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Improving understanding of client experiences of neuropsychological assessment

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Chapter 1: Systematic Review

A systematic review of clients' experiences of tele-neuropsychological assessment

Prepared in accordance with the author requirements for Archives of Clinical Neuropsychology

https://academic.oup.com/acn/pages/General_Instructions

Abstract

Objective: Tele-neuropsychological assessment (T-NPA) has been used for decades in clinical practice, although less commonly than face-to-face (FTF) assessment. Since the COVID-19 pandemic, the use of, and interest in, T-NPA has grown. Less is known about client experience of T-NPA. This review collates and critically analyses studies examining views of T-NPA.

Method: A systematic search, with no date restrictions, was completed in September 2022 in the following databases: CINAHL, EMBASE, Medline, Psychology and Behavioral Science Collection, PsycINFO and Web of Science Core Collection. Included articles underwent a quality appraisal using the Crowe Critical Appraisal Tool. Results were summarised using a narrative synthesis.

Results: Nineteen studies were eligible. The quality of studies varied with methodological limitations related to sampling and questionnaire reporting noted. Satisfaction with T-NPA was high and most participants would recommend and use it again. However, no participants stated T-NPA as their top preference for future input when compared with FTF, with either no preference or FTF more highly rated. Most participants expressed comfort with T-NPA, experienced no technical issues or privacy concerns, and could use the equipment required. The relationship and communication with the clinician were acceptable and the accessibility of T-NPA was valued. The most common barrier was technology issues.

Conclusions: Overall, T-NPA appears to be an acceptable method but the heterogenous populations included and closed-ended question designs used to collect experience data, may have obscured specific needs and barriers. Qualitative studies would allow greater insight into client experiences.

Keywords: Telemedicine; Remote Consultation; Neuropsychology; Patient Satisfaction

Introduction

Prior to the COVID-19 pandemic, the use of tele-neuropsychological assessment (T-NPA) was infrequently used in standard neuropsychological practice and was largely limited to serving rural populations. An evidence base for T-NPA was developing (Brearly et al., 2017) alongside recommendations for safe and effective practice (Grosch et al., 2011) due to its benefits which included increasing access to services for those unable to attend a clinic due to geographical, mobility or transport difficulties.

There have been rapid advances in telehealth since the pandemic when services had to adapt to remote methods to allow continuing care. Post-pandemic services are now redefining usual practice, with T-NPA now a permanent element of standard practice. T-NPA can include telephone or videoconferencing conducted either at the person's home or a satellite clinic and may have an assistant to support (Scott et al., 2022).

Since the pandemic, there is a growing evidence base for T-NPA indicating it is a valid and reliable approach when compared with face-to-face (FTF) methods (Marra et al., 2020; Watt et al., 2021). Potential threats to the effectiveness of T-NPA include internet connection problems, low familiarity with technology, display screen size, audio and visual quality or differences in test administration by examiners (Cernich et al., 2007). It is also acknowledged that remote methods preclude the opportunity for behavioural assessments which contribute towards interpretation of neuropsychological assessments.

Telehealth usage likely varied between countries but data addressing rates of use are sparse. Recent studies have explored changes in patterns of use and clinician views. Chapman et al. (2020) surveyed neuropsychologists and clinicians who expressed low confidence with, and had never conducted T- NPA. A willingness to attempt T-NPA for gathering a clinical history and providing feedback was reported, but in-person testing was preferred. Clinicians' confidence in T-NPA has increased but concerns remain about implementation including equity of access due to socioeconomic status, location or sensory impairments (Hewitt et al., 2022). An international survey

(Hammers et al., 2020) identified that pre-COVID-19, 25% of clinicians had used T-NPA for clinical interviews, providing feedback and delivering interventions but only 10% had used it for neuropsychological testing. A 9.74% increase in telephone and 17.74% increase in videoconferencing use post-pandemic was found in a study where pre-pandemic only 1% of clinicians had used telehealth (Webb et al., 2021).

Reported barriers to engagement with T-NPA include: lack of access to technology, audio and visual quality, frustration and fatigue due to unfamiliarity with technology, and greater challenge for people with sensory impairments (Watt et al., 2021). However, benefits include reduced costs and saved travel time. Some additional concerns expressed are the impact of digital exclusion, as well as possible difficulties establishing a therapeutic relationship. However, with fears of contracting infection, particularly for individuals shielding during the pandemic for health concerns, T-NPA may help clients feel safe to engage with services.

With the developing literature strengthening the evidence of the efficacy of T-NPA and contributing to the development of practice guidelines (Bilder et al., 2020) it is important to understand clients' views of this format. Satisfaction questionnaires are one method of engaging with clients who are actively using services to understand quality of care and determine areas for improvement for efficient and effective healthcare. Client satisfaction with telemedicine has been identified in a range of specialities since COVID-19 (Orrange et al., 2021; Pogorzelska & Chlabicz, 2022). The number of missed telehealth appointments during COVID-19 was lower than missed FTF appointments, both pre- and post-pandemic, in a primary care setting (Drerup et al., 2021) and attendance rates were 24% higher across a diverse population (Caze et al., 2020), but reasons for better engagement have not been explored.

Given the rapid expansion of T-NPA, and use of remote appointments in healthcare, this review aimed to describe and critically evaluate the literature for client experience of T-NPA. It was anticipated that literature focussed on client experience of T-NPA would be sparse across population groups. As there are no other reviews in this area to the researcher's knowledge, this review aimed to be inclusive of all adult populations receiving neuropsychological assessment remotely to attempt to provide a comprehensive understanding of this area.

Review questions

1. How is client experience data measured?
2. What do clients who undergo T-NPA report about their experience?
3. What aspects of T-NPA are valued by clients?
4. What barriers to T-NPA are identified by clients?

Methods

This systematic review was conducted in accordance with the PRISMA guidance (Page et al., 2021) and registered on Prospero (CRD42022351622).

Search Strategy

A systematic search with no date restrictions was conducted, on 26/09/2022, using the following databases: CINAHL (EBSCOhost), EMBASE (OVID), Medline (OVID), Psychology and Behavioral Science Collection (EBSCOhost), PsycINFO (EBSCOhost) and Web of Science Core Collection. Forward and backwards citation searching of included articles was completed and reference lists were searched. The search strategy was developed with guidance from a specialist librarian and full search strategies are available in Appendix 1.1.

Eligibility criteria

Inclusion criteria

- Adults aged 18 or over who had completed a neuropsychological assessment
- The neuropsychological assessment was completed in real-time using telephone or video to connect with a clinician (including hybrid studies where FTF may have formed part of the assessment)
- Qualitative or quantitative reports of participant experience
- Published in a peer-reviewed journal
- Written in English

Exclusion criteria

- Mixed age samples with participants aged 17 or under
- Computerised neuropsychological assessment with no clinician administering the testing
- Assessment was a cognitive screening tool only

Data Extraction and synthesis

A narrative synthesis was used to analyse and present the data and was considered the most appropriate due to the heterogenous nature of the included studies. This method adhered to guidance by Popay et al. (2006):

1. Developing a preliminary synthesis of the data
2. Exploring relationships within and between studies
3. Assessing the robustness of the synthesis

The Joanna Briggs Institute guidance for mixed method systematic reviews was considered when making decisions about the chosen narrative synthesis (Stern et al., 2020). For the stated research questions, a convergent integrated approach, whereby qualitative and quantitative data are extracted simulataneously and data is combined and transformed, is recommended. The approach involves "qualitizing" data; turning quantitative data in to textual description that can be integrated with qualitative results to form categories that represent similarity in meaning. At present there is no consensus in the literature regarding how best to "qualitize" data. Popay et al. (2006) guidance was implemented to support the process of integrating quantitative and qualitative data, through using idea webbing to explore relationships between studies and group data into categories based on similarity in meaning, which were then summarised in textual descriptions.

1: Preliminary synthesis

Data extraction was conducted manually with a tool designed by the researcher to provide a narrative summary of clients' experiences of T-NPA. It comprised the information presented in Table 1 and Table 3.

2: Exploring relationships between studies

Extracted study characteristics were then utilised to understand relationships between the studies in line with the review questions which included what people report about their experiences of using T-NPA and any areas valued or barriers identified.

Quality appraisal

The quality of the included studies was assessed using the Crowe Critical Appraisal Tool (CCAT; Crowe & Sheppard, 2011). The CCAT was chosen as it allows analysis across multiple research designs and it was anticipated that the included studies would be heterogenous. The measure has good inter-rater reliability (Crowe et al., 2012). Eight areas are evaluated and scored out of 5, with a total score out of 40. The areas include: preliminaries, introduction, design, sampling, data collection, ethical matters, results and discussion (Appendix 1.2). This measure does not specify cut-off scores for methodological quality. For the purposes of this study a rating above 75% was considered high quality, 50% to 74% was rated medium quality and less than 50% was considered low quality. It should be noted that the cut-offs provided may obscure important elements of study quality contained in the different sections so it is advised that the individual scores on the CCAT are considered when interpreting quality.

3: Assessing the robustness of the synthesis

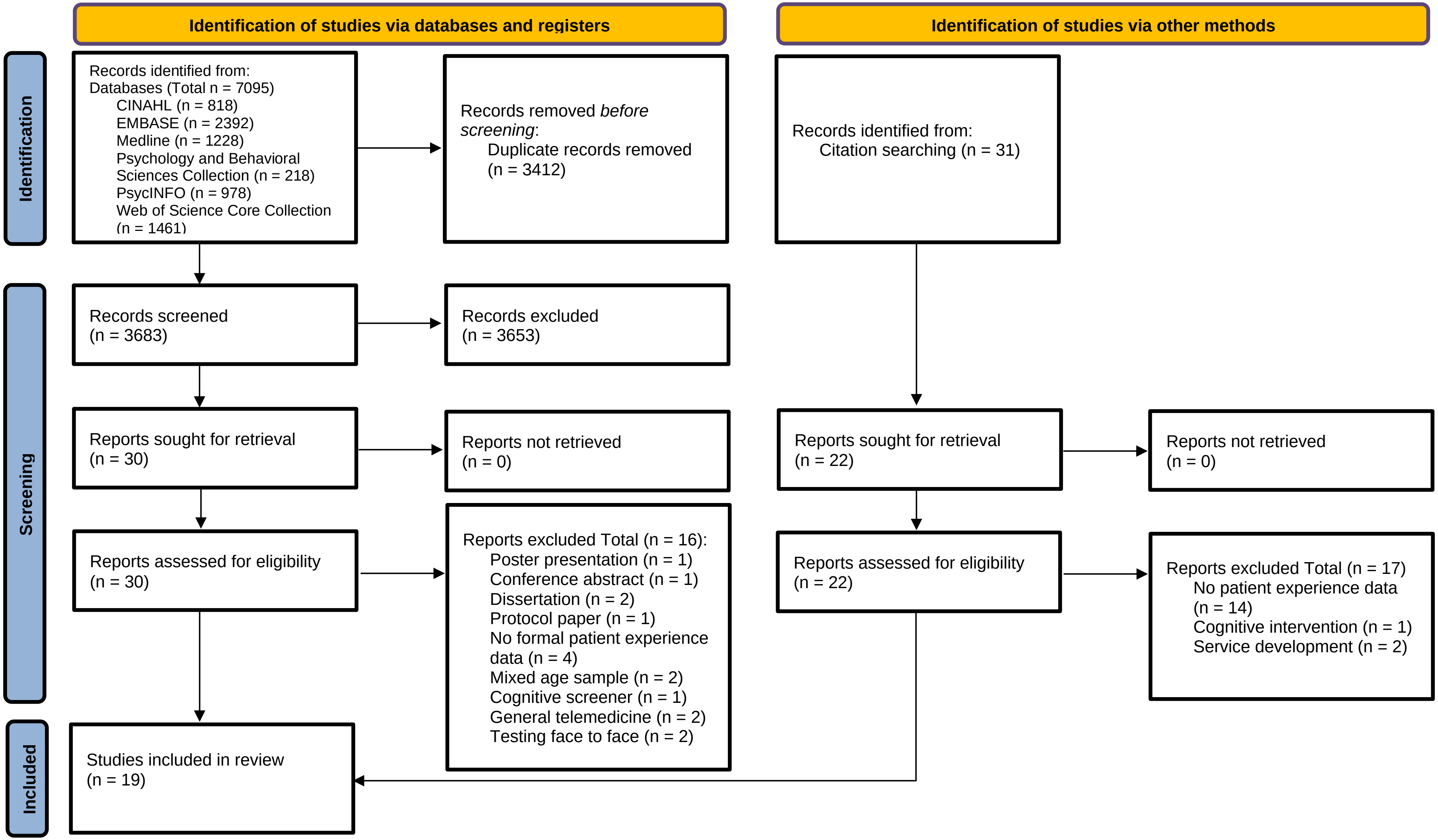
The methodological quality of included studies and the synthesis of this research are addressed in relation to the ability to draw conclusions from the data. A random sample of included studies were rated by a second researcher (N=5, 26%). Agreement between raters was 85%. There was no more than a maximum 3-point difference in total scores, and no more than 1-point difference in category scores. Disagreements were discussed until consensus was reached.

Results

Data Screening and selection

A total of 7095 studies were identified through database searching with duplicates removed (N= 3412). Titles and abstracts were screened for relevance for the remaining 3683 papers resulting in 30 papers being read in full and compared against the inclusion criteria. A second reviewer screened 30% against the inclusion criteria. The reference lists and forwards and backwards citation searching were then completed for the 14 included studies identifying a further 22 studies that were read in full. Five additional studies met the inclusion criteria, resulting in 19 studies included in the analysis. Figure 1 details this process.

Figure 1 PRISMA Flow Diagram



1. Preliminary synthesis

Study characteristics

Table 1 summarises the 19 included studies, published between 2000 and 2022. Nine were published prior to the pandemic and nine after. One study started prior to COVID-19 and recruited during the pandemic. The total combined sample across all papers was 1174 participants. At least 701 (59.71%) of these participants provided information of their experience of T-NPA. Two studies did not report completion rates of their participant experience questions (Jacobsen et al., 2003; Gnassounou et al., 2022). They had a combined sample size of 182 participants meaning if all participants responded, the maximum response rate would be 75.21%. The age range of participants was 18 to 90 years. On average 52.01% of the participants included were female. Ethnicity was poorly reported. The 6 studies that did report ethnicity included Hispanic, White, Black, Asian, African American, and other.

The populations and locations of the studies were heterogenous. Populations included: veterans reporting cognitive complaints (Appleman et al., 2021), memory clinic attenders (Gnassounou et al., 2022; Zeghari et al., 2022), community stroke survivors (Chapman et al., 2021), neuro-oncology patients (Gardner et al., 2021), community ICU survivors (Han et al., 2020), multiple sclerosis patients (Settle et al., 2015), individuals with substance misuse difficulties (Kirkwood et al., 2000), research participants with HIV (Gonzalez et al., 2022), neuropsychology service patients (Lacritz et al., 2020; Sarno et al., 2022; Sumpter et al., 2022), healthy adults and older adults (Ceslis et al., 2022; Hilderbrand et al., 2004; Jacobsen et al., 2003; Mahon et al., 2022; Stead & Vinson 2019; Zeghari et al., 2021) and healthy and cognitively impaired community older adults (Parikh et al., 2013).

Studies were conducted in seven countries: USA (N=9), France (N=3), Australia (N=2), Scotland (N=2), Canada (N=1), New Zealand (N=1) and Norway (N=1). Seven studies recruited from routine clinical practice (Appleman et al., 2021; Gardner et al., 2021; Gnassounou et al., 2022; Kirkwood et al., 2000; Lacritz et al., 2020; Sarno et al., 2022; Sumpter et al., 2022), three from a clinic setting but NPA was not part of routine care (Settle et al., 2015; Zeghari et al., 2021; Zeghari et al 2022), seven from university or research centres (Ceslis et al., 2022; Chapman et al., 2021; Gonzalez et al., 2022; Han et al., 2020 ; Mahon et al., 2022 ; Parikh et al., 2013; Stead & Vinson, 2019), one recruited hospital staff (Jacobsen et al., 2003) and the final setting was unknown (Hilderbrand et al., 2004).

Videoconferencing was the most utilised T-NPA method in 16 studies (Appleman et al., 2021; Ceslis et al., 2022; Chapman et al., 2021; Gardner et al., 2021; Gnassounou et al., 2022; Han et al., 2020 ; Hilderbrand et al., 2004; Jacobsen et al., 2003; Kirkwood et al., 2000; Mahon et al., 2022; Parikh et al., 2013; Sarno et al., 2022; Settle et al., 2015; Stead & Vinson, 2019; Zeghari et al., 2021; Zeghari et al., 2022). The location of videoconferencing varied between satellite clinics (N=11), participant's homes (N=3), mobile unit outside participants' homes (N=1) and a mix of at home and on site (N=1). An assistant was present during T-NPA to aid testing in four studies. Two studies used telephone only (Gonzalez et al., 2022; Lacritz et al., 2020) and one study utilised both telephone and videoconferencing with T-NPA conducted from the participants' homes (Sumpter et al., 2022). The studies incorporated a range of 60 individual cognitive screeners, neuropsychological tests, and test batteries.

Thirteen of the studies used quantitative methods to collect their client experience data (Appleman et al., 2021; Ceslis et al., 2022; Chapman et al., 2021; Gnassounou et al., 2022; Hilderbrand et al., 2004; Kirkwood et al., 2000; Lacritz et al., 2020; Mahon et al., 2022; Parikh et al., 2013; Sarno et al., 2022; Settle et al., 2015; Zeghari et al., 2021; Zeghari et al., 2022), five used mixed methods (Gardner et al., 2021; Gonzalez et al., 2022; Han et al., 2020; Stead & Vinson, 2019; Sumpter et al., 2022) and one used a qualitative approach (Jacobsen et al., 2003).

Table 1. Study characteristics

					Sample characteristics			
Citation	**Study location and setting**	**Pre or post COVID-19**	**Research design and T-NPA method**	**Neuropsychological assessment tools**	**Population** **Sample Size (N)**	**Age mean or median (range)** **Gender % female**	**Ethnicity/ Race** **Accessibility issues***	**Clinical diagnoses (N)**
Appleman et al. (2021)	USA Hospital and outpatient clinic	Started pre-COVID and continued during	Acceptability and feasibility study Videoconferencing Comparison of satisfaction for T-NPA versus FTF Attended satellite clinic - clinician assistant present	• Wide Range Achievement Test-Third Edition (WRAT3) - Reading Subtest • California Verbal Learning Test - Second Edition (CVLT-II) •Wechsler Memory Scale-Fourth Edition (WMS-IV) Logical Memory Subtest •Geriatric Evaluation of Mental Status Figure •Rey Osterrieth Complex Figure Test (ROCF) •Boston Naming Test (BNT) •Wechsler Adult Intelligence Scale-Fourth Edition (WAIS-IV)- Digit Span Forward (DSF) and Digit Span Backward (DSB) and Similarities subtests •Trail Making Test A and B •Controlled Oral Word Association (COWAT) – FAS letters and Animals. •Clock Drawing Test	Veterans with cognitive concerns T-NPA=67 FTF=64	T-NPA M=70 (54-90) FTF M=71.5 (50-88) T-NPA 9% FTF 5%	N/R N/R	• Mild Neurocognitive Disorder (T-NPA=23, F2F=23) • Major Cognitive Disorder (T-NPA=16, F2F=5) • Psychiatric Condition (T-NPA=13, F2F=15) • Serious Mental Illness (T-NPA=2, F2F=6) • Developmental Disorder (T-NPA=4, F2F=2) • Substance Use Disorder (T-NPA=0, F2F=3) • Traumatic Brain Injury (T-NPA=0, F2F=1) • HIV (T-NPA=1, F2F=0) • No Diagnosis (T-NPA=8, F2F=9)

					Sample characteristics			
Citation	**Study location and setting**	**Pre or post COVID-19**	**Research design and T-NPA method**	**Neuropsychological assessment tools**	**Population**	**Age mean or median (range)**	**Ethnicity/ Race**	**Clinical diagnoses (N)**
					Sample Size (N)	**Gender % female**	**Accessibility issues***	
Ceslis et al. (2022)	Australia University Neuropsychology Research Clinic	Post-COVID	Non-randomised pre-post Videoconferencing Comparison of NPA scores within and between groups Assessments 2 years apart Attended satellite clinic	•Weschler Abbreviated Scale of Intelligence (WASI) - Matrix reasoning (MR) subtest. •Rey Auditory Verbal Memory Test (RAVLT) • Topographical Recognition Memory Test (From Camden Memory Tests) •Graded Naming Test (GNT) • WAIS-IV – DSF and DSB • Hayling Sentence Completion Test (HSCT)	Healthy adults and older adults T-NPA=33 FTF=19	T-NPA M=62.8 (50-73) FTF M=62.5 (53-69) T-NPA 75.56% FTF 89.47%	Paper states “predominantly Caucasian and English Speaking” but no specific details reported N/R	Any clinical diagnosis was an exclusion criteria
Chapman et al. (2021)	Australia University research clinic	Pre-COVID	Non-randomised pre-post Videoconferencing Within-subjects comparison of NPA scores during FTF and T-NPA completed 2 weeks apart T-NPA was either at home, or a community or university site. An assistant was present	• Test Of Premorbid Functioning (TOPF) • Symbol Digit Modalities Test (SDMT) • WAIS-IV subtests – DS, Block Design, Similarities • BNT • Semantic Fluency and Letter fluency • Hopkins Verbal Learning Test-Revised (HVLT-R) •ROCF	Stroke survivors in the community 48	M=64.6 (35-88) 45.8%	N/R If language difficulty present and considered to impact NPA test then this test was excluded. Participants	Confirmed Stroke diagnosis

					Sample characteristics			
Citation	Study location and setting	Pre or post COVID-19	Research design and T-NPA method	Neuropsychological assessment tools	Population	Age mean or median (range)	Ethnicity/ Race	Clinical diagnoses (N)
					Sample Size (N)	Gender % female	Accessibility issues*	
				•WMS-IV – Visual reproduction subtest •Stroop Test •Trail Making Test			with sensory or motor impairments were only excluded if they could not provide informed consent	
Gardner et al. (2021)	USA Neuro-oncology clinic	Post-COVID	Acceptability and feasibility Videoconferencing Quality improvement study seeking participant and clinician feedback of home-based T-NPA	• WAIS-IV • RBANS • TOPF • BNT • Auditory Naming Test • Oral Trail Making Test • SDMT • DKEFS • COWAT • HVLT-R • Brief Visuospatial Memory Test-R • Test of Memory Malingering • Greek Cross • Clock • Loops and cube	Neuro-oncology patients 79	Mdn=59 (21-81) 41%	N/R N/R	•High-grade primary brain tumour=24 •Low-grade primary brain tumour=32 •Brain metastases=10 •Non-CNS cancers=34 •CNS lymphoma=9 •Brain mass unknown aetiology=5 •Other=5

					Sample characteristics			
Citation	**Study location and setting**	**Pre or post COVID-19**	**Research design and T-NPA method**	**Neuropsychological assessment tools**	**Population**	**Age mean or median (range)**	**Ethnicity/ Race**	**Clinical diagnoses (N)**
					Sample Size (N)	**Gender % female**	**Accessibility issues***	
Gnassounou et al. (2022)	France Memory clinic	Pre-COVID	Non-randomised pre-post Videoconferencing Within and between subjects comparison of NPA. One group completed NPA FTF and 4 months later were randomised to either FTF or T-NPA Satellite clinic – assistant present	• Mini-Mental State Examination (MMSE) •DSF and DSB •Free and Cued Selective Reminding Test (FCSRT) •Mahieux gestural praxis battery •Frontal Assessment Battery (FAB) •Trail Making Tests A & B •RL/RI-16 items •ROCF •Category and letter fluency tests •80 picture naming test	Patients attending memory clinic for cognitive complaints	Mdn=71.8 (60-81.3)	N/R	N/R
					150	58.65%	N/R	
Gonzalez et al. (2022)	USA Research setting	Post-COVID	Non-randomised pre-post Telephone Within-subjects comparison of FTF versus telephone NPA. FTF NPAs were completed pre-COVID	•HVLT-R •COWAT- FAS and Category fluency animals	A research sample of individuals living with HIV	M=61.3 (N/R)	Hispanic 23%, African American 52% Non-Hispanic white 20%	Diagnosis of HIV
					59	46%	N/R	

					Sample characteristics			
Citation	**Study location and setting**	**Pre or post COVID-19**	**Research design and T-NPA method**	**Neuropsychological assessment tools**	**Population**	**Age mean or median (range)**	**Ethnicity/ Race**	**Clinical diagnoses (N)**
					Sample Size (N)	**Gender % female**	**Accessibility issues***	
Han et al. (2020)	USA Academic Hospital	Pre-COVID	Feasibility study Videoconferencing Feasibility of T-NPA Satellite clinic – clinician present for assistance	•RBANS	ICU survivors 10	Mdn=63 (51-73) 40%	Non-White 10% Visual or hearing problems, or problems understanding commands, were excluded if considered to impact ability to engage with testing	N/R
Hilderbrand et al. (2004)	Canada Setting unknown	Pre-COVID	Feasibility study Videoconferencing Within-subject comparison of FTF and T-NPA scores Location of NPA unknown	•RAVLT • COWAT •WAIS-III -Vocabulary and MR •Brief Test of Attention •Clock Drawing test	Healthy adult volunteers 68	M=68 (N/R) 72.41%	N/R N/R	Reported that participants had no prior neurological or psychiatric diagnoses

					Sample characteristics			
Citation	Study location and setting	Pre or post COVID-19	Research design and T-NPA method	Neuropsychological assessment tools	Population Sample Size (N)	Age mean or median (range) Gender % female	Ethnicity/ Race Accessibility issues*	Clinical diagnoses (N)
Jacobsen et al. (2003)	Norway Rehabilitation Hospital	Pre-COVID	Non-randomised pre-post Videoconferencing Within-subject comparison of FTF and T-NPA completed same day or 3 days later Completed on hospital site	•Grooved pegboard •Seashore Rhythm Test •WMS-R - Logical Memory subtest •Benton Visual Retention Test •Visual Object and Space Perception Battery - The Silhouette subtest •WAIS-IV – Vocabulary and Digit Span subtest •Symbol Digit Motor Test	Healthy adult volunteer 32	M=34.8 (18-57) 59.38%	N/R N/R	Reported that participants had no prior neurological or psychiatric diagnoses
Kirkwood et al. (2000)	U.K NHS Clinical Psychology Department	Pre-COVID	Non-randomised pre-post Videoconferencing Within-groups comparison of NPA scores during FTF and T-NPA completed on the same day Satellite clinic on site	•National Adult Reading Test (NART) •Quick Test Forms 1 and 3 • Adult Memory and Information Processing Battery (AMIPB) - story recall, list learning, figure recall and Information Processing subtests	Substance misuse history recruited from inpatient, outpatient and community settings 27	M=46 (N/R) 25.93%	N/R N/R	N/R

Citation	Study location and setting	Pre or post COVID-19	Research design and T-NPA method	Neuropsychological assessment tools	Sample characteristics			
					Population	Age mean or median (range)	Ethnicity/ Race	Clinical diagnoses (N)
					Sample Size (N)	Gender % female	Accessibility issues*	
Lacritz et al. (2020)	USA University Medical Centre and Hospital	Post-COVID	Quality improvement project Telephone Quality improvement project requesting feedback from participants completing NPA via telephone at home	•Barona Premorbid IQ estimate •RBANS - DS, list learning, story memory subtests • HVLT-R •WMS-IV - Logical Memory I, II and recognition subtests •WAIS-IV - digit span and Information subtests • Oral Trail Making •Verbal fluency (FAS and animals) •The Verbal Naming Test (VNT) •Montreal Cognitive Assessment Basic (MOCA) - orientation and abstraction subtests •The Escala de Inteligencia Wechsler para Adultos-III Digit Span was substituted for the WAIS-IV Digit Span for monolingual Spanish speakers	Patients referred as part of routine clinical care for NPA 43	M=52.16 (24-75) 60.5%	Hispanic/ Latin 30.2% Black 32.6% White 32.6% Other 4.6% (16.6% tested in Spanish) N/R	N/R
Mahon et al. (2022)	New Zealand University setting	Post-COVID	Non-randomised pre-post Videoconferencing Within-group comparison of FTF versus at home T-NPA	•WAIS-IV	University convenience sample 30	M=23 (18-40) 63.33%	European= 56.67% Asian= 43.33%	N/R

					Sample characteristics			
Citation	Study location and setting	Pre or post COVID-19	Research design and T-NPA method	Neuropsychological assessment tools	Population	Age mean or median (range)	Ethnicity/ Race	Clinical diagnoses (N)
					Sample Size (N)	Gender % female	Accessibility issues*	
Parikh et al. (2013)	USA University Medical Centre	Pre-COVID	Acceptability study Videoconferencing Participant preferences requested for comparison of FTF and T-NPA with 20 minute break in between T-NPA appeared to be administered on site although not reported	• MMSE •HVLT-R •DSF and DSB •Oral Trail Making Test • Letter Fluency and Category Fluency •Boston Naming Test •Clock drawing	Healthy and cognitively impaired older adults in the community	HC M=66.6 CI M=73.9 (Overall sample range = 50-82)	N/R	•HC=21 •Alzheimer's Disease=7 •Mild Cognitive Impairment=12
					40	HC 75% CI 39% (Overall sample 62%)	Severe visual or hearing impairments were excluded	
Sarno et al. (2022)	USA Neuropsychology outpatient clinic	Post-COVID	Feasibility study Videoconferencing Exploring feasibility of T-NPA from participants' homes	•MOCA •WAIS-IV – DS, MR, Similarities •BNT •COWAT •CVLT •WMS-IV - Logical Memory subtest •Oral Trails B	Patients receiving pre-surgical NPA for DBS	M=63.3 (N/R)	Hispanic 49.3% Other 50.7% N/R	N/R
					73	34.2%	N/R	

					Sample characteristics			
Citation	**Study location and setting**	**Pre or post COVID-19**	**Research design and T-NPA method**	**Neuropsychological assessment tools**	**Population** **Sample Size (N)**	**Age mean or median (range)** **Gender % female**	**Ethnicity/ Race** **Accessibility issues***	**Clinical diagnoses (N)**
Settle et al. (2015)	USA Veterans Affairs MS Medical Centre	Pre-COVID	Non-randomised pre-post Videoconferencing Within-subjects comparison of NPA scores for FTF in clinic and T-NPA at home and in clinic	•Automated neuropsychological assessment metrics (ANAM-MS) •SDMT	Multiple Sclerosis 24	Group 1 FTF first M=46.6 (N/R) Group 2 T-NP first M=47.4 (N/R) Whole sample M N/R 66.67%	Black 75% White 25% N/R	•Relapse remitting MS=16 •Primary progressive MS=1 •Secondary progressive MS=7
Stead & Vinson (2019)	USA University research laboratory	Pre-COVID	Non-randomised pre-post Videoconferencing Within-subjects comparison of NPA scores between FTF and T-NPA. Completed 10 to 15 minutes apart at a university laboratory	•MMSE •HVLT-R • DSF and DSB •BNT	Healthy adults 27	Reported that 30% were 18-55 and 70% 56-89 59%	N/R N/R	Reported that participants had no prior neurological or psychiatric diagnoses

					Sample characteristics			
Citation	**Study location and setting**	**Pre or post COVID-19**	**Research design and T-NPA method**	**Neuropsychological assessment tools**	**Population** **Sample Size (N)**	**Age mean or median (range)** **Gender % female**	**Ethnicity/ Race** **Accessibility issues***	**Clinical diagnoses (N)**
Sumpter et al. (2022)	U.K NHS Institute of Neurological Sciences	Post-COVID	Acceptability and feasibility study Videoconferencing (75%) and telephone (25%) Feedback requested from clients, clinicians and referrers after T-NPA completed in participants' homes	• TOPF • Addenbrookes Cognitive Examination-III (ACE-III) • RBANS • Edinburgh Cognitive and Behavioural Amyotrophic Lateral Sclerosis Screen (ECAS) • Rey 15 item • WMS • The Brain Injury Rehabilitation Trust Memory and Information Processing Battery (BMIBP) • RAVLT • Phonemic and category fluency • Delis-Kaplan Executive Function System (DKEFS) – verbal fluency and category switching •WAIS-IV - Vocabulary, Similarities and Information subtests • BNT •GNT • Oral Trail Making Test • Hayling & Brixton, • WAIS-IV - MR	Neuropsychology service referrals 199	M=53.3 (17-84) 51%	N/R N/R	•Motor Neurone Disease=6 •Epilepsy=23 •MS=27 •Other=12 •Diagnosis unknown=124 • Presurgical assessment patients - epilepsy surgery=8 and DBS surgery=12

Citation	Study location and setting	Pre or post COVID-19	Research design and T-NPA method	Neuropsychological assessment tools	Sample characteristics			
					Population Sample Size (N)	Age mean or median (range) Gender % female	Ethnicity/ Race Accessibility issues*	Clinical diagnoses (N)
Zeghari et al. (2021)	France Hospital Memory Clinic	Post-COVID	Non-randomised pre-post Videoconferencing Within-subjects comparison of NPA scores during FTF clinic and T-NPA 2 weeks apart T-NPA completed in a mobile unit outside participants' homes	•MMSE • FAB •5 words •Semantic and phonemic verbal fluency •DSF and DSB	Referrals from a community service working with older adults 8	M=76.5 (69-86) 50%	N/R Severe visual or auditory difficulties were not included	N/R
Zeghari et al. (2022)	France Hospital Memory Clinic	Post-COVID	Non-randomised pre-post Videoconferencing Within-subjects comparison of NPA scores during FTF and T-NPA sessions delivered 2 weeks apart Completed on site at the memory clinic	•MMSE •FCSRT •STROOP test •Semantic and Phonological Verbal Fluency •Naming task (Lexis) •Brief screening scale evaluating praxis abilities	Memory Clinic 50	M=73.32 (40-86) 66%	N/R N/R	N/R

Abbreviations: T-NPA, Tele-neuropsychological assessment; FTF, face-to-face; N/R = not reported, NPA, neuropsychological assessment; DBS, Deep Brain Stimulation; HC, Healthy Controls; CI, Cognitively Impaired

*Accessibility issues = consideration of any cognitive, physical or sensory impairments that could impact engagement in research and any attempts to improve accessibility reported

2. Exploring relationships between studies

Quality appraisal

The quality of the included studies using the CCAT is summarised in Table 2. Methodological quality varied with scores ranging between 35% and 98%. Nine studies were above 75%, considered to be high quality. Six were medium quality (between 50% and 74%) and four were lower quality (between 35% and 49%).

The methodological limitations observed in the studies were largely related to sampling methods and unclear reporting hindering the replicability of the studies. Many of the studies included non-clinical populations recruited through convenience methods. Recruitment procedures were often unclear, with no clear rationale for sample sizes. It was difficult to assess bias in some studies as the questionnaires used were unavailable and questions asked were not clearly stated.

The researcher acknowledges that poor quality sampling methods will influence the participant experience data as representativeness cannot be assumed. The impact of this bias was weighed up against the aim to increase knowledge of a topic that had not previously been explored and, therefore, it was deemed useful to synthesise all available literature.

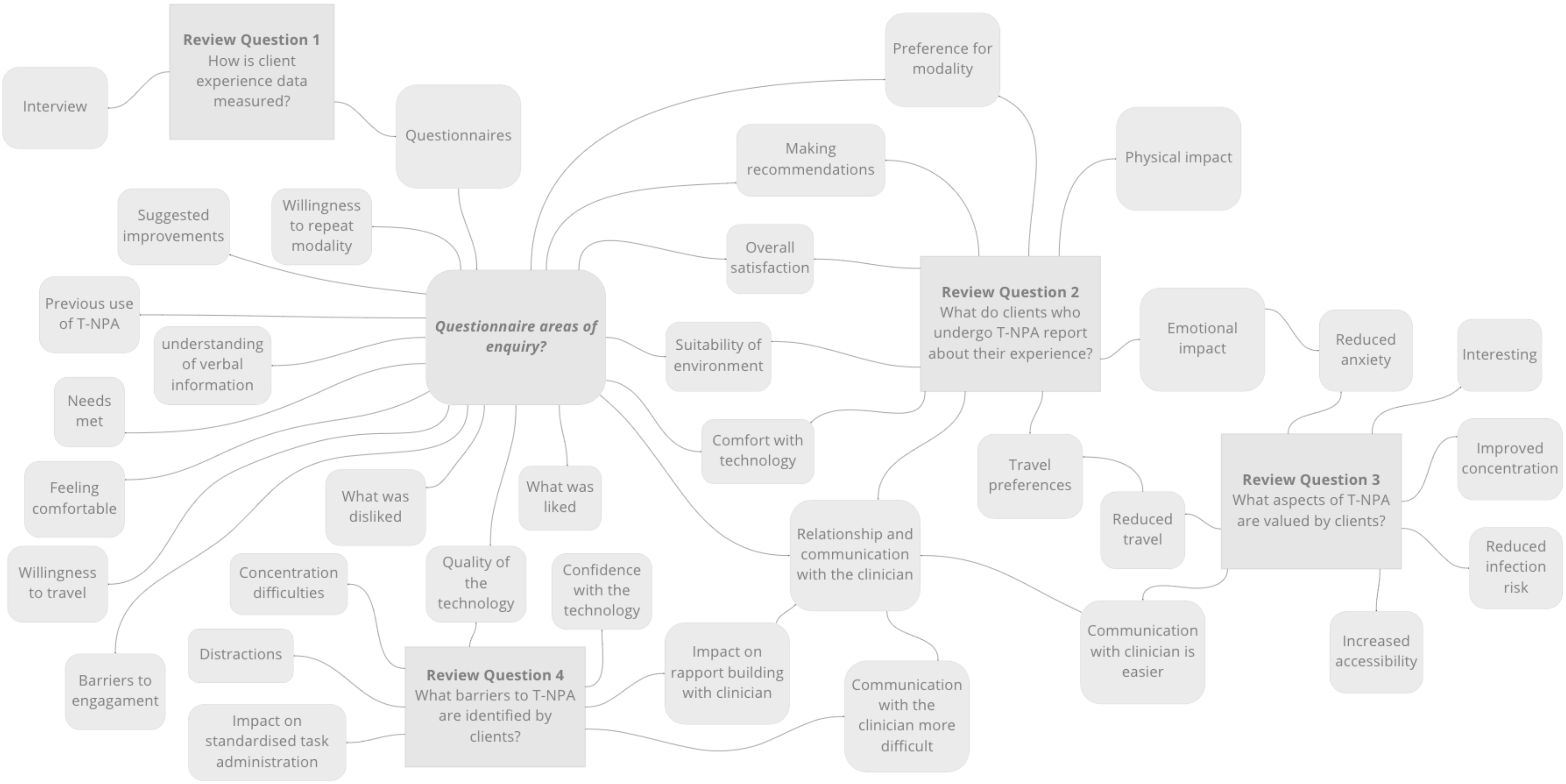
Idea webbing

Figure 2 visually represents the process used to explore relationships between the findings of the studies which are expanded on below in the narrative synthesis.

Table 2: Quality ratings using the CCAT

Article	Preliminaries (/5)	Introduction (/5)	Design (/5)	Sampling (/5)	Data collection (/5)	Ethical matters (/5)	Results (/5)	Discussion (/5)	Total (/40)	Total%
Appleman et al. (2021)	5	5	4	2	4	5	4	5	34	85
Ceslis et al. (2022)	5	5	5	4	5	5	5	5	39	98
Chapman et al. (2021)	4	5	4	3	5	4	5	5	35	88
Gardner et al. (2021)	4	3	4	5	5	4	4	4	33	83
Gnassouno et al. (2022)	4	5	4	3	5	5	5	5	36	90
Gonzalez et al. (2022)	5	5	3	4	5	4	5	5	36	90
Han et al. (2020)	3	2	4	1	3	4	4	3	24	60
Hilderbrand et al. (2004)	2	2	4	1	2	0	1	2	14	35
Jacobsen et al. (2003)	2	2	2	1	2	0	2	4	15	38
Kirkwood et al. (2000)	3	1	3	1	3	2	2	1	16	40
Lacritz et al. (2020)	4	5	4	4	4	4	4	4	33	83
Mahon et al. (2022)	3	5	3	1	4	4	4	4	28	70
Parikh et al. (2013)	3	5	3	1	2	1	3	3	21	53
Sarno et al. (2022)	1	3	3	3	4	0	1	2	17	43
Settle et al. (2015)	3	2	3	1	3	4	3	2	21	53
Stead and Vinson (2019)	3	5	3	1	3	4	3	3	25	63
Sumpter et al. (2022)	4	5	5	5	5	5	4	5	38	95
Zeghari et al. (2021)	4	5	4	1	4	4	4	4	30	75
Zeghari et al. (2022)	3	4	3	0	3	4	4	3	24	60

Figure 2. Idea webbing example exploring relationships within and between studies



Synthesis of study aims

A summary of the data included in the synthesis can be found in Table 3. The data extracted included frequencies, percentages and qualitative comments which are discussed below in a narrative synthesis.

How is client experience data measured?

Most studies used self-report Likert scales, ranging from 4 to 15 questions. One study completed interviews (Jacobsen et al., 2003) but no details on content were provided. It was often unclear if the questionnaires were pre-established, and none were validated. Parikh et al. (2013) developed a questionnaire, and this was adapted and used in three other studies (Chapman et al., 2020; Gardner et al., 2021; Sumpter et al., 2022). The validated Systems Usability Scale (Brooke, 1996) was used, but adapted in two studies with these adapted versions not being validated (Zegahri et al., 2021; Zeghari et al., 2022). Lacritz et al. (2020) adapted a questionnaire from children's health services. Only 11 of the studies were transparent with the format and content of questions but two (Zeghari et al., 2021; Zeghari et al., 2022) were in French meaning some information cannot be synthesised.

Only three studies using a questionnaire directly asked open-ended questions about what was liked, disliked or was difficult about the modality (Han et al., 2020; Mahon et al., 2022; Zeghari et al., 2022). Parikh et al. (2013), asked what was liked, however they used forced-choice questions with no option for comments. There were free-text options in a small number of studies (Gardner et al., 2021; Lacritz et al., 2020; Stead & Vinson., 2019; Sumpter et al., 2022; Zeghari et al., 2021; Zeghari et al., 2022) but this did not generate significant information for this synthesis.

What do clients who undergo T-NPA report about their experiences?

Overall satisfaction and recommendation of modality

Satisfaction with T-NPA was high across all studies who reported on this (Appleman et al., 2021; Ceslis et al., 2022; Chapmpan et al., 2021; Gnassounou et al., 2022; Gonzalez et al., 2022; Han et al., 2020; Kirkwood et al., 2000; Lacritz et al., 2020; Parikh et al., 2013; Sarno et al., 2022, Settle et al., 2015; Zeghari et al., 2021; Zeghari et al., 2022). T-NPA was able to meet participants' needs in most respondents (Lacritz et al., 2020; Stead & Vinson, 2019; Sumpter et al., 2022). Negative experiences of T-NPA were rarely reported however 10% thought they would perform better FTF (Hilderbrand et al., 2004), 1% described dissatisfaction (Gnassounou et al., 2022), and some felt less prepared for what to expect (Appleman et al., 2021). Across five studies, 68 to 90% of respondents reported that they would recommend T-NPA (Chapman et al., 2021; Settle et al., 2015; Sumpter et al., 2022; Zeghari et al., 2021; Zeghari et al., 2022).

Modality preference

Of the ten studies that asked about preferred modality, six favoured FTF (26-81%) (Hilderbrand et al., 2004; Lacritz et al., 2020; Mahon et al., 2022; Stead & Vinson, 2019; Sumpter et al., 2022; Zeghari et al., 2022). No study indicated an overall preference for T-NPA but 83-88% of participants (Kirkwood et al., 2000; Lacritz et al., 2020; Mahon et al., 2022) said they would use T-NPA again. Four studies stated that most participants reported "no preference" (50-60%) when given the option between FTF and T-NPA (Chapman et al., 2021; Jacobsen et al., 2003; Parikh et al., 2013; Zeghari et al., 2021).

Relationship with clinician and communication

The relationship with the clinician was generally positive with 100% of participants reporting good rapport (Ceslis et al., 2022), 83.7% were satisfied with the time spent together (Lacritz et al., 2020) and 75% agreeing no impact of modality on the relationship (Settle et al., 2015). Effective communication with the clinician was reported in 73-100% (Appleman et al.,2021; Hilderbrand et al., 2004; Jacobsen et al., 2003; Sumpter et al., 2022).

Environment and use of technology

Visual and sound quality was rated highly by most participants (Ceslis et al., 2022; Hilderbrand et al., 2004; Kirkwood et al., 2000; Lacritz et al., 2020; Parikh et al., 2013; Settle et al., 2015). The majority of participants rated comfort with the equipment highly (Chapman et al., 2021; Han et al., 2020; Hilderbrand et al., 2004; Kirkwood et al., 2000; Lacritz et al., 2020; Parikh et al., 2013; Settle et al., 2015; Sumpter et al., 2022; Zeghari et al., 2021; Zeghari et al., 2022). The majority of participants reported no privacy concerns (Appleman et al., 2021; Lacritz et al., 2020; Parikh et al., 2013; Settle et al., 2015; Sumpter et al., 2022) with only 5% in one study reporting privacy concerns (Settle et al., 2015).

Physical and emotional impact

There was limited information about the physical impact of T-NPA however fatigue (Gnassounou et al., 2022; Mahon et al., 2022) and eye pain (Zeghari et al., 2022) were reported. Emotional impacts also lacked exploration but reduced anxiety was reported in 15-70% (Gardner et al., 2021; Gnassounou et al., 2022; Parikh et al., 2013). One study reported frustration with T-NPA to be minimal (Han et al., 2020) however another reported stress was rated higher in T-NPA (Zeghari et al., 2021).

Travel preferences

The majority of participants would travel no more than 1 to 3 hours for FTF (Chapman et al., 2021; Gardner et al., 2021; Parikh et al., 2013) with only 30% stating they would travel over 3 hours (Parikh et al., 2013) and only 5% preferring to travel to see a clinician (Settle et al., 2015).

What aspects of T-NPA are valued by clients?

Reduced travel and increased accessibility

Several studies commented on the time saved and improved accessibility of T-NPA for those living remotely, with transport difficulties or reduced mobility (Kirkwood et al., 2000; Gardner et al., 2021; Lacritz et al., 2020; Stead and Vinson, 2019). This modality was viewed as being more convenient (Han et al., 2020; Lacritz et al., 2020; Sumpter et al., 2022).

Reduced infection risk

The post-COVID studies acknowledged the reduced infection risk (Ceslis et al., 2022; Sumpter at al., 2022) with 76-79% of participants endorsing this benefit (Gardner et al., 2021; Lacritz et al., 2020).

Improved concentration

A small number of participants (7-30%) reported it was easier to concentrate at home (Gardner et al., 2021; Lacritz et al., 2020; Parikh et al., 2013) with ability to focus on the tasks improved (Jacobsen et al., 2003; Zeghari et al., 2022).

Communication easier

A minority of participants (7-23%) endorsed that it was easier to communicate with the clinician or express concerns during T-NPA (Gardner et al., 2021; Lacritz et al., 2020; Parikh et al., 2013).

Interesting

Several participants noted the novelty of T-NPA was interesting (Han et al., 2020; Kirkwood et al., 2000) with 24-29% (Chapman et al., 2021; Parikh et al., 2013) stating it is more interesting than FTF.

What barriers to T-NPA are identified by client?

Quality of the technology and equipment use

Technical difficulties were described (Gonzalez et al., 2022; Han et al., 2020; Hilderbrand et al., 2004; Kirkwood et al., 2000; Lacritz et al., 2020; Mahon et al., 2022; Sumpter et al., 2022; Zeghari et al., 2022) including internet connectivity issues and poor sound quality. Lack of confidence and unfamiliarity with the technology or equipment increased anxiety (Mahon et al,. 2022).

Distractions and concentration

Three studies reported distractions at home affecting T-NPA (Gardner et al., 2021; Mahon et al., 2022 and Sumpter et al., 2022) and concentration difficulties were reported (Lacritz et al.,2020; Stead & Vinson, 2019; Zeghari et al., 2022). One study stated difficulties ensuring a private area at home (Mahon et al., 2022).

Relationship and communication with the clinician

Between 23% and 66% endorsed that FTF assessment would have led to a better connection with the clinician (Chapman et al., 2021; Gardner et al., 2021; Lacritz et al., 2020; Parikh et al. 2013). Other studies noted the lack of human presence (Zeghari et al., 2022) and robotic nature increased feelings of being judged (Han et al., 2020) and feeling less reassured than FTF (Sumpter et al., 2022). Communication being more difficult in T-NPA was reported in 20-42% (Chapman et al., 2021; Lacritz et al., 2020; Parikh et al., 2013).

Impact on standardised task administration

Participant feedback indicated an impact of T-NPA on effective administration of test materials. Han et al. (2020) reported difficulties seeing the test booklet on camera, and one participant described vertigo. Poor audio impacted administration of one of the subtests (Mahon et al., 2022) and one participant reported writing down numbers during the test (Stead & Vinson, 2019).

3. Assessing the robustness of the synthesis

Authors were not contacted to request access to the questionnaires where these were not made available. As the studies included sufficient information about the output from their questionnaires, it was judged that there was satisfactory information to assess the quality of included studies. However, the missing information impacted the synthesis of data in relation to how client experience data is measured.

Table 3. Summarised participant experience results

Citation	Sample size (% of total study sample)	Data collection method --- validated tool? --- Questions available to view	Areas of enquiry	Research aims
Appleman et al. (2021)	131 (100)	12-item self-report questionnaire (SRQ) Likert scale --- NNVQ --- Yes	•Satisfaction with visit •Clarity of instructions to find clinic •Feeling prepared for what to expect •Worry about the visit •Enough time to express concerns •Hear the provider clearly •Could be heard clearly by the provider •Felt like the provider cared about them •Visit was private and confidential •Felt comfortable sharing personal information •Environment was quiet and distraction free •Travel to the visit was easy and stress free Open ended questions •How long it took to travel to clinic • Previous use of T-NP •Other comments	**Reported experiences?** • 90% in T-NP and over 98% FTF agreed or strongly agreed “I was overall satisfied with my visit.” • 87% of T-NP and 84% of F2F agreed or strongly agreed “Travel to this visit was easy and stress-free.” •Easily communicate with clinicians •Testing environment was private, quiet and free from distractions •Comfortable sharing personal information and concerns •Felt clinician cared about them •Felt less prepared for what to expect and more reported worry **Valued aspects?** QNA **Identified barriers?** QNA

Ceslis et al. (2022)	63* *Questionnaires were completed by both healthy and clinical participants attending the research clinic but only healthy participants data included in the reported study.	7-item SRQ Likert scale survey --- NNVQ --- Yes	•Comfort during appointment •Procedures clearly explained •Reduced worry about infection control •Overall experience •Quality of the audio and visuals •Rapport with clinician in different room	**Reported experiences?** •100% strongly agreed or agreed they felt comfortable •98% felt procedures were clearly explained •41% less worried about infection control •92% experience was positive •98% rated sound quality to be excellent or good •94% rated video quality was excellent or good •100% had a good rapport with the clinician all or most of the time. **Valued aspects?** QNA **Identified barriers?** QNA
Chapman et al. (2021)	45 (93.75)	14-item SRQ Likert scale and select all that apply --- Modified Parikh et al. (2013) questionnaire --- Yes	•Overall satisfaction •Understanding of task instructions •Comfort with videoconferencing •Likeliness to recommend T-NP •Preference of modality •Willingness to travel for F2F and wait for F2F over T-NP •Comfort across modalities •Pre-defined advantages of F2F and T-NP	**Reported experiences?** •High satisfaction in both modalities •Comfort with the equipment was high •51.1% no preference of modality and 42.2% FTF and 6.6% Tele-NP •88.9% would recommend T-NP and 6.6% would not •73.3% rated equal comfort in both modalities •Majority would not be willing to wait over 3 months for F2F or travel over 3 hours **Valued aspects?** •24.4% endorsed T-NP as more interesting or fun **Identified barriers?** •66.7% endorsed easier to develop connection with examiner FTF •42.2% endorsed easier to communicate with examiner FTF

Gardner et al. (2021)	52 (65.82)	10-item SRQ Likert scale, select all that apply, and free text response options --- Modified Parikh et al. (2013) questionnaire --- Yes	•Overall satisfaction •Technical problems •Communication difficulties •Privacy concerns •Felt understood by the examiner •Recommend T-NP? •Benefits to T-NP •Possible improvements to T-NP •Willingness to travel for FTF	**Reported experiences?** •98% reported satisfaction with T-NP •92% would recommend to others •100% felt understood by the examiner •90% no technical difficulties •94% no communication challenges •98% no privacy concerns. •37% preferred T-NP over FTF **Valued aspects?** •88% felt travel time was saved (and qualitative comment that parking problems were avoided) •79% valued reduced infection risk (qualitative comment that spouse could attend from quarantine) •27% reduced anxiety •23% stated improved concentration •31% would drive up to 1 hour before choosing remote •8% thought it would be easier to express concerns. **Identified barriers?** •40% endorsed FTF in person would have improved personal connection with clinician •Qualitative comment that there are more distractions at home that could impact reliability of results

Gnassounou et al. (2022)	N/R	SRQ Likert-Scale --- NNVQ --- No	•Overall satisfaction with T-NP •Physical and emotional impact •Feelings about presence of assistant	**Reported experiences?** • 87.1% very satisfied with T-NP •82.9% reported FTF and T-NP were as effective •74.2% reported FTF and T-NP as tiring as each other •70% no anxiety with T-NP •2 participants reported being "rather unsatisfied" •100% reported very satisfied with the support of the assistant **Valued aspects?** QNA **Identified barriers?** QNA
Gonzalez et al. (2022)	59 (100)	SRQ Open ended survey --- NNVQ --- No	Specific questions and number asked is unclear Text states: •Participants asked about any difficulties and examples were provided of hearing difficulties or intrusions from other people •Any additional comments about the testing.	**Reported experience?** •93% participants indicated overall satisfaction either reporting enjoying the experience or they would not make any adjustments **Valued aspects?** QNA **Identified barriers?** •11.86% participants had hearing difficulties due to environmental distractions or sound quality issues • 2 participants stated difficulties understanding test instructions

Han et al. (2020)	10 (100)	6-item SRQ Likert scale and open-ended questions --- NNVQ --- Yes	•Overall experience • T-NP was viewed as a reasonable method for research • Degree of frustration with T-NP •What was liked about T-NP •What made T-NP more difficult •Suggested improvements	**Reported experiences?** •Majority of participants rated overall satisfaction highly (7 and above out of 10) - 7 (10%), 8 (50%), 9 (20%), 10 (2%)) •100% strongly or somewhat agreed T-NP was reasonable for research studies •90% somewhat or strongly disagreed that T-NP was frustrating and 10% somewhat agreed **Valued aspects?** •Novelty •Portability – bringing assessment to the patient/reaching more people long distance/can be done at home •Easy to use and understand •Comfortable and no pressure •Convenient •Preferrable to telephone based NPA **Identified barriers?** •Poor internet connection - quality was reduced and connection broke up impact on visuals and audio •Line orientation task difficult to complete as test booklet difficult to see over camera – 1 participant reported vertigo •Picture on screen could be larger for visual tasks •Robotic nature and lack of personal touch at the start led to feeling criticised and like they would be judged.

Hilderbrand et al. (2004)	19 (65.52)	Unknown --- Unknown --- No	Unknown	**Reported experiences?** •44% preferred FTF, 17% T-NP and 39% had no preference •All participants felt comfortable with the technology and communication •Image quality was acceptable •Able to understand directions given •11% stated quality of sound was not acceptable •10% thought they would have performed better FTF **Valued aspects?** QNA **Identified barriers?** QNA
Jacobsen et al. (2003)	N/R	Interview --- N/A --- No	•Communication •Distance •How instructions were presented •Preference for modality	**Reported experiences?** •Majority expressed no preference for either modality •1 participant's preference was FTF as distance felt impersonal •2 preferred T-NP reporting feeling less self-conscious being separated from the assessor •No communication difficulties or difficulties understanding instructions were reported during T-NP **Valued aspects?** •Multiple participants reported less distraction during T-NP – distance from assessor helped focus on tasks **Identified Barriers?** QNA

Kirkwood et al. (2000)	26 (96.30)	4-item SRQ Likert scale and open-ended questions --- NNVQ --- No	•Sound quality •Picture quality •Ability to communicate •Overall satisfaction Open ended questions not stated	**Reported experiences?** •Overall satisfaction M of 8.2 (out of 10) •Sound quality M = 7.6 •Visual quality M = 7.9 •22 of 26 participants would use T-NP again, 1 would not and 3 were unsure •Feeling relaxed and at ease •No effort needed to use the equipment **Valued aspects?** •Finding the experience interesting or unusual •Having access to a health professional **Identified barriers?** •Difficulty in understanding verbal information •Poor sound quality •Delays in communication
Lacritz et al. (2020)	43* *81 were contacted to complete questionnaire	15-item SRQ with free text comments ---	•Overall satisfaction •Method of delivery •Previous use of T-NP •Device used •Located during assessment •Satisfaction with information provided •Problems with technology	**Reported experiences?** •100% stated they were given adequate information about the technology •93% rated very good or good level of comfort with the technology •86% had no connection problems •14% reported technology related issues •93% had adequate privacy

	but only 43 participated (53% response rate) which is the total study sample	Adapted from a questionnaire used in children’s health services --- Yes	•Adequate privacy •Preference for future appointment modality •Advantages of T-NP •Disadvantages of T-NP •How well needs were met with T-NP •Comfort with the technology •Satisfaction with time with clinician •What was liked about T-NP	•79.1% rated T-NP as very good or good at meeting their needs •83.7% were very satisfied or satisfied with time spent with clinician •Overall satisfaction: 44.2% very satisfied, 34.9% satisfied, 18.6% somewhat satisfied and 2.3% (1 respondent) not satisfied •67.7% preference for FTF in future but 83.7% stated they would be interested in another T-NP appointment **Valued aspects?** •Helps with difficulties getting to clinic due to transportation difficulties, distance, or physical mobility difficulties •Reduced waiting times •More time to talk to the clinician •Less pressure and more relaxed by being in control of the setting Endorsed advantages from pre-provided options: •avoiding exposure to illness 76.7% •Flexibility/convenience 67.4% •Easier to communicate 23.3% •Easier to concentrate 30.2% **Barriers identified?** •Harder to concentrate in home environment 18.6% •Not feeling connected with the clinician as FTF 23.3% •Harder to communicate 20.9% •Concerns with the length of the appointment •Trouble tracking questions over the telephone

Mahon et al. (2022)	25 (83.33)	SRQ Likert scale and open-ended questions --- NNVQ --- No	Specific questions not reported •Audio and visual quality •Privacy and comfort of the different modalities •Convenience and ease of use •Perceived cultural barriers •Difficulties and barriers experienced during T-NP	**Reported experiences?** •22/25 reported very likely or likely they would complete NPA using T-NP •24/25 rated practicality of T-NP as adequate or higher •There was a modest but significant preference for FTF versus T-NP •Women preferred the privacy of FTF compared with men •5/25 rated the audio quality as less than satisfactory •Participants suggested having a practice session before T-NP to become familiar with equipment •Session was fatiguing and one recommendation to divide the session due to fatigue **Valued aspects?** QNA **Identified barriers?** •Distraction during home assessment due to children •Difficulties setting up area to ensure privacy and security at home •Challenge in pragmatics of setting up a second camera as requested by the researcher •Lack of confidence in using the software and cameras •Anxiety about the unfamiliar context of videoconferencing •Poor audio impacted on digit span assessment •No cultural barriers identified

Parikh et al. (2013)	40 (100)	10-item SRQ Likert scale and closed ended questions --- NNVQ --- Yes	•Overall satisfaction •Preference for modality •Level of comfort with the equipment •Understanding test instructions •Privacy •Comfort with the examiner in each modality •Would recommend T-NP? •What was liked about FTF and TNP •How far they would travel for T-NP	**Reported experiences?** •98% rated T-NP as acceptable and 2% were neutral •No concerns about privacy •No dissatisfaction with visual or audio stimuli •No problems with videoconferencing equipment •Group analysis - 95% of the cognitively impaired sample were satisfied with the approach and 5% were neutral •100% of healthy participants were satisfied with TNP •60% rated no preference for format, 30% stated a preference for FTF and 10% for videoconferencing •Group analyses - 63% of cognitively impaired participants stated no preference for modality and 37% FTF. No participants stated a preference for videoconferencing •Healthy participants - 57% stated no preference, 24% FTF and 19% stated a preference for videoconference •Around half of participants stated they would drive no more than 3 hours for FTF and 30% would drive more than 3 hours to be FTF **Valued aspects?** •15% felt less anxious without the examiner in the room •7% reported easier to communicate with the examiner via T-NP •7% reported easier to concentrate without examiner in the room •29% stated that T-NP was more interesting or fun **Identified barriers?** •63% reported it being easier to establish a connection with examiner FTF and 34% easier to communicate when in the same room •24% easier to manipulate test materials FTF

Sarno et al. (2022)	13 (17.81)	10-item SRQ Likert scale --- NNVQ --- No	•Ease of use •Technological concerns •Comfort with procedures	**Reported experiences?** •Stated that most reported satisfaction with T-NP • SRQ scored out of 70 (M = 58.6, Mdn = 60 and range 37 to 69) **Valued aspects?** QNA **Identified barriers?** QNA
Settle et al. (2015)	20 (83.33)	12-item SRQ Likert scale --- NNVQ --- Yes	•Comfort with the equipment •Thoughts on being unable to see the clinician in person •Any audio problems •Privacy concerns •Comfort asking questions •Felt understood by the clinician •Relationship with clinician •Willingness to travel for FTF •Were needs met with T-NP •Was good care received •Overall satisfaction •Recommend T-NP to others	**Reported experiences?** •100% (20%) agreed and (80%) strongly agreed they were comfortable with the equipment •85% disagreed or strongly disagreed that they did not like being unable to see their clinician. 10% strongly agreed with this •85% disagreed or strongly disagreed that they had trouble hearing the clinician, 10% were neutral and 5% agreed they had trouble •95% disagreed or strongly disagreed that they were concerned about their privacy and 5% agreed •15% agreed they were more comfortable asking questions FTF, 30% were neutral and 55% disagreed or strongly disagreed •90% agreed or strongly agreed that the clinician was able to understand their questions without being in the room with them and 5% were neutral

				•75% agreed or strongly agreed that their relationship with the clinician in the room was the same as T-NP and 20% neutral •80% disagreed or strongly disagreed they would prefer to travel to see a clinician rather than use T-NP, 10% were neutral and 5% agreed •80% agreed or strongly agreed that their needs could be met using T-NP, with 5% neutral and 10% disagreeing •85% agreed and strongly agreed that they could get good care with T-NP with 10% neutral •85% agreed or strongly agreed that they were overall satisfied with the T-NP part of the study and 10% were neutral •90% agreed or strongly agreed they would recommend T-NP with 5% neutral **Valued aspects?** QNA **Identified barriers?** QNA
Stead & Vinson (2019)	27 (100)	SRQ 5-item Likert scale and further open-ended questions --- NNVQ ---	•Was the T-NP modality liked •Previous understanding of telehealth •Perceived barriers	**Reported experiences?** •81% preferred F2F •Reported easier to concentrate FTF •Human contact with the assessor was reported as preferrable •M of 7.74 (out of 10) for T-NP meeting participants' needs •One participant stated they wrote down the numbers during the test and queried if this was cheating

		No		**Valued aspects?** •One report that T-NP could increase access to people less mobile **Identified barriers?** •Participants rating T-NP as less likely to meet their needs report this as due to them having less reliable internet connection or having difficulties using technology
Sumpter et al. (2022)	70* *199 were included in study but 212 were contacted to complete questionnaire so 33% response rate	SRQ Likert scale, yes/no and qualitative exploration --- Influenced by Parikh et al. (2013) and adapted for COVID-19 --- Yes	•Comfort with the T-NP equipment •Ability to communicate problems to clinician •Preferences were taken in to account •T-NP process was straightforward •Privacy concerns •Technical difficulties •Distractions or interruptions at home •Recommend T-NP •Preferences for future assessment – If COVID-19 no longer a risk	**Reported experiences?** •68% would recommend T-NP •84% were comfortable with the equipment •73% could describe their problems •82% thought their preferences were considered •74% found the process straightforward • 87% no privacy concerns •29% reported technical issues •14% reported distractions in the home •Preference for future testing: 55.7% F2F, 25.7% TNP and 18.6% no preference. **Valued aspects?** •Convenience •Reduced infection risk •Positive impact on wellbeing •Reduced travel and time •Equivalence to F2F testing

				Identified barriers? •More distractions •Not feeling comforted and reassured as you would when being with someone
Zeghari et al. (2021)	8 (100)	7-item SRQ Likert Scale with free text comment section --- Adapted from the System Usability Scale (Brooke, 1996) --- Available in French	•Overall satisfaction •Willingness to repeat experience •Level of stress •Clarity of instructions •Modality preference and why •Areas for improvement	**Reported experiences?** •High satisfaction with both F2F and T-NP •Systems were easy to use in F2F and T-NP •Instructions were clear in F2F and T-NP •They would repeat the experience in future for research in both F2F and T-NP •They would recommend both T-NP and FTF assessment methods •Slightly more people endorsed recommending T-NP compared to F2F •Stress level was rated slightly higher in T-NP •7 people answered the preferred method for assessment with 3 people choosing the F2F method and 4 stating either to be fine **Valued aspects?** QNA **Identified barriers?** QNA

				Reported experiences?
Zeghari et al. (2022)	50 (100)	10-item SRQ Likert scale with free text comment section and 3 open-ended questions --- Adapted from the System Usability Scale (Brooke, 1996) --- Available in French	•Overall satisfaction •Ease of use of system •Clarity of instructions •Willingness to repeat experience •Would method be recommended •What was missing or disappointing •What was most and least liked •Possible improvements to system	• M = 6.56 (out of 7) satisfaction rating • M = 6.5 (out of 7) for ease of system use • M = 6.71 (out of 7) for clarity of instructions • M = 6.53 (out of 7) would repeat experience in future • M = 9.06 (out of 10) for likeliness to recommend T-NP to others • 18 preferred FTF, 7 preferred T-NP and 18 selected both options **Valued aspects?** •1 participant reported being more free to focus when using T-NP **Identified barriers?** •Technical difficulties such as problems with the sound, computer not responding or internet connectivity issues •Sound impacted clarity of instructions for 1 participant •Eye pain due to screen •Difficulty concentrating •Lack of human presence

Abbreviations: NNVQ, Novel Non-Validated questionnaire; QNA, Question Not Asked; N/A, Not Applicable; M, Mean

Discussion

This review synthesised the experiences of participants who completed T-NPA to describe: the methods used to collect experience data, the typically reported experiences, and views about valued aspects and barriers. Overall, the methodological quality of the studies was mixed with sampling issues identified across many studies.

The 19 included studies were heterogenous with regards to the populations included, modality of T-NPA (i.e. video or telephone and at a satellite clinic or participant's home), the study designs, the methods for collecting experience information, and the countries conducting the research. This heterogeneity presented difficulties synthesising the results and forming confident conclusions about client experience of T-NPA. Most of the studies used videoconferencing and therefore limited conclusions can be drawn about telephone specific T-NPA.

Reported satisfaction of T-NPA was high and, for those asked, most stated they would recommend it. This finding is consistent with Pogorzelska and Chlabicz (2022) who found high satisfaction with telemedicine across a range of specialties. This review found a slightly higher preference for FTF assessment (when given the option between FTF, T-NPA or no preference) but a reasonable number endorsed no preference. Although preferences for FTF have been reported in a tele-mental health (Vera San Juan et al., 2021) these varied widely both across and within individuals and can fluctuate over time. Influencing factors included the content of the appointment and the nature of the difficulties they were experiencing. Factors affecting client preferences are likely more complex and person-specific than the current T-NPA literature has understood. For example physical health needs, mental health status, ease of access and how they interact with personal and environmental factors need to be more extensively explored. It is unknown if there are person-centred methods implemented by services when offering telehealth that take account of these factors.

This synthesis has highlighted key moderating factors that may impact reports of participant experience. Barriers to engagement with T-NPA were not commonly reported in the studies but key barriers stated were technology issues, confidence with technology and distractions in the home environment which mirrors barriers reported by clinicians using T-NPA (Fox-Fuller et el., 2022). The relationship with the clinician could be an important factor for client experience, as reported by Orrange et al. (2021), as this was rated high by most participants in this synthesis. There is evidence that T-NPA was better received when there was a pre-established relationship with the clinician (Schutz et al., 2022). Therefore, clinicians need to offer a flexible approach, taking account of these factors, to maximise engagement with T-NPA.

Participant experience data was limited by the design of the self-report questionnaires. The method of collecting data varied widely and several studies' questionnaires were unavailable to view. Synthesising the data was challenging due to variation in questioning: very few studies asked open-ended questions and forced-choice and free-text response options had low response rates. Few studies asked specifically about the benefits and challenges of T-NPA. Parikh et al. (2013), and those who adapted this questionnaire, asked about likes and dislikes but provided only forced-choice options which represented the researchers' preconceptions, potentially constraining understanding of participant experiences. More consistent use across the questionnaires of open-ended questions asking about perceived benefits and barriers may have mitigated this issue, and reduced researcher bias that is present in the current understanding gained. This synthesis did include free-text response comments however qualitative response options were inconsistently used within the studies when they were available, and they were inconsistently reported by the studies meaning that some data was not available for synthesis.

The lack of transparency regarding the questionnaire or questions asked may be due to most studies not assessing participant experience as their main aim. It was also unclear, how most questionnaires were completed e.g. completed anonymously, and this may have impacted participants' ability to respond honestly due to biases such as social desirability (Althubaiti, 2016).

The design of the studies meant that not all participants completed both FTF and T-NPA so comparisons may be difficult for those who only received T-NPA. It is therefore difficult to confidently interpret preferred modality and generalise this information. Hamad et al. (2021) found that new patients rated satisfaction with telemedicine significantly higher than follow-up patients, suggesting previous exposure to certain modalities may impact current experience. It should also be considered that during COVID-19 there was reduced access to healthcare services and therefore participants' feedback on T-NPA may differ post-pandemic when expected methods of accessing healthcare return. The researcher considered comparing findings from studies published prior to and after the commencement of COVID-19 however given the variety in questionnaire design and questions asked across studies it was thought that reducing the number of studies to allow for group comparison would dilute the richness of the data able to be synthesised for each group. Also It was considered that the limitations identified during the data quality appraisal, which included sampling and reporting issues, would further impact the representativeness when comparing these studies at a group level.

Strengths and limitations

This review is the first of its kind to synthesise clients' perceptions of T-NPA. It was considered important to understand and gather as much information of participant experiences whilst acknowledging that the heterogeneous nature of the included studies would limit the ability to draw firm conclusions.

Efforts were made to ensure a systematic search was completed however non-English and non peer-reviewed literature were excluded and therefore there may be publication bias. Also 26% of the papers included in the review were identified through forward and backwards citation searching of included papers. One paper did not have an abstract and for the others, as service-user satisfaction was often not the focus of the research, it varied how this information was reported and how explicitly it was mentioned in the title or abstract. Changes to the search strategy were not considered to likely improve sensitivity and specificity and increase the likelihood of retrieving these papers in the original search.

Ethnicity was poorly reported (6 of 19 studies), constraining interpretation of representativeness for different ethnic and cultural groups. A specific concern with this is that digital poverty is considered to impact Black, Asian and Minority Ethnic groups disproportionately (Zhai, 2021) and therefore understanding barriers to engaging with T-NPA in these populations would be important to ensure equity in clinical practice.

With seven of the studies including healthy volunteers and a further five using research samples, a high proportion of included participants were willing participants rather than clinical service-users. Therefore views of those who would be required to engage with T-NPA in clinical practice may not be well represented.

Implications for practice

Although the heterogeneity of the populations sampled makes it difficult to form strong conclusions, this does indicate that T-NPA has scope to be useful in healthcare systems worldwide, with wide ranging populations. Clients report high levels of satisfaction with healthcare in this format and for some it will increase accessibility to services, therefore clients will likely benefit from T-NPA being an available option.

Clinicians will need to be mindful of barriers that may preclude clients from T-NPA such as digital poverty, and those whose experience would be impacted by poor quality technology or distractions in a remote setting. Few of the studies included T-NPA from clients' homes and so additional barriers to access may become apparent as research continues and clinical practice with T-NPA expands.

Future research

Given the expansion of T-NPA during the COVID-19 pandemic, T-NPA may remain a common option for health services alongside traditional FTF, and so establishing for whom and when this option should be offered would benefit from further investigation. As the sampling methods in some of the included studies were of poorer quality and less likely to be representative of clinical populations who would be offered T-NPA for healthcare purposes, it would be beneficial to conduct further studies within healthcare setting with appropriate sampling to increase the generalisability of findings. Increasing the diversity of samples, including with regards to socioeconomic status and ethnicity, would further assist in understanding barriers and benefits of T-NPA in specific groups of individuals.

Qualitative studies understanding the how the interaction of person-specific factors such as mental health, physical health, environmental conditions and access to technology impacts upon client experience and willingness to engage with T-NPA would allow insights that could help services to better tailor their resources to client needs. This could allow services to be more efficient in directing their resources appropriately and in a person-centred way by offering T-NPA to clients where it is more suitable and less likely to lead to disengagement.

Standardising measures for collecting client experience data for neuropsychological assessment and remote methods would further benefit the literature base. Daramilas and Jaspal (2017) recommend that a suitable satisfaction measure should explore client perceptions and experience, be culturally sensitive and capture physical and psychological aspects of care received, but no measure currently exists. Including service-user representatives in this process would help ensure key information relevant to client experience is captured when services evaluate the use of T-NPA.

Conclusion

This review synthesised the literature reporting client experiences of T-NPA. Overall, Satisfaction with T-NPA was high and although more people stated a preference for future FTF appointments, a high number of people stated no preference between T-NPA and FTF, which indicates that this method may be a suitable alternative.

Services must consider the suitability of T-NPA for their area but given the range of populations included, this indicates that T-NPA can be applied to numerous populations requiring neuropsychological assessment. However, services must take account of possible challenges affecting successful implementation of this method including technology difficulties, reduced privacy, increased chance of distraction and how these factors effect the validity of the assessment.

Further research prioritising client experience should be conducted in larger, and socioeconomically and ethnically diverse clinical populations. Qualitative research could allow better understanding of how person-specific factors interact to impact client experience and engagement with T-NPA. The development of standardised self-report questionnaires for collating satisfaction data should also be considered.

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Chapter 2: Major Research Project

Clinician and client reports of the negative effects of neuropsychological assessment for dementia

Prepared in accordance with the author requirements for The Clinical Neuropsychologist

https://www.tandfonline.com/action/authorSubmission?show=instructions&journalCode=ntcn20

Plain Language Summary

Title: Clinician and client reports of the negative effects of neuropsychological assessment for dementia

Background: When further information is needed to help identify if someone has dementia, a neuropsychological assessment (NPA) can be requested. There is limited research to help clinicians understand what negative experiences might occur when taking part in a NPA. However, some research suggests that testing can trigger negative emotions such as anxiety and frustration. It is unclear if clinicians who undertake NPA are aware of any negative effects on their clients.

Aims: To find out what possible negative experiences clients have when going through NPA and to identify any similarities or differences in what is reported by clinicians and clients.

Methods: Two groups were recruited. First, clinical psychologists from across Scotland who conduct dementia assessments with older adults were interviewed and/or completed a questionnaire to determine if they had seen negative effects of NPA in their practice. The second group was a sample of people who had recently had a NPA and they completed a similar questionnaire asking about their experience.

Main Findings: Eleven clinicians completed interviews and 25 clinicians and 12 clients completed the questionnaire. Clinicians stated that they observed a range of negative experiences including feeling anxious about taking part in the tests, feeling disappointed in their performance on the tests, becoming critical of themselves, worrying about the outcome, as well as noticing stress, worry and frustration. They expressed an awareness of other factors which could increase the chance that clients might experience negative effects such as being pressured in to participating in the NPA or previous difficulties with academic assessments. Clinicians also explained that from the outset they try to adapt the assessment to meet their clients' needs, create a comfortable and friendly environment and ensure that their clients continue to consent to taking part. The highest rated negative effects present for clients matched

those reported by clinicians and included feeling stressed, worried, disappointed with their performance on testing, frustrated with themselves, critical of themselves and worried about the outcome of assessment.

Conclusions: This study adds to our understanding of the negative experiences that clients have whilst attending for NPA and describes clinicians’ awareness of these negative experiences. Some caution is needed in interpreting the results as the client sample size was small. Further studies with a larger sample sizes and consideration of how best to engage clients in research to express their experiences would be beneficial.

Abstract

Objective: Neuropsychological assessment (NPA) is recommended to support differential diagnosis of dementia however little is known about its impact on clients and their experience of negative effects. This study aimed to investigate clinicians' understanding of their clients' negative experiences and whether clinicians and clients report similar negative effects.

Method: Semi-structured interviews with clinicians, and a questionnaire for clinicians and clients who had completed NPA were collected from NHS settings across Scotland. Reflexive Thematic Analysis was used to analyse 11 clinician interviews. Descriptive statistics were reported for the 25 clinician and 12 client questionnaires and exploratory analysis using Fisher's Exact tests investigated associations between clinician and clients reporting of negative experiences.

Results: Three overarching themes and 13 sub-themes were identified. These included testing producing negative impacts, factors that indirectly affect experience, and clinicians taking action to reduce adverse effects of NPA. The most endorsed negative effects were the same for clients and clinicians and included feeling stressed, worried, disappointed with their performance on testing, frustrated, critical of themselves and worried about the outcome of assessment.

Conclusion: This study provides insight into negative effects experienced by clients during NPA. Future research would benefit from understanding barriers to recruitment and data completion as well as investigating acceptable and feasible methods of obtaining client experience feedback as client recruitment was low.

Keywords: Neuropsychological assessment, client experience, negative effects

Introduction

Reported benefits of a dementia diagnosis include increased autonomy, ability to make decisions about future care and access to services (Bamford et al., 2004; Van Den Dungen et al., 2014). National and international guidance (Scottish Government, 2017a; World Health Organization [WHO], 2017) emphasises improving quality of services for people with dementia and providing timely access to diagnosis. Neuropsychological assessment (NPA) is sought to help with diagnosis and subtyping of dementia (National Institute for Health and Care Excellence, 2018). Little is known about clients' experience of NPA and any negative effects experienced.

Iatrogenesis, an unintended adverse outcome for a client due to a healthcare intervention, is seen in many forms of medical assessment and intervention. For example, damage to skin from the side effects of chemotherapy (Choi, 2011) and false positive diagnosis in breast cancer screening leading to psychological and emotional distress (Adami et al., 2019). However, harm through psychological assessment and intervention receives little attention in the literature (Knox, 2019). Avoidance of harm is a key ethical principle (British Psychological Society [BPS], 2019) but there is limited understanding of how standard psychological practices may cause unintended harm nor is there guidance on how to identify and prevent this. Studies investigating clinicians' awareness of harm have identified that 28% of American Psychological Association clinicians were unaware that clients could experience negative effects of therapy (Boisvert & Faust, 2006), and only 11% reported learning about negative effects during their training (Bystedt et al., 2014). Researchers have begun to acknowledge possible harms of psychotherapy, (Dimidjian & Hollon, 2010; Lilienfeld, 2007), and measures have been developed to identify the type and occurrence of harms in practice (Herzog et al., 2019), although this has not extended to NPA.

Studies of client experience of NPA in adult populations have reported that most people find NPA useful, and that feedback on cognitive strengths and weaknesses was valued (Bennett-Levy et al., 1994; Donofrio et al., 1999; Foran et al., 2016; Westervelt et al., 2007). Reported negative experiences suggest that around half of patients find assessments frustrating and tiring (Bennett-Levy et al., 1994), and feedback sessions can be draining and difficult to understand (Foran et al., 2016).

In qualitative studies exploring client experiences (Blake, 2004; Gruters et al., 2020; Krohne et al., 2011; Owen, 2012; Robinson, 2016; Sweetman, 2018), reported benefits of NPA include an increased awareness and understanding of difficulties (Gruters et al., 2020; Owen, 2012; Sweetman, 2018). The relationship with the clinician was described as key to improving the experience, helping them relax, and helping facilitate coping and increased self-esteem (Blake, 2004; Owen, 2012; Sweetman, 2018).

These studies have also provided insight into negative experiences. Participants felt poorly prepared for what to expect, which increased anxiety as they expected similarities to previously unpleasant medical investigations (Blake, 2004) and there was poor retention of information increasing uncertainty (Gruters et al., 2020). Emotional responses included anxiety, confusion, distress, frustration, anger, and feeling stupid, worried or a failure due to struggling with testing (Blake, 2004; Gruters et al., 2020; Owen, 2012; Robinson, 2016; Sweetman, 2018). Fatigue triggered by the assessment was reported to impact on the overall experience (Owen, 2012).

A hospitalised population completing cognitive screening expressed they did not understand the testing purpose and found it stressful due to feeling pressure to perform well (Krohne et al., 2011). Participants perceiving their performance to be poorer described shame and irritation. Robinson (2016) also described that negative self-appraisals of performance affected mood and occurred in the absence of feedback.

The above studies focused on a range of populations such as people attending a neuropsychology service (Bennett-Levy et al., 1994; Donofrio et al., 1999; Westervelt et al., 2007), traumatic brain injury (TBI; Owen, 2012), neurodegenerative conditions (Sweetman, 2018), dementia assessment in a memory clinic (Gruters et al., 2020; Robinson, 2016), unspecified neurological conditions (Blake, 2004), and hospitalised older adults (Krohne et al., 2011).

This study aims to gain insight into experiences of NPA and increase understanding of potential negative effects in a population of clinicians and clients utilising NPA for diagnostic assessment of dementia. By 2030, 78 million people are expected to have dementia, with 10 million diagnoses per year it is one of the biggest causes of disability in older people (WHO, 2022) and demands on memory clinics will increase. There is less emphasis on pre-diagnostic phase of assessment in the literature or Government strategy but services need to understand how best to deliver person-centred care and avoid harm at this key stage of a person's dementia journey. Only two of the studies above focussed on memory clinic populations (Gruters et al., 2020; Robinson, 2016) and both identified negative experiences during the NPA process.

If clinicians have a limited understanding of negative effects of NPA, it could be argued that clients will not get a comprehensive understanding of the process to allow them to give valid informed consent, which is a key ethical principal clinicians must adhere to (BPS, 2016). Therefore, this study aims to explore clinicians' understanding of and clients' reports of negative effects of NPA for dementia.

Research Questions

- What understanding do clinicians have about the negative effects experienced by their clients in relation to NPA for possible dementia?
- What negative effects do clients report from NPA?
- What similarities and differences are there in client and clinician reports of client negative effects?

Method

Design

This study used a mixed method approach. Qualitative analysis of semi-structured interviews with clinicians, and quantitative analysis of questionnaires completed by clinicians and clients were used to understand clients' experiences of NPA.

Participant recruitment procedures

Clinician Interview

A purposive sampling approach was taken. Clinical psychologists delivering NPA in NHS Lanarkshire's Psychological Therapies for Older People Team (PTOP) were invited to participate. Clinicians were eligible if:

- They had completed at least one NPA with feedback within the last 12 months
- The NPA purpose was for assessment of dementia

Clinicians were emailed the study documentation, which included the participant information sheet (Appendix 2.1), privacy notice (Appendix 2.2) and consent form (Appendix 2.3). The semi-structured interviews (Appendix 2.4) were completed on Microsoft Teams and were recorded and transcribed. After their interview, clinicians were emailed the online questionnaire to anonymously take part in this part of the study if they wished.

Sampling for clinician Interviews

Recruitment of clinicians for semi-structured interviews was in line with recommendations made by Clarke and Braun (2013) of between 6 and 10 participants. PTOP had 11 eligible clinicians.

Clinician and client questionnaires

- NHS Scotland older adult clinicians were sought by email via the Heads of Older People's Psychology Services (HOOPPS). The participant information sheet (Appendix 2.5) and consent form (Appendix 2.6) embedded within the online questionnaire.

Inclusion criteria:

- Qualified clinical psychologist
- Completed at least one NPA for possible dementia in the last 12 months

PTOP clinicians identified eligible clients using the following criteria:

Inclusion criteria

- Currently on a clinician's caseload and receiving NPA for assessment of dementia (invited to participate as soon as NPA feedback had taken place) or those discharged within the last 3 months
- English speaking

Exclusion criteria

- Inability to provide informed consent

Eligibility guidance was provided (Appendix 2.7). If clients expressed an interest in the study to their clinician, they were telephoned by the researcher to discuss, and the participant information sheet (Appendix 2.8), privacy notice (Appendix 2.9) and consent form (Appendix 2.10) were posted to them. Participants were given options for completing the questionnaire including posting the questionnaire with a pre-paid return envelope, completing an online questionnaire, or completing it on an NHS site with the researcher.

Sampling for clinician and client questionnaires

As the questionnaires were developed by the researcher and were being piloted, there were no *a priori* assumptions. Recruitment of client participants was pragmatic and determined by the number of eligible clients within the recruitment timeframe.

PTOP referral data for 2020 was calculated to estimate possible number of eligible participants. There were 133 clients referred for NPA and so during this study's recruitment period an estimation of 50 clients were expected to complete NPA.

Rates of reported adverse experiences in the psychotherapy literature have been estimated between 5 and 10% (Farquharson, 2020). Although it cannot be assumed that rates of negative experience in a NPA population would be similar, this data was considered to acknowledge that recruiting as many eligible participants as possible would increase the chance of identifying negative effects in this sample if they exist. Based on these figures, with a proposed eligible sample of 50 participants, it could be hypothesised that 3 to 5 would report negative experiences.

Similarly, there were no *a priori* assumptions for clinician questionnaire recruitment. An inclusive recruitment strategy was used with the aim of achieving a representative sample of views and experience.

Measures

Due to the lack of a suitable measure we developed a questionnaire to assess experiences of NPA for use in this study (Appendix 2.11 and 2.12). This involved the following steps:

- First items were adapted from an existing measure of negative effects of psychological therapy (Rozental et al., 2019) and findings from reported negative effects of NPA from the literature described in the introduction
- A clinician and client version of the questionnaire was then developed
- Feedback was sought from clients in PTOP undergoing NPA who were approached by the study field supervisor
- Clinicians outwith the research team and PTOP service who had expertise with NPA provided feedback on questionnaire drafts
- The West of Scotland (WoS) Research Ethics Committee (REC) then provided feedback during the review process
- The questionnaires were adapted following feedback from the above parties resulting in a reduction in question items (49 to 28)

The content of the questions was the same across both versions to allow comparison, with some completion instructions differing. The questionnaires included 28 questions, demographic information (which was reported in a free text format), and free text option for additional comments.

Data analysis

Clinician Interviews

Reflexive Thematic Analysis (RTA; Braun & Clarke, 2022) was used to explore themes in clinicians' perception of clients' experience. This approach allows patterns to be identified across transcripts, leading to the development of themes and it was chosen due to its flexibility and not being restricted to a specific theoretical base (Braun & Clarke, 2006). The six phases as recommended by Braun and Clarke (2022) were followed: 1. familiarisation with the transcripts, 2. coding the data, 3. generating themes, 4. reviewing and developing themes, 5. Refining, defining and naming themes, and 6. producing the report. A sample of transcripts were analysed by the research supervisor during the coding process to reduce bias and codes were discussed. NVivo9 assisted with coding and theme development. Clinicians were asked to estimate the approximate number of NPA's they have completed and this was reported to give an indication of the experience of clinicians.

Theoretical framework

A critical-realist stance was observed which assumes a reality in the data but acknowledges that data requires interpretation to access this reality. As interviews were conducted with clinicians, the data reflects their perceptions of their clients' negative experiences which is shaped by their own assumptions and knowledge, and this is then interpreted by the researcher based on their understanding, experience and knowledge. A data-driven inductive approach was taken with the aim of developing themes from the content of the data rather than based on pre-existing theories or assumptions.

Reflexivity

I am a trainee clinical psychologist and have worked in the older adult team where the interviews were conducted during my first and third years of training. Therefore, I had my own views of possible negative experiences during NPA having worked with a number of clients throughout training, and having completed NPA as part of previous roles. I entered the study with some general understanding of the process and interest in this area. The participants in the study were colleagues and so there was a pre-existing professional relationship. It was important to consider how my professional experiences and relationships could impact when conducting interviews and interpreting the data. A reflective diary was kept throughout the process to help consider any interaction of prior assumptions and views on relating to the current information being collected and the themes being developed. It was important to ensure that information was not being discounted because of any beliefs I had from my own personal experience and that views of clinicians were not being given more weight if they were in line with views I previously held.

Clinician and client questionnaires

Questionnaire data were analysed using IBM SPSS (v28, 2021). Descriptive statistics were used to summarise patterns in the results and reported as frequencies. Exploratory analysis using Fisher's Exact tests, explored associations between clinician and client endorsement of negative effects (two-tailed, $p = 0.05$).

Ethics

Approval was obtained from the WoS REC (22/WS/0064; Appendix 2.13) and NHS Lanarkshire Research and Development (L22004; Appendix 2.14). NHS Lanarkshire's Information Governance Department approved the use of the online questionnaire using JISC Online Surveys.

Results

Clinician Interviews

Clinician interview demographics

Eleven clinicians participated in the interviews. Demographic information was aggregated to protect confidentiality. Participants were qualified between 1 and 16 years (M = 6.55, SD = 4.80) and estimations of completed NPAs was around 1718 (range 25 to 200, M = 156.18, SD = 166.09).

Thematic Analysis

Interview duration ranged from 29 to 43 minutes (M = 33m). Three overarching themes and 13 subthemes were identified and are summarised in Table 1. Further detail of quotes for each theme is provided in Appendix 2.15.

Table 1. Overarching themes and sub-themes

Overarching theme	Sub-theme (N participants sub-theme occurred)
Testing can produce negative impacts on clients	Emotional experiences (11)
	Testing increasing insight into difficulties (8)
	Impact on physical wellbeing (7)
	Reduced self-confidence and self-criticism (6)
	Negative affect during feedback (10)
Indirect factors can produce harmful effects of NPA	Power dynamics and external pressures (5)
	Not understanding how clients' history and characteristics can impact experience (7)

Clinicians can take action to reduce adverse effects of NPA	The importance of rapport and a calm atmosphere (11) Adapting assessments to accommodate clients' needs (10) Using clinical skills to administer tests thoughtfully and retain validity (10) Clinical judgment on proceeding with NPA (6) Informed consent (9)

Testing can produce negative impacts on clients

Clinicians did observe negative experiences through the NPA process. Emotional and physical impacts were identified particularly related to the testing process, and clinicians identified that there can be negative experiences during feedback.

Emotional experiences

The most observed emotional impact was anxiety, with embarrassment, frustration, and stress also reported. "Test anxiety" was considered common but clinicians acknowledged that this was low-level and not disruptive to the validity of testing and the wellbeing of the clients:

> *I would say a mild level of anxiety would probably be present in most of the people I would see, not necessarily to clinical extent … but certainly some nervousness and apprehension about completing the testing.* (P4)

Clinicians noted that negative affect was an understandable part of the process and there is an unavoidable element to this given the context of the situation:

> *Yes, it will be upsetting but ultimately, people go through that, though, to get to an answer to help any kind of interventions that might be there. So while there's discomfort, perhaps some distress, it’s a necessary evil in the overall process. As long as the clinicians attuned to their patient, you should be able to manage that in a session by session basis.* (P6)

Testing increasing insight into difficulties

Clinicians described how the process of testing can bring difficulties to the forefront that have been able to be avoided in daily life forcing clients to confront a deficit.

For some clients it was acknowledged that testing contributed to them developing insight about a problem:

> *It's quite confronting in that it's right there in front of you, like I can't remember this list, I can't remember that picture. I don't even remember you asking me about the picture. You know, there's that kind of very, I think we can sort of avoid that in day-to-day life by avoiding things that are hard or whatever or just kind of playing to our strengths*. (P9)

For other clients testing was preventing them from continuing to use self-protective methods to avoid acknowledging their difficulty:

> *The carer was like, ‘you've definitely got a problem with your memory’ and they were like, ‘no, I don't’. But it came out through the testing process that actually they knew they did. They just didn't want to admit it. So that kind of not being able to live in denial really being confronted with it. And they were quite happy in denial. Like, that was good for their self-esteem. (P2)*

Impact on physical wellbeing

There was an acknowledgment that the test environment can fail to provide the optimum conditions for clients:

> *It is also important in terms of a person's comfort and now comorbidities with older people, chronic pain, arthritis, osteoporosis, emm, poor vision poor hearing, toileting issues … because of lack of rooms, that are adequately resourced, we will find ourselves cramped in small rooms using tables that are at knee height where older people need to bend over.* (P6)

And an awareness that testing can have an impact on clients' physical health outwith the appointment and interact with comorbid conditions:

> *A huge comorbidity seems to be chronic pain. So when people go home, they'll be absolutely shattered and probably usually do nothing for the rest of the day.* (P8)

Reduced self-confidence and self-criticism

Developing insight and increased awareness of difficulties was observed to impact on clients' confidence and self-critical comments were common:

> *And you can see the frustration and you can see also the element of self-criticism that comes into that. Sometimes there's a commentary during testing where someone will say something like that was stupid, you know, or that wasn't very good.* (P11).

And a knock-on effect of this was considered in terms of clients' mood and their view of themselves:

> *It's particularly difficult for people who have good insight into their difficulties but do have significant difficulties and have previously been very independent, high functioning people, it can just really knock they're kind of sense of self, sense of self-worth.* (P3)

Negative affect during feedback

Clinicians were aware that feedback appointments can elicit negative affect in anticipation of dementia diagnosis and acknowledged this is an expected part of the process however some factors may increase negative affect.

Some clinicians acknowledged that clients lacking insight into their difficulties can find feedback sessions difficult as a diagnosis comes as a surprise:

> *It's more common with Alzheimer's clients to have poor insight into their memory deficits. It's sometimes they could seem a touch taken aback when you're explaining the severity of their memory impairment.* (P1)

Another situation where clinicians observe upset in clients during feedback is when they are not given a diagnosis and this is what they were expecting because they feel it helps explains their difficulties, and so they do not receive clarity about the cause of their difficulties:

> *The ones that come to mind, who have maybe not been happy with the outcome, not agreed with the outcome being a bit frustrated, have been the ones who've not got a diagnosis. And it's a wait and see. So it's mostly it's when*

> *they're lived experience doesn't quite map on to how I've put it under the diagnostic criteria.* (P7)

Indirect factors can produce harmful effects of NPA

There are 2 sub-themes of factors that could indirectly negatively impact the client experience.

Power dynamics and external pressures

The power imbalance in clients' relationships and the impact it could have on informed consent and their engagement in NPA was highlighted:

> *Then you have ones who will say yes to anything a doctor says so you worry about power differentials within that and you think are they fully consenting and engaged in a process.* (P6)

And expectations of family or doctors involved in the client's care may influence their decision to attend:

> *Often the clients themselves don't have much of an expectation, they come along because they've been sent by their psychiatrists and their families think they should come along.* (P10)

Not understanding how patients' history and characteristic can impact experience

The impact of past educational experiences on clients' current feeling about engaging with NPA was acknowledged:

> *Nobody wants to do badly on it. It feels like a test. And there's like, I think there's also, like, people who maybe are a bit insecure about their intelligence or their, like, performance at school if they didn't, if they weren't particularly academic at school or they struggled with tests. I think that can also be quite a source of anxiety and stress about not doing well.* (P9)

Clinicians can take action to reduce adverse effects of NPA

Clinicians often actively make decisions to ensure clients had a good experience and they mitigate potential risk of harm during client interactions.

The importance of rapport and a calm atmosphere

Clinicians talked about the importance they put on providing a relaxed, supportive and friendly atmosphere.

Some clinicians mentioned the importance of investing in building a relationship with the client:

> *So not just kind of getting people into the appointment and jumping straight into testing, maybe kind of checking in with them and having a bit of chat.* (P2)

The importance of this for ensuring optimal test performance and thus assessment validity was considered:

> *You just want them to be as calm as possible and have less cortisol running around their body. Because then that means that their frontal lobe won't shut off, which is something that you're trying to study.* (P8)

Clinicians believed that positive rapport can help the clients have a better feedback experience:

> *I think with patients, with whom you've had perhaps a better alliance, you do find that at the end at the feedback appointment they sort of perhaps they feel a bit safer in receiving whatever news they get.* (P10)

Adapting assessments to accommodate clients' needs

Clinicians were considerate of clients physical and sensory needs when deciding where to offer appointments and how to adapt the session structure to limit any negative impacts and get the best performance was acknowledged:

> *I think we're quite flexible in how we offer things. So if people were struggling to travel, as well in my area because it's quite rural, that if they couldn't travel, we would go to them*. (P2)

When meeting the client, clinicians explored physical health difficulties that could be exacerbated by NPA and considered how they can set up appointments to maintain comfort and retain the validity.

> *If someone has um, particular physical issue, chronic pain, or is going to be uncomfortable for them to, I would usually be assessing that before I would start. "How long do you feel comfortable sitting?", you know, and "when do you take your pain medication?". Things like that to try and arrange it so that you're getting the best conditions.* (P11)

Using clinical skills to administer tests thoughtfully and retain validity

Clinicians described the importance of considering which tests to administer and when, and how to administer these in a way that engages the client whilst minimising the possibility of testing eliciting a negative emotional experience.

Clinicians explained they provide encouragement rather than giving no feedback, to celebrate clients' effort but avoiding telling them how they are performing to retain test validity:

> *Sometimes I'll give slightly arbitrary just little bits of something just like, 'Yep, that's great. Yup. Well done." And it doesn't necessarily literally mean like, "hey, you just performed very well above the norms". It just means well done for like, trying your best at that.* (P1)

Considering the clients presentation at the time of testing helps clinicians to consider what tests to administer and in what order:

> *So if people are particularly anxious not doing like a really difficult test straight off the bat, so maybe kind of easing them in.* (P2)

Clinicians described being attuned to how their clients are responding to the testing process and offering reassurance if necessary:

> *I probably just support it quite a lot of like validating you know spotting the frustration and labelling it and validating it early on. I always say to people if you get 100% and come out of here feeling that you've done really well, I've picked the wrong tests.* (P7)

Clinical judgment on proceeding with NPA

From the point of referral to assessment clinicians considered the value of undertaking NPA with the client and remained attuned to changes which might suggest continuing with NPA was not useful.

Clinicians attempt to proactively reduce anxiety levels when this is identified as a difficulty:

> *I have had a few cases where I've done like kind of relaxation breathing techniques with before we even started testing and kind of that was the only way that I could get an accurate valid test performance*. (P2)

Clinicians are conscious of the confounding impact that anxiety can have on cognition and test performance:

> *So it's not nice to see someone feeling anxious while doing tests. I discontinue at that point. Because one, it's unethical and two you're not assessing that organic abilities, you're assessing how performance anxiety effects cognitive performance."* (P5)

Informed consent

Clinicians invest time in ensuring clients are fully informed and consent to the process and make attempts to ensure this information is remembered:

> *I do prediagnostic counselling, many times. I circle around because I think perspective, insight, retention. I don't think it's, I don't think it's something you can do in one conversation. I don't think it's accurate. And I think, the educational component needs a bit of time to digest and to think through. And*

> *the layers of protective defences and and so on, I think you need to give give folks a chance.* (P7)

Clients' choice remains at the forefront of clinicians' decision-making and consent was revisited throughout testing:

> *I mean, people, people have rights to decline treatment and even if it is in their best interest and they still have a right to decline. And I think we don't emphasise that enough with patients*. (P10)

Clinician and client questionnaires

Sample Characteristics

Twenty-five clinicians completed the questionnaire between the 27th July and 22nd November. Participating clinicians had been qualified between 1 and 21 years (M = 8.5, SD = 5.5).

During the recruitment process, described in Figure 1, 46 clients were estimated to have received NPA feedback. Twelve questionnaires were returned, representing 26% of the clients receiving NPA. Table 2 summarises the demographic information which was requested in a free text format with no pre-existing options provided.

Missing data

Missing data and response percentages for each question are reported for transparency in Appendix 2.16. Four of the returned client questionnaires had substantial missing data and for the whole dataset, missing responses ranged from 16.7% to 41.7% for each question. All returned data is included in the results to ensure the breadth of client experiences were included. The impact of this on representativeness of the sample, feasibility of data collection and possible explanations for high rates of missing data will be considered in the discussion.

Figure 1. Client recruitment flowchart

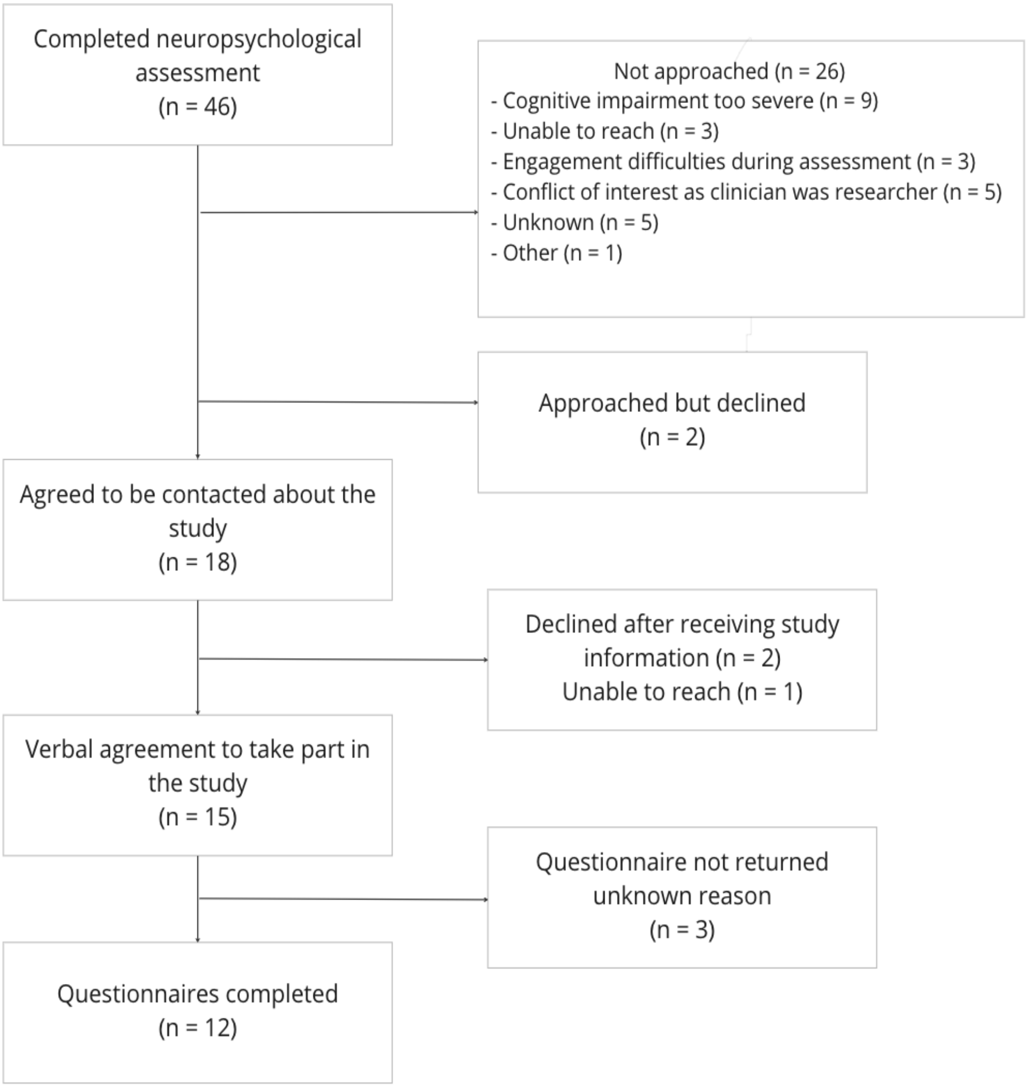


Table 2. Client demographic information

Demographics	Frequency(%)
Age (N=12)	
Range: 62-81	
M: 71.5	
SD: 5.89	
Sex	
Female	7(58.33)
Male	5(41.67)
Diagnosis after assessment	
AD	2(16.67)
VD	2(16.67)
MCI	4(33.33)
Medication/psychiatric related CI	1(8.33)
No diagnosis	3(25.00)
Ethnicity	
Scottish	3(25.00)
British	1(8.33)
British White	2(16.67)
White	2(16.67)
Unknown	4(33.33)
Mental Health difficulties	
Anxiety	1(8.33)
Depression	1(8.33)
Mixed anxiety/depression	1(8.33)
None	5(41.67)
Not reported	4(33.33)
Physical Health difficulties	
Diabetes	2(16.67)
Osteoarthritis	2(16.67)
Arthritis	1(8.33)
Hypertension	2(16.67)
Epilepsy	1(8.33)
Diverticulitis	1(8.33)
None	5(41.67)
No health information reported	3(25.00)

Abbreviations: AD, Alzheimer's Disease; VD, Vascular Dementia, MCI, Mild Cognitive Impairment; CI, Cognitive Impairment

The negative effects reported by clinicians and clients

Table 3 presents the endorsements of negative effects for clinicians and clients. The top six negative effects were the same for clinicians and clients. For clinicians, 100% endorsed disappointment with performance on the tasks, frustrated with self, critical of self and worried about the outcome of assessment. Stressed and worried were observed by 96% of clinicians. For clients, worried about the outcome of assessment was reported by 83.3%, worried and disappointed in performance on tasks reported by 66.7, stressed and frustrated was reported by 58.3%, and critical of self by 41.7% clients.

Summary of the most endorsed negative effects

For those who endorsed the presence of an effect, the questionnaire also asked participants if they thought the effect was due to the assessment itself or other circumstances, the extent the effect impacted on the client and at what point during the assessment process the effects were observed. These results are summarised in Appendix 2.17 and 2.18. A visual summary of the results from these six most endorsed effects are presented in Figures 2 to 7. Participants selected one option for the cause of the effect and extent the effect impacted. They were also asked to select all options that applied when answering when the effect was experienced.

Comparison of clinician and clients reporting of negative effects

Fisher’s exact tests compared reporting of negative effects between clinicians and clients. The results are summarised in Table 3. Fifteen of the question items were not significant which suggests that clinicians and clients endorsed the presence of these effects to the same degree. Thirteen question items were significant indicating a difference in the levels of endorsement between clinician and clients. For all significant results, these items were endorsed by a greater percentage of clinicians than clients.

Table 3. Clinician and client responses for presence of negative effects with Fisher's Exact Test results, odds ratios and confidence intervals

	Endorsement of negative effects		Fisher's Exact Test						
	Clinician N(%)	Clients N(%)	P value	Odds ratio	95% CI Lower-upper	Clinician N		Client N	
						Yes	No	Yes	No
Q1 Stressed	24(96%)	7(58.3%)	.061	.097	.009–1.088	24	1	7	3
Q2 Worried	24(96%)	8(66.7%)	.190	.167	.013–2.093	24	1	8	2
Q3 Hopeless	14(56%)	1(8.3%)	.047*	.098	.011-.908	14	11	1	8
Q4 Sad	17(68%)	3(25%)	.116	.235	.047–1.190	17	8	3	6
Q5 Disappointed in performance on the tasks	25(100%)	8(66.7%)	.265			25	0	8	1
Q6 Frustrated	25(100%)	7(58.3%)	.242			25	0	7	1
Q7 Critical of self	25(100%)	5(41.7%)	.010*			25	0	5	1
Q8 Suicidal ideation	13(52%)	0(0%)	.012*			13	11	0	8
Q9 Irritable	19(76%)	2(16.7%)	.015*	.105	.017-.666	19	6	2	5
Q10 Angry	15(60%)	1(8.3%)	.039*	.095	.010-.897	15	10	1	7
Q11 Embarrassed	21(84%)	4(33.3%)	.034*	.152	.028-.830	21	4	4	5
Q12 Disempowered	12(48%)	2(16.7%)	.416	.361	.061–2.146	12	13	2	6
Q13 Stupid	21(84%)	4(33.3%)	.074	.190	.033–1.097	21	4	4	4
Q14 Confused	23(92%)	4(33.3%)	.007*	.070	.010-.491	23	2	4	5
Q15 Worried about the outcome	25(100%)	10(83.3%)	.099			25	0	10	2
Q16 Physically tired	23(92%)	1(8.3%)	<.001*	.012	.001-.158	23	2	1	7
Q17 Mentally drained	23(92%)	3(25%)	.004*	.052	.007-.399	23	2	3	5
Q18 Headaches	12(48%)	3(25%)	.458	.464	.097–2.217	12	13	3	7
Q19 Problems with sleep	19(76%)	3(25%)	.082	.189	.035–1.038	19	6	3	5

	Endorsement of negative effects		Fisher’s Exact Test						
	Clinician N(%)	Clients N(%)	P value	Odds ratio	95% CI Lower-upper	Clinician N		Client N	
Q20 Strain on family relationships	20(80%)	1(8.3%)	.001*	.036	.004-.361	20	5	1	7
Q21 Lost out financially to attend appointments	9(36%)	1(8.3%)	.225	.222	.024–2.074	9	16	1	8
Q22 Gave up significant amounts of time to attend	17(68%)	2(16.7%)	.025*	.134	.023-.799	17	8	2	7
Q23 Lost driver’s license	19(76%)	0(0%)	<.001*			19	6	0	8
Q24 Did not understand the purpose of assessment	20(80%)	1(8.3%)	.001*	.036	.004-.361	20	5	1	7
Q25 Did not understand the results of assessment	12(48%)	1(8.3%)	.108	.155	.017–1.450	12	13	1	7
Q26 Was not made aware of the risks involved in assessment	1(4%)	2(16.7%)	.113	9.600	.723-127.532	1	24	2	5
Q27 Did not feel prepared for what the assessment involved	3(12%)	2(16.7%)	.591	2.095	.289–15.191	3	22	2	7
Q28 Waited too long to receive feedback	7(28%)	1(8.3%)	.403	.321	.034–3.064	7	18	1	8

Note: Odds ratios and confidence intervals were unable to be calculated for questions that had 0 counts in one or more cells

*Significant result (at p < .05) indicating a difference in level of endorsement by clinicians and clients.

Figure 2. Summary of clinician and client percentage responses for question item 'Disappointment with performance on the tasks'

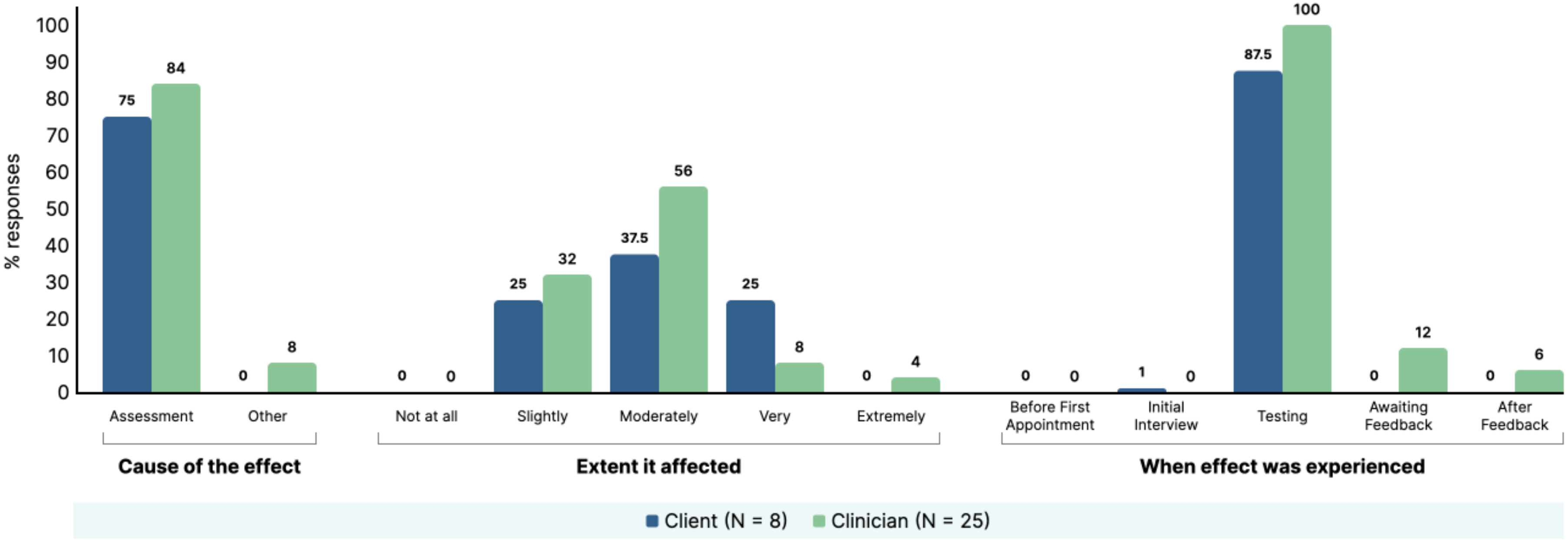


Figure 3. Summary of clinician and client percentage responses for question item 'Frustrated with self'

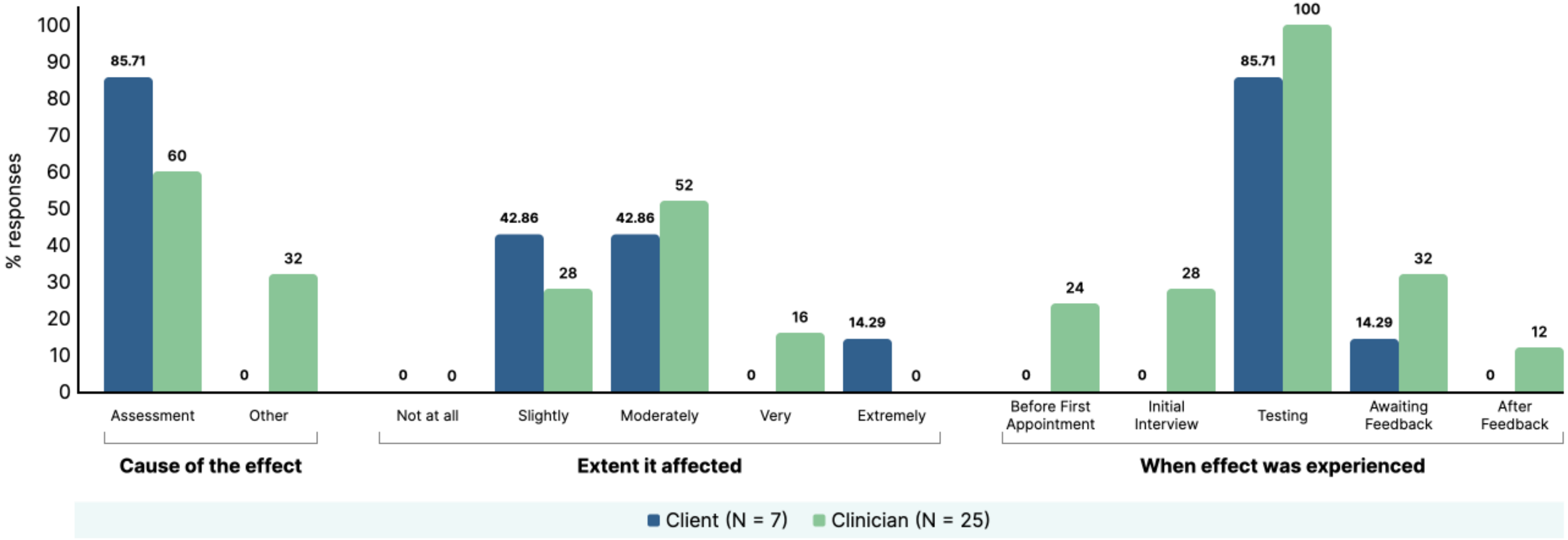


Figure 4. Summary of clinician and client percentage responses for question item 'Critical of self'

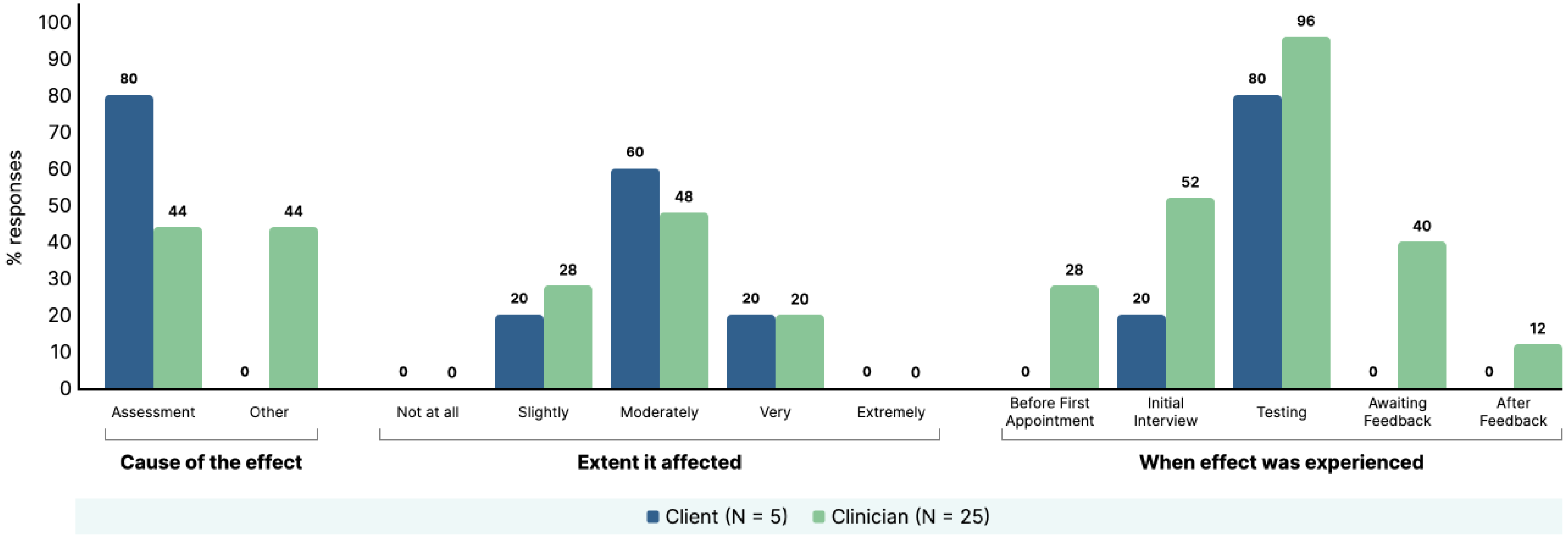


Figure 5. Summary of clinician and client percentage responses for question item 'Worried about the outcome of assessment'

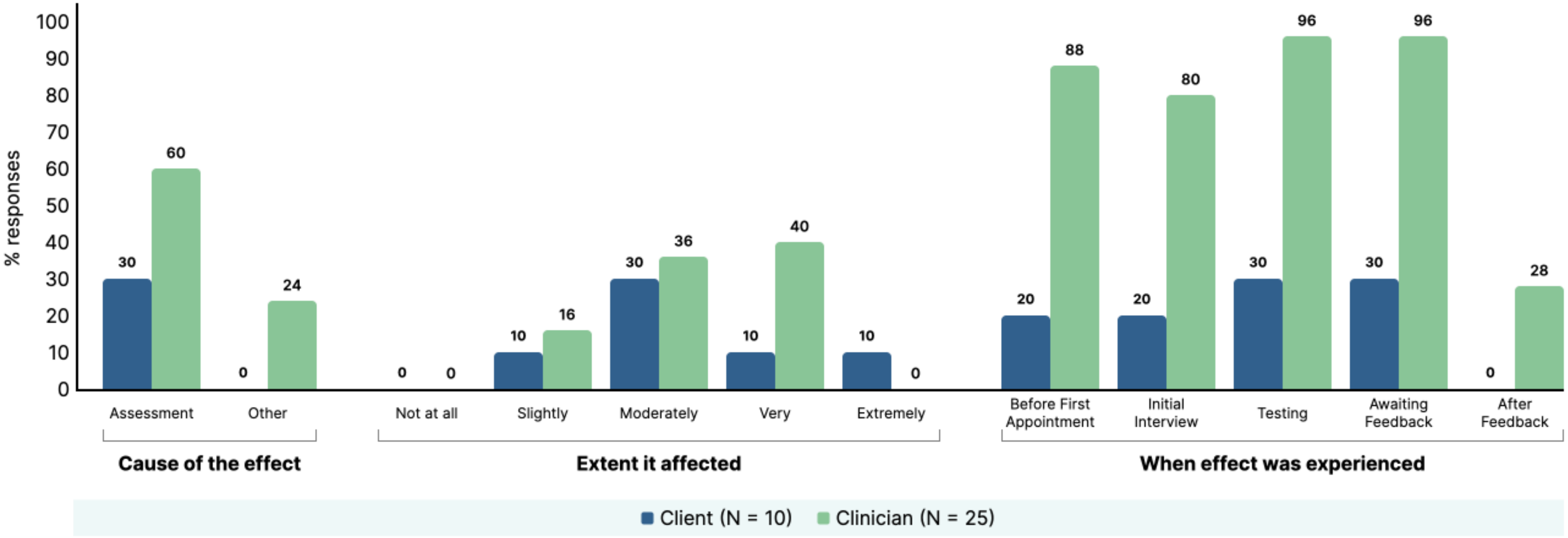


Figure 6. Summary of clinician and client percentage responses for question item 'Stressed'

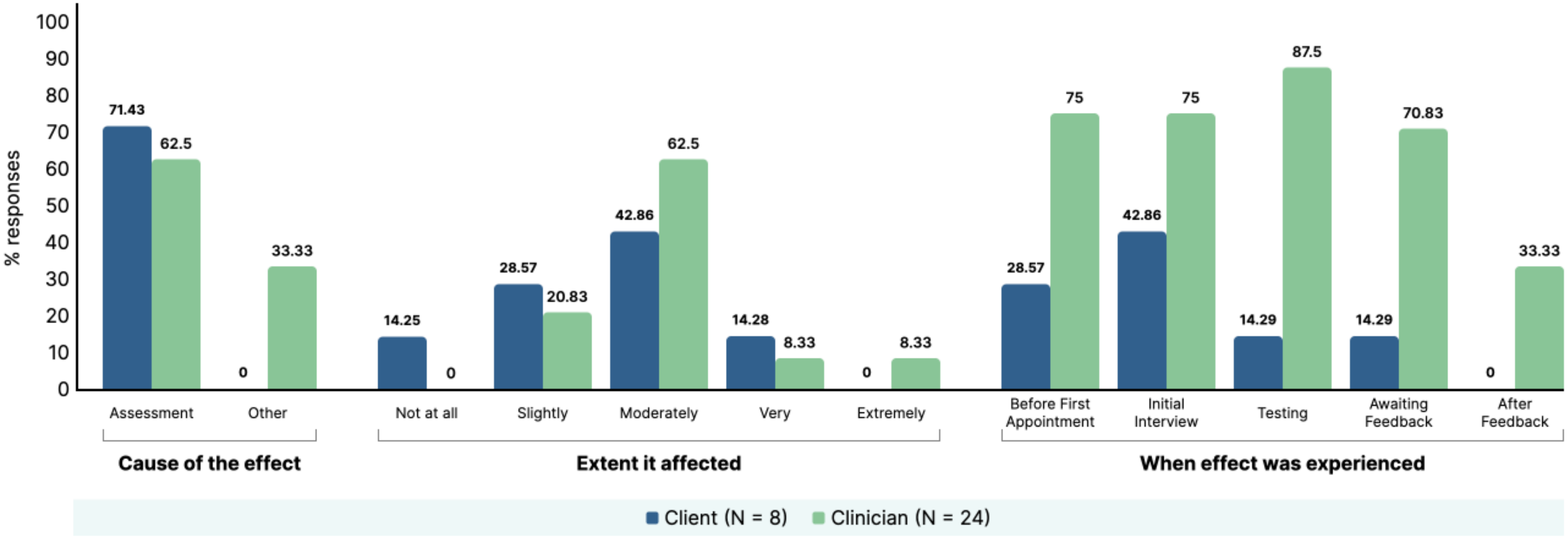
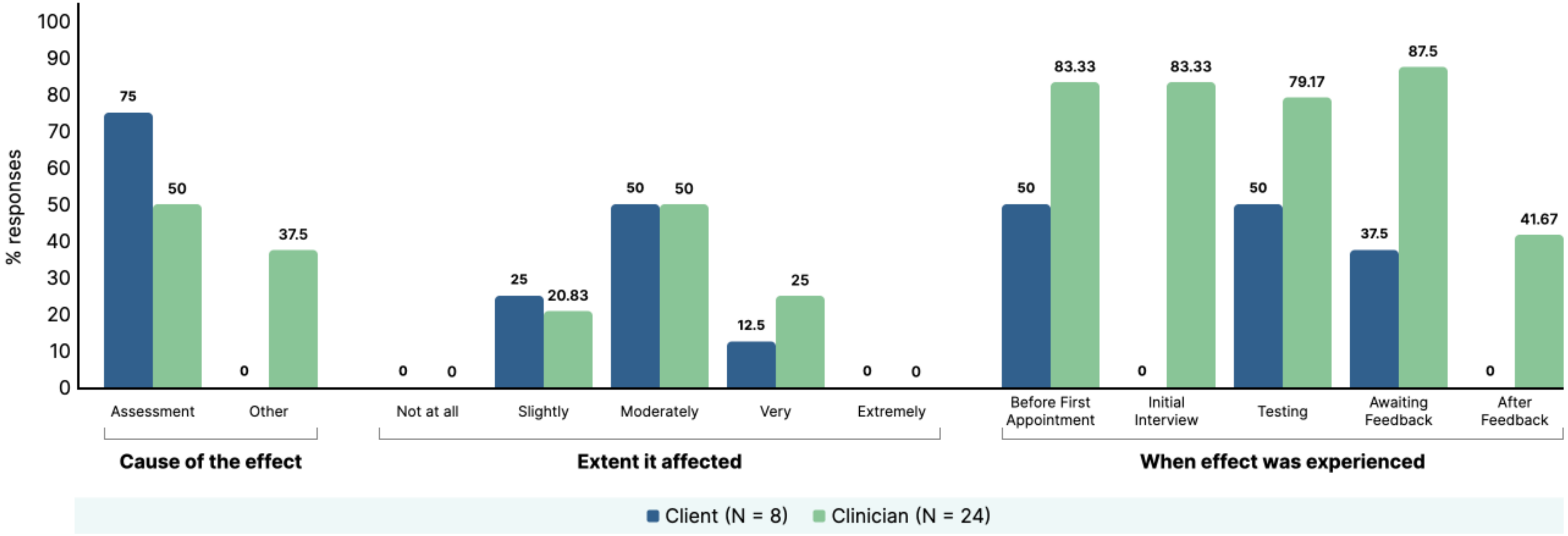


Figure 7. Summary of clinician and client percentage responses for question item 'Worried'



Discussion

This study aimed to investigate clinicians' understanding of negative effects experienced by their clients and explore similarities in what negative effects clients report.

Clinicians understanding of negative effects

RTA identified three key themes describing testing producing negative impacts on clients, indirect factors producing harmful effects of NPA, and clinicians taking action to reduce harmful impacts. All negative effects stated in the questionnaire were endorsed by at least one clinician, indicating all the effects have been observed to a greater or lesser extent. The most endorsed effects were stressed, worried, disappointed with performance on the testing, frustrated with self, critical of self and worried about the outcome. These results are consistent with the emotional experiences reported from clients' experience of NPA in a range of populations with neurological conditions including dementia (Blake, 2004; Gruters et al., 2021; Owen, 2012; Robinson, 2016; Sweetman, 2018). The results indicate that within NPA for assessing dementia, clinicians are aware of potential negative effects. This is a contrast to psychological therapy research where only 28% of clinicians reported awareness of harms (Boisvert & Faust, 2006). With 11% of clinicians reported learning about negative effects during training (Bystedt et al., 2014), there is a need for teaching on possible harms from psychological practice and how clinicians navigate these.

This study supports previous research (Gruters et al., 2021; Robinson 2016), that testing increases awareness of difficulties which impacts self-confidence and increases self-criticism. As contact with the assessing clinician often ceases after NPA concludes, it is unknown whether these impacts persist, and whether clinician intervention can minimise the possibility of lasting negative effects.

Robinson (2016) reported that clients' self-perceptions of their performance influenced their affect, and perceiving poor performance triggered negative emotional experiences and worry about decline in cognition. These self-appraisals are more common in the absence of performance feedback which is standard procedure in NPA administration. In this study clinicians spoke of praising efforts throughout testing when they cannot give feedback and validating frustration when it arises. Clinicians' interpersonal skills and ability to remain attuned to clients, appear critical for minimising possible harms and is reflected in NPA guidance (Lezak et al., 2004) stating a clinicians' role is to be aware of all the factors that would be detrimental for clients' performance.

The importance of a good rapport as identified in previous studies (Blake, 2004; Owen, 2012; Sweetman, 2018) was emphasised by clinicians in this study, who acknowledged their role in creating an environment that was conducive to a valid and comfortable assessment. Clinicians acknowledged the presence of power dynamics and the influence of external factors on their clients' attendance at appointments. It was clear from clinician reports that gaining informed consent and ensuring clients felt involved in the decision making on whether to proceed was a key part of the assessment. Research has found that most older adults want to be active participants in decisions around healthcare (Wolff & Boyd, 2015) however this conflicts with research suggesting older adults are more passive in healthcare decisions place trust in their doctor's view of their needs (Kahana et al., 2018). Clinicians in the context of dementia assessment are in a position of power and encouraging clients to be active participants in decisions about engaging in the process is crucial when the outcome may involve a terminal diagnosis and they may have felt external pressure to attend NPA.

Negative effects reported by clients

The most endorsed effect for clients was worry about the outcome of the assessment, followed by general worry, disappointment with their performance on tasks, stress, frustration and self-criticism. Recruitment difficulties and high rates of missing data necessitate cautious interpretation.

Four of the questionnaires had significant missing data. Missing data rates were higher for all, in the follow up questions which included the extent it the effect impacted them, when it was present during NPA and whether it was due to the assessment specifically or other circumstances. These questions may not have been as well understood as the initial yes/no presence of negative effects. Level of cognitive impairment has been found to impact data quality (Kutschar et al., 2019) and response patters in questionnaires were associated with risk of future dementia diagnosis (Schneider et al., 2021). Levels of cognitive impairment in this study may have impacted completion of the questionnaire and it is imperative that researchers ensure accessible methods of collecting feedback. Factors that could improve data quality such as support from a caregiver were not investigated in this study, but it is feasible that reducing the cognitive burden of the questionnaire may improve engagement. The researcher supported two participants to complete the questionnaire and there was no missing data.

Representative recruitment of people with dementia in research has faced challenges, with prevalence rates, specific subtypes and comorbidities not accurately reflected in research (Jongsma et al., 2016). Key challenges have included ill health, adjustment to diagnosis and study burden (Field et al., 2019), and extended timeframes to successfully recruit were needed.

Clinicians are often the gatekeepers to clients accessing research, and recruitment challenges may be further impacted by clinicians' reservations. Duty of care to patients, worries about burdening them, and clinician attitudes towards research can prevent research referrals (Kars et al., 2015). Clinician gatekeeping has been argued to have adverse ethical implications such as denying clients self-determination, and preventing representative samples which creates biases in understanding true effectiveness of interventions (Sharkey et al., 2010). In this study clinicians' decision making is not well understood but client distress and level of cognitive impairment was expressed.

What similarities and differences are noted in client and clinician reports of client negative effects?

Descriptive statistics and Fisher's Exact comparisons must be interpreted with caution, however it was of interest that the top six most endorsed effects were the same between clinicians and clients. There were similar agreement levels of endorsement for some negative effects but significant differences in others. Larger recruitment numbers would be required to make inferences about these trends. Clinicians more commonly reported negative effects to be present compared with clients, which could be due to their wide-ranging experience conducting NPA and clients only having their own experience to draw on, or it may be due to the larger sample of clinicians in this study.

Strengths and limitations

This study is the first to understand clinicians' views of negative effects experienced by their clients. The exploration of views of clinicians and reports from clients has added to the limited understanding of negative effects from NPA. Another strength was the representation of different diagnoses, despite low recruitment numbers, as this is reflective of the range of clients attending NPA.

There are several limitations impacting the credibility and generalisability of the results. Recruitment of client participants was lower than expected and, missing data was relatively high. Although feedback from clients was sought at the development stage, formal acceptability and feasibility investigations have not been undertaken. This would be beneficial given the difficulties with recruitment and data quality.

Due to the possibility of clinician gatekeeping, this may have introduced bias as the participants not referred, particularly those due to concerns about distress, may have been more likely to report negative experiences. Additionally those who were referred who had negative affect may have been less willing to engage with research, or those given a diagnosis may not have felt the time was right to engage in research as noted by Field et al. (2019). Increasing access to research to ensure representative samples could be improved by working closely with clinicians and embedding a culture of research within healthcare settings.

There was no ethnic diversity in the client sample. This was consistent with census data indicating Scotland to be predominantly White (96.02%; Scotland's Census, 2011). Thus, the views identified in this study cannot be said to be representative of those from minority ethnic groups, as cultural factors can impact client experience, and clinician interpretation, of NPA (Ardila, 2020).

Clinical implications

Although there are limitations in this study as identified above, the interviews and questionnaires identified commonly experienced negative effects. It is good clinical practice to explain to clients during pre-diagnostic counselling (PDC) possible negative experiences they might encounter to ensure they are fully informed before proceeding. An update of Williams (2002) PDC guidance to include recognised negative effects may help to better inform future clients and guide clinicians.

This study also highlighted some of the challenges in obtaining client experience data which ultimately prevents services from evaluating their service delivery. The challenge of seeking views of older adults may be further complicated by possible cognitive impairment but it is important for clinicians to adapt current methods to improve accessibility to methods of feedback rather than exclude them from this opportunity.

These implications are in line with Scotland's vision of Realistic Medicine, to provide healthcare that is valued by the people receiving the services by listening to what matters to them (Scottish Government, 2017b). This approach encourages value-based health care and highlights that informing clients about possible risks and benefits of a service is key to reduce harm and ensure efficiency of services. It is important to ask clients directly about possible negative effects to show them that there is a willingness to understand these factors to improve their experience, particularly if older adults are indeed more likely to trust their clinician (Kahana et al., 2018) as they may less spontaneously report negative effects.

Future Research

Acceptability and feasibility studies with larger samples would be important to gain a better understanding of how accessible this questionnaire is for a range of cognitive presentations, and what factors could improve accessibility to reduce missing data. With no current valid or reliable measure, obtaining accurate information of prevalence rates of negative effects of NPA during dementia assessment is prevented.

It may also be that clients did not endorse particular question items because they were not in the language they would use to describe their difficulties. Further qualitative research to include views of clients and families would help our understanding of what negative effects are present, how people describe these and in what ways they feel able to share their feedback with services.

When progressing this research it would be important to operationalise what is meant by negative effects. Parry et al. (2016) acknowledged the problem in psychotherapy harm literature is that improved understanding has been hindered by a lack of consistent language and definition of what constitutes harm, and additionally a lack of reporting harms within published research. It would be important to distinguish between expected negative effects that are transitory and those that may be more severe and enduring as this study did not identify if the reported effects had a longer-term impact than the duration of assessment.

Conclusions

This study has provided insights into the negative experiences of clients undergoing NPA for differential diagnosis of dementia as observed by clinicians and reported by clients.

The study has highlighted challenges in obtaining client perspectives due to barriers in engaging them in research processes, and possible barriers completing the questionnaire used.

Future research would benefit from examining acceptability and feasibility of this questionnaire by recruiting larger sample of participants, considering qualitative methods to explore client and family perception of NPA, and operationalising the definition of negative effects.

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Appendices

Appendix 1.1 Search strategies

CINAHL (EBSCOhost)

1. (MH "Telecommunications") OR (MH "Telepsychiatry") OR (MH "Telehealth") OR (MH "Remote Consultation") OR (MH "Teleconferencing") OR (MH "Telemedicine") OR (MH "Videoconferencing") OR (MH "Digital Health") OR (MH "Telephone") (52,535)
2. TI ("tele*" OR "video*" OR "remote" OR "online" OR "cyber" OR "digital" OR "distance" OR "internet*" OR "computer*" OR "web*" OR "ehealth" OR "e-health") OR AB ("tele*" OR "video*" OR "remote" OR "online" OR "cyber" OR "digital" OR "distance" OR "internet*" OR "computer*" OR "web*" OR "ehealth" OR "e-health") (451,563)
3. S1 OR S2 (471,818)
4. (MH "Neuropsychological Tests") OR (MH "Neuropsychology") (40,206)
5. TI (("neuropsychol*" OR "cogniti*") n3 ("test*" OR "assess*" OR "batter*" OR "screen*" OR "evaluation" OR "task*")) OR AB (("neuropsychol*" OR "cogniti*") n3 ("test*" OR "assess*" OR "batter*" OR "screen*" OR "evaluation" OR "task*")) (34,296)
6. S4 OR S5 (62,809)
7. S3 AND S6 (5,464)
8. (MH "Patient Satisfaction") OR (MH "Patient Attitudes") OR (MH "Consumer Attitudes") OR (MH "Consumer Satisfaction") OR (MH "Patient-Reported Outcomes") (135,879)
9. TI (("patient*" OR "participant*" OR "user*" OR "consumer*" OR "client*") n10 ("experience*" OR "satisfaction" OR "view*" OR "accept*" OR "feedback" OR "perception*" OR "perspective*" OR "report*" OR "attitude*")) OR AB (("patient*" OR "participant*" OR "user*" OR "consumer*" OR "client*") n10 ("experience*" OR "satisfaction" OR "view*" OR "accept*" OR "feedback" OR "perception*" OR "perspective*" OR "report*" OR "attitude*")) (455,320)
10. S8 OR S9 (534,803)
11. S7 AND S10 (820)
12. S7 AND S10 with English limiter (818)

EMBASE (OVID)

1. telecommunication/ or teleconference/ or teleconsultation/ 43346
2. telemedicine/ or telehealth/ or telepsychiatry/ or telepsychology/ or video consultation/ 54006
3. videoconferencing/ 7519
4. telephone/ 43162
5. online system/ 29638

6. (tele* or video* or remote or online or cyber or digital or distance or internet* or computer* or web* or ehealth or e-health).tw. 1852549
7. 1 or 2 or 3 or 4 or 5 or 6 1900465
8. neuropsychological test/ 69642
9. neuropsychology/ 20227
10. ((neuropsychol* or cogniti*) adj3 (test* or assess* or batter* or screen* or evaluation or task*)).tw. 135420
11. 8 or 9 or 10 184589
12. patient satisfaction/ 159656
13. patient preference/ 24023
14. ((patient* or participant* or user* or consumer* or client*) adj10 (experience* or satisfaction or view* or accept* or feedback or perception* or perspective* or report* or attitude*)).tw. 1855204
15. 12 or 13 or 14 1937340
16. 7 and 11 and 15 2436
17. limit 16 to english 2392

Medline (OVID)

1. telecommunications/ or telemedicine/ or telephone/ or videoconferencing/ (52641)
2. Remote Consultation/(5595)
3. (tele* or video* or remote or online or cyber or digital or distance or internet* or computer* or web* or ehealth or e-health).tw. (1178935)
4. 1 or 2 or 3 (1192699)
5. Neuropsychological Tests/ (101774)
6. Neuropsychology/ (2565)
7. ((neuropsychol* or cogniti*) adj3 (test* or assess* or batter* or screen* or evaluation or task*)).tw. (77813)
8. 5 or 6 or 7 (148915)
9. patient satisfaction/ or patient preference/ (98031)
10. ((patient* or participant* or user* or consumer* or client*) adj10 (experience* or satisfaction or view* or accept* or feedback or perception* or perspective* or report* or attitude*)).tw. (1030100)
11. 9 or 10 (1075656)
12. 4 and 8 and 11 (1262)
13. limit 12 to english language (1228)

Psychology and Behavioral Sciences Collection (EBSCOhost)

1. DE "DIGITAL health" OR DE "TELEMEDICINE" OR DE "MOBILE health" OR DE "TELEPSYCHOLOGY" OR DE "VIDEOCONFERENCING" (1,662)
2. TI ("tele*" OR "video*" OR "remote" OR "online" OR "cyber" OR "digital" OR "distance" OR "internet*" OR "computer*" OR "web*" OR "ehealth" OR "e-health") OR AB ("tele*" OR "video*" OR "remote" OR "online" OR "cyber" OR "digital" OR "distance" OR "internet*" OR "computer*" OR "web*" OR "ehealth" OR "e-health") (89,032)
3. S1 OR S2 (89,375)
4. DE "NEUROPSYCHOLOGICAL tests" (4,664)
5. TI (("neuropsychol*" OR "cogniti*") n3 ("test*" OR "assess*" OR "batter*" OR "screen*" OR "evaluation" OR "task*")) OR AB (("neuropsychol*" OR "cogniti*") n3 ("test*" OR "assess*" OR "batter*" OR "screen*" OR "evaluation" OR "task*")) (14,102)
6. S4 OR S5 (16,189)
7. S3 AND S6 (1,565)
8. DE "PATIENT satisfaction" (1,865)
9. TI (("patient*" OR "participant*" OR "user*" OR "consumer*" OR "client*") n10 ("experience*" OR "satisfaction" OR "view*" OR "accept*" OR "feedback" OR "perception" OR "perspective" OR "report*" OR "attitude*")) OR AB (("patient*" OR "participant*" OR "user*" OR "consumer*" OR "client*") n10 ("experience*" OR "satisfaction" OR "view*" OR "accept*" OR "feedback" OR "perception" OR "perspective" OR "report*" OR "attitude*")) (63,514)
10. S8 OR S9 (64,165)
11. S7 AND S10 (218)
12. S7 AND S10 with English limiter (218)

PsycInfo (Ebscohost)

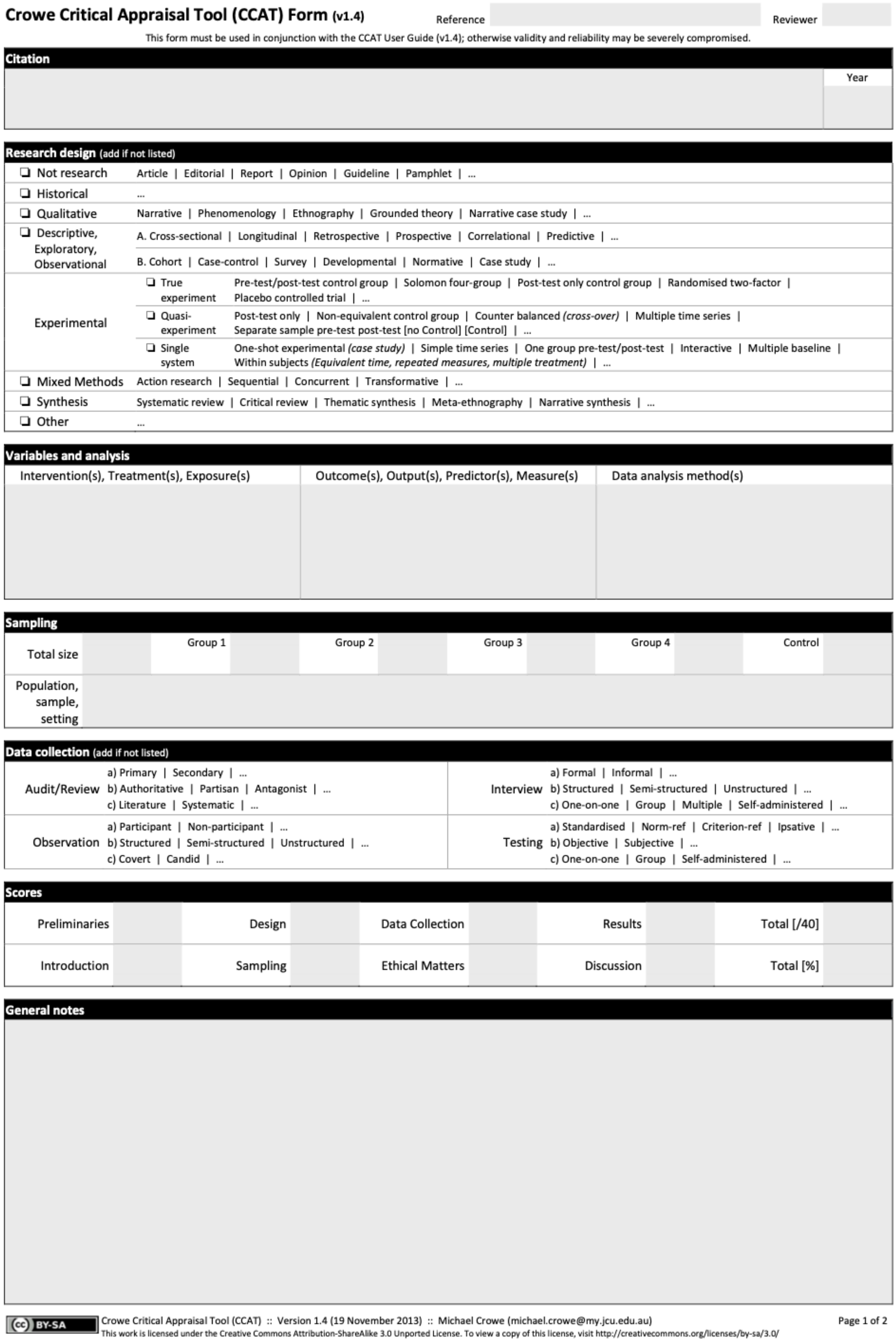
1. DE "Telemedicine" OR DE "Teleconferencing" OR DE "Teleconsultation" OR DE "Telepsychiatry" OR DE "Telepsychology" OR DE "Digital Interventions" OR DE "Videoconferencing" (10,863)
2. TI ("tele*" OR "video*" OR "remote" OR "online" OR "cyber" OR "digital" OR "distance” OR "internet*" OR "computer*" OR "web*" OR "ehealth" OR "e-health") OR AB ("tele*" OR "video*" OR "remote" OR "online" OR "cyber" OR "digital" OR "distance” OR "internet*" OR "computer*" OR "web*" OR "ehealth" OR "e-health") (447,273)
3. S1 OR S2 (448,543)
4. DE "Neuropsychological Assessment" OR DE "Cognitive Assessment" (21,521)
5. TI (("neuropsychol*" OR "cogniti*") n3 ("test*" OR "assess*" OR "batter*" OR "screen*" OR "evaluation" OR "task*")) OR AB (("neuropsychol*" OR "cogniti*") n3 ("test*" OR "assess*" OR "batter*" OR "screen*" OR "evaluation" OR "task*")) (86,695)
6. S4 or S5 (94,564)
7. S3 AND S6 (9,141)

8. DE "Client Attitudes" OR DE "Client Satisfaction" OR DE "Consumer Attitudes" OR DE "Consumer Satisfaction" (45,531)
9. TI (("patient*" OR "participant*" OR "user*" OR "consumer*" OR "client*") n10 ("experience*" OR "satisfaction" OR "view*" OR "accept*" OR "feedback" OR "perception*" OR "perspective*" OR "report*" OR "attitude*")) OR AB (("patient*" OR "participant*" OR "user*" OR "consumer*" OR "client*") n10 ("experience*" OR "satisfaction" OR "view*" OR "accept*" OR "feedback" OR "perception*" OR "perspective*" OR "report*" OR "attitude*")) (351,327)
10. S8 OR S9 (374,159)
11. S7 AND S10 (994)
12. S7 AND S10 with English limiter (978)

Web of Science: Core Collection

1. (TI=("tele*" OR "video*" OR "remote" OR "online" OR "cyber" OR "digital" OR "distance" OR "internet*" OR "computer*" OR "web*" OR "ehealth" OR "e-health")) OR AB=("tele*" OR "video*" OR "remote" OR "online" OR "cyber" OR "digital" OR "distance" OR "internet*" OR "computer*" OR "web*" OR "ehealth" OR "e-health") (4,592,148)
2. (TI=(("neuropsychol*" OR "cogniti*") NEAR/3 ("test*" OR "assess*" OR "batter*" OR "screen*" OR "evaluation" OR "task*")) OR AB=(("neuropsychol*" OR "cogniti*") NEAR/3 ("test*" OR "assess*" OR "batter*" OR "screen*" OR "evaluation" OR "task*"))). **(**117,395)
3. (TI=(("patient*" OR "participant*" OR "user*" OR "consumer*" OR "client*") NEAR/10 ("experience*" OR "satisfaction" OR "view*" OR "accept*" OR "feedback" OR "perception*" OR "perspective*" OR "report*" OR "attitude*")) OR AB=(("patient*" OR "participant*" OR "user*" OR "consumer*" OR "client*") NEAR/10 ("experience*" OR "satisfaction" OR "view*" OR "accept*" OR "feedback" OR "perception*" OR "perspective*" OR "report*" OR "attitude*"))) (1,378,783)
4. #1 AND #2 AND #3 (1,483)
5. #1 AND #2 AND #3 **and** English (Languages) (1461)

Appendix 1.2 CCAT Quality Appraisal Tool



Crowe Critical Appraisal Tool (CCAT) Form (v1.4) Reference Reviewer

This form must be used in conjunction with the CCAT User Guide (v1.4); otherwise validity and reliability may be severely compromised.

Citation

Year

Research design (add if not listed)

☐ Not research		Article | Editorial | Report | Opinion | Guideline | Pamphlet | …
☐ Historical		…
☐ Qualitative		Narrative | Phenomenology | Ethnography | Grounded theory | Narrative case study | …
☐ Descriptive, Exploratory, Observational		A. Cross-sectional | Longitudinal | Retrospective | Prospective | Correlational | Predictive | …
		B. Cohort | Case-control | Survey | Developmental | Normative | Case study | …
Experimental	☐ True experiment	Pre-test/post-test control group | Solomon four-group | Post-test only control group | Randomised two-factor | Placebo controlled trial | …
	☐ Quasi-experiment	Post-test only | Non-equivalent control group | Counter balanced *(cross-over)* | Multiple time series | Separate sample pre-test post-test [no Control] [Control] | …
	☐ Single system	One-shot experimental *(case study)* | Simple time series | One group pre-test/post-test | Interactive | Multiple baseline | Within subjects *(Equivalent time, repeated measures, multiple treatment)* | …
☐ Mixed Methods		Action research | Sequential | Concurrent | Transformative | …
☐ Synthesis		Systematic review | Critical review | Thematic synthesis | Meta-ethnography | Narrative synthesis | …
☐ Other		…

Variables and analysis

Intervention(s), Treatment(s), Exposure(s)	Outcome(s), Output(s), Predictor(s), Measure(s)	Data analysis method(s)

Sampling

Total size		Group 1		Group 2		Group 3		Group 4		Control	
Population, sample, setting											

Data collection (add if not listed)

Audit/Review	a) Primary | Secondary | … b) Authoritative | Partisan | Antagonist | … c) Literature | Systematic | …	Interview	a) Formal | Informal | … b) Structured | Semi-structured | Unstructured | … c) One-on-one | Group | Multiple | Self-administered | …
Observation	a) Participant | Non-participant | … b) Structured | Semi-structured | Unstructured | … c) Covert | Candid | …	Testing	a) Standardised | Norm-ref | Criterion-ref | Ipsative | … b) Objective | Subjective | … c) One-on-one | Group | Self-administered | …

Scores

Preliminaries		Design		Data Collection		Results		Total [/40]	
Introduction		Sampling		Ethical Matters		Discussion		Total [%]	

General notes

Appraise research on the merits of the research design used, not against other research designs.

Category Item	Item descriptors [☑ Present; ☒ Absent; ■ Not applicable]	Description [Important information for each item]	Score [0–5]
1. Preliminaries			
Title	1. Includes study aims ☐ and design ☐		
Abstract (assess last)	1. Key information ☐ 2. Balanced ☐ and informative ☐		
Text (assess last)	1. Sufficient detail others could reproduce ☐ 2. Clear/concise writing ☐, table(s) ☐, diagram(s) ☐, figure(s) ☐		
		Preliminaries [/5]	
2. Introduction			
Background	1. Summary of current knowledge ☐ 2. Specific problem(s) addressed ☐ and reason(s) for addressing ☐		
Objective	1. Primary objective(s), hypothesis(es), or aim(s) ☐ 2. Secondary question(s) ☐		
	Is it worth continuing?	**Introduction [/5]**	
3. Design			
Research design	1. Research design(s) chosen ☐ and why ☐ 2. Suitability of research design(s) ☐		
Intervention, Treatment, Exposure	1. Intervention(s)/treatment(s)/exposure(s) chosen ☐ and why ☐ 2. Precise details of the intervention(s)/treatment(s)/exposure(s) ☐ for each group ☐ 3. Intervention(s)/treatment(s)/exposure(s) valid ☐ and reliable ☐		
Outcome, Output, Predictor, Measure	1. Outcome(s)/output(s)/predictor(s)/measure(s) chosen ☐ and why ☐ 2. Clearly define outcome(s)/output(s)/predictor(s)/measure(s) ☐ 3. Outcome(s)/output(s)/predictor(s)/measure(s) valid ☐ and reliable ☐		
Bias, etc	1. Potential bias ☐, confounding variables ☐, effect modifiers ☐, interactions ☐ 2. Sequence generation ☐, group allocation ☐, group balance ☐, and by whom ☐ 3. Equivalent treatment of participants/cases/groups ☐		
	Is it worth continuing?	**Design [/5]**	
4. Sampling			
Sampling method	1. Sampling method(s) chosen ☐ and why ☐ 2. Suitability of sampling method ☐		
Sample size	1. Sample size ☐, how chosen ☐, and why ☐ 2. Suitability of sample size ☐		
Sampling protocol	1. Target/actual/sample population(s): description ☐ and suitability ☐ 2. Participants/cases/groups: inclusion ☐ and exclusion ☐ criteria 3. Recruitment of participants/cases/groups ☐		
	Is it worth continuing?	**Sampling [/5]**	
5. Data collection			
Collection method	1. Collection method(s) chosen ☐ and why ☐ 2. Suitability of collection method(s) ☐		
Collection protocol	1. Include date(s) ☐, location(s) ☐, setting(s) ☐, personnel ☐, materials ☐, processes ☐ 2. Method(s) to ensure/enhance quality of measurement/instrumentation ☐ 3. Manage non-participation ☐, withdrawal ☐, incomplete/lost data ☐		
	Is it worth continuing?	**Data collection [/5]**	
6. Ethical matters			
Participant ethics	1. Informed consent ☐, equity ☐ 2. Privacy ☐, confidentiality/anonymity ☐		
Researcher ethics	1. Ethical approval ☐, funding ☐, conflict(s) of interest ☐ 2. Subjectivities ☐, relationship(s) with participants/cases ☐		
	Is it worth continuing?	**Ethical matters [/5]**	
7. Results			
Analysis, Integration, Interpretation method	1. A.I.I. method(s) for primary outcome(s)/output(s)/predictor(s) chosen ☐ and why ☐ 2. Additional A.I.I. methods (e.g. subgroup analysis) chosen ☐ and why ☐ 3. Suitability of analysis/integration/interpretation method(s) ☐		
Essential analysis	1. Flow of participants/cases/groups through each stage of research ☐ 2. Demographic and other characteristics of participants/cases/groups ☐ 3. Analyse raw data ☐, response rate ☐, non-participation/withdrawal/incomplete/lost data ☐		
Outcome, Output, Predictor analysis	1. Summary of results ☐ and precision ☐ for each outcome/output/predictor/measure 2. Consideration of benefits/harms ☐, unexpected results ☐, problems/failures ☐ 3. Description of outlying data (e.g. diverse cases, adverse effects, minor themes) ☐		
		Results [/5]	
8. Discussion			
Interpretation	1. Interpretation of results in the context of current evidence ☐ and objectives ☐ 2. Draw inferences consistent with the strength of the data ☐ 3. Consideration of alternative explanations for observed results ☐ 4. Account for bias ☐, confounding/effect modifiers/interactions/imprecision ☐		
Generalisation	1. Consideration of overall practical usefulness of the study ☐ 2. Description of generalisability (external validity) of the study ☐		
Concluding remarks	1. Highlight study's particular strengths ☐ 2. Suggest steps that may improve future results (e.g. limitations) ☐ 3. Suggest further studies ☐		
		Discussion [/5]	
9. Total			
Total score	1. Add all scores for categories 1–8		
		Total [/40]	

Appendix 2.1 Clinician Interview Participant Information Sheet

https://osf.io/nve7y

Appendix 2.2 Privacy Notice Clinicians

https://osf.io/cf2d6

Appendix 2.3 Clinician Interview Consent Form

https://osf.io/cvyk4

Appendix 2.4 Topic Guide Clinician Interview

https://osf.io/yf9bc

Appendix 2.5 Participant Information Sheet Clinician Participant Questionnaire

https://osf.io/ncxj6

Appendix 2.6 Clinician Questionnaire Participant Consent Form

https://osf.io/9azuv

Appendix 2.7 Staff Information sheet

https://osf.io/eyn9z

Appendix 2.8 Client Participant Information Sheet

https://osf.io/n9m37

Appendix 2.9 Privacy Notice Clients

https://osf.io/4yqvr

Appendix 2.10 Client Consent Form

https://osf.io/89zqm

Appendix 2.11 Clinician questionnaire

Negative effects of neuropsychological assessment for dementia. Participant ID: _______________ Date: _______________

University of Glasgow NHS Lanarkshire

Clinician experiences of neuropsychological assessment questionnaire (v1.1)

This questionnaire contains a number of statements about your experience of providing neuropsychological assessment. The questionnaire will ask you to think about how the assessment impacted your clients and specifically will focus on possible negative effects they experienced. We recognise that clients will likely have had positive experiences of assessment but for the purpose of this questionnaire we would ask you to consider only negative experiences.

Read through the following statements. You will be asked to indicate if, to your knowledge, any of your clients experienced the effect at any point during your assessment. If you answer yes you will be asked to rate the severity of this. You will also be asked at what point during the assessment process your clients experienced this. For this question, please mark all options that apply. You will also be asked if you think the neuropsychological assessment was the most likely cause of the effect in question or if it was more likely due to some other circumstance that was happening in clients' lives at the same time as the assessment. When completing this question, consider all clients you think this impacted and select the option you think was more representative for the majority of your clients. Please put a cross (X) in the appropriate boxes. If you answer no initially to any of the experiences, please move on to the subsequent question. You will also be asked to rate the percentage of patients you have worked with that you think this has been a problem for. Please provide an estimate between 0 to 100%. If you had not ever considered prior to completing this questionnaire that the negative effect in question could arise from neuropsychological assessment, please put a cross in the box in the final column.

You can find an example of how to complete the questionnaire on the following page.

Negative effects of neuropsychological assessment for dementia. Participant ID: ______________ Date: ______________

University of Glasgow NHS Lanarkshire

Example completion of questionnaire

	Have any of your clients experienced this before, during or after the assessment?			When it happened, to what extent do you think it affected your client(s)?					At what point in the assessment did they experience this? [Mark all that apply]					In general, what do you think was most likely the cause of this effect?			
	No	Yes	If yes complete next section	Not at all	Slightly	Moderately	Very	Extremely	Before 1st session	During initial interview	During testing	Awaiting feedback	After feedback	The assessment	Other circumstances	Roughly what percentage of your clients do you think this has been a problem for? (0-100%)	Never previously considered effect
1. Stressed	x																
2. Worried		x				x			x		x	x		x		40%	

Negative effects of neuropsychological assessment for dementia. Participant ID: ______________ Date: ______________

Please answer the following questions:	Have any of your clients experienced this before, during or after the assessment?			When it happened, to what extent do you think it affected your client(s)?					At what point in the assessment did they experience this? [Mark all that apply]					In general, what do you think was most likely the cause of this effect?			
	No	Yes	If yes complete next section	Not at all	Slightly	Moderately	Very	Extremely	Before 1st session	During initial interview	During testing	Awaiting feedback	After feedback	The assessment	Other circumstances	Roughly what percentage of your clients do you think this has been a problem for? (0-100%)	Never previously considered effect
1. Stressed																	
2. Worried																	
3. Hopeless																	
4. Sad																	
5. Disappointment with their performance on the tasks																	
6. Frustrated with themselves																	

Please answer the following questions:	Have any of your clients experienced this before, during or after the assessment?			When it happened, to what extent do you think it affected your client(s)?						At what point in the assessment did they experience this? [Mark all that apply]						In general, what do you think was most likely the cause of this effect?				
	No	Yes	If yes complete next section	Not at all	Slightly	Moderately	Very	Extremely		Before 1st session	During initial interview	During testing	Awaiting feedback	After feedback		The assessment	Other circumstances		Roughly what percentage of your clients do you think this has been a problem for? (0-100%)	Never previously considered effect
7. Self-critical																				
8. Had thoughts like it would be better if they did not exist anymore” or that they should take their own life																				
9. Irritable																				
10. Angry																				
11. Embarrassed																				
12. Disempowered																				
13. Stupid																				

Negative effects of neuropsychological assessment for dementia. Participant ID: _______________ Date: _______________

Please answer the following questions:	**Have any of your clients experienced this before, during or after the assessment?**			**When it happened, to what extent do you think it affected your client(s)?**					**At what point in the assessment did they experience this? [Mark all that apply]**					**In general, what do you think was most likely the cause of this effect?**			
	No	**Yes**	**If yes complete next section**	**Not at all**	**Slightly**	**Moderately**	**Very**	**Extremely**	**Before 1st session**	**During initial interview**	**During testing**	**Awaiting feedback**	**After feedback**	**The assessment**	**Other circumstances**	**Roughly what percentage of your clients do you think this has been a problem for? (0-100%)**	**Never previously considered effect**
14. Confused																	
15. Worried about the outcome of the assessment																	
16. Physically tired																	
17. Mentally drained																	
18. Headaches																	
19. Problems with their sleep																	
20. Strain on their family relationships																	

Please answer the following questions:	**Have any of your clients experienced this before, during or after the assessment?**			**When it happened, to what extent do you think it affected your client(s)?**						**At what point in the assessment did they experience this? [Mark all that apply]**						**In general, what do you think was most likely the cause of this effect?**				
	No	**Yes**	**If yes complete next section**	**Not at all**	**Slightly**	**Moderately**	**Very**	**Extremely**		**Before 1st session**	**During initial interview**	**During testing**	**Awaiting feedback**	**After feedback**		**The assessment**	**Other circumstances**		**Roughly what percentage of your clients do you think this has been a problem for? (0-100%)**	**Never previously considered effect**
21. Lost out financially (e.g. travel costs, loss of employment/wages) to attend appointments																				
22. Had to give up significant amounts of their (and/or carer's) time to attend their appointments																				
23. Lost their driver's license																				

Please answer the following questions:	Have any of your clients experienced this before, during or after the assessment?			When it happened, to what extent do you think it affected your client(s)?						At what point in the assessment did they experience this? [Mark all that apply]						In general, what do you think was most likely the cause of this effect?				
	No	Yes	If yes complete next section	Not at all	Slightly	Moderately	Very	Extremely		Before 1st session	During initial interview	During testing	Awaiting feedback	After feedback		The assessment	Other circumstances		Roughly what percentage of your clients do you think this has been a problem for? (0-100%)	Never previously considered effect
24. Did not understand the purpose of the assessment																				
25. Expressed that they did not understand the results of their assessment																				
26. Expressed that they were not made aware of risks involved in the assessment																				

Please answer the following questions:	**Have any of your clients experienced this before, during or after the assessment?**			**When it happened, to what extent do you think it affected your client(s)?**						**At what point in the assessment did they experience this? [Mark all that apply]**						**In general, what do you think was most likely the cause of this effect?**				
	No	**Yes**	**If yes complete next section**	**Not at all**	**Slightly**	**Moderately**	**Very**	**Extremely**		**Before 1st session**	**During initial interview**	**During testing**	**Awaiting feedback**	**After feedback**		**The assessment**	**Other circumstances**		**Roughly what percentage of your clients do you think this has been a problem for? (0-100%)**	**Never previously considered effect**
27. Expressed that they did not feel prepared for what the assessment would involve																				
28. Expressed that they waited too long to receive feedback from their assessment																				

Additional question:

Describe briefly in your own words any additional negative effects related to the assessment process you think your clients have experienced that have not been covered above:

____

____

____

Please also complete the following questions:

1. **How long have you been qualified as a Clinical Psychologist?** ______________
2. **How long have you been administering neuropsychological assessments?** __________________
3. **How many neuropsychological assessments roughly have you completed?** _________________
4. **What service do you currently work in?** ____
5. **What services have you previously worked in administering neuropsychological assessment?** ____

Appendix 2.12 Client questionnaire

Negative effects of neuropsychological assessment for dementia Participant ID: ____________________ Date: ________________

University of Glasgow NHS Lanarkshire

Client experiences of Neuropsychological assessment questionnaire (v1.1)

This questionnaire contains a number of statements about your recent experience of neuropsychological assessment. The questionnaire will ask you to think about how the assessment impacted you and will focus on any possible negative effects you might have experienced. We recognise that you might have had a positive experience but for the purpose of this questionnaire we would ask you to consider only negative experiences.

Read through the following statements. You will be asked to indicate if you experienced the effect at any point during your assessment. If you answer yes you will be asked to rate the severity of this. You will then be asked when in the assessment process you experienced this. Please mark all options that apply to you. You will also be asked if you think the neuropsychological assessment was the direct cause of this or if it was because of some other circumstance that was happening in your life at the same time as your assessment. Please put a cross (X) in the appropriate boxes. If you answer no to experiencing any of the effects, please move on to the subsequent question.

Example of how to complete the questionnaire

	Did you experience this before, during or after the assessment?			To what extent did this affect you?						At what point in the assessment did you experience this? [Mark all that apply]						Cause of this negative effect?	
	No	Yes	If yes complete next section	Not at all	Slightly	Moderately	Very	Extremely		Before 1st session	During initial interview	During testing	Awaiting feedback	After feedback		My assessment	Other circumstances
1. I felt stressed	X																
2. I felt worried		X			X					X		X				X	

Negative effects of neuropsychological assessment for dementia Participant ID: ____________________ Date: _________________

University of Glasgow NHS Lanarkshire

Please answer the following questions:	**Did you experience this before, during or after the assessment?**			**To what extent did this affect you?**						**At what point in the assessment did you experience this? [Mark all that apply]**						**Cause of this negative effect**	
	No	**Yes**	**If yes complete next section**	**Not at all**	**Slightly**	**Moderately**	**Very**	**Extremely**		**Before 1st session**	**During initial interview**	**During testing**	**Awaiting feedback**	**After feedback**		**My assessment**	**Other circumstances**
1. I felt stressed																	
2. I felt worried																	
3. I felt hopeless																	
4. I felt sad																	
5. I was disappointed with my performance on the tasks																	
6. I was frustrated with myself																	
7. I was critical of myself																	
8. I got thoughts like “it would be better if I did not exist anymore” or that “I should take my own life”																	
9. I felt irritable																	
10. I felt angry																	

Please answer the following questions:	**Did you experience this before, during or after the assessment?**			**To what extent did this affect you?**						**At what point in the assessment did you experience this? [Mark all that apply]**						**Cause of this negative effect**	
	No	**Yes**	**If yes complete next section**	**Not at all**	**Slightly**	**Moderately**	**Very**	**Extremely**		**Before 1st session**	**During initial interview**	**During testing**	**Awaiting feedback**	**After feedback**		**My assessment**	**Other circumstances**
11. I felt embarrassed																	
12. I felt disempowered																	
13. I felt stupid																	
14. I felt confused																	
15. I worried about the outcome of the assessment																	
16. I felt physically tired																	
17. I felt mentally drained																	
18. I had headaches																	
19. I had problems with my sleep																	
20. I experienced strain on my family relationships																	

Please answer the following questions:	Did you experience this before, during or after the assessment?			To what extent did this affect you?						At what point in the assessment did you experience this? [Mark all that apply]						Cause of this negative effect	
	No	Yes	If yes complete next section	Not at all	Slightly	Moderately	Very	Extremely		Before 1st session	During initial interview	During testing	Awaiting feedback	After feedback		My assessment	Other circumstances
21. I lost out financially (e.g. travel costs, loss of employment/wages) to attend the appointments																	
22. I (or my family member/carer) had to give up significant amounts of time to attend the appointments																	
23. I lost my drivers license																	
24. I did not understand the purpose of the assessment																	
25. I did not understand the results of the assessment																	
26. I was not made aware of risks involved in the assessment																	
27. I did not feel prepared for what the assessment involved																	

Please answer the following questions:	**Did you experience this before, during or after the assessment?**			**To what extent did this affect you?**						**At what point in the assessment did you experience this? [Mark all that apply]**						**Cause of this negative effect**	
	No	**Yes**	**If yes complete next section**	**Not at all**	**Slightly**	**Moderately**	**Very**	**Extremely**		**Before 1st session**	**During initial interview**	**During testing**	**Awaiting feedback**	**After feedback**		**My assessment**	**Other circumstances**
28. I waited too long to receive feedback from my assessment																	

Additional question:

Describe briefly in your own words whether you experienced any other negative effects directly related to the assessment process that have not been covered above

____
____
____
____
____
____
____

Please also complete the following questions:

1. **What age are you?** ____________
2. **What is your gender?** __________
3. **What is your ethnicity?** ________
4. **Did your neuropsychological assessment lead to any diagnoses (e.g mild cognitive impairment, dementia), if yes please specify** _____________
5. **What, if any, physical health conditions have you been diagnosed with?** ____
6. **What, if any, mental health conditions have you been diagnosed with?** ____

Appendix 2.15 Summary of themes

Theme	Subordinate theme (n participant expressing theme)	Quotes to illustrate theme
Testing can produce negative impacts on clients	**1. Emotional experiences (11)**	P1 “general test anxiety that some people will say in advance that you know that they don't enjoy such tests or they're not good at them. And they're so you can see some people seeming to tense up around certain tests just at the outset.” P1 “if you or I went in for a test of any sort, you might have sort of you know a slight sort of anticipation or just the kind of anxiety that sharpens you up” P1 “it's a bit like if you are going in for a blood test for something or if you're going in for a scan of a certain part of your body because there's things being queried. So you are in for a medical investigation in a clinical setting. And I mean, these things are sort of inherently a little bit ((in overlap Researcher: Mmm. Yeah)) anxiety provoking and serious aren't they” P2 “So I had somebody recently who's breathing, got quite laboured, and there were was quite an audible change emm some people might kind of give up in the middle of testing. Like, say, ‘oh, it's too hard. I can't do it’.”PI02 “then the feedback, I think some anxiety is normal because they don't know what outcome they're gonna get. But I'd say there's less like visible signs of anxiety or distress.” P2 “a large number might predict anxiety so during like the pre diagnostic counselling might say, ‘oh, I'm not sure if I want to do this, the testing, I’m a bit anxious about it’. I've had quite a few people recently say, ‘oh, that wasn't as bad as I thought’” P3 “some people find it a very high pressure emm kind of aversive experience and for some people it is very difficult to tolerate and that's not always kinda correlating with the extent to which they're having, you know, cognitive difficulties” P4 “I think any of us would would feel quite anxious in that kind of situation, getting put on the spot. Particularly when it can have, you know, quite significant life changing, kind of consequences the outcome of this assessment”

		P4 “I would say a mild level of anxiety would probably be present in most of the people I would see, not necessarily to clinical extent not, you know, can talk about kind of clinical presentation of anxiety, but certainly some nervousness and apprehension about completing the testing I would say is present in. I don't know. Maybe like 80% of the people that I've seen in the past. In terms of a kind of clinical level anxiety would be much lower.” P5 “So people do get anxious about their performance at times. So it's not nice to see someone feeling anxious while doing tests. I discontinue at that point. Because one, it’s unethical and two you’re not assessing that organic abilities, you're assessing how performance anxiety effects cognitive performance.” P6 “you’ll get test anxiety performance, where people, it's almost like a school test they get worked up. You can see it in their face, you can see in the body language and it’s usually up the clinician at that point to pick up on that and say do you want to pause? Like what's going on for you at this point in your mind? Now the manuals might not tell you to do that but psychological assessment is a process and a tool, the manuals are very academic, they are made in academic settings, when it comes to real life practice with human beings across from us. So I'd say that's where it becomes a bit of an art” P6 “Yes, it will be upsetting but ultimately, people go through that, though, to get to an answer to help any kind of interventions that might be there. So while there's discomfort, perhaps some distress, it’s a necessary evil in the overall process. As long as the clinicians attuned to their patient, you should be able to manage that in a session by session basis” P7 “less often I get anxiety type distress and anticipatory anxiety type distress, but I suppose probably having done it for so long, I can I can I can see it. You can support people around the anticipatory anxiety a lot easier than you can this sort of feeling a bit stupid when you're doing it angst that that some get.” P9 “especially people who've been like maybe professionals or been quite high functioning. I think they can just be a bit, they can be a bit embarrassed, you know”

		P11 “Maybe sort of low level anxiety is a little bit more frequent, but not so to the extent that it's disrupting” P11 “The frustration is very common. I would say in terms of this frustration generally, probably 80% of my cases.” P11 “I suppose you know when you’re doing an assessment process that has the potential at the end of it to tell someone that they have a terminal diagnosis I think we have to as clinicians recognise that is that is very likely to cause someone distress and we cannot mitigate that, and nor should we.”
	2. Reduced self-confidence and self-criticism (6)	P2 “I definitely do think that people report throughout it ‘Oh I'm doing really bad’ and ‘all this is terrible’ and so that kind of impact on self-confidence” P3 “It's particularly difficult for people who have good insight into their difficulties but do have significant difficulties and have previously been very independent, high functioning people, it can just really knock they're kind of sense of self, sense of self-worth.” P4 “But suppose sometimes I've seen people who can be quite self critical sometimes if they’ve got insight into maybe doing poorly on on some of the tests and so that can lead to a bit of a dip in mood for some people as well.” P5 “Or they would say like the person I had this morning “oh I’m making a total mess of this. Just making this worse. God, this is terrible”. Those kind of self-narrations. So I'm labeling all of those loss of confidence. But maybe I should say, awareness of insight, maybe I’m making an assumption but you can see it in people’s faces they are a wee bit surprised at times” P9 ‘I think we can sort of avoid that in day-to-day life by avoiding things that are hard or whatever or just kind of playing to our strengths, but when you're confronted with it and paper in a test, it can be quite upsetting” P11 “And you can see the frustration and you can see also the element of self-criticism that comes into that. Sometimes there's a commentary during testing where someone will say something like that was stupid, you know, or that wasn't very good.”
	3. Testing increasing	P2 “I had somebody recently who the carer was like, ‘you've definitely got a problem with your memory’ and they were like, ‘no, I don't’. But it came out through the

	insight into difficulties (8)	testing process that actually they knew they did. They just didn't want to admit it. So that kind of not being able to live in denial really being confronted with it. And they were quite happy in denial. Like, that was good for their self-esteem” P3 “so you know someone then being a bit more aware of of difficulties that they're having or a bit more anxious about that. And you know, moments afterwards of just feeling a bit out of, out of control say” P4 “That kind of frustration and feeling they should be doing better than they are, and it kind of I guess it brings people's difficulties to the fore and even if they haven't, maybe had much insight into them in their day-to-day lives, when you put them in the testing situation that maybe highlights them more so” P5 “I have seen people's confidence reduce in that moment in their abilities because they maybe have insight problems and they're not being challenged and then all of a sudden in this moment they have a realisation and reflective moment that actually they're struggling.” P7 “Why are we doing this? repeated questions? How is this helping me oh well, that's just a stupid question. Nobody would know that. You know, that kind of awareness that they're not doing well, but trying to just sort of, not having the insight to just run with it. I, that, I find that really uncomfortable as a clinician, when I see somebody going through that.” P9 “It's quite confronting in that it's right there in front of you, like I can't remember this list, I can't remember that picture. I don't even remember you asking me about the picture. You know, there's that kind of very, I think we can sort of avoid that in day-to-day life by avoiding things that are hard or whatever or just kind of playing to our strengths” P11 “for some people, there's also that realisation when they when they're doing the tests. Ohh actually you know there is something here and although that's not an easy thing necessarily for them to comes to terms with. I think that it can be, uh, it, it's it's helpful for them overall, because it sort of reduces the tendency to minimise, like, oh, no, actually OK, no, this was really

		hard, you know. Umm, there is something here that that I need to deal with.”
	4. Impact on physical wellbeing (7)	P1 “sleepless nights before the test because he was just sort of, you know, because he knew he was going to find it difficult” P2 “Just the need to sit for a long period of time and attend emm physically had an impact on pain levels.” P6 “It is also important in terms of a person's comfort and now comorbidities with older people, chronic pain, arthritis, osteoporosis, emm, poor vision poor hearing, toileting issues. All these things, I would say are really common in older people and in some cases some of the situations we find ourselves in just because of lack of rooms, that are adequately resourced, we will find ourselves cramped in small rooms using tables that are at knee height where older people need to bend over” P6 “it's sustained attention for that 50 minutes. And if they're in an uncomfortable position, you don't want them to walk out there with stiff legs or like pins and needles because they have been sitting in an awkward position, or straining their neck, all that sort of stuff.” P7 “I think the sort of tiredness is is a big one that? I always ask after the initial interview, which is often 55 minutes an hour, I always ask the next appointment if they were tired after that” P7 “either having a wee break in the middle, having shorter appointments, encouraging them if they're OK to be tired, and they're sort of expecting that to to just really encouraging them to take it easy that day.” P8 “A huge comorbidity seems to be chronic pain. So when people go home, they'll be absolutely shattered and probably usually do nothing for the rest of the day.” P11 “there are some patients who really insist on pushing forward, even if maybe they have got a bit of pain and so it can exacerbate their experience of pain that can become quite distracting for them.”
	5. Negative affect during feedback (10)	P1 “It's more common with Alzheimer's clients to have poor insight into their memory deficits. It's sometimes they could seem a touch taken aback when you're explaining the severity of their memory impairment.” P2 “there was this gentleman who himself lacked insight into his difficulties so the diagnosis, just didn't marry up with his reality, and so he had quite an

		extreme reaction. He stated that he was going to end his life … and once he'd calmed down from receiving the diagnosis, there was no intent there.” P2 “the testing showed that they they were actually performing really well and that obviously caused a lot of anxiety. So the testing, they they didn't get the diagnosis that they had related to and wanted.” P4 “I've only once had someone be disappointed that I wasn't giving them a dementia diagnosis because they were convinced that that's what it was going on for them. And they were, I think they were a bit miffed that we didn't give them a doing to diagnosis” P5 “a handful of people who were maybe upset in the session, where people with quite, dementias were they had a severe anosognosia, lacking insight of their difficulties and disagreed with the diagnosis.” P6 “The thing I have noticed and this happens on the odd occasion is where a diagnosis is reached through the neuropsychological assessment process that the family didn’t expect and that can be a real tricky one for clincians to handle. They’ve perhaps for whatever reason, rejection of what they are seeing in front of them or their loved one is blinding them to the issues at hand so when they actually get the diagnosis it can be very emotive” P7 “The ones that come to mind, who have maybe not been happy with the outcome, not agreed with the outcome being a bit frustrated, have been the ones who've not got a diagnosis. And it's a wait and see. So it's mostly it's when they're lived experience doesn't quite map on to how I've put it under the diagnostic criteria.” P8 “So I suppose people are disappointed because they’ve got something in their heads of what's going on, and then there's something totally jarring” P9 “I think sometimes the people who don't get diagnosis are the most upset because it's like there's no answer. It's just i'm still experiencing all this stuff, but I don't know why and you can't tell me and there's nothing that can help.” P10 “an example would be of a woman who didn't get a diagnosis and she had an impairment, but it wasn't a degenerative kind of impairment and she was not sort

		of satisfied with it because she felt like it didn't validate her difficulties." P11 "I think one of the hardest is when somebody you know, thinks they've done pretty well and their insight is, you know, is impaired and it can be, Ive witnessed it to be quite a surprise, quite a shock to some patients."
Indirect factors can produce harmful effects of NPA	**1. Power dynamics and external pressures (5)**	P4 "Occasionally you'd have people that may be a bit ambivalent and it was more the family that were really keen in and the persons like, "well, I don't really mind, but I'll come along because my son or my daughter wants me to"" P5 "Because they were acquiescer's, they were passive patients and patients would do it and so I had to be their advocate and say, no, we're not doing this." P6 "Then you have ones who will say yes to anything a doctor says so you worry about power differentials within that and you think are they fully consenting and engaged in a process" P9 "I think that can be really quite difficult because you've got that bit of a power dynamic that you're trying to minimize that, but there always just is a power dynamic that exists, I think so that can be tricky." P9 "And there's people who just don't want to be there, their family are kind of their family are kind of pushing them into it. And they say they wanna do it but then when you start testing, it can be quite challenging" P10 "Often the clients themselves don't have much of an expectation, they come along because they've been sent by their psychiatrists and their families think they should come along." P10 "you feel the expectations of your family and you feel the expectations of your therapist sitting in front of you, who is an authority figure. And often it's the authority figures I had you know that trauma happened through to some extent. No in every case, but in some cases, it can be quite a triggering process so that's something to sort of to think about and kind of be mindful of I think."
	2. Not understanding how patients'	P2 "sometimes it goes into a bit of a discussion about previous performance on tests or anxieties about tests. Emm so probably explore that with them and then try and normalise it a little bit"

	history and characteristics can impact experience (7)	P2 “a lot of the maybe more negative responses i've observed have been because people have comorbid mental health problems that maybe need managed or they they completely lack insight into their difficulties and they're kind of maybe a bit more ambivalent about testing” P3 “long standing beliefs about self-esteem or you know, educational attainment, or being judged by other people. So yeah, a lot of people can find it very anxiety provoking.” P7 “if they say, “Oh, that's not for me” Is it because they didn't do well at school exams and they're scared they're gonna fail? Is that something we can support them to overcome? Or is it something that they're making an informed decision that and and that's that's tricky when you don't know what somebody's cognitive abilities are” P9 “Nobody wants to do badly on it. It feels like a test. And there's like, I think there's also, like, people who maybe are a bit insecure about their intelligence or their, like, performance at school if they didn't, if they weren't particularly academic at school or they struggled with tests. I think that can also be quite a source of anxiety and stress about not doing well.” P11 “I think for some people, where there's there's a high level of anxiety generally, maybe they've had long standing difficulties with anxiety, or they have particular anxiety in terms of their memory.”
Clinicians can take action to reduce adverse effects of NPA	**1. The importance of rapport and a calm atmosphere (11)**	P1 “my personal style is to try and keep things reasonably informal and light and just in the interest of just getting the best from the clients, I suppose, and for their experience of it to be as positive as possible.” P2 “So not just kind of getting people into the appointment and jumping straight into testing, maybe kind of checking in with them and having a bit of chat.” P2 “Emm noticing any like visible signs of distress or anxiety and kind of managing that, just usually a bit of a judgment about whether you continue or you stop and kind of attend to it or take a break or stop the appointment.” P3 “So you know, being being quite jokey, having breaks if required, emmm knowing that person and their circumstances. I often have longer chats”

		P3 "I would argue that you know you need, you need to have that relationship emm to, in order to be able to do it effectively. It's important that you get the best out of them for the assessment, but also you don't want to put them through an unpleasant experience." P4 "you can try and have a wee bit of banter with people or a bit of humor with people and and I think it really helps to build up that that relationship because hopefully then by the time it comes to the feedback, they feel that they can, they can trust you in, in what you're saying to them," P4 "being kind of compassionate and and empathic in the approach so you can put yourself in their shoes, if this was or a family member, how would you want that information to be shared" P5 "If you just go straight in and throw a test at someone, but I suppose not having a genuine understanding of their difficulties, then you know it would just feel quite mechanical and robotic, so you have to make it meaningful for the person and you can only do that by having a really good therapeutic clinical interview." P7 "it's just imperative that that relationship is invested in and I I think so much of what I've done throughout my career is really nicely captured by the trauma informed principles from that trauma flower of, you know, choice, collaboration, trust, empowerment, safety. So these are people coming in feeling like they are losing their mind and they're potentially going to get a terminal diagnosis" P7 "So we need to be bringing out the big guns of our interpersonal skills and our clinical skills to support them and their family to be able to participate and engage in that without sugar coating it without," P8 "if you you want people to be in the absolute best state of mind, because that's when you get the most out of someone" P8 "You just want them to be as calm as possible and have less cortisol running around their body. Because then that means that their frontal lobe won't shut off, which is something that you're trying to study."

		P10 “I think with patients, with whom you've had perhaps a better alliance, you do find that at the end at the feedback appointment they sort of perhaps they feel a bit safer in receiving whatever news they get.” P11 “if you're going to tell them at the end of it that you think they have dementia, it's so important that you know the the person feels safe with you and trusting of you.” P11 “if you're not building that rapport if you're kind of say, detached or cold or aloof, that very sort of you know, I was thinking about this sort of like White Coat syndrome kind of thing if you're just, if you're just very, very obviously presenting yourself as you're the professional, you’re the expert. You know, rather than approaching it from a more sort of human perspective.”
	2. Adapting assessments to accommodate clients’ needs (10)	P2 “I think we're quite flexible in how we offer things. So if people were struggling to travel, as well in my area because it's quite rural, that if they couldn't travel, we would go to them.” P2 “I had somebody who had chronic pain and they had to get up quite regularly to kind of move around the room. So just with like between subtests when there was an appropriate time I had to kind of prompt them like, ‘this is a good time to get up’” P3 “it's tiring, it's exhausting doing neuropsych assessment. So we just always acknowledge that and you know, we tried to be as accommodating as possible in terms of how we schedule the appointment, where the appointment is, emmm yeah, to try and limit any kind of practical things that we can” P4 “there is always kind of that bit of having to navigate kind of existing health conditions or disabilities or sensory impairments that people might have.” P4 “I had one lady I worked with who had quite significant respiratory issues. Emm and when we were doing the testing the testing kind of increased anxiety which led to an exacerbation in her respiratory issues and so we, we had to kind of set up a bit of a plan of how to pace the session, shorter sessions, we can spread out over more appointments and have more regular breaks during testing.” P5 “when I do my assessment and I’m asking a physical health history I’ll find out if they’ve got pain or arthritis so I’ll say to them what's the longest you can sit for

		without feeling, feeling sore? Or you know, I’ll say to them, how long will you sit and watch the telly at home, you know. So I'll judge that. Emm if someone struggles physically, I would go into DV or home visit.” P6 “vision and hearing some people come along with issues for that, which we need to accommodate for and, and you can do it. Test aren’t really designed with that in mind” P7 “if they don't have their glasses with them, I I I generally don't let them do the visual test. But even if they say but I can see it cause I I worry it'll give them a bit of a headachy eye strain headache.” P7 “I think that's up to us to tune into our patient, know their history and their current medical picture and functional picture and adapt accordingly. They shouldn't have, they absolutely shouldn't have any physical discomfort or strain from doing this. And we have plenty tools in our toolkit to pick around that.” P7 “even if we have a sort of the the gold standard set of neuropsych tests, I would do for this differential question is A, B and C, If that patient's gonna find that really distressing or physically uncomfortable, they are no longer the gold standard because we're not going to get the best out of the patient’ P7 “And you just have to tailor it to the person. Informed consent. For some is lots of detail, for others is they don't want all the detail. But are they able to make that judgment choice? Every part of it is tailored to the person, and to do that tailoring, we need to slow it down and think about how able they are to collaborate with us.” P8 “There's obviously occasions where mobility will stop them from coming, and that's where a home visit would be more appropriate.” P9 “I guess sometimes if someone had a stroke or there's been some sort of limitation with hands then you might have to do more verbal stuff” P10 “and try to really just use tests that need to be, the least amount of testing that that you can kind of get away with” P11 “If someone has um, particular physical issue, chronic pain, or is going to be uncomfortable for them

		to, I would usually be assessing that before I would start. "How long do you feel comfortable sitting?", you know, and "when do you take your pain medication?". Things like that to try and arrange it so that you're getting the best conditions."
	3. Using clinical skills to administer tests thoughtfully and retain validity (10)	P1 "Sometimes I'll give slightly arbitrary just little bits of something just like, 'Yep, that's great. Yup. Well done." And it doesn't necessarily literally mean like, "hey, you just performed very well above the norms". It just means well done for like, trying your best at that." P2 "I do think that like test selection and the order can have an impact at times. So if people are particularly anxious not doing like a really difficult test straight off the bat, so maybe kind of easing them in." P2 "checking in with them how they're getting on, providing appropriate reassurance so not kind of telling them they're doing great. But just, you know, 'you're putting in a lot of effort', that sort of thing." P6 "Try to reassure them that you know, some people, you have strength and weaknesses, not using that language, but you'd be good at some stuff and not so good that other stuff. And that's OK because we're all different human beings and we've all got different characteristics and experience" "I flex a little bit more than some clinicians I know by trying to, I won't be a read from the manual instructions dead pan to get the test purity, sort of reliability, validity stuff at at its peak because I don't think with older people who are anxious and frustrated, you're getting the best out of them." P7 "I probably just support it quite a lot of like validating you know spotting the frustration and labelling it and validating it early on. I always say to people if you get 100% and come out of here feeling that you've done really well, I've picked the wrong tests." P7 "And even if we have a sort of the the gold standard set of neuropsych tests, I would do for this differential question is A, B and C, If that patient's gonna find that really distressing or physically uncomfortable, they are no longer the gold standard because we're not going to get the best out of the patient and that's that's why we're not having computerized batteries and that's why it's the skill of clinical psychologist doing these is so that you can flex and adapt as and when it's needed an

		interpret with when you've got not not maybe the ideal tests and results and you can still interpret it.” P10 “I'm trying to know think a bit more about administering only what needs to be administered. You know, trying to steer away from doing multiple kind of battery testing, but just kind of what I've experienced when I was training.” P11 “I think one of the biggest things is not being sensitive to their experience. If they're quite clearly struggling and you're just you know, rattling through test after test after test, I think that could feel incredibly overwhelming.”
	4. Clinical judgment on proceeding with NPA (6)	P2 “I have had a few cases where I've done like kind of relaxation breathing techniques with before we even started testing and kind of that was the only way that I could get an accurate valid test performance.” P2 “there have been times, maybe more of when I was training that if I picked up on their anxiety, I would maybe change how I administered things like if I gave them a bit more leniency in terms of breaks or checked in with them more. And I remember getting feedback from an observation where they were like just keep going, like you're kind of showing anxiety based on their anxiety because I was trying to be more gentle with them and they were like no this is a test you have just got to run it the same as you would for everyone else but I think it goes the other way if you are too clinical or too the book that can make people feel uneasy and under pressure” P2 “I don't think there's much you can do with the actual testing because we need to do certain tests to get the information. But I guess the very first point is really deciding if the neuropsych’s helpful and if they need to go through the process to start with and yeah.” P4 “I've only once experienced someone kind of getting quite kind of panicky in the session and actually having to stop the session because the person was getting quite anxious. So kind of set the testing to the side and kind of managed that with them” P5 “So people do get anxious about their performance at times. So it's not nice to see someone feeling anxious while doing tests. I discontinue at that point. Because one it’s unethical and two your not assessing that organic abilities, you're assessing how performance anxiety effects are going cognitive performance.”

		P6 “the key tool that I guess qualified, experienced clinicians have is asking the question why? Why are we doing this assessment? That should always be the kind of guiding point of of the kind of hypothesis method is, as you know, like this this information I have in front of me is requesting psychological assessment. Why? is this appropriate.” P8” if you are thinking more neuropsychologically then if someone's anxious then they can't take in information and they're working memory will be impacted by that. And if someone's working memory's impacted, then everything else is because attention is kind of the the centre of a lot of different things. And it means that cause instructions are quite complicated, so if they can't be retained, you're not necessarily measuring the thing that you are setting out to measure and you can't really rely on the neuropsych.” P8 “if people are too high stressed, just stopping it because there’s absolutely no point battering through a neuropsych when the person is stressed. From a colder side for the vitality of it, but from the human side you can't just, you know, make people keep going when they're clearly distressed.”
	5. Informed consent (9)	P2 “So I think setting clear expectations, making sure it's informed consent, that they're really consulted and feel involved in the process” P3 “I'll have that conversation first appointment, I'll give them a written summary away and then we'll kinda revisit that question at the start of pretty much every appointment.” P5 “They shouldn't be stepping in to the unknown with any uncertainty. They should know what they're going into with their eyes open and aware, even if they forget. The next day, the next time I would see the patient I’d review really briefly what we discussed, what we agreed, were they still OK with that. So giving choice. Choice, choice, choice, ensuring that they they want to do it is just so important.” P6 “So I always do a mini PDC and go over it again briefly before each session” P7 “I do prediagnostic counselling, many times. I circle around because I think perspective, insight, retention. I don't think it's, I don't think it's something you can do in one conversation. I don't think it's accurate. And I think,

		the educational component needs a bit of time to digest and to think through. And the layers of protective defences and and so on, I think you need to give give folks a chance.” P8 “it just gives you the validity to be able to carry out because if the person’s not wanting to do it because of various reasons then it makes it invalid anyway, so you're absolutely pointless 4 hours.” P8 “I mean some people will say “what? I don't, I don't remember that”. So we'll have to go through again. So it does cause more time, but I mean you know it's that, you need to give the person, you need to be taking their consent properly.” P9 “it's the trauma informed principles, 100%. It's trust, safety, empowerment, choice, collaboration. Like, if you can do all that, I feel like that's the whole thing, like that explains everything. If they feel safe with you, if they feel involved, if they feel that you care about them, if they trust you as a clinician, that you're, you're sort of you're looking into it properly, you're not just kind of fobbing them off or you're not like rushing them out the door or whatever.” P10 “I really just try to revisit it every time I see the patient so that by the time we do get a feedback appointment, they have, you know they have a full understanding as to, umm yeah kind of what am I trying to say here.” P10 “I mean, people, people have rights to decline treatment and even if it is in their best interest and they still have a right to decline. And I think we don't emphasise that enough with patients.” P11 “I think for me the most important thing when it comes to neuropsych is informed consent and that's, I mean, that's why I take as long as I take, I would take a whole session sometimes just to get that informed consent, because I think it's that important.”

Appendix 2.16 Table summarising the negative effect percentage responses by question item for clinician and clients

Negative Effects Reported in NPA	No N (%)		Yes N (%)		Missing data	
	Clinicians	**Clients**	**Clinicians**	**Clients**	**Clinicians**	**Clients**
Q1 Stressed	1 (4%)	3 (25%)	24 (96%)	7 (58.3%)	0 (0%)	2 (16.7%)
Q2 Worried	1 (4%)	2 (16.7%)	24 (96%)	8 (66.7%)	0 (0%)	2 (16.7%)
Q3 Hopeless	11 (44%)	8 (66.7%)	14 (56%)	1 (8.3%)	0 (0%)	3 (25%))
Q4 Sad	8 (32%)	6 (50%)	17 (68%)	3 (25%)	0 (0%)	3 (25%)
Q5 Disappointed in performance on the tasks	0 (0%)	1 (8.3%)	25 (100%)	8 (66.7%)	0 (0%)	3 (25%)
Q6 Frustrated	0 (0%)	1 (8.3%)	25 (100%)	7 (58.3%)	0 (0%)	4 (33.3%)
Q7 Critical of self	0 (0%)	3 (25%)	25 (100%)	5 (41.7%)	0 (0%)	4 (33.3%)
Q8 Suicidal ideation	11 (44%)	8 (66.7%)	13 (52%)	0 (0%)	0 (0%)	4 (33.3%)
Q9 Irritable	6 (24%)	5 (50%)	19 (76%)	2 (16.7%)	0 (0%)	4 (33.3%)
Q10 Angry	10 (40%)	7 (58.3%)	15 (60%)	1 (8.3%)	0 (0%)	4 (33.3%)
Q11 Embarrassed	4 (16%)	5 (41.7%)	21 (84%)	4 (33.3%)	0 (0%)	3 (25%)
Q12 Disempowered	13 (52%)	6 (50%)	12 (48%)	2 (16.7%)	0 (0%)	4 (33.3%)
Q13 Stupid	4 (16%)	4 (33.3%)	21 (84%)	4 (33.3%)	0 (0%)	4 (33.3%)
Q14 Confused	2 (8%)	5 (41.7%)	23 (92%)	4 (33.3%)	0 (0%)	3 (25%)
Q15 Worried about the outcome	0 (0%)	2 (16.7%)	25 (100%)	10 (83.3%)	0 (0%)	0 (0%)
Q16 Physically tired	2 (8%))	7 (58.3%)	23 (92%)	1 (8.3%)	0 (0%)	4 (33.3%)
Q17 Mentally drained	2 (8%)	5 (41.7%)	23 (92%)	3 (25%)	0 (0%)	4 (33.3%)
Q18 Headaches	13 (52%)	7 (58.3%)	12 (48%)	3 (25%)	0 (0%)	2 (16.7%)
Q19 Problems with sleep	6 (24%)	5 (41.7%)	19 (76%)	3 (25%)	0 (0%)	4 (33.3%)

	Negative Effects Reported in NPA					
	No N (%)		Yes N (%)		Missing data	
	Clinicians	**Clients**	**Clinicians**	**Clients**	**Clinicians**	**Clients**
Q20 Strain on family relationships	5 (20%)	7 (58.3%)	20 (80%)	1 (8.3%)	0 (0%)	4 (33.3%)
Q21 Lost out financially to attend appointments	16 (64%)	8 (66.7%)	9 (36%)	1 (8.3%)	0 (0%)	3 (25%))
Q22 Gave up significant amounts of time to attend	8 (32%)	7 (58.3%)	17 (68%)	2 (16.7%)	0 (0%)	3 (25%)
Q23 Lost driver's license	6 (24%)	8 (66.7%)	19 (76%)	0 (0%)	0 (0%)	4 (33.3%)
Q24 Did not understand the purpose of assessment	5 (20%)	7 (58.3%)	20 (80%)	1 (8.3%)	0 (0%)	4 (33.3%)
Q25 Did not understand the results of assessment	13 (52%)	7 (58.3%)	12 (48%)	1 (8.3%)	0 (0%)	4 (33.3%)
Q26 Was not made aware of the risks involved in assessment	24 (96%)	5 (41.7%)	1 (4%)	2 (16.7%)	0 (0%)	5 (41.7%)
Q27 Did not feel prepared for what the assessment involved	22 (88%)	7 (58.3%)	3 (12%)	2 (16.7%)	0 (0%)	3 (25%)
Q28 Waited too long to receive feedback	18 (72%)	8 (66.7%)	7 (28%)	1 (8.3%)	0 (0%)	3 (25%)

Appendix 2.17 Table summarising the reported extent the negative effect impacted the client and most likely cause of the effect

	To what extent did it affect?										Most likely cause of the effect?			
	Not at all		**Slightly**		**Moderately**		**Very**		**Extremely**		**Ax**		**Other**	
Question Total N responses	**Clin** **N** **%**	**Client** **N** **%**	**Clin** **N** **%**	**Client** **N** **%**	**Clin** **N** **%**	**Client** **N** **%**	**Clin** **N** **%**	**Client** **N** **%**	**Clin** **N** **%**	**Client** **N** **%**	**Clin** **N** **%**	**Client** **N** **%**	**Clin** **N** **%**	**Client** **N** **%**
Q1 Stressed Clinician = 24 Client = 7	0 0	1 14.28	5 20.83	2 28.57	15 62.5	3 42.86	2 8.33	1 14.28	2 8.33	0 0	15 62.5	5 71.43	8 33.33	0 0
Q2 Worried Clinician = 24 Client =8	0 0	0 0	5 20.83	2 25	12 50	4 50	6 25	1 12.5	0 0	0 0	12 50	6 75	9 37.5	0 0
Q3 Hopeless Clinician = 14 Client =1	0 0	0 0	6 42.86	0 0	4 28.57	0 0	3 21.43	1 100	1 7.14	0 0	3 21.43	0 0	11 78.57	1 100
Q4 Sad Clinician = 17 Client =3	0 0	0 0	8 47.06	0 0	8 47.06	0 0	0 0	1 33.33	0 0	0 0	4 23.53	1 33.33	11 64.71	1 33.33
Q5 Disappointed in performance on the tasks Clinician =25 Client =8	0 0	0 0	8 32	2 25	14 56	3 37.5	2 8	2 25	1 4	0 0	21 84	6 75	2 8	0 0
Q6 Frustrated Clinician =25 Client =7	0 0	0 0	7 28	3 42.86	13 52	3 42.86	4 16	0 0	0 0	1 14.29	15 60	6 85.71	8 32	0 0

Question Total N responses	To what extent did it affect?										Most likely cause of the effect?			
	Not at all		Slightly		Moderately		Very		Extremely		Ax		Other	
	Clin N %	Client N %	Clin N %	Client N %	Clin N %	Client N %	Clin N %	Client N %	Clin N %	Client N %	Clin N %	Client N %	Clin N %	Client N %
Q7 Critical of self Clinician =25 Client =5	0 0	0 0	7 28	1 20	12 48	3 60	5 20	1 20	0 0	0 0	11 44	4 80	11 44	0 0
Q8 Suicidal ideation Clinician = 13 Client =0	3 23.08	N/A	4 30.77	N/A	0 0	N/A	5 38.46	N/A	2 15.38	N/A	12 92.31	N/A	0	N/A
Q9 Irritable Clinician =19 Client =2	0 0	0 0	8 42.11	1 50	9 47.37	1 50	1 5.26	0 0	0 0	0 0	8 42.11	1 50	10 52.63	1 50
Q10 Angry Clinician =15 Client =1	0 0	0 0	8 53.33	0 0	3 20	1 100	3 20	0 0	10 66.67	0 0	8 53.33	0 0	6 40	1 100
Q11 Embarrassed Clinician =21 Client =4	0 0	0 0	7 33.33	3 75	11 52.38	0 0	2 9.52	1 25	0 0	0 0	16 76.19	2 50	3 14.29	1 25
Q12 Disempowered Clinician =12 Client =2	0 0	0 0	7 58.33	1 50	4 33.33	0 0	1 8.33	1 50	0 0	0 0	7 58.33	1 50	6 50	1 50
Q13 Stupid Clinician =21 Client =4	0 0	0 0	8 38.10	2 50	11 52.38	1 25	1 4.76	0 0	0 0	1 25	18 85.71	3 75	2 9.52	0 0
Q14 Confused Clinician =23	0 0	0 0	8 34.78	2 50	8 34.78	0 0	4 17.39	1 25	1 4.35	0 0	9 39.13	3 75	12 52.17	0 0

	To what extent did it affect?										Most likely cause of the effect?			
	Not at all		Slightly		Moderately		Very		Extremely		Ax		Other	
Question Total N responses	**Clin N %**	**Client N %**	**Clin N %**	**Client N %**	**Clin N %**	**Client N %**	**Clin N %**	**Client N %**	**Clin N %**	**Client N %**	**Clin N %**	**Client N %**	**Clin N %**	**Client N %**
Client =4														
Q15 Worried about the outcome Clinician =25 Client =10	0 0	0 0	4 16	1 10	9 36	3 30	10 40	1 10	0 0	1 10	15 60	3 30	6 24	0 0
Q16 Physically tired Clinician =23 Client =1	0 0	1 100	8 34.78	0 0	10 43.48	0 0	2 8.70	0 0	1 4.35	0 0	10 43.48	0 0	10 43.48	0 0
Q17 Mentally drained Clinician =23 Client =3	0 0	0 0	9 39.13	1 33.33	7 30.43	1 33.33	5 21.74	0 0	0 0	1 33.33	14 60.87	2 66.67	0 0	0 0
Q18 Headaches Clinician =12 Client =3	0 0	1 33.33	8 66.67	1 33.33	3 25	0 0	1 8.33	0 0	0 0	0 0	3 25	1 33.33	9 75	0 0
Q19 Problems with sleep Clinician =19 Client =3	2 10.53	0 0	4 21.05	2 66.67	9 46.37	0 0	3 15.79	1 33.33	0 0	0 0	1 5.26	2 66.67	15 78.95	0 0
Q20 Strain on family relationships Clinician =20	0 0	0 0	4 20	0 0	8 40	0 0	7 35	0 0	0 0	1 100	3 15	0 0	17 85	1 100

	To what extent did it affect?										Most likely cause of the effect?			
	Not at all		Slightly		Moderately		Very		Extremely		Ax		Other	
Question Total N responses	**Clin N %**	**Client N %**	**Clin N %**	**Client N %**	**Clin N %**	**Client N %**	**Clin N %**	**Client N %**	**Clin N %**	**Client N %**	**Clin N %**	**Client N %**	**Clin N %**	**Client N %**
Client =1														
Q21 Lost out financially to attend appointments Clinician =9 Client =1	0 0	0 0	6 66.67	0 0	1 11.11	1 100	0 0	0 0	0 0	0 0	7 77.78	1 100	2 22.22	0 0
Q22 Gave up significant amounts of time to attend Clinician =17 Client =2	0 0	0 0	8 47.06	0 0	6 35.29	1 50	1 5.88	1 50	0 0	0 0	16 94.12	0 0	1 5.88	1 50
Q23 Lost drivers license Clinician =19 Client =0	0 0	N/A	0 0	N/A	2 10.53	N/A	6 31.58	N/A	4 21.05	N/A	10 52.63	N/A	5 26.36	N/A
Q24 Did not understand the purpose of assessment Clinician =20 Client =1	1 5	0 0	6 30	0 0	5 25	0 0	4 20	1 100	0 0	0 0	2 10	0 0	15 75	1 100
Q25 Did not understand the	0 0	1 100	3 25	0 0	5 41.67	0 0	0 0	0 0	0 0	0 0	1 8.33	0 0	8 66.67	0 0

	To what extent did it affect?										Most likely cause of the effect?			
	Not at all		Slightly		Moderately		Very		Extremely		Ax		Other	
Question Total N responses	**Clin** **N** **%**	**Client** **N** **%**	**Clin** **N** **%**	**Client** **N** **%**	**Clin** **N** **%**	**Client** **N** **%**	**Clin** **N** **%**	**Client** **N** **%**	**Clin** **N** **%**	**Client** **N** **%**	**Clin** **N** **%**	**Client** **N** **%**	**Clin** **N** **%**	**Client** **N** **%**
results of assessment Clinician =12 Client =1														
Q26 Was not made aware of the risks involved in assessment Clinician =1 Client =2	0 0	0 0	0 0	1 50	1 100	1 50	0 0	0 0	0 0	0 0	0 0	1 50	1 100	0 0
Q27 Did not feel prepared for what the assessment involved Clinician =3 Client =2	0 0	0 0	1 33.33	1 50	2 66.67	1 50	0 0	0 0	0 0	1 50	2 66.67	0 0	1 33.33	2 100
Q28 Waited too long to receive feedback Clinician =7 Client =1	0 0	0 0	2 28.57	0 0	3 42.86	0 0	1 14.29	1 100	0 0	0 0	5 71.43	1 100	1 14.29	0 0

Abbreviations: Clin, Clinician

Appendix 2.18 Table summarising at what point during the NPA negative effects were experienced

	At what point in the assessment was this experienced? Before 1st appointment		During initial interview		During testing		Awaiting feedback		After feedback	
Question Total N responses	**Clinician** **N** **%**	**Client** **N** **%**	**Clinician** **N** **(%)**	**Client** **N** **(%)**	**Clinician** **N** **(%)**	**Client** **N** **(%)**	**Clinician** **N** **(%)**	**Client** **N** **(%)**	**Clinician** **N** **(%)**	**Client** **N** **(%)**
Q1 Stressed Clinician =24 Client =7	18 75	2 28.57	18 75	3 42.86	21 87.5	1 14.29	17 70.83	1 14.29	8 33.33	0 0
Q2 Worried Clinician =24 Client =8	20 83.33	4 50	20 83.33	0 0	19 79.17	4 50	21 87.5	3 37.5	10 41.67	0 0
Q3 Hopeless Clinician = 14 Client =1	9 64.29	1 100	7 50	0 0	8 57.14	0 0	5 35.71	0 0	6 42.86	0 0
Q4 Sad Clinician =17 Client =3	8 47.06	1 33.33	10 58.82	2 66.67	5 29.41	1 33.33	3 17.65	0 0	11 64.71	0 0
Q5 Disappointed in performance on the tasks Clinician =25 Client =8	0 0	0 0	0 0	1 12.5	25 100	7 87.5	12 48	0 0	6 24	0 0
Q6 Frustrated Clinician =25 Client =7	6 24	0 0	7 28	0 0	25 100	6 85.71	8 32	1 14.29	3 12	0 0
Q7 Critical of self	7	0	13	1	24	4	10	0	3	0

	At what point in the assessment was this experienced?									
	Before 1st appointment		**During initial interview**		**During testing**		**Awaiting feedback**		**After feedback**	
Question Total N responses	**Clinician** **N** **%**	**Client** **N** **%**	**Clinician** **N** **(%)**	**Client** **N** **(%)**	**Clinician** **N** **(%)**	**Client** **N** **(%)**	**Clinician** **N** **(%)**	**Client** **N** **(%)**	**Clinician** **N** **(%)**	**Client** **N** **(%)**
Clinician =25 Client =5	28	0	52	20	96	80	40	0	12	0
Q8 Suicidal ideation Clinician =13 Client =0	11 84.62	N/A	4 30.77	N/A	2 15.38	N/A	4 30.77	N/A	5 38.46	N/A
Q9 Irritable Clinician =19 Client =2	11 57.89	1 50	14 73.68	1 50	15 78.95	0 0	8 42.11	0 0	8 42.11	0 0
Q10 Angry Clinician =15 Client =1	8 53.33	1 100	12 80	0 0	10 66.67	0 0	5 33.33	0 0	8 53.33	0 0
Q11 Embarrassed Clinician =21 Client =4	4 19.05	1 25	10 47.62	3 75	19 90.48	4 100	3 14.29	3 75	6 28.57	0 0
Q12 Disempowered Clinician =12 Client =2	8 66.67	0 0	7 58.33	1 50	6 50	0 0	4 33.33	1 50	3 25	0 0
Q13 Stupid Clinician =21 Client =4	8 38.10	0 0	9 42.86	0 0	19 90.48	3 75	6 28.57	1 25	1 4.76	0 0
Q14 Confused Clinician =23 Client =4	16 69.57	0 0	15 65.22	0 0	18 78.26	3 75	10 43.48	0 0	9 39.13	0 0
Q15 Worried about the outcome Clinician =25 Client =10	22 88	2 20	20 80	2 20	24 96	3 30	24 96	3 30	7 28	0 0

	At what point in the assessment was this experienced?									
	Before 1st appointment		During initial interview		During testing		Awaiting feedback		After feedback	
Question Total N responses	**Clinician** **N** **%**	**Client** **N** **%**	**Clinician** **N** **(%)**	**Client** **N** **(%)**	**Clinician** **N** **(%)**	**Client** **N** **(%)**	**Clinician** **N** **(%)**	**Client** **N** **(%)**	**Clinician** **N** **(%)**	**Client** **N** **(%)**
Q16 Physically tired Clinician =23 Client =1	7 30.43	0 0	11 47.83	0 0	20 86.96	0 0	22 95.65	0 0	5 21.74	0 0
Q17 Mentally drained Clinician =23 Client =3	4 17.39	0 0	9 39.13	0 0	21 91.30	2 66.67	3 13.04	0 0	5 21.74	0 0
Q18 Headaches Clinician =12 Client =3	6 50	0 0	5 41.67	0 0	11 91.67	0 0	6 50	1 33.33	5 41.67	0 0
Q19 Problems with sleep Clinician =19 Client =3	12 63.16	0 0	12 63.16	0 0	13 68.42	0 0	9 47.37	1 33.33	10 52.63	0 0
Q20 Strain on family relationships Clinician =20 Client =1	20 100	0 0	19 95	0 0	11 55	1 100	15 75	0 0	14 70	0 0
Q21 Lost out financially to attend appointments Clinician =9 Client =1	3 33.33	1 100	6 66.67	0 0	7 77.78	1 100	3 33.33	1 100	2 22.22	1 100
Q22 Gave up significant amounts of time to attend Clinician =17 Client =2	6 35.29	0 0	11 64.71	0 0	14 82.35	1 50	5 29.41	0 0	7 41.17	1 50
Q23 Lost driver's license Clinician =19 Client =0	5 26.31	N/A	1 5.26	N/A	2 10.53	N/A	2 10.53	N/A	13 68.42	N/A

	At what point in the assessment was this experienced?									
	Before 1st appointment		During initial interview		During testing		Awaiting feedback		After feedback	
Question Total N responses	**Clinician N %**	**Client N %**	**Clinician N (%)**	**Client N (%)**	**Clinician N (%)**	**Client N (%)**	**Clinician N (%)**	**Client N (%)**	**Clinician N (%)**	**Client N (%)**
Q24 Did not understand the purpose of assessment Clinician =20 Client =1	15 75	1 100	15 75	0 0	7 35	0 0	1 5	0 0	1 5	0 0
Q25 Did not understand the results of assessment Clinician =12 Client =1	0 0	1 100	0 0	0 0	0 0	0 0	2 16.67	0 0	11 91.67	0 0
Q26 Was not made aware of the risks involved in assessment Clinician =1 Client =2	1 100	2 100	1 100	1 50	0 0	0 0	0 0	0 0	0 0	0 0
Q27 Did not feel prepared for what the assessment involved Clinician =3 Client =2	1 33.33	1 50	2 66.67	1 50	2 66.67	1 50	1 33.33	1 50	0 0	0 0
Q28 Waited too long to receive feedback Clinician =7 Client =1	2 28.57	0 0	1 14.29	0 0	1 14.29	1 100	6 85.71	0 0	3 42.86	0 0

Appendix 2.19 MRP Proposal

https://osf.io/tfky4