepsies in children, young people and adults: Diagnosis and management (NICE Guideline NG217). National Institute for Health and Care Excellence. https://www.nice.org.uk/guidance/ng217/evidence/13-referral-and-surgical-interventions-pdf-398366282776
National Institute for Health and Care Excellence. (2022). Epilepsies in children, young people and adults: Diagnosis and management (NICE Guideline NG217). https://www.nice.org.uk/guidance/ng217
National Institute for Health and Care Excellence [NICE]. (2025). *Epilepsies in children, young people and adults NICE guideline*. www.nice.org.uk/guidance/ng217
Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., Shamseer, L., Tetzlaff, J. M., Akl, E. A., Brennan, S. E., Chou, R., Glanville, J., Grimshaw, J. M., Hróbjartsson, A., Lalu, M. M., Li, T., Loder, E. W., Mayo-Wilson, E., McDonald, S., … Moher, D. (2021). The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. *BMJ*, *372*. https://doi.org/10.1136/bmj.n71
Rausch, R., Kraemer, S., Pietras, C. J., Le, M., Vickrey, B. G., & Passaro, E. A. (2003). Early and late cognitive changes following temporal lobe surgery for epilepsy. Neurology, 60(6), 951–959. https://doi.org/10.1212/01.WNL.0000048203.23766.A1
Sablik, M., Fleury, M. N., Binding, L. P., Carey, D. P., d'Avossa, G., Baxendale, S., Winston, G. P., Duncan, J. S., & Sidhu, M. K. (2025). Long-term neuroplasticity in language networks after anterior temporal lobe resection. *Epilepsia*, *66*(1), 207–225. https://doi.org/10.1111/epi.18147
Salvato, G., Scarpa, P., Francione, S., Mai, R., Tassi, L., Scarano, E., Lo Russo, G., & Bottini, G. (2016). Declarative long-term memory and the mesial temporal lobe: Insights from a 5-year postsurgery follow-up study on refractory temporal lobe epilepsy. *Epilepsy and Behavior*, *64*, 102–109. https://doi.org/10.1016/j.yebeh.2016.08.029
Shakhatreh, L., Foster, E., Siriratnam, P., Neal, A., Carney, P. W., Jackson, G. D., O'Brien, T. J., Kwan, P., Chen, Z., & Ademi, Z. (2023). Impact of epilepsy surgery on quality of life: Systematic review and meta-analysis. *Epilepsia*, *64*(7), 1709–1721. https://doi.org/10.1111/epi.17644
Sherman, E. M. S., Wiebe, S., Fay-Mcclymont, T. B., Tellez-Zenteno, J., Metcalfe, A., Hernandez-Ronquillo, L., Hader, W. J., & Jetté, N. (2011). Neuropsychological

outcomes after epilepsy surgery: Systematic review and pooled estimates. *Epilepsia*, *52*(5), 857–869. https://doi.org/10.1111/j.1528-1167.2011.03022.x

Scottish Intercollegiate Guidelines Network. (2018). Diagnosis and management of epilepsy in adults (SIGN Guideline No. 143). SIGN.

Simcik, M., Andel, R., Pytelova, V., Javurkova, A., Zalud, J., Kalina, A., Kalinova, M., Stanzelova, K., Marusic, P., & Amlerova, J. (2026). Social cognition after epilepsy surgery in temporal lobe epilepsy: A long-term follow-up. *Epilepsy and Behavior*, *175*. https://doi.org/10.1016/j.yebeh.2025.110839

Squire, L. R., & Zola-Morgan, S. (1991). The medial temporal lobe memory system. Science, 253(5026), 1380–1386. https://doi.org/10.1126/science.1896849

Stavem, K., Bjørnæs, H., & Langmoen, I. A. (2008). Long-term seizures and quality of life after epilepsy surgery compared with matched controls. *Neurosurgery*, *62*(2), 326–335. https://doi.org/10.1227/01.neu.0000315999.58022.1c

Tanriverdi, T., Poulin, N., & Olivier, A. (2008). Life 12 years after temporal lobe epilepsy surgery: A long-term, prospective clinical study. *Seizure*, *17*(4), 339–349. https://doi.org/10.1016/j.seizure.2007.11.003

Téllez-Zenteno, J. F., Dhar, R., & Wiebe, S. (2005). Long-term seizure outcomes following epilepsy surgery: A systematic review and meta-analysis. *Brain*, *128*(5), 1188–1198. https://doi.org/10.1093/brain/awh449

Thaweepoksomboon, J., Chinvarun, Y., Sakoolnamarka, S., Udommongkol, C., & Sithinamsuwan, P. (2016). Global Outcomes of Epilepsy Surgery in Drug-Resistant Focal Epilepsy: A Longitudinal Survey. *J Med Assoc Thai*, *99*(7), 764–771.

Usami, K., Kubota, M., Kawai, K., Kunii, N., Matsuo, T., Ibayashi, K., Takahashi, M., Kamada, K., Momose, T., Aoki, S., & Saito, N. (2016). Long-term outcome and neuroradiologic changes after multiple hippocampal transection combined with multiple subpial transection or lesionectomy for temporal lobe epilepsy. *Epilepsia*, *57*(6), 931–940. https://doi.org/10.1111/epi.13374

2. Chapter 2: Major Research Project

Patient Experiences of Cognitive Prehabilitation on the Epilepsy Surgery Pathway

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MRP Plain Language Summary

Title: Patient Experiences of Prehabilitation on the Epilepsy Surgery pathway.

Background

Some people with epilepsy still have seizures even when they take medicine. For some people, surgery may help reduce their seizures. Epilepsy surgery can sometimes affect memory, language, and other thinking skills. Prehabilitation means getting ready for these changes before surgery. It involves learning and using new ways to help with memory, language, and thinking. Learning these skills before surgery may help people if they have changes after surgery. It also gives them time to practise these skills before their surgery. Prehabilitation is a new area of research. We still need to learn more about how best to use it and how it can help people who are having epilepsy surgery.

Aim

This study looked at what it was like for patients to take part in prehabilitation before epilepsy surgery.

Research Questions

The study looked at:

- How people felt when taking part in the prehabilitation programme.
- What people found helpful or hard about the programme.
- Whether the timing of the programme was right for them.

Methods

Seven people took part in the study. They were patients from two regional centres in England and Scotland. Each person was given a sheet with information about the study. They were then asked if they would like to take part in an interview. The interviews asked people about their views and their time in the prehabilitation programme. All interviews took place online using Microsoft Teams.

Findings

The interviews showed five main themes. People talked about their choice to have surgery. They also talked about what they thought surgery might do for them. Some people said that prehabilitation helped them know what to expect. This included learning that surgery could affect their memory, language, or other thinking skills. People also talked about hope. Hope helped them cope with not knowing what would happen after surgery. Some people felt more ready for surgery after taking part in prehabilitation. They felt that they had learned useful ways to cope with changes after surgery. People also talked about what made it easy or hard to take part in the programme.

Conclusions

This study suggests that prehabilitation may be a useful part of getting ready for epilepsy surgery. People felt that it helped them get ready for possible changes after surgery. It also helped some people feel more informed and ready for what might happen. Future programmes should be based on each person's needs. For example, the support could be changed to match a person's memory and thinking skills. Prehabilitation may also help people understand what surgery may and may not achieve. This may help people make choices about surgery and know what to expect.

Abstract

Background: Surgery for intractable epilepsy is an elective procedure, which carries risks, including the possibility of cognitive impairment, which must be balanced against the potential for seizure reduction. Prehabilitation involves learning and practising strategies before surgery to reduce the impact of possible cognitive changes. In epilepsy surgery, it remains a developing area of research and intervention; many questions remain about patients' experiences of prehabilitation.

Aims: This qualitative study aimed to deepen understanding of the lived experience of patients undergoing prehabilitation, including its associated challenges.

Methods: Seven participants with intractable epilepsy who were candidates for, or had completed, epilepsy surgery were purposively recruited from regional centres in England and Scotland and completed semi-structured interviews that were analysed using reflexive thematic analysis.

Results: Data were analysed using Braun and Clarke's framework for reflexive thematic analysis, which yielded five key themes: *Consent without clarity; Worth the risk? Thinking through surgery; Anchored in hope: tolerating uncertainty; Engagement in prehabilitation; and Feeling empowered.*

Conclusions: Findings can inform the further development of prehabilitation programmes for epilepsy surgery and provide researchers and healthcare professionals with key insights into the lived experiences of those with intractable epilepsy. More generally, this study highlighted informed consent as an ongoing process, in which prehabilitation helped to shape more balanced and realistic expectations of surgical outcomes. These insights should be considered by all healthcare professionals involved in the surgical pathway.

Keywords: Epilepsy, thematic analysis, epilepsy surgery, resective surgery, neuropsychology, prehabilitation, cognition, compensatory strategies, patient

experiences, hope, uncertainty, preparedness, informed consent, confidence, empowerment.

Funding: No funding was received for this project
Disclosure Statement: There are no competing interests to declare.

Introduction

Intractable epilepsy refers to the situation when anti-epileptic medication fails to improve the severity or frequency of seizures. It can have a significant impact on the physical, cognitive, emotional, and social functioning of individuals (Hermann & Jacoby, 2009; Mula & Sander, 2016). There is a higher prevalence of psychological disorders, learning disabilities and neurodevelopmental disorders such as ADHD or autism spectrum disorder, dementia, and a higher risk of suicide in people with epilepsy compared to the general population (National Institute for Health and Care Excellence [NICE], 2022). Previous research has identified that living with a seizure disorder significantly impacts the individual's quality of life, sense of independence, and self-efficacy (de Boer et al., 2008). People with epilepsy may feel socially excluded and stigmatised (de Boer et al., 2008).

Epilepsy surgery is an invasive technique where areas of the brain that are associated with focal seizures are surgically removed, ideally leading to a significant reduction or cessation of seizures (Baxendale, 2008). Neuropsychological assessment is an important part of the patient selection process (Baxendale et al., 2019). The results of the neuropsychological assessment can be useful for establishing a cognitive baseline, supporting seizure localisation and characterisation, identifying potential cognitive risks of surgery, and informing patient counselling, expectation-setting, and prehabilitation before treatment (Baxendale et al., 2019).

Temporal lobe epilepsy is the most common cause of drug-resistant seizures (Engel et al., 2012), therefore making it the most common anatomical target for resective surgery in epilepsy surgery. This may include resection of the amygdala, hippocampus, and/or temporal neocortex (Engel et al., 2012). These areas of the brain are associated with language and memory but can also significantly influence executive function and behaviour, therefore these are also domains of cognitive function that can be affected following surgery (Baxendale, 2008).

Factors such as the possibility of cognitive changes following surgery are one of the reasons why resective epilepsy surgery remains an elective procedure (Baxendale, 2008).

Cognitive changes are often viewed as a cost of surgery rather than a risk of surgery, referred to as the "cognitive cost" of epilepsy surgery. Therefore, having a clear understanding of the possible benefits and risks of surgery remains very important (Baxendale & Thompson, 2018). They observed that, one year after surgery, 42.1% of patients reported no memory decline and were seizure-free; 20% experienced no memory decline but continued seizures; 25.5% were seizure-free despite experiencing memory decline; and 12.3% had both memory decline and ongoing seizures. The combination of memory loss and persistent seizures is often called "double loss" (Baxendale & Thompson, 2018).

Predictors of "double loss" following surgery include those with pathologies other than hippocampal sclerosis and those with signs of limited cognitive reserve in overall intellectual ability and memory function. Other factors that may be associated with double loss include ipsilateral functional integrity, which refers to the brain's ability to preserve cognitive function in the hemisphere where surgery is to be performed, and contralateral reserve, which refers to the brain's ability to compensate for cognitive function following an injury sustained in the opposite hemisphere during surgery (Baxendale & Thompson, 2018).

There is a continuing need for empirical studies examining cognitive rehabilitation for those with epilepsy. While traditional cognitive rehabilitation tends to occur after the development of a cognitive deficit, by implementing 'prehabilitation' before further neuropsychological deficits arise from epilepsy surgery, the aim is to utilise pre-surgical abilities to establish adaptive strategies, before they are possibly lost to surgery (Baxendale, 2020). Patients who are at high risk of cognitive decline can learn cognitive rehabilitation strategies before resection surgery, while they have the increased capacity to learn effectively. Recommended stages in the prehabilitation process ideally include the creation of a likely postoperative cognitive profile, feedback and education, mapping of anticipated deficits onto real-world function, the creation of a personalised package of

solutions using appropriate strategies, and the implementation of prehabilitation (Baxendale, 2020). Baxendale and colleagues refer to an "SOS toolbox", which are specific cognitive rehabilitation strategies that may be useful for individuals experiencing cognitive decline following epilepsy surgery. Employing these strategies and routines before surgery may help with cognitive changes as the patient will be already familiar with the strategies and may have supportive routines before surgery (Baxendale, 2020). The feasibility and efficacy of a manualised cognitive prehabilitation programme for epilepsy, called "readiness brain operation optimisation training" (ReBOOT), were recently found to be feasible with participants reporting high satisfaction and preparedness (Arrotta et al., 2025). As prehabilitation before epilepsy resection surgery is still a novel developing area of research and intervention, many questions are still unanswered as regards the optimisation of prehabilitation, including what factors may promote participation in rehabilitation before surgery and how appropriate prehabilitation feels to the individual before surgery (Baxendale, 2020). By incorporating patients' lived experience of prehabilitation, we may gain important insights into optimising prehabilitation approaches and elucidate factors that may promote greater psychological engagement.

Aims and Research Questions

This project aimed to contribute to a better understanding of the lived experience of patients undergoing prehabilitation and a better assessment of the prehabilitation approach and associated challenges, drawing on patient experiences across multiple centres. The aim was to assess the psychological experiences, engagement and challenges of those who have completed a prehabilitation programme, including patients who are awaiting surgical input as well as those who have completed both prehabilitation and surgical input.

Methods

Ethics

This study was granted ethical approval (Research and Ethics Committee Wales 4[REC4], REC Reference: 25/WA/0171; *Appendix 2.3*). Two amendments were approved to reflect a change in site recruitment, allowing recruitment from additional sites (*Appendix 2.4*). Management approval was granted by all recruitment sites (*Appendix 2.5*).

Design

As prehabilitation is a relatively novel intervention and research on this approach is limited, this study adopted a cross-sectional qualitative methodology using Reflexive Thematic Analysis (RTA) (Braun & Clarke, 2006; 2022) to understand the lived experiences of patients undergoing prehabilitation. Semi-structured interviews were conducted with patients who had completed the prehabilitation programme in preparation for their epilepsy surgery. Given the small population size, RTA allowed the researcher to explore the nuance of the participants' experiences. It enabled iterative exploration of patterns across participants' experiences and perceptions, staying close to the data without being constrained by prior theoretical stances. A RTA approach is also frequently used in health and medical settings, supporting the development of actionable insights from patient experiences. Given that patients' perceptions of prehabilitation may vary depending on the stage of the surgical pathway, patients at various stages (pre- or post-surgery) were interviewed. RTA enables the identification of patterns and meaning across individual experiences whilst remaining theoretically flexible. RTA also allows for an inductive approach to analysis that is compatible with the identified research questions.

Participants

A purposeful sampling approach was used to recruit participants for the present study. Clinical Psychologists from within the participating regional specialist epilepsy and neuropsychology services identified possible participants. Those

interested provided contact details, which were shared with the principal investigator. Follow-up calls were made to discuss the study, review participant information, and obtain verbal consent. An epilepsy safety protocol was discussed if applicable. Informed consent was obtained before the interview, with verbal consent recorded if the signed form was not returned (*Appendix 2.8*).

To maximise participant eligibility and recruitment, this study included participants who had completed both prehabilitation and surgery, as well as those awaiting surgical intervention. Participants were provided with a £10 gift voucher as a token of appreciation for their time.

Inclusion Criteria

- The participant has a diagnosis of refractory temporal or extratemporal lobe epilepsy.
- The participant is an adult (18+ years).
- The participant has proceeded through all investigations that led them to be put forward as a candidate for resective epilepsy.
- The participant has met the inclusion criteria for the prehabilitation programme and surgical input.
- Participants with presurgical cognitive difficulties will be included in the study, provided that they are able to engage and participate in the prehabilitation programme and study interview process.
- The participant has sufficient language competence to undertake an interview either in English or via an interpreter.
- Participant has completed a course of prehabilitation in preparation for their surgery or has completed both prehabilitation and surgical input.

Exclusion Criteria

- The participant has a significant learning disability which would exclude them from being a part of the prehabilitation programme.
- Participants whose presurgical cognitive impairments are significant enough that they cannot participate in the prehabilitation programme or interview process.

- Insufficient language competence to undertake an interview either in English or via an interpreter.

Ten participants expressed interest and provided consent to be contacted by the PI, three withdrew interest. Seven individuals participated. All participants had a diagnosis of drug-resistant temporal lobe epilepsy. Participants consisted of six females and one male. The mean age of participants was 40.9 years (range: 26–57 years). Six participants had completed prehabilitation but were still awaiting surgery, and one participant had completed both prehabilitation and surgery at the time of interview. Due to the small population size, more precise demographic data is not reported to ensure participants' anonymity.

Justification for Sample size

We aimed to recruit a sample of 6-10 participants, which is consistent with thematic analysis recommendations (Braun & Clarke, 2013) and represented a feasible sample size given the small numbers of people undergoing prehabilitation programmes in the timescale of this study. After seven interviews, there were evident patterns of consistency across participants' experiences, and they provided detailed accounts. We therefore judged that the data had sufficient depth and richness to provide adequate information to answer the original questions.

Procedure

Regional Neuropsychology Centres in England and Scotland offer a flexible, in-house-prepared prehabilitation protocol that provides sessional guidance on cognitive rehabilitation approaches, with clinician discretion regarding which strategies and psychoeducational components are applicable to the individual patient in relation to their upcoming epilepsy surgery. A more detailed account of participant recruitment can be found in *Appendix 2.14*.

The researcher was a white, female trainee clinical psychologist currently working within a community mental health team in NHS Greater Glasgow and Clyde. Consenting participants completed a semi-structured interview facilitated by the researcher. All participants completed interviews virtually, either via telephone or

Microsoft Teams. Before the interview, they were reminded of confidentiality limits, their right to refuse questions, to take breaks, and to withdraw. After, participants were redirected to the participant information summary for support resources (*Appendix 2.6*). Interviews lasted between 15-65 minutes. No repeat interviews were required, and no participant was observed to have a seizure during the interview process. Interviews were audio-recorded using Microsoft Teams on a secure NHS device and email account, and an encrypted Dictaphone was also used in case of any technical issues. Microsoft Teams was used to transcribe interviews, which were then reviewed by the researcher to correct any errors. This also helped the researcher to begin to note any interesting features related to the research questions, as well as more general questions about what was occurring in the data. The transcripts were then analysed using RTA (Braun & Clarke, 2013) to identify key themes. The researcher made reflective notes post-interview and through reviewing the transcription. Transcripts were not returned to participants for comment, as RTA does not require participant validation and recognises interpretation as part of the analytic process and participants were also not contacted to provide feedback on findings.

Given the possibility of current cognitive difficulties, the researcher considered the participants' neuropsychological profiles and discussed with each participant before the interview to assess whether any reasonable adjustments could be made at any stage of the interview process. Adaptations considered included breaks, pacing, providing a written copy of interview questions, providing extra time during interviews for participants to formulate responses, and considering the complexity of interview language to reduce cognitive load for participants with reduced processing speed or working memory capacity.

Topic Guide

A topic guide (*Appendix 2.9*) was designed and reviewed by members of a participating epilepsy service to ensure the relevance of questions, and they were satisfied with the proposed questions. The topic guide was used flexibly to conduct semi-structured interviews focusing on patient experiences of prehabilitation.

Data Analysis

Data analysis followed the Braun and Clarke six-phase process (Familiarisation with the data, Coding, Searching for Themes, Reviewing Themes, Defining and Naming Themes, Writing Up) to ensure data verification. The researcher listened to interview recordings and reviewed transcripts to correct errors and facilitate immersion in the data. Initial familiarisation notes and ideas were noted by hand. Features of the data were systematically coded in NVivo across the entire data set, and data relevant to each code were collated. This analysis followed an inductive method of reasoning, which made it primarily data-driven and less prone to researcher bias. Codes were organised into themes and then reviewed against the data set. An initial thematic map was developed using MindMup (*Appendix 2.10*) to visualise the relationships between candidate themes. The details of each theme were refined to gain clear definitions. Supervision was used to review transcripts, the coding process and the generation of themes. The chief investigator reviewed elements of the data analysis, including coding on NVivo and initial thematic maps, to assess the reliability of the coding process and to confirm the consistency of themes.

Results

Throughout the reflective thematic analysis, the researcher identified five main themes, which are summarised in *Table 2.1* and discussed below.

Table 2.1: Summary of Main Themes

Theme	**Key Characteristics**
Consent without clarity	Describes perspectives that initial consent was often given with limited understanding of cognitive risks. • Prehabilitation enhanced informed decision-making and awareness. • Increased sense of agency alongside reflection on independence and responsibility.
Worth the risk? Thinking through surgery	Patients' active reflection and on-going weighing of surgical risks against the burden of living with epilepsy. • Increased recognition that surgery is not a guaranteed "fix" and may involve losses. • Consideration of identity, future functioning, and impact on others.
Anchored in hope: tolerating uncertainty	Participants use of hope to manage uncertainty while awaiting surgery. • Focus on controllable aspects and use of coping strategies (e.g., avoidance, reframing). • Explored tension between desire for improvement and fear of cognitive decline.
Engagement in prehabilitation	• Patients report that engagement in prehabilitation was facilitated by trust, therapeutic relationships, and personalised care. Appreciation of clear communication and social support enhanced participation. • Barriers noted by participants included cognitive difficulties, attention, and practical session challenges.
Feeling empowered	Participants' perceived outcomes of prehabilitation: • Increased confidence, preparedness, and sense of control. • Strengthening and validation of existing coping strategies. • Enhanced autonomy, resilience, and readiness for post-surgical adjustment.

Consent without clarity

Several participants shared that prehabilitation inspired them to reflect more on their decision to have surgery.

"It made me... Consider what was actually going to happen, and it made me... look... deeper into the actual surgery. And then I had blindly, I realised, I had blindly said, Yes"- P6.

Participant 6 expressed that she felt she had consented to surgery due to deterioration in function because of her epilepsy, believing 'anything' would be preferable to her present situation, and that prehabilitation gave her additional time to consider more carefully how these changes might affect her situation, including both potential improvements and challenges.

Many participants emphasised the importance of maintaining their independence. This was described as a balancing act, weighed against the possibility of needing more help and support from others (explored further below in relation to anticipated loss). Most participants reported that prehabilitation reaffirmed their decision to proceed with surgery, though they noted that their awareness of potential changes varied before completing prehabilitation.

"Now from the information I'm a bit scared, but I don't know how they're going to change my seizures and I'm also thinking maybe I'm going to take the chance or to risk because I don't want to be worse or yeah, so I'm between at the moment. Yeah, but was helpful"- P3.

Participant 3 discussed how prehabilitation had led them to reconsider whether or not to proceed with surgery. They were no longer sure that the benefits outweighed the risks of undergoing surgery and considered their decision in light of its potential impact on others around them, such as his wife, who would likely be his primary caregiver if there were significant changes to his cognition. Participant 3 also noted that, although he was reconsidering surgery, he felt that going through prehabilitation was a positive experience that increased his understanding of the surgery and that it was important to be told the truth regarding seizure freedom and cognitive change. Whilst participant 3 was the only participant reconsidering surgery, there was a shared sense of prehabilitation building on participants' informed consent to surgery and highlighting the

importance of providing potential surgical candidates with sufficient information about cognitive risks following surgery.

I think without the meeting with her… it would have been a real shock afterwards. A real shock because she just explained everything to me… the surgeon just didn't say anything of the sort. Yeah, which is obviously the likes of yourselves. It's your job."- P4.

Participants also reflected upon their personal agency in making the decision to undergo surgery, occasionally expressing a sense of responsibility for any adverse outcomes due to having chosen to go ahead with an elective procedure.

"It is weird to think. Essentially, I will be ill, but it's not like... ill is it, like I've not been in a car accident or something, it's something I've chosen to do. So anything that needs changing or I need help with afterwards, it's sort of like, it's something to help me because I've made the choice to have the surgery."- P5

Numerous participants reported a heightened sense of certainty about their decision to undergo surgery, citing a broader understanding of the implications for themselves and their family and friends. The weighing of potential benefits, such as seizure freedom, against cognitive changes is illustrated in the theme below and reflects the significance of agency in decision-making, enabled by the information provided by prehabilitation.

"I've obviously thought about it and I think about the risks and I think about the positives and I've weighed it up. I'm able to make that decision."- P7.

Worth the risk- Thinking Through Surgery.

"My main goal was to get through the surgery with as least harm done as possible."- P6.

When discussing their prehabilitation experience, participants noted that prehabilitation was a space to reflect on their decision to proceed with surgery

and discuss issues, particularly when considering the possibility of post-surgery changes to themselves and others. Whilst the earlier theme of consent without clarity reflects participants' experience of becoming aware of having agreed to surgery without fully understanding/considering the potential consequences of surgery, this theme highlights the active role prehabilitation played in thinking through the decision to proceed with surgery in more depth.

"It was like, right, okay, surgery, if I'm going to look into this, what do we need to know? Like, what's it going to change? How's it going to affect me? And in terms of that, the main thing that worried me there was like, if it affects my brain or the way I recognise, like, you know, social cues, how much will it change me as a person?"- P5

Many participants reflected on the impact of epilepsy on their lives. They discussed how epilepsy affects their quality of life, including their inability to drive, the impact on their work, and the effects of medication, noting that epilepsy often affected their ability to *'live normally'*. One participant noted that epilepsy medication had affected her ability to start a family.

"Like for me. It's mainly starting my own family. But I've never been able to do that because I can't get pregnant on my epilepsy tablets and obviously I would never be able to be left alone with my wain if I was still taking my fits the way I was taking them"-P1

Participant 1 reflected on how she has been unable to get pregnant and start a family due to the potential adverse effects of her epilepsy medication, and how, on balance, potential cognitive changes feel like a risk she would be willing to take to achieve this life goal, highlighting the role of agency in weighing up the risks of surgery. Participants indicated that a decline in cognitive functioning significantly influenced their surgical decision-making process, with one participant reflecting on the reconsideration of surgery due to further cognitive deterioration and changes in life circumstances.

"I was offered surgery when my son was 12, I think, and I had said no, because I didn't want to lose the quality of life that I had. But things have got so much worse…

it's just we're at a better time of... easier time of life to deal with it. So yeah, so I felt that I was in an easier place to go into surgery." -p6

Participants frequently described surgery as a way of preventing further functional deterioration and an opportunity to regain control over their lives alongside seizure reduction.

"It'd be so nice to have the surgery and then be free of just that constant like worry... I've been waiting for a long time for just something that might help because I knew that my medication wasn't helping"- p5

Current cognitive difficulties were also described as having significant consequences on participants' lives. Memory impairment affected participants' confidence in interacting with others and maintaining employment, leading to feelings of frustration and limitation. One participant explained:

"*I do have a terrible memory. Like, sometimes, like, we met up with friends yesterday. And like, I can't remember the last thing that I'd done with them, even though it was only a few weeks ago."- P2*

Whilst considering current cognitive difficulties, participants also acknowledged the cognitive cost of surgery. They described a sense of shock or uncertainty about what postoperative changes may realistically look like when they were initially provided this information in prehabilitation. During the programme, some became aware of the potential *'cost of surgery'*. Some participants reported that they thought they would be *'fixed'* following surgery and realised, through prehabilitation, that this was not necessarily the case. One participant noted that prehabilitation helped them appreciate their current '*complete physical ability*' after completing prehabilitation. Another participant noted that, before prehabilitation, they believed there was a possibility of their cognition improving following surgery, but realised that it is more likely that they will *'never be on the level they are on now'.*

"Well, I just didn't know what to expect. I just really didn't know what to expect is the only way to describe it. I mean, I just thought, you know, you think surgery, you're going to be fixed, but then it's not quite like that. And then, of course, she explained everything to me"- P4.

Participants reported feeling less aware of potential changes before prehabilitation. Many conversations with healthcare professionals focused on seizure freedom, reduction, and the general risks of surgery. Some participants reported not having considered these changes before prehabilitation, while others found researching possible changes helpful and appreciated the guided support. One participant expected *'better results'* when thinking about postoperative changes alongside seizure reduction. They described prehabilitation as a space that provided more specific information about the likely changes caused by surgery. Participants also felt that prehabilitation was tailored and personalised to their type of epilepsy and neuroanatomical presentation.

"How did she put it? .... she said there's some things that the bit of brain that I'll be losing, Someone might tell me that, that their parents died and I'll be terribly upset and I'll give them sympathy or whatever, but then I might not see them for months or whatever and then I might ask, oh, how's your parent… you won't remember that they've told you that..."-P6

Participants also reported feeling a sense of anticipated loss. When exploring how cognitive changes affected them, possible future shifts in self-identity following surgery and worries about potential loss due to surgery seemed to shape their attitudes toward the procedure. Prehabilitation played a significant role in shaping this perception by increasing awareness of the risks associated with potential changes. When participants considered what their lives might look like after surgery, heightened existential anxiety was experienced during prehabilitation discussions about possible changes. These concerns included memory loss or personality changes, and they considered how this may affect their identity, independence, and functioning. They also recognised that prehabilitation helped develop strategies to manage these changes, either directly by creating routines

and structures or indirectly through discussions with support networks, such as updating wills or lasting power of attorney. Additionally, participants reflected on how these changes might affect others and wished to avoid becoming a *'burden'* to loved ones.

"We've redone our will and done lasting power of attorneys for health and stuff like that. So, just in case, but it is just because I want to be certain that everything's in place for, but you know what I mean... I want to be in control whilst I have all my faculties… It's not fair to leave this and that to the other (person)"- P6.

The possibility of such changes and their impact on others was a reason for P3 to reconsider surgery, highlighting the importance of a support system in decision-making. Participants spent time in interviews discussing the likely impact of cognitive changes on themselves and those around them. They found that prehabilitation provided them with space to consider how they might need to rely on their support system following surgery.

"*So today, or any day before I've had my surgery really, I could get up from this chair, I could go and get myself a drink or a hot drink or cook myself a hot meal, or I could go upstairs and run a bath, get myself in the bath, get myself changed, get myself in bed. It's just everything I think I would do day-to-day because I'm not sure how much I'll need somebody else's help"- P5*.

Participant 5 expressed both uncertainty about how surgery might impact their daily functioning and confidence in their willingness to seek help if required, and cited their support system as a reassuring factor when considering potential changes. By addressing expectations around independence, potential losses, and available support networks, prehabilitation reinforced individuals' sense of agency by helping them anticipate challenges and identify resources to support their adjustment following treatment.

Anchored in Hope- Tolerating Uncertainty

Participants described a sense of uncertainty following completion of the prehabilitation programme. Whilst they now had strategies to help with potential cognitive changes, many of them found themselves 'in limbo' awaiting surgery. They described different ways of tolerating uncertainty, with many noting the importance of hope in helping them do so. One participant noted that there was a lot of hope of surgery going well as it would positively affect *'their whole future'* (*P1*) and noted that they are putting a ' *lot of hope in this… Thinking that this will improve everything"*. Some participants also acknowledged that they may at times be using hope or thoughts of '*definite improvements'* as reassurance, even when this belief may not be accurate.

"I'm going to have a surgery that should improve things. Even if it doesn't stop it completely, it's going to decrease it...Which is what I'm hoping for. So that might not be accurate, I don't know, but I'm going to tell myself that it is..."- P5.

Participant 5 discussed the belief that surgery would improve their current situation, even if the surgery did not result in seizure freedom, whilst also holding the belief that changes in their cognition would be temporary. They acknowledge this belief may be inaccurate but continue to use it to cope with the uncertainty about what those changes might be.

"I want to learn the strategies and then not think about it too much."- P7

When considering how to tolerate uncertainty, participants also spoke of focusing on what is within their control. When thinking about the surgery itself, participants understandably regarded what happens on the day as *'out of their hands'* and the responsibility of the surgical team. Prehabilitation allowed participants to more clearly identify and focus on aspects of their recovery that felt within their control. Through developing and utilising strategies during prehabilitation, participants built resources and coping strategies that enhanced their perceived capacity to manage potential cognitive changes resulting from surgery. This encouraged a greater sense of agency and empowerment, which in turn may have helped in tolerating uncertain surgical outcomes.

Yeah, and I want it to, and I got to go and wake up and then I'll carry on as I am with the strategies that I've got"- P7.

Participant 7 also highlighted that developing strategies through prehabilitation helped them feel more prepared for post-surgical changes. Whilst participants explained that focusing on what was *'within their control'* reduced feelings of worry, there also appeared at times to be a sense of avoidance in anticipatory thinking about surgery.

"Obviously, what happens on the day is out of my hands, but then... everything after and onwards and in the future, that will be up to me. So maybe I've chosen to focus on that instead"- P5

Several participants noted that they felt a sense of detachment about surgery, as well as an increased avoidance of dwelling on the fears or anxieties of surgery during prehabilitation. Some described a sense of choosing not to think too much about it for fear of 'talking themselves' out of surgery. Most participants found themselves weighing the potential cognitive risks associated with surgery against the cognitive difficulties they were already experiencing because of ongoing epilepsy. Many regarded surgical intervention as preferable to the prospect of continued decline in its absence. For several participants, they often viewed surgery as their only option, perhaps stemming from a sense of being *'unable to carry on like I am'*.

"Although I am using the strategies, I'm trying not to think too much about it. Although it's almost like it's just going to happen and I'm going to wake up and it's going to be... Because you just... It's your brain, isn't it... It's like, if I thought too much about it, I think I'd freak out a little bit." -P7.

Engagement in Prehabilitation

Participants reported largely positive experiences with prehabilitation and would recommend it to other surgical candidates. Two subthemes were identified from the discussion of factors influencing engagement: facilitators and barriers. Participants noted that engagement in prehabilitation was enhanced by trust, personal relevance, and collaborative support. Participants emphasised that their engagement was reinforced when prehabilitation was viewed not just as a means of providing information, but also as a personalised, relational process that boosted their confidence, preparedness, and motivation.

A key factor in fostering engagement was the therapeutic rapport established with the psychology team. Participants frequently highlighted the value of feeling heard, understood, and emotionally supported by clinicians and perceived engagement to be facilitated by their perceptions of the clinicians' expertise and competence, which they found reassuring.

"it's okay if something happens, because we know there's people we can speak to. and yeah, so like, I just feel really positive, sort of almost excited about it really… Those appointments definitely increased that, like the way I felt just excited about it, because I probably was still on the worried side before I actually met her and spoke to her"- P5.

Several participants felt that personalised care enhanced support in patient-centred approaches. Feeling heard and validated fostered psychological safety, promoted open discussions and encouraged participation. It also highlighted that tailoring prehabilitation to individuals' needs and interests helped engagement and made prehabilitation feel more meaningful.

Honest communication about expectations of surgery reduced uncertainty and promoted psychological readiness, and recognised the essential role of family and friends in supporting their prehabilitation engagement. This process also encouraged more open conversations with loved ones about postoperative needs.

"Well, it was nice to have the conversations arising afterwards with my husband that it just sparked a load of new information and this and that and yeah, and the interest and yeah, that was, I didn't always expect that..." P6

Support systems enabled participants to integrate strategies into their lives, which they noted as beneficial for continued engagement in reinforcing strategies. Participants also described how noticing the benefits of strategies before surgery reinforced continued engagement with the strategies, potentially increasing participants' confidence in them.

One of the key facilitators of engagement in prehabilitation was the emphasis on communication throughout the prehabilitation process. Participants reflected on how psychologists often served as the facilitating link between the surgical team and the patient. They noted that prehabilitation often felt like a space to discuss concerns and worries and to get answers to questions they felt they could not ask the surgical team.

"It's just, yeah, because I know it's only so much you can say to the doctor and only so much you can say to the surgeon and then you just hope that the psychologist will chivvy them all together."-P6.

Issues around communication were highlighted as a source of frustration for participants more generally on the surgical pathway. They valued how prehabilitation provided clearer communication in a style that *'took the medical terms out of it.'* One participant said prehabilitation felt timely and appreciated the chance to ask non-medical questions.

"*The main things of how I might act or how I might be. I mean, I know there's chances of like psychosis and things like th*at… *it just felt like it was like sort of at the right time that we were able to just ask questions you know, it's okay if something happens, because we know there's people we can speak to..."* -P5.

Participants reflected on how internal factors, such as personality and mood, affected engagement. They noted prehabilitation made them realise that they 'needed' these strategies. All participants described openness and curiosity towards prehabilitation, which in turn aided engagement with the process, reflecting a low-risk attitude towards prehabilitation and enjoyment in consolidating strategies.

"*Hearing what the suggestions were. For the things, it's... I mean… I think I'd be foolish not to take them on, really, because it's like, what else are you going to do? And you've got to help yourself somehow. And you're being stupid not to give it a whirl"- P6*.

Participants mainly emphasised facilitators of engagement rather than barriers. Barriers that were mentioned by some participants included occasionally feeling discussions were 'long-winded '. Other barriers included the impact of medication on their mood or the impact of epilepsy/medication on their memory function, which affected their engagement or implementation of strategies. One participant reported that being provided with copies of the information from the sessions may be helpful, though they also noted difficulty in recalling this had been facilitated.

"The only thing I remember was getting dropped off at the hospital and then coming out and thinking, oh, it was quite helpful. And then instantly forgetting it and not doing anything." -P2

Outcomes of Prehabilitation: Feeling Empowered

Lastly, a key theme identified when discussing the outcomes of prehabilitation, was a sense of empowerment and control when approaching surgery or considering possible cognitive outcomes and their potential impact. Several participants noted that strategies developed during prehabilitation helped them focus more intentionally on recovery after surgery and on managing potential cognitive changes.

"Obviously, after surgery, it's no longer up to my consultant or my surgeon or anything like that. It's up to me about how I get better."- P1.

P1 highlighted a sense of responsibility for their recovery following surgery. P1 was also the only participant interviewed who had completed both prehabilitation and surgery and highlighted the importance of the strategies developed in prehabilitation as aids in their recovery. Many participants also described feeling more prepared, '*secure'*, and '*ready'* for surgery following prehabilitation, which may have arisen from an increased sense of control over potential changes established through the prehabilitation process via the development of meaningful strategies.

"Because of those appointments I've had and all the information that we've got… I feel as okay as I could possibly feel, which might seem crazy, but looking back on the fact that I didn't want it at all, I suppose it is quite strange, but I really do feel like confident about it."-P5.

Participants also reported a sense of comfort and reassurance because of the prehabilitation programmes. Rather than introducing entirely unfamiliar concepts or strategies, participants perceived prehabilitation as a process that acknowledged, validated, and further developed the coping mechanisms and adaptive skills they had already established in response to the cognitive challenges associated with epilepsy and medication. This continuity appeared to foster greater confidence in their existing ability to manage cognitive difficulties, while also enhancing feelings of self-determination, autonomy, and self-reliance.

"I didn't know what I was going into, and she sort of gave me extra tools and reinforced what I was doing; it gave me a bit more confidence to help the process as well."- P7.

Participants noted that the intervention boosted their sense of capability and competence. Many felt they were already managing their difficulties well and saw prehabilitation as an opportunity to refine and develop their existing strategies.

Instead of being corrective, prehabilitation was experienced as a supportive and empowering extension of the strategies participants already used successfully in daily life, which might be especially helpful after resective surgery.

*The tools she gave me, I suppose a confidence in some ways to be able to speak up with colleagues and speak and explain when I am struggling because I've always hid it for a long time, and it is going to get worse, isn't it? So I do need to prepare for that now in my role"-P*7.

Prehabilitation impacted their attitude towards surgery and helped them feel reassured with their decision, which is developed in further detail within the theme of 'thinking through surgery'. Having a plan post-surgery that had been developed through prehabilitation allowed them to feel more confident in their decision to have surgical intervention. It provided them with reassurance about the process and potential changes of surgery.

"So when we spoke to her… it was a calm atmosphere… So it's more than just like my reassurance, it's everybody around me as well, which sometimes can be more important because obviously if I am unwell and need their help after"- P5.

Participants noted that discussions in prehabilitation about the surgery itself, and a focus on their involvement in prehabilitation to reduce the impact of possible cognitive changes following surgery, helped to normalise the process, reassure them and the important people around them about their decision, and reshape their attitude towards surgery more generally.

"That was weird to think because… I didn't know how much, you know, it would change. But then those appointments, with having spoken through any questions I had... It was going through all those simple things to actually find out whether they would be changed or not."- P5.

Participants described a sense of resilience, feeling confident in their ability to manage these changes should they occur, drawing on the skills developed in

prehabilitation, and knowing that their support team would be there as well (both healthcare and personal support systems). Having a well-developed plan made them feel more confident and reassured in their ability to remain as independent as possible post-resective surgery, and it also increased their sense of autonomy in how they approached the surgical process.

"it's okay if something happens, because we know there's people we can speak to. and yeah, so like, I just feel really positive, sort of almost excited about it really, just because... Those appointments definitely increased that, like the way I felt just excited about it, because I probably was still on the worried side before I actually met her and spoke to her"- P5.

When considering the psychological outcomes of prehabilitation, participants described it as helpful, interesting, comforting, comprehensive, and validating, emphasising its value as an intervention.

"Yeah. I wasn't too sure. No, I was really, yeah, really in the dark with it. I wasn't too sure at all. No, I wasn't, no. But she did definitely help and she helped ease my mind. Yeah, so it was worth it."- P4

Participants identified the prehabilitation strategies as essential in building confidence in managing the process of undergoing surgery, highlighting the empowering impact of being actively involved in their own preparation and recovery. Through education, physical preparation, and psychological support, prehabilitation enabled participants to develop a greater understanding of what to expect, reduce uncertainty, and feel more equipped to navigate the challenges associated with surgery.

Discussion

This study aimed to deepen the understanding of patients' experiences during prehabilitation before resective epilepsy surgery. The five main themes identified included: *Consent without clarity; Worth the risk? Thinking through surgery*; *Anchored in hope: tolerating uncertainty*; *Engagement in prehabilitation;* and *Feeling empowered*.

One framework that is useful in understanding participants' experience of prehabilitation is Folkman and Lazarus's (1984) Stress and Coping Theory (Folkman & Lazarus's 1984). This theory considers how individuals initially evaluate a situation for potential threats and then evaluate the resources they have to handle it. For many participants, the idea of surgery increased existing uncertainty, with worries not only about seizure control but also about possible changes in cognition, identity, and social life. Cognitive prehabilitation appeared to influence these appraisal processes by providing information, facilitating better-informed decision-making, and offering practical strategies for coping with anticipated challenges. Whilst prehabilitation increased awareness that surgery was not a guaranteed solution and may have initially increased uncertainty about the surgery through a greater understanding of risk, it also appeared to enhance participants' perceived ability to cope with it, as reflected in themes of feeling empowered and worth the risk, which highlight increased confidence and more realistic expectations.

Additionally, when considering the subtheme of facilitators of engagement in prehabilitation, participants emphasised the importance of clear communication and social support, which align with Lazarus and Folkman's conceptualisation of coping resources (Folkman & Lazarus, 1984). These resources may influence individuals' appraisal of the surgical pathway by enhancing perceived control, predictability, and confidence in their ability to manage stressors. Participants' expressions of hope may also be understood as a psychological coping resource that supports adaptive appraisal and coping, enabling engagement with the surgical pathway despite uncertainty regarding outcomes. Cognitive prehabilitation may function as both a problem-focused and emotion-focused

coping intervention, providing patients with strategies to prepare for potential cognitive changes while supporting psychological adjustment to the challenges associated with epilepsy surgery**.**

Consent without clarity was a prominent theme in discussions about the role of cognitive prehabilitation in supporting informed decision-making about surgery, where psychoeducation about potential cognitive consequences facilitated understanding about the possible impact of surgery on their daily lives. Several participants reported that they had not fully understood the cognitive risks of surgery before cognitive prehabilitation. Dewar and colleagues (2021) explored patients' experiences of the informed consent process on the temporal lobe epilepsy surgical pathway. They suggested that informed consent is a systematic, structured, interdisciplinary process that unfolds over time, which aligns with the present study's finding that informed consent continues to develop after participants agree to proceed with surgery. Baxendale (2020) also highlighted the importance of providing accurate information about the *'neuropsychological cost'* of surgery for individuals considering surgery, to strengthen informed decision-making. Baxendale also suggests that developing an understanding and acceptance of possible cognitive consequences is an essential first step in the prehabilitation process and a prerequisite for informed consent (Baxendale, 2020). Our results develop this perspective by illustrating how patients may use prehabilitation not only to acquire information but also to contextualise it within their personal circumstances, values, and future goals, thereby facilitating engagement in prehabilitation and the development and use of appropriate strategies. Similar research has noted patients' perceptions of inadequate information about surgery and argued that more information could improve decision-making (Dewar & Pieters, 2015)**.** Clinically, the findings highlight the value of prehabilitation on the pre-operative pathway to support decision-making and patient preparedness, and the importance of recognising informed consent as an ongoing process rather than a single clinical event.

This difference between receiving information and understanding it is also reflected in the wider informed consent literature. A systematic review by Pietrzykowski & Smilowska (2021) found that patients' comprehension of

important components of informed consent was often limited, with only a small minority demonstrating understanding of risks, side effects, and other safety-related information. Similarly, another systematic review by Glaser and colleagues (2020) evaluated the characteristics and outcomes of interventions to improve patient comprehension in clinical informed consent and found that standard consent practices do not always result in adequate patient comprehension, with understanding of procedural risks being a particular focus of the literature. A recent review by Sprosen and colleagues (2026) further highlighted the complexity of informed choice, noting that existing approaches often focus on knowledge, while giving less attention to whether decisions are consistent with patients' values. Together, this literature suggests that informed decision-making involves not only receiving information, but understanding and relating it to individual circumstances. These findings support the present study's observation that being told information does not necessarily mean that it is understood. Prehabilitation may therefore provide an opportunity to revisit and contextualise information, helping patients relate potential risks and benefits to their individual circumstances and future goals and supporting informed decision-making.

Key aspects of the *'worth the risk—thinking through surgery*,' theme included active reflection and continuous weighing of surgical risks against the current difficulties of living with epilepsy. Dewar & Pieters' (2015) systematic review revealed that patients' decisions about epilepsy surgery are influenced by their understanding of treatment options, perceived surgical risks, and expected outcomes. The review noted ongoing gaps in how risks, benefits, and potential cognitive and psychosocial effects are communicated and understood, indicating that patients often need more personalised information to make well-informed choices. This was echoed in the current study, where participants expressed that prehabilitation offered more individualised information, helping them better understand the risks and benefits, beyond just seizure reduction.

In relation to existing literature, these ideas align with the Y-shaped model of adjustment, which explains how individuals adapt to major life changes, such as brain injury (Gracey et al., 2009). This model, often used in brain injury rehabilitation, focuses on rebuilding individuals' identities, learning new skills, and redefining independence through cognitive management strategies, such as the development of routines and the use of memory aids (Gracey et al., 2009). In prehabilitation, the model may shift from post-loss adjustment to anticipatory adjustment, recognising the importance of preparing for possible future changes. Rather than simply providing a clearer understanding of potential postsurgical outcomes, participants valued prehabilitation as an opportunity to prepare for and integrate the complex interplay between their current self and a possible future self that may be seizure-free but experience cognitive or identity changes. This preparation may support the development of coping strategies before surgery and facilitate adaptation afterwards. However, some participants noted they avoided thinking about potential cognitive or identity changes to prevent anxiety, which may serve as a coping mechanism. This was evident when participants mentioned trying not to think about potential changes 'too much' for fear they might influence their decision to proceed with surgery, and sometimes used this avoidance to cope with uncertainty. By creating space to consider and prepare for multiple possible futures, prehabilitation may support the adaptability of multiple selves, enabling individuals to navigate anticipated trade-offs between present and future identities. Through this preparation process, individuals may make more informed decisions about surgery while developing strategies to manage uncertainty and adapt to potential postsurgical changes. Engaging in prehabilitation may promote graded preparation and psychological flexibility, helping individuals better accept changes in identity and cognition following resective surgery. These findings suggest that the outcomes of prehabilitation extend beyond cognitive readiness to include psychological adjustment, providing information, coping strategies, and reflection on changes in cognition and identity. Interventions should also be tailored to individual coping styles, especially for those who use avoidance to help manage uncertainty.

A paper by Coleman and colleagues (2020) explored how individuals make sense of their lives 15-20 years after resective epilepsy surgery. They argued that the long-term impact of epilepsy surgery is not only about seizure cessation but also involves a prolonged process in which people reconstruct their understanding of themselves, their lives, and their future. This is reflected in the present study's findings, which show that participants reflected on potential changes to their identity following surgery, for example, reflections on potential changes to their personality, '*will I still be a nice person/will I be nasty'* or being a '*burden'* or not useful to others. Clinically, beginning this process earlier through prehabilitation may help individuals adjust to the potential and help patients anticipate and cope with the psychosocial consequences of epilepsy surgery.

Previous research has highlighted how hope can exist alongside uncertainty, difficult information, and potential negative outcomes (Curtis et al., 2008). In major surgery, hope is described alongside fear and uncertainty (Baur et al., 2019). In the "*Anchored in hope"* theme, participants learned to tolerate uncertainty regarding postsurgical cognitive outcomes through prehabilitation. This future-oriented approach may foster realistic hope by helping patients actively prepare for surgery while recognising the uncertainties in outcomes. It also explored tensions between the desire to improve and the fear of decline, with participants reflecting on how prehabilitation helped them focus on controllable aspects and develop coping strategies.

Curtis and colleagues (2008) showed that patients and families can seek hope while also engaging with prognostic information and uncertainty. Hope does not require avoiding difficult possibilities but may coexist with the acknowledgement of challenges and changing circumstances. Participants in this study described balancing hope for positive cognitive outcomes with awareness that postoperative changes are unpredictable. Participants also described cognitive prehabilitation as helping manage this uncertainty by focusing on aspects of surgical preparation they could influence. This suggests that instead of reducing uncertainty, cognitive prehabilitation helps maintain hope by fostering a sense of agency and active engagement.

Baur and colleagues (2019) suggested that healthcare professionals can foster hope during the surgical pathway by supporting patients in the preoperative period. Participants in the present study viewed prehabilitation as an opportunity to develop strategies for postoperative changes. Rather than promising to prevent cognitive decline, prehabilitation fostered a form of hope grounded in preparation and active engagement, aligning with their study's idea of a supportive role.

Another key research question in the present study was to address participants' experiences of prehabilitation programmes and identify facilitators and barriers to engagement. Participants highlighted facilitators to engagement such as clear communication, integration of support systems into strategy development, therapeutic rapport, and personalised care. Whilst limited research has examined specific facilitators and barriers to cognitive prehabilitation in epilepsy surgery, a systematic review looking more generally at engagement in prehabilitation found some similar themes in terms of facilitators, such as personalised care, impact of social support and the involvement of resources such as education and skill building, facilitated adherence to prehabilitation and noted similar barriers including the impact of medical conditions and mood influences (Berrio-Valencia et al., 2025). Previous research has examined patients' experiences of prehabilitation, with patients reporting high satisfaction with a prehabilitation programme. They reported that the programme was beneficial and helpful, that the information was valuable, that it increased readiness for surgery, reduced uncertainty, and increased the use of compensatory strategies, and that they would recommend it to others (Arrotta et al., 2025). Many of these findings are reflected in the present study regarding patients' self-reported engagement and prehabilitation outcomes. The facilitators and barriers identified in prehabilitation engagement should be taken into consideration when developing future prehabilitation programmes or adapting current prehabilitation programme protocols.

Participants' increased confidence and perceived resilience following prehabilitation may reflect enhanced self-efficacy derived from acquiring practical cognitive strategies and knowledge about potential challenges. Increased

confidence appeared to stem from a greater sense of preparedness, knowledge, and familiarity with strategies to use after surgery. TBaxendale's (2020)sistent with Baxendale's (2020) proposed framework, which recommends implementing strategies prior to surgery and beginning with achievable goals that help to build confidence and realistic expectations. From this perspective, confidence may represent an important outcome of prehabilitation. Participants' self-efficacy may improve through the development and integration of cognitive strategies, which may also support psychological adjustment throughout the surgical pathway.

Although the current study did not directly assess coping styles, these findings are consistent with emerging evidence suggesting that presurgical coping processes influence postsurgical adaptation. Research examining psychosocial functioning after epilepsy surgery found that active coping, planning, and positive reinterpretation prior to epilepsy surgery were associated with higher self-efficacy, self-esteem, better social adaptation, and lower perceived stigma following surgery (Selçukoğlu Kilimci et al., 2024). Their findings suggest that psychosocial outcomes are influenced not only by seizure freedom but also by how individuals cognitively and emotionally prepare for surgery. Cognitive prehabilitation may also serve as a mechanism to strengthen patients' adaptive coping resources before surgery, which may facilitate more effective engagement in managing uncertainty and adjusting to changes after surgery.

Strengths and Limitations

A key strength of the present study is its ability to explore aspects of cognitive prehabilitation that may not be captured by quantitative outcome measures alone, and it contributes to a patient-centred approach to understanding prehabilitation through their perspectives. Existing literature has largely focused on implementation and efficacy outcomes of prehabilitation; the present study also explores broader psychosocial experiences. These findings provide insight into the subjective meaning and perceived value of cognitive prehabilitation within the epilepsy surgery pathway, which was enabled through the thematic analysis

design. It also provided insight into the personal meanings attached to surgery preparation, uncertainty, and cognitive risk.

As with most qualitative studies, these findings should be considered within the constraints of the small sample size. While the focus was on gaining deep insight rather than statistical generalisation, the experiences shared might not represent all individuals who undergo epilepsy surgery or partake in cognitive prehabilitation.

Six out of seven participants who were interviewed following completion of prehabilitation were still awaiting resective surgery, this likely impacted the conversations which focused on anticipated cognitive outcomes rather than their experienced postoperative changes. Future longitudinal research that follows patients from prehabilitation through postoperative recovery may help determine how these expectations relate to actual cognitive and psychosocial outcomes. This approach would allow researchers to examine whether changes in confidence, coping, preparedness, and perceived self-efficacy during prehabilitation influence longer-term cognitive and psychosocial outcomes. Future research may also consider whether aspects of the presented themes serve as mechanisms through which cognitive prehabilitation exerts its effects.

From a methodological perspective, one theme exhibits somewhat less alignment with the others in terms of narrative coherence: the prehabilitation engagement theme. While the remaining themes primarily examined patient perspectives from a psychological standpoint, this theme emphasised the pragmatic aspects of prehabilitation facilitation. Despite its weaker connection to the other themes, it addressed one of the key research questions, how to optimise engagement in prehabilitation in future initiatives.

Clinical Implications

The findings suggest that prehabilitation is a valuable component of person-centred care within the epilepsy surgery pathway, supporting patients to feel informed, empowered and better able to manage the psychological and practical

challenges associated with surgery. Clinically, this highlights the importance of maintaining personalised information, psychological support and practical coping strategies within prehabilitation. Involving patients' support networks, where appropriate, may further reinforce these strategies and provide continuity of support before and after surgery.

The findings also highlight the importance of cognitive accessibility when delivering information. Written summaries, take-home resources and recorded information may support understanding and recall, while repeated opportunities to review surgical risks and potential outcomes could help address changes in patients' understanding over the prolonged surgical pathway. Clinicians may therefore benefit from adopting flexible approaches to information provision rather than relying on a single point of communication. Additionally, explicitly addressing uncertainty within psychological support may help patients develop strategies to manage the unpredictability of surgical outcomes.

Finally, the timing of prehabilitation requires consideration. Although participants valued receiving support when surgery felt sufficiently imminent, earlier intervention may provide greater opportunity for informed decision-making. However, given the length and complexity of the epilepsy surgery pathway, a staged approach may be more appropriate, allowing information and strategies to be introduced and revisited according to patients' readiness and changing needs. Overall, these findings support continued refinement of prehabilitation towards a flexible, person-centred and cognitively accessible model of care.

Conclusions

This study explored patient experiences of prehabilitation in the epilepsy surgery pathway. There was evidence that participants valued the prehabilitation process, feeling supported, empowered and better equipped to manage potential consequences of surgery, and tolerate uncertainty.

Participants appreciated personalised information, psychological support, and practical strategies, indicating prehabilitation meets key needs during the surgical process. The findings also suggested that adding more opportunities to review understanding of surgical risks and outcomes may be helpful along the surgical pathway more generally. Overall, the research suggests that while the current prehabilitation programme is perceived as valuable and beneficial by participants, there are opportunities to further optimise its delivery through continued person-centred refinement, consideration of cognitive accessibility, greater involvement of support systems, and careful consideration of how and when information is delivered across the surgical pathway.

References

Arrotta, K., Babiker, S., Lake, J., Thompson, N., Lioi, A. B., Najm, I., & Busch, R. M. (2025). Feasibility of and patient satisfaction with Readiness Brain Operation Optimization Training, a manualized cognitive prehabilitation program for epilepsy surgery. *Epilepsia, 66*(10), 3830–3838. https://doi.org/10.1111/epi.18445

Baur, K. M., Chamberlain, J., Wendler, M. C., Harwood, P., Colle, J., & Yeaman, D. (2019). The expressions of hope in the face of complex surgery: Experiences of patients and their loved ones. *Journal of Patient Experience, 6*(4), 278–286. https://doi.org/10.1177/2374373518803618

Baxendale, S. (2008). The impact of epilepsy surgery on cognition and behavior. *Epilepsy & Behavior, 12*(4), 592–599. https://doi.org/10.1016/j.yebeh.2007.12.015

Baxendale, S. (2020). Cognitive rehabilitation and prehabilitation in people with epilepsy. *Epilepsy & Behavior, 106*, 107027. https://doi.org/10.1016/j.yebeh.2020.107027

Baxendale, S., & Thompson, P. (2018). Red flags in epilepsy surgery: Identifying the patients who pay a high cognitive price for an unsuccessful surgical outcome. *Epilepsy & Behavior, 78*, 269–272. https://doi.org/10.1016/j.yebeh.2017.08.003

Baxendale, S., Wilson, S. J., Baker, G. A., Barr, W., Helmstaedter, C., Hermann, B. P., Langfitt, J., Reuner, G., Rzezak, P., Samson, S., & Smith, M. L. (2019). Indications and expectations for neuropsychological assessment in epilepsy surgery in children and adults: Report of the ILAE Neuropsychology Task Force Diagnostic Methods Commission: 2017–2021 neuropsychological assessment in epilepsy surgery. *Epileptic Disorders, 21*(3), 221–234. https://doi.org/10.1684/epd.2019.1065

Berrio-Valencia, M. I., Al-Bayati, M., Baxi, A., Branje, K., Chitiva-Martinez, I., Hladkowicz, E., Kidd, G., Hutton, B., Wolfe, D. M., Lalu, M., Boet, S., Gillis, C., & McIsaac, D. I. (2025). Adherence to prehabilitation in adult surgical patients: A systematic review, meta-analysis, meta-regression, and qualitative synthesis. *British Journal of Anaesthesia, 135*(3), 582–593. https://doi.org/10.1016/j.bja.2025.06.003

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Braun, V., & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners*. SAGE.

Braun, V., & Clarke, V. (2022). *Thematic analysis: A practical guide*. SAGE.

Coleman, H., McIntosh, A., & Wilson, S. J. (2020). A patient-centered approach to understanding long-term psychosocial adjustment and meaning-making, 15 to 20 years after epilepsy surgery. *Epilepsy & Behavior, 102*, 106656. https://doi.org/10.1016/j.yebeh.2019.106656

Curtis, J. R., Engelberg, R., Young, J. P., Vig, L. K., Reinke, L. F., Wenrich, M. D., McGrath, B., McCown, E., & Back, A. L. (2008). An approach to understanding the interaction of hope and desire for explicit prognostic information among individuals with severe chronic obstructive pulmonary disease or advanced cancer. *Journal of Palliative Medicine, 11*(4), 610–620. https://doi.org/10.1089/jpm.2007.0209

de Boer, H. M., Mula, M., & Sander, J. W. (2008). The global burden and stigma of epilepsy. *Epilepsy & Behavior, 12*(4), 540–546. https://doi.org/10.1016/j.yebeh.2007.12.019

Dewar, S. R., & Pieters, H. C. (2015). Perceptions of epilepsy surgery: A systematic review and an explanatory model of decision-making. *Epilepsy & Behavior, 44*, 171–178. https://doi.org/10.1016/j.yebeh.2014.12.027

Dewar, S. R., Pieters, H. C., & Fried, I. (2021). Surgical decision-making for temporal lobe epilepsy: Patient experiences of the informed consent process. *Frontiers in Neurology, 12*, 780306. https://doi.org/10.3389/fneur.2021.780306

Engel, J., McDermott, M. P., Wiebe, S., Langfitt, J. T., Stern, J. M., Dewar, S., Sperling, M. R., Gardiner, I., Erba, G., Fried, I., Jacobs, M., Vinters, H. V., Mintzer, S., & Kieburtz, K. (2012). Early surgical therapy for drug-resistant temporal lobe epilepsy: A randomized trial. *JAMA, 307*(9), 922–930. https://doi.org/10.1001/jama.2012.220

Folkman, S., & Lazarus, R. S. (1984). Personal control and stress and coping processes: A theoretical analysis. *Journal of Personality and Social Psychology, 46*(4), 839–852. https://doi.org/10.1037/0022-3514.46.4.839

Glaser, J., Nouri, S., Fernandez, A., Sudore, R. L., Schillinger, D., Klein-Fedyshin, M., & Schenker, Y. (2020). Interventions to improve patient comprehension in informed consent for medical and surgical procedures: An updated systematic review. *Medical Decision Making, 40*(2), 119–143. https://doi.org/10.1177/0272989X19896348

Gracey, F., Evans, J. J., & Malley, D. (2009). Capturing process and outcome in complex rehabilitation interventions: A "Y-shaped" model. *Neuropsychological Rehabilitation, 19*(6), 867–890. https://doi.org/10.1080/09602010903027763

Hermann, B., & Jacoby, A. (2009). The psychosocial impact of epilepsy in adults. *Epilepsy & Behavior, 15*(Suppl. 1). https://doi.org/10.1016/j.yebeh.2009.03.029

Mula, M., & Sander, J. W. (2016). Psychosocial aspects of epilepsy: A wider approach. *BJPsych Open, 2*(4), 270–274. https://doi.org/10.1192/bjpo.bp.115.002345

National Institute for Health and Care Excellence. (2022). *Epilepsies in children, young people and adults* (NG217). https://www.nice.org.uk/guidance/ng217

Pietrzykowski, T., & Smilowska, K. (2021). The reality of informed consent: Empirical studies on patient comprehension: Systematic review. *Trials, 22*(1), 57. https://doi.org/10.1186/s13063-020-04969-w

Selçukoğlu Kilimci, Ö., Turan, Ş., İşler, C., Kara Esen, B., Baş, G., & Özkara, Ç. (2024). Psychosocial outcomes six months after epilepsy surgery: A perspective on coping strategies. *Epilepsy & Behavior, 156*, 109843. https://doi.org/10.1016/j.yebeh.2024.109843

Sprosen, H., Re, C., Stewart, G. D., & Usher-Smith, J. A. (2026). Operationalizing and measuring informed choice in health care: An umbrella review. *Medical Decision Making, 46*(4), 501–526. https://doi.org/10.1177/0272989X251413276

Appendices

3. Systematic Review Appendix

Appendix 1.1: PRISMA Checklist

Table 3.1: PRISMA Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	p. 11
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	p.12
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	p.14-15
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	p.15
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	p. 16-17
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.	p.16
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	p. 16, 107-111

Section and Topic	Item #	Checklist item	Location where item is reported
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.	p. 13-17
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.	p. 13-17
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.	p. 13-17
	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.	p. 10, 13-17
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.	p.16
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.	p. 16-17
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)).	p. 15-17
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	p. 15-17
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	p. 15-17
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If	p. 15-17

Section and Topic	Item #	Checklist item	Location where item is reported
		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).	p. 15-17
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	N/A
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	p. 17
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	p. 15-17
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.	p. 18-20
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	p. 28-20
Study characteristics	17	Cite each included study and present its characteristics.	p. 21- 23
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	p. 24-29
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.	p. 18- 23, 32-44,
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	p. 19-29
	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.	p. 30-47

Section and Topic	Item #	Checklist item	Location where item is reported
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	p. 30-47
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	N/A
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	p. 24-29
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	p. 30-47
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	p. 48-52
	23b	Discuss any limitations of the evidence included in the review.	p. 51-52
	23c	Discuss any limitations of the review processes used.	p. 51-52
	23d	Discuss implications of the results for practice, policy, and future research.	p. 52-54
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.	p. 13
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	p. 13
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	N/A
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	p. 10
Competing interests	26	Declare any competing interests of review authors.	p. 10
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.	p. 13

Appendix 1.2: Search Terms

Table 3.2: Search Terms (Ran on 2nd April 2026)

Database	Filters	Search Terms
Pubmed	Filters applied: English, Humans, Adult: 19+ years	Search: ((((("Epilepsy, Temporal Lobe"[Mesh] OR "Epilepsy, Temporal Lobe/surgery"[Mesh] OR "drug-resistant epilepsy"[Title/Abstract] OR "refractory epilepsy"[Title/Abstract] OR "intractable epilepsy"[Title/Abstract] OR "treatment-resistant epilepsy"[Title/Abstract] OR "pharmacoresistant epilepsy"[Title/Abstract] OR "temporal lobe epilepsy"[Title/Abstract] OR "focal epilepsy"[Title/Abstract] OR "refractory temporal seizures"[Title/Abstract])) AND (("Epilepsy Surgery"[Mesh] OR "Neurosurgical Procedures"[Mesh] OR "epilepsy surgery"[Title/Abstract] OR "resective surgery"[Title/Abstract] OR "surgical resection"[Title/Abstract] OR "temporal lobectomy"[Title/Abstract] OR "anterior temporal lobectomy"[Title/Abstract] OR "selective amygdalohippocampectomy"[Title/Abstract] OR "amygdalohippocampectomy"[Title/Abstract] OR "lesionectomy"[Title/Abstract] OR "corticectomy"[Title/Abstract]))) AND (("Neuropsychological Tests"[Mesh] OR "Cognition"[Mesh] OR "Quality of Life"[Mesh] OR "Depression"[Mesh] OR "Anxiety"[Mesh] OR "Adaptation, Psychological"[Mesh] OR "cognitive outcome"[Title/Abstract] OR "cognitive function"[Title/Abstract] OR cognition[Title/Abstract] OR memory[Title/Abstract] OR "memory function"[Title/Abstract] OR "executive function"[Title/Abstract] OR attention[Title/Abstract] OR IQ[Title/Abstract] OR "intellectual function"[Title/Abstract] OR "cognitive change"[Title/Abstract] OR "neuropsychological outcome"[Title/Abstract] OR "neuropsychological effects"[Title/Abstract]

		OR "psychological outcome"[Title/Abstract] OR behaviour[Title/Abstract] OR behavior[Title/Abstract] OR mood[Title/Abstract] OR depression[Title/Abstract] OR anxiety[Title/Abstract] OR "emotional wellbeing"[Title/Abstract] OR "psychosocial outcome"[Title/Abstract] OR "psychosocial wellbeing"[Title/Abstract] OR "social adjustment"[Title/Abstract] OR "employment outcome"[Title/Abstract] OR "functional outcome"[Title/Abstract] OR "quality of life"[Title/Abstract]))) AND (("Follow-Up Studies"[Mesh] OR "Longitudinal Studies"[Mesh] OR "Treatment Outcome"[Mesh] OR "Prognosis"[Mesh] OR "long-term follow-up"[Title/Abstract] OR "long-term outcome"[Title/Abstract] OR "long-term effects"[Title/Abstract] OR "longitudinal study"[Title/Abstract] OR "longitudinal outcome"[Title/Abstract] OR "follow-up study"[Title/Abstract] OR "prospective study"[Title/Abstract] OR "chronic outcome"[Title/Abstract] OR "extended follow-up"[Title/Abstract] OR outcome*[Title/Abstract] OR result*[Title/Abstract])) Filters: English, Humans, Adult: 19+ years
PsychoInfo (EMBSCO)	Peer Reviewed; Language: English; Age Groups: Adulthood (18 yrs & older); Population Group: Human AND Apply equivalent subjects	“((DE “Epilepsy” OR DE “Temporal Lobe Epilepsy” OR DE “Drug Resistant Epilepsy” OR TX (“temporal lobe epilepsy” OR “focal epilepsy” OR “drug-resistant epilepsy” OR “refractory epilepsy” OR “intractable epilepsy” OR “treatment-resistant epilepsy” OR “pharmacoresistant epilepsy” OR “refractory temporal seizures”))) AND ((DE “Epilepsy Surgery” OR DE “Neurosurgery” OR DE “Brain Surgery” OR TX (“epilepsy surgery” OR “resective surgery” OR “surgical resection” OR “temporal lobectomy” OR “anterior temporal lobectomy” OR “amygdalohippocampectomy” OR “selective amygdalohippocampectomy” OR “lesionectomy” OR “corticectomy”))) AND ((DE “Neuropsychological Assessment” OR DE “Cognitive Functioning” OR DE “Memory” OR DE “Executive Function” OR DE “Attention” OR DE “Intelligence” OR DE “Psychological

		Adjustment" OR DE "Psychosocial Adjustment" OR DE "Depression" OR DE "Anxiety" OR DE "Mood" OR DE "Quality of Life" OR DE "Well Being" OR TX ("neuropsychological outcome*" OR "cognitive outcome*" OR cognition OR memory OR "executive function" OR attention OR IQ OR "intellectual function" OR "cognitive change" OR "cognitive decline" OR "psychosocial outcome*" OR "psychosocial wellbeing" OR "emotional wellbeing" OR "psychological outcome*" OR depression OR anxiety OR mood OR "quality of life" OR wellbeing OR "social adjustment" OR "functional outcome*"))) AND ((DE "Followup Studies" OR DE "Longitudinal Studies" OR DE "Prospective Studies" OR DE "Treatment Outcomes" OR DE "Prognosis" OR TX ("long-term follow-up" OR "long-term outcome*" OR "longitudinal study" OR "follow-up study" OR "prospective study" OR "chronic outcome*" OR "extended follow-up" OR "treatment outcome*" OR "postoperative outcome*" OR "surgical outcome*" OR "long-term effects")))
Embase OVID	8 limit 7 to (human and english language and (adult <18 to 64 years> or aged <65+ years>))	exp epilepsy/ or exp temporal lobe epilepsy/ or exp drug resistant epilepsy/ or (temporal lobe epilepsy or focal epilepsy or drug-resistant epilepsy or refractory epilepsy or intractable epilepsy or treatment-resistant epilepsy or pharmacoresistant epilepsy or refractory temporal seizures).tw. 2 exp epilepsy surgery/ or exp neurosurgery/ or exp brain surgery/ or exp temporal lobectomy/ or (epilepsy surgery or resective surgery or surgical resection or temporal lobectomy or anterior temporal lobectomy or selective amygdalohippocampectomy or amygdalohippocampectomy or lesionectomy or corticectomy).tw. 3 exp neuropsychology/ or exp neuropsychological test/ or exp cognitive function/ or exp cognition/ or exp memory/ or exp executive function/ or exp attention/ or exp intelligence/ or (neuropsychological outcome* or cognitive outcome* or cognition or cognitive function or cognitive change or cognitive decline or memory or memory

		function or executive function or attention or IQ or intellectual function).tw. 4 exp psychosocial outcome/ or exp psychological adjustment/ or exp emotional adjustment/ or exp depression/ or exp anxiety/ or exp mood disorder/ or exp quality of life/ or exp wellbeing/ or (psychosocial outcome* or psychosocial wellbeing or emotional wellbeing or psychological outcome* or behavioural outcome* or behavioral outcome* or depression or anxiety or mood or low mood or quality of life or wellbeing or social adjustment or functional outcome*).tw. 5 exp follow up/ or exp longitudinal study/ or exp prospective study/ or exp treatment outcome/ or exp prognosis/ or (long-term follow-up or long-term outcome* or long-term effects or longitudinal study or longitudinal outcome or follow-up study or prospective study or chronic outcome* or extended follow-up or postoperative outcome* or surgical outcome*).tw. 6 3 or 4 7 1 and 2 and 5 and 6
MEDLINE OVID	8 limit 7 to (english language and humans and ("young adult (19 to 24 years)" or "adult (19 to 44 years)" or "young adult and adult (19-24 and 19-44)" or "middle age (45 to 64 years)" or "middle aged (45 plus years)" or "all aged (65 and over)" or "aged (80 and over)"))	1 exp Epilepsy/ or exp Epilepsy, Temporal Lobe/ or exp Drug-Resistant Epilepsy/ or (temporal lobe epilepsy or focal epilepsy or drug-resistant epilepsy or refractory epilepsy or intractable epilepsy or treatment-resistant epilepsy or pharmacoresistant epilepsy or refractory temporal seizures).tw. 2 exp Epilepsy Surgery/ or exp Neurosurgical Procedures/ or exp Temporal Lobectomy/ or (epilepsy surgery or resective surgery or surgical resection or temporal lobectomy or anterior temporal lobectomy or selective amygdalohippocampectomy or amygdalohippocampectomy or lesionectomy or corticectomy).tw. 3 exp Neuropsychological Tests/ or exp Cognition/ or exp Memory/ or exp Executive Function/ or exp Attention/ or exp Intelligence/ or (neuropsychological outcome* or cognitive outcome* or cognition or cognitive function or cognitive change or cognitive decline or memory or memory

		function or executive function or attention or IQ or intellectual function).tw. exp psychosocial outcome/ or exp psychological adjustment/ or exp emotional adjustment/ or exp depression/ or exp anxiety/ or exp mood disorder/ or exp quality of life/ or exp wellbeing/ or (psychosocial outcome* or psychosocial wellbeing or emotional wellbeing or psychological outcome* or behavioural outcome* or behavioral outcome* or depression or anxiety or mood or low mood or quality of life or wellbeing or social adjustment or functional outcome*).tw. 5 exp Follow-Up Studies/ or exp Longitudinal Studies/ or exp Prospective Studies/ or exp Treatment Outcome/ or exp Prognosis/ or (long-term follow-up or long-term outcome* or long-term effects or longitudinal study or longitudinal outcome or follow-up study or prospective study or chronic outcome* or extended follow-up or postoperative outcome* or surgical outcome*).tw. 6 3 or 4 7 1 and 2 and 5 and 6

4. Major Research Project Appendix

Appendix 2.1: COREQ Checklist

Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

Developed from:
Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. International Journal for Quality in Health Care. 2007. Volume 19, Number 6: pp. 349 – 357

Table 4.1: COREQ Checklist

Item No	Guide Questions/Description	Reported on Page #
Domain 1: Research team and reflexivity		
Personal Characteristics		
1. Interviewer/ facilitator	Which author/s conducted the interview or focus group?	Pg 69-71
2. Credentials	What were the researcher's credentials? E.g., PhD, MD	Pg 1
3. Occupation	What was their occupation at the time of the study?	Pg 69
4. Gender	Was the researcher male or female?	Pg 69
5. Experience and training	What experience or training did the researcher have?	Pg 1, 69
Relationship with participants		
6. Relationship established	Was a relationship established prior to study commencement?	Pg 68-71
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research?	Pg 68-71
8. Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	Pg 139-140, 143
Domain 2: study design		
Theoretical framework		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	Pg 67
Participant selection		
10. Sampling	How were participants selected? e.g., purposive, convenience, consecutive, snowball	Pg 67-69, 139-140

Item No	Guide Questions/Description	Reported on Page #
11. Method of approach	How were participants approached? e.g., face-to-face, telephone, mail, email	Pg 70, 71, 140
12. Sample size	How many participants were in the study?	Pg 69
13. Non-participation Setting	How many people refused to participate or dropped out? Reasons?	Pg 69
14. Setting of data collection	Where was the data collected? e.g., home, clinic, workplace	Pg 69-70
15. Presence of nonparticipants	Was anyone else present besides the participants and researchers?	N/A
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	Pg 69-70
Data collection		
17. Interview guide	Were questions, prompts, and guides provided by the authors? Was it pilot tested?	Pg. 70, 138
18. Repeat interviews	Were repeat interviews carried out? If yes, how many?	N/A
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	Pg. 71
20. Field notes	Were field notes made during and/or after the interview or focus group?	Pg 69, 70, 139-140
21. Duration	What was the duration of the interviews or focus group?	Pg. 69-70
22. Data saturation	Was data saturation discussed?	Pg 69, 70, 139-140
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	Pg. 70
Domain 3: analysis and findings		
Data analysis		
24. Number of data coders	How many data coders coded the data?	Pg 70, 71, 138-140
25. Description of the coding tree	Did the authors provide a description of the coding tree?	N/A
26. Derivation of themes	Were themes identified in advance or derived from the data?	Pg 70, 71, 139-140
27. Software	What software, if applicable, was used to manage the data?	Pg 70, 71, 139-140
28. Participant checking	Did participants provide feedback on the findings?	Pg. 70
Reporting		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g., participant number	Pg 72-86

Item No	Guide Questions/Description	Reported on Page #
30. Data and findings consistent	Was there consistency between the data presented and the findings?	Pg 72-86
31. Clarity of major themes	Were major themes clearly presented in the findings?	Pg 72-86
32. Clarity of minor themes	Is there a description of diverse cases or a discussion of minor themes?	Pg 72-86

Appendix 2.2: Final MRP Proposal

Available at: (https://osf.io/cr5nk)

Appendix 2.3: Ethic Approval Letter

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

Wales REC 4
Health and Care Research Wales
Castlebridge 5
15-19 Cowbridge Road East
CF11 9AB

Please note: 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

23 July 2025

Prof. Jonathan Evans
Clarice Pears Building
90 Byres Rd,
Glasgow
G12 8TB

Dear Prof. Evans

Study title:	**Patient Experiences of Cognitive Prehabilitation on the Epilepsy Surgery Pathway**
REC reference:	**25/WA/0171**
Protocol number:	**UGN25NE230**
IRAS project ID:	**352783**

Thank you for your letter of , responding to the Research Ethics Committee's (REC) request for further information on the above research and submitting revised documentation.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

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
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 public registry before the first participant is recruited and no later than six weeks after. 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.

A 'public registry' means any registry on the WHO list of primary registries or the ICMJE list of registries provided the registry facilitates public access to information about the UK trial.

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).

Where a deferral is agreed we expect the sponsor to publish a minimal record on a publicly accessible registry. When the deferral period ends, the sponsor should publish the full record on the same registry, to fulfil the condition of the REC favourable opinion.

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.

Where the study is registered on ClinicalTrials.gov, please inform deferrals@hra.nhs.uk and the Research Ethics Committee (REC) which issued the final ethical opinion so that our records can be updated.

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. Where a deferral is agreed, a minimum research summary will still be published in the research summaries database. At the end of the deferral period, we will publish the full research summary.

Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit: Research summaries - Health Research Authority (hra.nhs.uk)

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

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

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 Managing your approval - Health Research Authority (hra.nhs.uk)

Ethical review of research sites

NHS/HSC sites

The favourable opinion applies to all NHS/HSC sites taking part in the study, subject to confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or 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.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [UoG - Clinical Trials - 2024-2025 Client Information Letter (003)]	v.1.0	28 June 2024
Interview schedules or topic guides for participants [Interview Topic Guide V.1.1. 14.07.25 Clean]	v.1.1.	14 July 2025
Interview schedules or topic guides for participants [Interview Topic Guide V.1.1. 14.07.25 TRACKED]	V.1.1.	14 July 2025
IRAS Application Form [IRAS_Form_14052025]		14 May 2025
Letter from funder [Proceed to Ethics Siofra Burns 09.12.24]	v.1.0	12 May 2025
Letter from sponsor [Proceed to Ethics Siofra Burns 09.12.24]	v.1.0	12 May 2025
Other [Privacy Notice V.1.0 12.05.25]	v.1.0	12 May 2025
Other [Ethics Response Letter]	V1.0.	27 June 2025

Other [Privacy Notice V1.1. 14.07.25 Clean]	V.1.1.	14 July 2025
Other [Privacy Notice V1.1. 14.07.25 TRACKED]	v.1.1.	14 July 2025
Other [MRP Research Proposal V.1.1 27.06.25]	v.1.1.	27 June 2025
Other [MRP Research Proposal 27.06.25 TRACKED]	1.1	27 June 2025
Participant consent form [Participant Consent Form V.1.1. 16.06.2025 Clean]	V.1.1.	16 June 2025
Participant consent form [Consent Form V.1.1. 16.06.25 TRACKED]	v.1.1.	16 June 2025
Participant information sheet (PIS) [Participant Information sheet V.1. 11. 27.06.25 Clean]	v.1.1.	27 June 2025
Participant information sheet (PIS) [Participant information sheet v.1.1. 27.06.25 TRACKED]	V.1.1.	27 June 2025
Summary CV for Chief Investigator (CI) [JonEvansCV 2 Page Signed 13.01.25]	v.1.0	13 January 2025
Summary CV for student [SB CV]		22 July 2025
Summary CV for supervisor (student research) [JonEvansCV 2 Page Signed 13.01.25]	v.1.0	13 January 2025
Summary of any applicable exclusions to sponsor insurance (non-NHS sponsors only) [UoG - Clinical Trials - 2024-2025 Client Information Letter (003)]	v.1.0	28 June 2024

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.

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: Quality assurance - Health Research Authority (hra.nhs.uk)

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: Learning - Health Research Authority (hra.nhs.uk)

IRAS project ID: 352783	**Please quote this number on all correspondence**

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

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

Yours sincerely

PP: Anne Gell – Approvals Specialist

Dr Julie Latchem-Hastings
Chair

Email:Wales.REC4@wales.nhs.uk

Enclosures: "After ethical review – guidance for researchers" *[SL-AR2]*

After ethical review guidance for sponsors and investigators – Non CTIMP Standard Conditions of Approval]

Copy to: Dr Alastair Wilson

PP gram.nrspcc@nhs.scot

Appendix 2.4: Amendments

Figure 1: First Amendment

Thursday, July 16, 2026 at 16:00:42 British Summer Time

Subject: IRAS 352783. Amendment
Date: Monday, 20 October 2025 at 12:29:05 British Summer Time
From: no-reply-IRAS
To: Siofra Burns (PGR)

IRAS Project ID: 352783
Sponsor amendment reference: NSA01

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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Figure 2: 2nd Amendment Approval

Thursday, July 16, 2026 at 16:00:11 British Summer Time

Subject: IRAS 352783. Amendment
Date: Monday, 24 November 2025 at 09:20:09 Greenwich Mean Time
From: no-reply-IRAS
To: Siofra Burns (PGR)

IRAS Project ID: 352783
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, but you should share the amendment by email directly with those Research team/s.

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

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Appendix 2.5: Management Approval Letters

Figure 3: NHS Greater Glasgow and Clyde

Coordinator/administrator: Rozanne Suarez
Telephone Number: NA
E-Mail: Rozanne.Suarez2@nhs.scot
Website: https://www.nhsggc.org.uk/about-us/professional-support-sites/research-innovation

Research & Innovation
Gartnavel Royal Hospital
Admin Building, Level 2
1055 Great Western Road
Glasgow, G12 0XH
Scotland, UK

11/08/2025

Ms Siofra Burns
Trainee Clinical Psychologist
NHSGGC
Gartnavel General Hospital
Glasgow
G12 0XH

NHS GG&C Board Approval

Dear Ms Burns

Study Title:	Patient Experiences of Cognitive Prehabilitation on the Epilepsy Surgery Pathway
Principal Investigator:	Ms Siofra Burns
GG&C HB site	Institute of Neurological Sciences, QEUH
Sponsor	University of Glasgow
R&I reference:	UGN25NE230
REC reference:	25/WA/0171
Protocol no: (including version and date)	V1.1 – 27.06.2025

I am pleased to confirm that Greater Glasgow & Clyde Health Board is now able to grant **Approval** for the above study.

Conditions of Approval

1. **For Clinical Trials** as defined by the Medicines for Human Use Clinical Trial Regulations, 2004
   a. During the life span of the study GGHB requires the following information relating to this site
      i. Notification of any potential serious breaches.
      ii. Notification of any regulatory inspections.

It is your responsibility to ensure that all staff involved in the study at this site have the appropriate GCP training according to the GGHB GCP policy (www.nhsggc.org.uk/content/default.asp?page=s1411), evidence of such training to be filed in the site file. Researchers must follow NHS GG&C local policies, including incident reporting.

2. **For all studies** the following information is required during their lifespan.
   a. First study participant should be recruited within 30 days of approval date.
   b. Recruitment Numbers on a monthly basis
   c. Any change to local research team staff should be notified to R&I team

d. Any amendments – Substantial or Non Substantial
e. Notification of Trial/study end including final recruitment figures
f. Final Report & Copies of Publications/Abstracts
g. You must work in accordance with the current NHS GG&C COVID19 guidelines and principles.

Please add this approval to your study file as this letter may be subject to audit and monitoring.

Your personal information will be held on a secure national web-based NHS database.

I wish you every success with this research study

Yours sincerely,

Rozanne Suarez
Senior Research Administrator

CC: **Professor Jonathan Evans, University of Glasgow**
Dr Steven Meldrum, NHSGGC
Alastair Wilson, University of Glasgow

Figure 4: Email Management Approval from National Hospital for Neurology and Neurosurgery UCLH

---------- Forwarded message ---------
From: **RANDD (UNIVERSITY COLLEGE LONDON HOSPITALS NHS FOUNDATION TRUST)** <uclh.randd@nhs.net>
Date: Tue, 18 Nov 2025 at 12:08
Subject: RE: R&D Ref 183578– IRAS 352783. Confirmation of Capacity and Capability at University College London Hospitals NHS Foundation Trust
To: Baxendale, Sallie <s.baxendale@ucl.ac.uk>, @student.gla.ac.uk @student.gla.ac.uk>, PAPATHANASIOU, Anastasia (UNIVERSITY COLLEGE LONDON HOSPITALS NHS FOUNDATION TRUST) <anastasia.papathanasiou3@nhs.net>, JOSHI, Pushpsen (UNIVERSITY COLLEGE LONDON HOSPITALS NHS FOUNDATION TRUST) <pushpsen.joshi1@nhs.net>

⚠ Caution: External sender

Dear Sponsor Representative,

RE: R&D Ref 183578– IRAS 352783. Confirmation of Capacity and Capability at University College London Hospitals NHS Foundation Trust

Full Study Title: Patient Experiences of Cognitive Prehabilitation on the Epilepsy Surgery Pathway

Project R&D Ref: 183578

IRAS ID: 352783

REC Ref: 25/WA/0171

UCLH Principal Investigator: Dr Sallie Baxendale

This email confirms that University College London Hospitals NHS Foundation Trust has the capacity and capability to deliver the above referenced study. Please find attached our signed agreement as confirmation.

We agree to start this study on **18.11.2025**, as previously discussed.

You have 30 days from this email or from the date of Sponsor Greenlight Site Activation email (whichever is latest) to recruit your first patient at UCLH. Please forward any sponsor greenlight emails to UCLH.RandD@nhs.net

This study is now registered on Epic; active and you are now able to associate research patients to this study. All staff listed in the delegation log must have completed their Epic Research Add-on training prior to using UCLH EHRS. Any queries about the use of Epic should be directed to your department's Epic floor walker or research super user in the first instance.

As from 1st April 2019, participants no longer need to be added to Edge by the study teams. However, NIHR portfolio adopted studies still require recruitment updates to the NIHR's Central Portfolio Management System (CPMS).

UCLH Study teams are still required to populate EDGE (www.edge.nhs.uk) with the following information for each study that falls within their remit:

- Planned recruitment start date at UCLH
- SIV dates
- Status updates at UCLH
- Open to Recruitment dates
- Planned Recruitment end date
- Actual recruitment end date at UCLH
- Planned UCLH closing date
- Actual study closure date at UCLH

I attach a user guide which provides information around how to complete the above. If anything is unclear, a member of the JRO Research Data and Information team will be happy to help. Please make contact via UCLH.RandD@nhs.net

Kind regards,

Tolu Adebanjo

Portfolio and Database Administrator, UCLH

UCLH/UCL Joint Research Office , part of the Research Directorate

Telephone: 020 3447 9928

Joint Research office

4th Floor, West

250 Euston Road

London

NW1 2PG.
Web: www.ucl.ac.uk/jro

We are committed to delivering top-quality patient care, excellent education and world class research

safety **kindness** **teamwork**



****
** **********

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ii) do not disclose, copy or distribute information in this e-mail or take any action in relation to its content (to do so is strictly prohibited and may be unlawful).
Thank you for your co-operation.

NHS.net Connect is the secure email, collaboration and directory service available for all NHS staff in England. NHS.net Connect is approved for exchanging patient data and other sensitive information with NHS.net Connect and other accredited email services.

For more information and to find out how you can switch visit Joining NHS.net Connect - NHS.net Connect Support

Figure 5: NHS Grampian Management Approval Letter

Research & Development

Foresterhill House Annexe
Foresterhill
Aberdeen
AB25 2ZB

NHS Grampian

Síofra Burns
Commonwealth House,
32 Albion Street,
Glasgow,
G1 1LH

Date	12/01/2026
Enquiries to	Email box as below
Extension	59452
Direct Line	01224 552690
Email	gram.researchpassports@nhs.scot

Dear Síofra,

Letter of access for research

As an existing NHS employee you do not require an additional honorary research contract with this NHS organisation. We are satisfied that the research activities that you will undertake in this NHS organisation are commensurate with the activities you undertake for your employer. Your employer is responsible for ensuring such checks as are necessary have been carried out. This letter confirms your right of access to conduct research through NHS Grampian for the purpose and on the terms and conditions set out below. This right of access commences on *12/01/2026 and ends on 30/09/2026 unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this NHS organisation. ***Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving permission to conduct the project.**

You are considered to be a legal visitor to NHS Grampian premises. You are not entitled to any form of payment or access to other benefits provided by this organisation to employees and this letter does not give rise to any other relationship between you and this NHS organisation, in particular that of an employee.

While undertaking research through NHS Grampian, you will remain accountable to your employer NHS Greater Glasgow and Clyde but you are required to follow the reasonable instructions of your nominated manager Dr Fiona Summers in this NHS organisation or those given on her behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by this NHS organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

You must act in accordance with NHS Grampian policies and procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate with NHS Grampian in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on NHS Grampian premises. Although you are not a contract holder, you must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of a contract holder and you must act appropriately, responsibly and professionally at all times.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf) and the current Data Protection legislation. Furthermore you should be aware that under the legislation, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

NHS Grampian will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the current Data Protection legislation. Any breach of the current Data Protection legislation may result in legal action against you and/or your substantive employer.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you are able to prove your identity if challenged. Please note that this NHS organisation accepts no responsibility for damage to or loss of personal property.

We may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS organisation or if you are convicted of any criminal offence. Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

If your circumstances change in relation to your health, criminal record, professional registration or any other aspect that may impact on your suitability to conduct research, or your role in research changes, you must inform the NHS organisation that employs you through its normal procedures. You must also inform your nominated manager in this NHS organisation.

Yours sincerely

Jane Lloyd
Assistant HR Manager, NHS Grampian

cc: R&D office at NHS Grampian

HR department of the substantive employer (and provider of honorary clinical contract, where applicable)

Figure 6: NHS Lanarkshire Management Approval Letter

Professor Jonathan Evans
Professor of Clinical Neuropsychology
University of Glasgow
Clarice Pears Building
90 Byres Rd,
Glasgow
G12 8TB

R&D Department
David Matthews Building
University Hospital Monklands
Monkscourt Avenue
AIRDRIE
ML6 0JS

Date: 16th January 2026
Enquiries to: Claire McKenzie, Senior R&D Facilitator
Email: claire.Mckenzie@lanarkshire.scot.nhs.uk

Dear Professor Evans,

Project title:	Patient Experiences of Cognitive Prehabilitation on the Epilepsy Surgery Pathway
Short title:	Patient Experiences of Cog Prehab on the Epilepsy Surgery pathway
NRS Reference:	NRS25/352783
REC No.:	25/WA/0171
NHS Lanarkshire R&D ID:	L25119

I am writing to you as Chief Investigator of the above study to advise that R&D Management approval has been granted for the conduct of your study within NHS Lanarkshire as detailed below:

NAME	TITLE	ROLE	NHSL SITE TO WHICH APPROVAL APPLIES
Dr Andrew Wood	Consultant Clinical Neuropsychologist	Principal Investigator	University Hospital Monklands

For the study to be carried out you are subject to the following conditions:

- You are required to comply with Good Clinical Practice, Ethics Guidelines, Health & Safety Act 1999 and relevant UK-GDPR and Data Protection 2018 legislation.
- The research is carried out in accordance with the Scottish Executive's Research Governance Framework for Health and Community Care (copy available via the Chief Scientist Office website: http://www.cso.scot.nhs.uk/ or the Research & Development Intranet site: http://firstport2/staff-support/research-and-development/default.aspx
- You must ensure that all confidential information is maintained in secure storage. You are further obligated under this agreement to report to the NHS Lanarkshire Data Protection Office and the Research & Development Office infringements, either by accident or otherwise, which constitutes a breach of confidentiality.

- Clinical trial agreements (if applicable), or any other agreements in relation to the study, have been signed off by all relevant signatories.
- You must contact the Lead Nation Coordinating Centre if/when the project is subject to any minor or substantial amendments so that these can be appropriately assessed, and approved, where necessary.
- You notify the R&D Department if any additional researchers become involved in the project within NHS Lanarkshire
- You notify the R&D Department when you have completed your research, or if you decide to terminate it prematurely.
- You must send brief annual reports followed by a final report and summary to the R&D office in hard copy and electronic formats as well as any publications.
- If the research involves any investigators who are not employed by NHS Lanarkshire, but who will be dealing with NHS Lanarkshire patients, there may be a requirement for an SCRO check and occupational health assessment. If this is the case, please contact the R&D Department to make arrangements for this to be undertaken and an honorary contract issued.

I trust these conditions are acceptable to you.

Yours sincerely,

Claire McKenzie – Senior R&D Facilitator

cc.

NAME	TITLE	CONTACT ADDRESS	ROLE
Dr Andrew Wood	Consultant Clinical Neuropsychologist	Andrew.Wood@lanarkshire.scot.nhs.uk	Principal Investigator
Siofra Burns	University of Glasgow PhD Student	@student.gla.ac.uk	Researcher
Dr Alastair Wilson	Research Regulation and Compliance Team	alastair.wilson@glasgow.ac.uk	Sponsor Contact

Appendix 2.6: Participant Information Sheet

Available at: (https://osf.io/cr5nk)

Appendix 2.7: Privacy Notice

Available at: (https://osf.io/cr5nk)

Appendix 2.8: Consent Form Template

Available at: (https://osf.io/cr5nk)

Appendix 2.9: Topic Guide

Available at: (https://osf.io/cr5nk)

Appendix 2.10: Detailed Data-Analysis Plan

Available at**:** (https://osf.io/cr5nk)

Appendix 2.11: Record of Data Analysis Process

Available at**:** (https://osf.io/cr5nk)

Appendix 2.12: Data Availability Statement

This study's data is not publicly available. Reasonable requests are subject to review and approval from the research team.

Appendix 2.13: Researcher Reflexivity Statement

Reflexive thematic analysis allowed the researcher to employ a reflexive, inductive, and interpretative approach to the study. Using an inductive method involved coding and identifying themes directly from the data, rather than being constrained by a pre-existing descriptive or theoretical framework that reflects the researcher's personal beliefs and worldview; this was also important given the relatively novel area of research being explored. As a trainee clinical psychologist, the researcher had previously worked in neuropsychological services. This experience provided familiarity with the organisational context and facilitated understanding of the language, processes, and challenges described by participants. However, the researcher recognised that this familiarity also brought assumptions regarding how services operate and how individuals may experience them. During analysis, I remained mindful of the possibility that I might privilege interpretations consistent with my professional experiences or overlook accounts that challenged these assumptions. I also wished to reduce the impact of my being on placement at a recruitment site on participant recruitment and on participants' comfort sharing their experiences with me. It was agreed with my placement supervisor that I would not take part in the epilepsy prehabilitation programme, which was ongoing, to reduce the participants' feeling of obligation to agree to participate in the research. I also kept a reflexive journal and engaged in reflexive conversations, especially during supervision, to identify emerging themes, which helped me navigate this journey.

Appendix 2.14: Participant Recruitment Procedure

Available at**:** (https://osf.io/cr5nk)

Appendix 2.15: Final Thematic Map

Figure 4.1: Thematic Map from MindMup



Appendix 2.15: A 15-point checklist of Criteria for Good Thematic Analysis Process (Braun and Clarke 2006)

Table 4.2: A 15-point checklist of Criteria for Good Thematic Analysis Process (Braun and Clarke 2006)

Process	No.	Criteria	Response
Transcription	1	The data have been transcribed to an appropriate level of detail, and the transcripts have been checked against the tapes for 'accuracy	Yes, all 7 transcripts transcribed to an appropriate level of detail and checked against Teams/Dictaphone recording
Coding	2	Each data item has been given equal attention in the coding process	All quotations were reviewed to generate coding.
	3	Themes have not been generated from a few vivid examples (an anecdotal approach), but instead the coding process has been	Yes. Themes were developed from a complete coding process of the entire dataset using NVivo. The coding process was thorough, inclusive and comprehensive and discussed detailed data analysis record. Each theme was developed based on multiple codes that were gathered across all participants transcripts and further developed and refined using NVivo and MindMup.
	4	All relevant extracts for all each theme have been collated	Yes
	5	Themes have been checked against each other and back to the original data set	Yes

	6	Themes are internally coherent, consistent, and distinctive	Yes
Analysis	7	Data have been analysed-interpreted, made sense of- rather than just paraphrased or described	Yes (See Results Section)
	8	Analysis and data match each other- the extracts illustrate the analytic claims	Yes (See Results Section)
	9	Analysis tells a convincing and well organised story about the data and topic	Yes
	10	A good balance between analytical narrative and illustrative extracts is provided	Yes (Results section includes synthesis and quotations)
Overall	11	Enough time has been allocated to complete all phases of the analysis adequately, without rushing a phase or giving it a once-over-lightly	Yes, discussed in detailed data analysis record
Written Report	12	The assumptions about, and specific approach to, thematic analysis are clearly explicated	Yes, discussed in methods and researcher reflexivity statement.
	13	There is good fit between what you claim you do, and what you show you have done- i.e. described method and reported analysis are consistent	Yes

	14	The language and concepts used in the report are consistent with the epistemological position of the analysis	Yes
	15	The researcher is positioned as active in the research process; themes do not just 'emerge'	Yes