

# **Service users' experiences of Neuropsychological assessment feedback**

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## **1. Introduction**

### **1.1 Neuropsychological feedback**

Following a neuropsychological assessment, feedback about an individual's cognitive strengths and difficulties is shared with them in an accessible way (Gruters et al., 2021; Postal & Armstrong, 2013; Rosado et al., 2018). Feedback allows individuals to develop an understanding of their condition, the results of the assessment and how their difficulties might present in everyday life (Postal & Armstrong, 2013). Feedback is usually provided verbally and in a written report. There is no set protocol for verbal feedback, however, sessions often involve a review of the purpose of the assessment, a summary of the tests and test results, discussion of strengths and difficulties, recommendations, and discussion about further support, as well as a space to ask questions (Gass & Brown, 1992; Postal & Armstrong, 2013; Brenner, 2003). Reports can vary in how they are written and presented depending on the reason for referral, service users' presentation, the service, and the clinician (Baum et al., 2018; Mahoney et al., 2017). The report usually includes reason for referral, background information, observations, test results, impressions, summary, and recommendations (Mahoney et al., 2017). There is no set order as to how feedback is shared, with some clinicians providing the report first, and others offering verbal feedback first (Postal & Armstrong, 2013).

### **1.2 Guidelines**

The British Psychological Society (BPS; 2004) Code of Good Practice for Psychological Testing discusses the need for feedback to be provided in a way which makes the implications of the results clear to the service user and be presented in a style appropriate to the service users' level of understanding. They also discuss the need to consider factors, such as ethnicity, age,

disability, and level of ability. More recent guidelines from the American Psychological Association (APA, 2020) and American Academy of Clinical Neuropsychology (AACN; Heilbronner, 2007) discuss the importance of describing findings in a way that recipients understand, considering language, reading level and general ability.

### **1.3 Literature review**

In a scoping review Gruters et al. (2021) found that there were high levels of satisfaction for neuropsychological assessment and feedback reported by family members (Bodin et al., 2007; Farmer & Brazeal, 1998; Kirkwood et al., 2017; Tremont et al., 2002; Vandermorris et al., 2021; Westervelt et al., 2007) and service users (Bennett-Levy et al., 1994; Donofrio, 1999.; Foran et al., 2016; Vandermorris et al., 2021; Westervelt et al., 2007). Referrers also value neuropsychological assessment and feedback (Bishop et al., 2003; Mahoney et al., 2017; Postal et al., 2018; Tremont et al., 2002). There is a lack of research looking at adult service users' experiences of receiving feedback, with most of the research focusing on child services, or on the entire assessment process. In research involving children, satisfaction with feedback was high, but some parents found that the assessment and feedback did not provide as much help as expected (Griffin & Christie, 2008) and that reports were difficult to understand (Evans et al., 2019). The researchers discuss the importance of keeping in mind possible barriers in understanding feedback such as cultural and linguistic differences, or education level (Evans et al., 2019; Griffin & Christie, 2008).

There is also lack of research on service users' views of their written report. Instead, referrers and clinicians have offered their views on reports through surveys (Mahoney et al., 2017; Smith et al., 2007; Tremont et al., 2002). Although many referrers found reports helpful, only around half read the entire report (Mahoney et al., 2017; Postal et al., 2018; Tremont, 2002).

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The most read sections were the summary of results and recommendations, and referrers preferred these to be in a table, bulleted or numbered format (Mahoney et al., 2017; Postal et al., 2018). Postal et al. (2018) found that almost half of referrers felt it would be helpful if reports contained less jargon or included explanations of terms. Mahoney et al. (2017) and Postal et al. (2018) recommend changes in report writing practice, for example, shorter reports, summaries of findings and recommendations as well as simplifying language. In an analysis of neuropsychological reports within a service for children and adolescents with neurological conditions, Baum et al. (2018) found that reports were consistently written at a college level, which exceeded the reading ability of some audiences. They revised reports, making them shorter, more readable, and focused more so on the impressions and recommendations sections. It was concluded that changing reports is feasible and that shorter reports were as effective as longer reports.

Some research, mainly using questionnaires, has focused on feedback from service users within adult outpatient neuropsychology clinics (Bennett-Levy et al., 1994; Donofrio, 1999; Foran et al., 2016; Rosado et al., 2018; Vandermorris et al., 2021; Westervelt et al., 2007). Donofrio (1999) reported that 96.7% of service users found provision of a written summary helpful; they discuss the importance of providing this. Rosado et al. (2018) found that service users that received feedback reported greater improvement in quality of life, increased understanding of their condition, and an increased ability to cope with their condition compared to those that did not receive feedback. They discuss the importance of feedback in terms of helping with decision-making, treatment planning as well as a space to ask questions. Westervelt et al. (2007) found that many service users found a detailed understanding of their strengths and difficulties to be beneficial, even when this just provided confirmation of suspicions.

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Bennett-Levy et al. (1994) found that service users were more likely to have a positive experience if they felt prepared for feedback and perceived the feedback as useful. They found that service users who scored higher on a measure of anxiety were more likely to report a change in self-confidence, either increasing or decreasing depending on results. Although many service users found feedback understandable and memorable, a number forgot or did not understand the feedback, and most reported they would have liked more information. Past research into medical consultations has reported similar issues, such issues are important to consider because recall and understanding can impact on adherence to recommendations (Ley, 1979). Foran et al. (2016) found that feedback was the most critiqued part of the neuropsychological assessment. Similar to Bennett-Levy et al. (1994), critique included difficulty understanding results, but also included the emotional impact of receiving diagnostic information. It was recommended that feedback should be useful and understandable, and that clinicians are sensitive towards possible emotional impact (Bennett-Levy, 1994; Foran, 2016).

### **1.4 Commissioning Service**

The Clinical Health Psychology Service at Pinderfields General Hospital and Dewsbury District Hospital provides psychology services to adults living with neurological conditions. The service is offered to those who are under the care of Mid Yorkshire Neurosciences service. The service offers neuropsychological assessment, neuropsychological therapy, and rehabilitation, and has a pathway for Functional Neurological Disorder. This Service Evaluation Project (SEP) focused on service users that had accessed neuropsychological assessment. There are three Clinical Psychologists working in the service as well as Trainee Clinical Psychologists. Within the service there are no consistent ways as to how feedback is delivered across psychologists in terms of timings, order of feedback or report structure.

## **1.5 Rationale**

There appears to be a lack of research focusing on adult service user experiences of neuropsychological feedback. Research to date has relied on questionnaires with limited qualitative information, so although many service users report that they are satisfied with feedback, we do not understand what they found useful or what could be improved. Also, practice varies greatly across different services making results difficult to generalise. Due to these reasons, the lack of consistency with feedback within the service and due to feedback never being previously evaluated within the service, it was felt that an evaluation would be beneficial.

## **1.6 Aims**

To explore service users' experiences of receiving feedback following neuropsychological assessment, including what has been useful and what could be improved.

## **2. Method**

### **2.1 Design**

To gain an understanding of what it is like to be given feedback following a neuropsychological assessment, we need to understand the experience of service users. Although questionnaires would allow feedback from a wider range of participants, most previous research has been based on questionnaires and lacks in-depth information about service users' experiences. Therefore, a qualitative design using individual semi-structured interviews was used. Qualitative research allows us to gain in-depth information about the inner experiences of participants (Willig, 2013).



## **2.2 Participants**

Service users were invited to take part by the psychologist who carried out their assessment and feedback. Eligible service users included anyone that had completed their neuropsychological assessment and received feedback within one month prior to the interview. Service users were excluded if they had cognitive deficits of a severity that would preclude successful completion of evaluation consent or procedures. There was a total of 10 service users identified, six of whom consented to take part. Service users included two men and four women, and presented with different neurological conditions including brain injury, Multiple Sclerosis, stroke, and Parkinson's Disease. Reasons for referral included suggestions from other professionals, and due to individuals noticing difficulties at work or in everyday life. All participants were given the option of involving a family member or friend in the evaluation if they had been involved in the feedback process, or felt they required support; however, none chose this option.

## **2.3 Procedure**

The researcher contacted service users that were interested in taking part and provided them with the information sheet and a link to access the consent form through Bristol Online Surveys (Appendix 1 and 2). All interviews were conducted remotely, two via Microsoft Teams and four via phone, dependent on participant choice. Interviews followed an interview guide (Appendix 3) which was developed with the psychologists within the service. Interviews took place between March and August 2021 and each one lasted between 45 and 70 minutes. Interviews were audio recorded and then transcribed by the researcher immediately following each interview.

## 2.4 Analysis

Interview data was analysed using thematic analysis (Braun & Clarke, 2006). Braun and Clarke (2006) describe thematic analysis as a method for “identifying, analysing and reporting patterns (themes) within data” (p. 79). This method was chosen because unlike other qualitative methods it is not tied to a particular theoretical or epistemological position, therefore it benefits from flexibility whilst also providing a rich and detailed account of data (Willig, 2013; Braun and Clarke, 2006). It allowed the experiences of service users to be captured, summarised into themes and for recommendations to be drawn. Braun and Clarke (2006) phases of thematic analysis were followed, as shown in Table 1.

**Table 1**

*Phases of thematic analysis*

<b>Phase</b>	<b>Description of the process</b>
1. Familiarising yourself with your data	Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas.
2. Generating initial codes	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3. Searching for themes	Collating codes into potential themes, gathering all data relevant to each potential theme.
4. Reviewing themes	Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set

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	(Level 2), generating a thematic ‘map’ of the analysis.
5. Defining and naming themes	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.
6. Producing the report	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

*Note.* From “Using thematic analysis in psychology” by V. Braun, V. and V. Clarke, 2006.

*Qualitative Research in Psychology*, 3(2), 77–101.

(<https://www.tandfonline.com/doi/abs/10.1191/1478088706qp063oa>). CC BY.

### 2.5 Credibility check

A credibility check of themes was carried out by another independent trainee clinical psychologist. Themes were also discussed and agreed on with the project commissioner and an academic supervisor.

### 2.6 Reflexivity

Reflexivity means to “recognise and take responsibility for one’s own situatedness within the research and the effect that it may have on the setting and people being studied, questions being asked, data being collected and its interpretation” (Berger, 2015, p. 220). I have previous

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experience of working in neuropsychological assessment service and was already aware of some of the benefits of feedback as well as difficulties that service users might experience. To ensure that results were not biased by my previous experiences, I was mindful of these and any pre-existing assumptions that I might have had.

### **2.7 Ethical considerations**

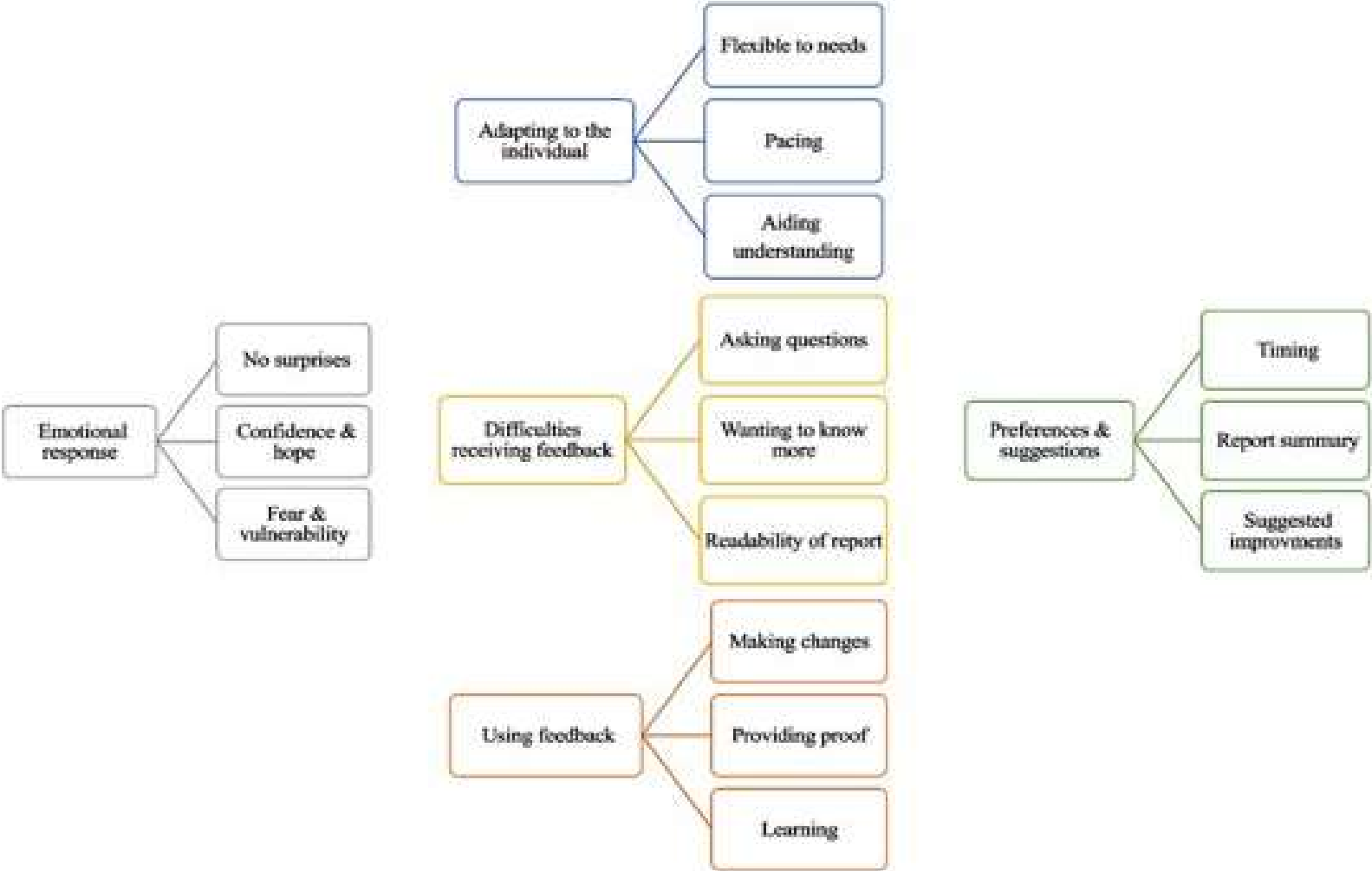
Ethical approval was granted by the University of Leeds School of Medicine Research Ethics Committee (DClinREC 20-004) on 18<sup>th</sup> February 2021. Approval was also granted by the Mid Yorkshire NHS Trust R&D department (Appendix 4). Participants were provided with an information sheet and the researcher ensured participants were reminded of key information prior to interview e.g. their right to withdraw up to one week post interview. All participants provided informed consent. Participants were given the option of involving a family member or friend in their interview for support. All participant details have been anonymised and contextual information has been removed. Due to psychologists from the service identifying potential participants, further demographic information is not included to maintain the anonymity of participants.

## **3. Results**

As illustrated in the thematic map in Figure 1, five themes were generated from the data, each consisting of three subthemes. These themes are described in further detail below. See Appendix 5 for a table of themes, subthemes and additional illustrative quotes.

Figure 1

Thematic map of themes and subthemes



### 3.1 Theme 1: Emotional response

Participants reflected on their emotional responses to receiving feedback.

**3.1.1 Subtheme 1a. No surprises.** No participants were surprised by their results, for many, their suspicions were confirmed.

*“The outcome was as I expected really... that I don’t retain information.”* (Participant 1).

*“To be honest, I had a rough idea of where I were after doing the tests. Doing the tests made me realise where I am actually lacking.”* (Participant 5).

**3.1.2 Subtheme 1b. Fear and vulnerability.** Some participants talked about their fears of receiving feedback and feeling vulnerable.

*“It was fine. I was a bit apprehensive and anxious because you are not sure what someone is going to say to you.”* (Participant 2).

*“You are putting your vulnerable self out there, especially when reading their report.”*  
(Participant 1).

**3.1.3 Subtheme 1c. Confidence and hope.** For some participants the feedback they received made them feel more confident and hopeful for the future.

*“Having that feedback and them saying categorically my cognitive abilities are as they would be expected, has boosted my confidence in myself.”* (Participant 6).

*“But every little bit of information helps. It gives me hope, if you know where I’m coming from. That hope for the future.”* (Participant 5).

### 3.2 Theme 2: Adapting to the individual

Participants discussed different ways in which psychologists adapted their feedback for them.

**3.2.1 Subtheme 2a. Flexible to needs.** Participants talked about how psychologists provided feedback in flexible ways depending on their needs.

*“(Psychologist) listened to me and took time out and listened to my needs and I got what I needed.”* (Participant 6).

*“I asked for an edited version, which is just the introduction, all about the assessment and then summary and recommendations. So, they cut out what I feel was my personal things.... things work didn’t need to know.”* (Participant 1).

**3.2.2 Subtheme 2b. Pacing.** Participants described how their feedback was paced in helpful ways.

*“In terms of style and bringing it in slowly, it was paced well for me, it wasn’t just a direct tell.”* (Participant 2).

*“She sent me an email with information about certain things that I could read later because she knew how tired I had been.”* (Participant 3).

**3.2.3 Subtheme 2c. Aiding understanding.** Participants talked about the ways in which psychologists found different ways to aid their understanding.

*“She showed me charts on sort of where, from a nationally representative point of view, where they would expect people with my condition, my age, what you would expect and what it meant to be above the curve, below the curve or whatever. That really helped me to understand.”*  
(Participant 6).

*“There were things like GAD scores and things like that and I didn't know what they meant, so she went into detail.” (Participant 3).*

### **3.3 Theme 3: Difficulties receiving feedback**

Participants shared some of the difficulties they experienced when receiving feedback.

**3.3.1 Subtheme 3a. Wanting to know more.** Some participants were left feeling like they wanted to know more about the testing, their results or advice as to the next steps.

*“There were some parts of it around the memory stuff that I was concerned about, where I am in 5<sup>th</sup> percentile in one area and the 50<sup>th</sup> in others. That fluctuation, I would have liked to know more about it, but time was a bit of an issue and I thought about it after the session, when I saw the report.” (Participant 2).*

*“The whole reason why I did it was to get some practical advice, but I never got that.”*  
(Participant 4).

**3.3.2 Subtheme 3b. Asking questions.** Some participants talked about their difficulties with asking questions during the feedback session due to not feeling prepared, or not knowing what to ask.

*“I was not prepared for it, and I like to be prepared. Later I thought of things and wish I had written them down like what was the purpose of the test with the blue circles?” (Participant 2).*

*“I didn't have anything to benchmark it against so I didn't know what sort of questions I should be asking.” (Participant 6).*



**3.3.3 Subtheme 3c. Readability of report.** Participants talked about how they found their report difficult to read and understand due to the terminology used or the way the report was presented.

*“Some of the academic language was difficult to understand. Explaining tests like this assessment is a rule attainment test blah, blah, blah. That doesn’t mean anything to me, I have no idea.”* (Participant 2).

*“Some of it was technical stuff I wouldn’t have known anyway. Like, she had put little asterisks where the scores were displayed lower down, but it was partly because I had not been able to make the connection.”* (Participant 3).

### **3.4 Theme 4: Using feedback**

Despite difficulties, all participants were using their feedback in their day-to-day lives and described the different ways in which they were doing this.

**3.4.1 Subtheme 4a. Making changes.** Some participants were using what they had learned to make changes or access support.

*“The things I am doing as a result of the tests are less complicated things that I once used to try and do, like multitask. If I have multiple things going on at once, I can't focus.”* (Participant 3).

*“She has put me forward now to another session with another person... we are coming up with a programme of things to do, working in the areas I was struggling with.”* (Participant 5).

**3.4.2 Subtheme 4b. Providing proof.** Most participants were using their feedback as proof of their difficulties, or strengths, for themselves and others.

*“It was evidence that I know where I am struggling. I understand where I'm struggling but it's evidence to me.”* (Participant 5).

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*'I need to pass this report on to my bosses because its good sort of evidence and documentation why I do need to have my hours reduced'* (Participant 1).

**3.4.3 Subtheme 4c. Learning.** Feedback helped participants to learn about themselves and their condition.

*"The whole process has definitely helped my perception of myself. That because my MS isn't causing whatever is happening, maybe it's just a confidence thing."* (Participant 6).

*"I know I am weaker than expected in some areas, but I have found out the majority of it was what was expected with my condition."* (Participant 2).

## 3.5 Theme 5: Preferences & suggestions

Participants described their preferences for feedback and made suggestions for improvements.

**3.5.1 Subtheme 5a. Report summary.** Participants preferred the edited summary of their report or the summary section of their main report.

*"The edited version summed it up in a nutshell what happened to me, what the assessment entailed and what the outcome is. These were important bits to me."* (Participant 1).

*"It's quite a long report they get back to you. The introduction and summary were the best bits. It was easier to understand and made more sense than the whole report."* (Participant 2).

**3.5.2 Subtheme 5b. Timing.** Participants were generally happy with the timing of their report. Some participants received their report first, others received verbal feedback first. However, all participants preferred the order of the feedback they received and gave reasons why.

*“I got the report two or three weeks after the last appointment, before I had the verbal video link. So, I sort of knew what was coming. It helped me feel not quite so bad.”* (Participant 1).

*“She got the report to me the following week, had a week to consider it, then she phoned me last Thursday. It gave me time to read it, digest it and make notes, that really helped because then she was able to answer my questions.”* (Participant 3).

**3.5.3 Subtheme 5c. Suggested improvements.** Some participants provided suggestions as to how feedback could be improved. This included making changes to the report and the suggestion of interim feedback.

*“There's quite a few of them (tests) that don't mean anything to me. If you put in brackets, the blue circle one, I know it makes the report less clinical, but it would be better from the recipient's point of view to know the detail.”* (Participant 2).

*“It would have been nice to have some more immediate feedback. I wish I understood more about the tests at the time, like why it didn't matter if you guessed it.”* (Participant 2).

## **4. Discussion**

The aim of this SEP was to gain an understanding of service users' experiences of receiving feedback following neuropsychological assessment, including what they found useful and what could be improved. Five main themes were identified: emotional response, adapting to the individual, difficulties receiving feedback, using feedback, and preferences and suggestions

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The first theme was around service users' emotional responses to the feedback they received. None of the service users were surprised by their feedback, with many finding that feedback confirmed their suspicions. Past research has found feedback to be valuable even if it did only confirm suspicions (Westervelt et al., 2007). Despite having an awareness of possible results, some service users worried about their feedback and found the report difficult to read. Research has discussed the importance of considering emotional response (Bennett-Levy et al., 1994; Foran et al., 2016) and how emotional response can impact on retention and understanding (Gruters et al., 2021). In terms of emotional response to reading the report, Postal et al. (2013) discuss how seeing difficulties in writing can make things seem more real and overwhelming. For some service users it may be easier to hear their feedback within a verbal feedback session where they have the support of the clinician (Postal & Armstrong, 2013). Although some service users experienced worry, others talked about how it provided them with hope for the future and confidence in their abilities. Postal and Armstrong (2013) describe hope as one of the most important 'gifts' of feedback.

The second theme was around adapting to the individual. Service users described ways that psychologists had adapted to their needs, paced feedback in helpful ways and found different ways to aid their understanding. Some service users described receiving the edited report, either for employers or others, as being the most useful part of their feedback. Past research recommends being flexible with feedback depending on individual needs and has discussed the importance of individualised feedback in helping service users make important decisions e.g. whether they should resume employment (Brenner, 2003; Postal & Armstrong., 2013; Rosado et al., 2018).

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There was also a theme around the difficulties of receiving feedback. Service users experienced difficulties in terms of understanding the report, difficulties asking questions and wanting more information. This is in keeping with some of the earlier research (Bennett-Levy et al., 1994; Foran et al., 2016; Griffin & Christie, 2008; Ley, 1979). The report was the most critiqued part of feedback, with all service users finding the report difficult to read due to the terminology used or the way it was presented. Research and guidelines discuss the need to consider the readability of neuropsychological reports, due to the varied knowledge and abilities of the different audiences that read them (Baum et al., 2018; Brenner, 2003; Gruters et al., 2021). It is important that service users understand their report because written information can improve recall of recommendations and utility (Baum et al., 2018; Fallows & Hilsabeck, 2013; Gruters et al., 2021). Some recommendations offered for report writing include, using appropriate language for the audience, keeping in mind what needs to be communicated, using as little information as possible, removing jargon, translation of scores to daily life, and attaching a summary cover letter to the main report which summarises the main findings (Harvey, 1997; Baum et al., 2018; Evans et al., 2019; Mahoney et al., 2017; Postal & Armstrong., 2013; Postal et al., 2018). The service users that received verbal feedback before their report were the ones that wanted to know more and that had difficulties asking questions. For some of these service users, having an additional phone call with the psychologist after receiving their report gave them chance to clarify misunderstandings and ask questions. Postal and Armstrong (2013) suggest an offer of a second feedback session or ‘check-in’ for some service users.

The fourth theme was on using feedback. Service users were using their feedback in different ways, such as making changes in their day-to-day life, providing proof to themselves or others, or learning about themselves or their condition. Most service users seemed to be aware of

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their cognitive strengths and difficulties, how these related to everyday experiences and what they needed to change or work on. This fits with one of the main purposes of neuropsychological feedback, in that it should provide an opportunity for individuals to develop an understanding of their difficulties that they can then use in their day-to-day life (Postal & Armstrong, 2013).

Research has found that understanding of strengths and difficulties to be beneficial and related to higher utility ratings of neuropsychological feedback (Arffa & Knapp, 2008; Gruters et al., 2021; Westervelt, 2007).

The final theme was around preferences and suggestions. Service users described their preferences for feedback and suggestions for improvements. They discussed how feedback was well timed, and all stated that they preferred the order they received their feedback in and gave reasons why. For example, those receiving their report first talked about how this allowed them to prepare, and those that received verbal feedback first talked about how they would have found their report difficult to read and understand if they had received it first. Service users either preferred an edited report or the summary section of the main report, this was understandable seeing as they had shared their difficulties with reading their reports. Preferring the summary section of the report is also in keeping with the research looking at referrer's preferences (Mahoney et al., 2017; Postal et al., 2018). As well as simplifying the report, service users suggested that feedback could be improved by offering interim feedback instead of feedback at the end of the assessment, and for reports to contain a glossary page of terms at the end of the report.

The findings from this evaluation are in keeping with some of the earlier research and provide additional qualitative information from a service user perspective. Feedback was useful when it was timely, adapted to the individual, presented in a way that they can understand and

use. Difficulties with feedback occurred when it was difficult to understand, when service users didn't know what to ask or when they were left feeling like they needed to know more.

Emotional responses are also important to consider.

#### **4.1 Strengths and Limitations**

A strength of this evaluation was that service users were able to share their views and experiences through individual interviews. It can be challenging to interview individuals with cognitive difficulties due to problems, such as difficulties with memory or fatigue, but it is important they have the opportunity to share their experiences (Paterson & Scott-Findlay, 2002). Steps were taken to try and reduce any potential issues e.g. using simple interview questions with additional prompts, offering the support of a family member or friend if needed, checking understanding. A qualitative design was appropriate in meeting the aims of the evaluation and Elliott et al. (1999) provided guidelines to enhance quality and validity of qualitative data. These guidelines include the use of reflexivity, offering examples of quotes for themes and credibility checks, which have all been used within this evaluation.

There are some limitations to this evaluation. Only six service users consented to take part and although Braun and Clarke (2013) recommend a sample size of 6-10 participants for interviews for small projects, a larger sample would have been more representative. There are a wide number of different neurological conditions that people experience, as well as many different reasons why people seek or are referred for neuropsychological assessment, some of which were not represented in this sample. It would also have also been interesting to understand the experiences of service users from different ethnic backgrounds or people whose first language is not English. Despite a lack of diversity and small sample size, the sample was sufficient to identify shared patterns and themes.

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There may have been some selection bias due to service users being identified by psychologists completing their assessments. It is possible that psychologist's awareness of the evaluation and feedback being evaluated may have influenced their practice. They may also have selected service users that seemed to have more positive experiences. Psychologists were also involved in inviting service users to take part in the evaluation; therefore some service users may have declined if they had a negative experience or may have responded to interview questions in a more positive way, due to worries that this might impact on them negatively. To try and reduce the impact of these potential issues, participants were reminded of their anonymity and the researchers independence from the service.

Covid-19 has continued to impact on services throughout this evaluation. Service users were asked about whether they felt changes in the service due to Covid-19 restrictions had impacted on their experience of feedback. Although many service users accessed feedback remotely, none reported any issues.

### **4.2 Conclusion and Recommendations**

This SEP achieved its aims of exploring service user experiences of neuropsychological assessment feedback, including what has been useful and what could be improved. This evaluation indicates that the team are already providing useful feedback to service users in a way that is timely, adapted to individual needs, that they can understand and use in their day-to-day life. However, this evaluation also highlighted some of the areas in which feedback within the service could be improved, these are shown in Table 2:



**Table 2**

*Recommendations*

**Recommendations**

1. It is recommended that there is a review of feedback within the service. At present all clinicians provide feedback in different ways and although it is important to be flexible depending on individuals, it would be helpful for the service to discuss a more consistent approach. For example, if the report is sent following the verbal feedback, then a follow up ‘check-in’ phone call could be offered to aid understanding and allow for additional questions.
2. It is also recommended that reports are adapted so that they are easier for service users to understand. Feedback on changes to the report could be discussed with service users from the patient experience group within the Trust. Based on this evaluation and earlier research, changes could include:
  - Providing a summary report instead of the full report
  - Putting the summary at the start of the report so the service user is aware of the overall results and recommendations.
  - Simplifying the report by reducing complex terminology, including explanations of terms, or by including a glossary page as part of the report.
3. Following a review of feedback and changes to the report, further evaluation of the feedback process would be beneficial to evaluate any changes and to capture a wider audience.

## **5. Dissemination**

Findings presented at the Leeds DClin Psychology SEP Conference and at the Clinical Health Psychology Departmental meeting, Pinderfields Hospital.

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## 7. Appendices

### Appendix 1- Participant Information Sheet

#### INVITATION TO TAKE PART IN A SERVICE EVALUATION PROJECT

## Service users' experiences of Neuropsychological assessment feedback

### *Introduction*

You are invited to take part in a Service Evaluation Project. This project is commissioned by Dr Charlotte Baker, Consultant Clinical Neuropsychologist at Mid Yorkshire Hospitals NHS Trust. The aim of the project is to gain an understanding of service users' experiences of receiving verbal and written feedback following neuropsychological assessment. Before you decide whether you wish to take part, it is important you understand why the evaluation is being conducted and what your participation would involve. Please take time to read the following information carefully.

#### **1. What is the purpose of this evaluation and why have I been chosen?**

You are being asked to take part because you have recently had a neuropsychological assessment and been given feedback. I am interested in hearing about your experience of the feedback process, including what you found helpful and how feedback could be improved.

#### **2. Do I have to take part?**

No, it is entirely up to you whether you decide to take part. After we discuss the evaluation, you will be given up to two weeks to let me know your decision. It is important that you let me know within two weeks so that the time frame between your neuropsychological assessment and feedback and interview is limited. When we discuss the research, I will ask whether it is acceptable to contact you to hear your decision about whether you wish to take part. If so, we will arrange a date for this one week after our discussion. If you do not answer I will leave a message and ask you to contact me within one week to let me know about your decision. If you do answer but feel you need more time to decide, I will give you another week to do so. If you decide you want to take part, I will provide you with a consent form or record your consent verbally.

If you decide to take part but then change your mind after your interview, your interview data can be withdrawn from the evaluation for up to one week following the interview. The reason for this is because once your interview has been typed up it is anonymised it cannot be withdrawn. You can withdraw from the evaluation by contacting me using the details provided at the end of the information sheet.

#### **3. What would the evaluation involve?**

I would like to interview you once. During the interview you will be asked a number of questions relating to your experiences of receiving feedback following your neuropsychological assessment. The duration

## **Service Evaluation Project: Service users experience of neuropsychological assessment feedback**

of this interview will be approximately one hour, and the interview will be recorded. We can take a break during the interview if you are feeling tired. If you are not able to complete the whole interview, your answers would still be valuable for the evaluation. The interview will take place in a way that you would prefer, either via phone or video platform (using Microsoft Teams), at a time that is convenient for you. If you would like to use Microsoft Teams but are unsure of how to access and use this, I will provide you with a user guide.

If you would prefer to have someone else present during the interview, you can also ask a family member or friend to take part. They would also need to sign a consent form to show they have agreed to be involved. If your family member or friend decides to withdraw, your interview data would still be included in the evaluation, unless you also decide to withdraw.

### ***4. What are the possible disadvantages and risks of taking part?***

While some people may find it helpful to think about and talk about their experiences of receiving feedback, a few people may find this difficult. Please remember that you do not have to answer any interview questions that you do not feel comfortable answering. You can also let me know if you want to stop the interview at any time. If you feel upset or worried following the interview and feel that you require further support, I will advise you to contact your GP.

### ***5. What are the benefits of taking part?***

There is no direct benefit to you for taking part. However, your input will help us think about how the service can be improved for the future.

### ***6. Will my taking part in the research remain confidential?***

Your participation and the information I collect about you during the evaluation will be kept strictly confidential. The only time that confidentiality would be broken would be if you disclosed anything of serious concern about your own or others health, safety, or wellbeing. If this occurred and I had to inform an appropriate professional I would always discuss this with you beforehand.

I will make some notes during the interview and record the interview using a Dictaphone. After the interview, the recording will be used to check my notes about everything that was discussed. Once this has been done, the recording will be deleted. Some of the words you use may be included as quotes in reports, but these will be pseudonymised. This means that to protect your privacy, your identifiable data will be replaced by a code. Your name and other information that can directly identify you, will be removed. All electronic data will be stored securely, and password protected. Although this evaluation is commissioned by Mid Yorkshire Hospitals NHS Trust, I will be working independently. Your choice to take part or any information you share will not impact on your care.

### ***7. What will happen to the results of the evaluation?***

The results from the evaluation will be written up in a report and presented to the service commissioning the project.

### ***8. What might happen to my data in the future?***

## **Service Evaluation Project: Service users experience of neuropsychological assessment feedback**

Paper consent forms will be held by Mid Yorkshire NHS Trust for 30 years after the evaluation is completed, this is in keeping with Trust policies. All electronic data will be held until September 2022 when I complete my doctorate programme, after which it will be deleted. During this time, your rights to access, change or move your information are limited, as your information need to be managed in specific ways for the evaluation to be reliable and accurate. To safeguard your rights, we will use the minimum personally identifiable information possible. You can find out more about how we use your information at: <https://dataprotection.leeds.ac.uk/wp-content/uploads/sites/48/2019/02/Research-Privacy-Notice.pdf>.

### **9. Who has reviewed the evaluation?**

Ethical approval has been granted by the School of Medicine Research Ethics Committee.

### **10. What if I have any complaints?**

If you have a concern about any aspect of this evaluation, then please contact me using the contact details below and I will do my best to answer your questions. If you have any concerns, or wish to make a complaint to the University, please contact Dr Gary Latchford, Academic Supervisor, Clinical Psychology Training Programme, email: [G.Latchford@leeds.ac.uk](mailto:G.Latchford@leeds.ac.uk).

If you have and concerns or wish to make a complaint about your care, you can get free support from the Mid Yorkshire Hospitals Trust Patient Advice and Liaison Services (PALS) 01924 542972 or email: [pals@midyorks.nhs.uk](mailto:pals@midyorks.nhs.uk).

### **11. Contact for further information**

If you have any questions about this evaluation or would like further information, please contact me:

Sarah Rudkin, Psychologist in Clinical Training, Email: [umser@leeds.ac.uk](mailto:umser@leeds.ac.uk), Phone: 01924 541510 (Neuropsychology department number- please leave a message and I will get back to you as soon as possible).

**Thank you for taking the time to read this information sheet**



Appendix 2- Consent Form

**PARTICIPANT CONSENT FORM**

**Service users' experiences of Neuropsychological assessment feedback**

*Two copies of the consent form will be signed – one copy is for you as the participant and one copy will be kept by the researcher. Please see the information sheet for details regarding the University's policy for storing documents.*

Please initial boxes

- 1) I have read and understand the information sheet dated 13 February 2021 (version 2)
- 2) I have had the opportunity to consider the information, and to ask questions and have had these answered satisfactorily.
- 3) I understand that my participation is voluntary and that I am free to withdraw from the evaluation up until the interview has been typed up (one week after interview), without giving a reason. If I choose to withdraw my care will not be affected.
- 4) I agree to my interview being audio recorded.
- 5) I understand the information collected in the evaluation is held in confidence and that, when presented or written up, all my personal details will be removed.
- 6) I agree that anonymised extracts from my interview can be used as part of the evaluation write up.
- 7) I give permission for the information to be held in a computer (in a coded anonymised way) until the researcher completes their training programme.
- 8) I agree to take part in the study.

\_\_\_\_\_  
**Name of Participant**

\_\_\_\_\_  
**Date**

\_\_\_\_\_  
**Signature**

\_\_\_\_\_  
**Name of Person taking consent**

\_\_\_\_\_  
**Date**

\_\_\_\_\_  
**Signature**

## Appendix 3- Interview Guide

### Interview guide

#### Opening

Introduce yourself and the project.

#### **Purpose**

Explain the aims of the interviews- These interviews will help us to understand service users experience of feedback following a neuropsychological assessment. Understanding people's experiences can help us to inform clinical practice, for example, how feedback is presented to service users in the future.

#### **Practicalities**

Explain how long the interview should take, that they can take breaks whenever needed and that they can utilise the support of their family member or friend during the interview, if they are present. Adhere to ethical standards: explain the audio-recording, confidentiality, their right to opt-out, that they have one week after interview to withdraw their data (due to transcription). Also reminder that if family member or friend decides to withdraw, all interview data will be retained unless the service user also decides to withdraw (it cannot be separated). Ask if any questions.

*Start audio-recording and state number of the interview.*

#### **Consent to participate**

Let the participant know the recording has started and that you are going to discuss consent to participate. If a physical consent form has been signed reconfirm the participant is happy to continue and gives their consent to participate. If no physical consent form can be taken (i.e. phone/video call interview) then run through the participant consent form with them, asking them to state that they consent to participate.

Stop recording following consent and start again before commencing with interview.

#### **1. Clinical information**

*I am interviewing people living with different types of conditions and with different cognitive difficulties during this evaluation so it would be helpful if you could tell me...*

- Why you had a neuropsychological assessment?
- When did this assessment happen?
- What were your expectations/what were you hoping to get from this assessment?

#### **2. Feedback**

- How was feedback presented to you?
  - Was it verbal, written or both?
  - Was it face-to-face or remote?

**3. Verbal feedback**

- What happened/what was it like to be given verbal feedback?
  - How was this information presented?
  - How soon did this happen after your assessment?
  - Who was with you?
  - What if anything did you find helpful?
  - What if anything did not like or not find helpful?
  - How did you feel after being given this feedback?
  -

**4. Written feedback**

- What was it like to read your assessment report?
  - Were there any parts you found helpful?
  - Were there any parts you did not find helpful?
  - Were there any parts you did not understand?
  - Was there anything missing?
  - How was the format of the report (font/size)? Was it easy to read?
- How soon was this provided after your verbal feedback?
  - Was this timeframe appropriate? would it have been more helpful before/after?

**5. Using feedback**

- What did you take away from the feedback you were given?
  - Understanding of your condition?
  - Anything you do now that you did not do before?
  - Have you used any strategies?
  - Have you had any further input?
- How has this feedback impacted on your relationships with family members or friends? (Can ask family member directly if present).
  - Have you shared it with them? - if so, how was this?
  - Has it been helpful for them?

**6. Evaluation of feedback**

- What was most helpful?
- What was least helpful?
- How do you think feedback could be improved?
- Did the assessment and feedback meet your hopes or expectations? Or was there anything else you were hoping for?
- Were there any specific barriers to accessing feedback that come to mind?
- 

**7. End of interview**

- Is there anything else that you think we need to know?

## Service Evaluation Project: Service users experience of neuropsychological assessment feedback

- Do you have any questions?
- How have you found this interview?

*Turn off audio-recorder.*

Explain following procedure. Provide contact information to contact me if anything is unclear or they need further information. Remind them of their right to withdraw their interview data. Thank the participant for his/her time.

*Note time end interview.*

### **Standard follow-up questions**

- What do you mean exactly?
- In what way?
- Could you explain that a bit more?
- What else can you tell me about that? There is no right or wrong, just tell me what you are thinking right now.
- Could you explain why (you feel like that)?
- Could you explain that further, in your own words?
- Is there anything else that pops up?

## Appendix 4- R&D Approval

Re: Service Evaluation

MYRESEARCH (MID YORKSHIRE HOSPITALS NHS TRUST) <midyorks.my.research@nhs.net>

Tue 1/5/2021 10:42 PM

To: Sarah Rudkin <umsr@leeds.ac.uk>

Cc: MYRESEARCH (MID YORKSHIRE HOSPITALS NHS TRUST) <midyorks.my.research@nhs.net>

Good afternoon,

Thank you for sending that through

As your study is not research, you do not need approval from RM&S, please ensure that you obtain Head of Clinical Service approval before you begin your project.

Unfortunately, the HRA are currently not reviewing Undergraduate or Masters student research at the moment. Any updates will be notified on the HRA website here <https://www.hra.nhs.uk/planning-and-improving-research/research-planning/student-research/> Sadly, this has been extended to September 2021

Kind regards,

**Alice Kershaw**

Research Assistant | Research Management and Support | Mid Yorkshire Hospitals NHS Trust

8, 01924 543956 | e. [alice.kershaw4@nhs.net](mailto:alice.kershaw4@nhs.net) | Research Office, Unit 15, Clarke Hall Farm, Aberford Road, Wakefield, WF1 4AL.

The Research Team are part of the Medical Directorate

Please note I am working from home.

---

From: Sarah Rudkin <umsr@leeds.ac.uk>

Sent: 05 January 2021 18:42

To: MYRESEARCH (MID YORKSHIRE HOSPITALS NHS TRUST) <midyorks.my.research@nhs.net>

Subject: Re: Service Evaluation

Hi Alice,

Thank you for your reply.

Please find attached results confirming that the study is not research.

Thanks,

Sarah

RE: Approval for Service evaluation project

FRIZELLE, Dorothy (MID YORKSHIRE HOSPITALS NHS TRUST) <d.frizelle@nhs.net>

Tue 1/5/2021 5:18 PM

To: BAKER, Charlotte (MID YORKSHIRE HOSPITALS NHS TRUST) <cbaker@nhs.net>

Cc: Sarah Rudkin <umsr@leeds.ac.uk>

Absolutely - looks great

D

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From: BAKER, Charlotte (MID YORKSHIRE HOSPITALS NHS TRUST)

Sent: 05 January 2021 17:09

To: FRIZELLE, Dorothy (MID YORKSHIRE HOSPITALS NHS TRUST)

Cc: Sarah Rudkin

Subject: Approval for Service evaluation project.

Hi Dorothy,

Sarah is planning to do her SEP in our service, looking at service users experience of neuropsychological assessment reports and feedback. I've attached the commissioning form for more information. We just need your approval to go ahead with it, are you happy for her to do this? Let me know if you need any further information.

BW

Charlotte

Dr Charlotte Baker  
Consultant Clinical Neuropsychologist



[My Wellbeing Matters](http://my.wellbeingmatters)  
[Midyorks.MyWellbeingMatters@nhs.net](mailto:Midyorks.MyWellbeingMatters@nhs.net)

Department of Clinical Health Psychology  
Rehabilitation Department Gate 3a  
Pinderfields Hospital  
Wakefield  
WF1 4DG  
01924 541510/541512  
[Clinical Psychology Intranet Page](#)

Appendix 5- Table of themes, subthemes and additional illustrative quotes

Theme	Subthemes	
Emotional response	No surprises	<p>The outcome was as I expected really...that I don't retain information (Participant 1).</p> <p>It confirms what I already knew. (Participant 2).</p> <p>It wasn't good news, but I kind of knew that. (Participant 3).</p> <p>Nothing too shocking. (Participant 4).</p> <p>To be honest, I had a rough idea of where I were after doing the tests. Doing the tests made me realise where I am actually lacking. (Participant 5).</p> <p>After the second session and the last one I knew what the feedback was going to be. I had a good idea where I struggled and where I wasn't. (Participant 5).</p>
	Fear and vulnerability	<p>I was frightened. Really apprehensive. Because I know how I felt and how it has affected me, so I was frightened of the outcome. (Participant 1).</p> <p>You are putting your vulnerable self out there', especially when reading their report. (Participant 1).</p> <p>With the original report I felt too stripped bare with it. Like I could have been stood there with no clothes on. It was making me feel very vulnerable. (Participant 1).</p> <p>I was quite worried actually. There was a lot of feedback in a 30 or so minute session. A huge amount of feedback. I came out feeling a bit... well there was just a lot to take in. (Participant 2)</p> <p>I was a bit apprehensive and anxious because you are not sure what someone is going to say to you. (Participant 2)</p>

**Service Evaluation Project: Service users experience of neuropsychological assessment feedback**

		Well there was a lot that I didn't like but that wasn't (psychologist) fault, it was the news, and it wasn't good news. Although it was scary, I kind of knew that. (Participant 3)
	Confidence and hope	<p>I guess it has given me some confidence...I don't have to underestimate what happened to me. (Participant 1).</p> <p>But every little bit of information helps. It gives me hope if you know where I'm coming from. That hope for the future. (Participant 5).</p> <p>I can see a glimmer of light into the future. (Participant 5).</p> <p>Having that feedback and them saying categorically my cognitive abilities are as they would be expected, has boosted my confidence in myself. (Participant 6).</p> <p>It has given me confidence in myself to the extent that I have now not only found employment but have several other interviews lined up. (Participant 6).</p>
Adapting to the individual	Flexible to needs	<p>I asked for an edited version, which is just the introduction, all about the assessment and then summary and recommendations. So, they cut out what I feel was my personal things... things work didn't need to know.' (Participant 1).</p> <p>I think that she (psychologist) did me proud doing that (edited report for work), she acknowledged how I was feeling, and she was happy to spend her time doing that. (Participant 1).</p> <p>She (psychologist) very kindly said she would so an in a nutshell report to sum up my various problems for my solicitor. (Participant 3).</p> <p>She said she is going to write a special report for work, she went through what it would say and whether I would be happy for certain things to be included. So, I was happy with that. (Participant 4).</p> <p>She (psychologist) listened to me and took time out and listened to my needs, and I got what I needed. (Participant 6).</p>
	Pacing	In terms of style and bringing it in slowly, it was paced well for me, it wasn't just a direct tell. (Participant 2).

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		<p>The session was well paced and the way it was delivered, she explained well. (Participant 3).</p> <p>She sent me an email with information about certain things that I could read later because she knew how tired I had been. (Participant 3).</p> <p>I prefer straight up feedback like (psychologist) gave me. Just telling it like it is so I can start working on it. (Participant 5).</p> <p>She took her time. I was very relaxed. She explained all the different tests that were involved, what they meant, what she was looking for. There wasn't anything I didn't rate her for. (Participant 6)</p>
	Aiding understanding	<p>There were things like GAD scores and things like that and I didn't know what they meant, so she went into detail. (Participant 3).</p> <p>She kept it on a level that I could cope with and understand, which was very kind of her (Participant 3).</p> <p>It was helpful to talk through the report so I could understand some of the points. (Participant 4).</p> <p>Anything I didn't understand, she just said it in a different way. (Participant 6).</p> <p>She showed me charts on sort of where, from a nationally representative point of view, where they would expect people with my condition, my age, what you would expect and what it meant to be above the curve, below the curve or whatever. That really helped me to understand. (Participant 6).</p> <p>There were times she stopped and started the sentence again because she could see by the look on my face that I didn't understand what she was talking about. Then, she just said it in a different way. (Participant 6).</p>
Using feedback	Making changes	<p>I've learned to hold myself back. I get so tired. I am absolutely shattered and that is post stroke fatigue. (Participant 1).</p>



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		<p>The things I am doing as a result of the tests are less complicated things that I once used to try and do, like multitask. If I have multiple things going on at once, I can't focus. (Participant 3).</p> <p>I knew I was speaking to you today, so I made sure I had time around our meeting, so I wasn't too tired, and left time for a nap after. (Participant 3).</p> <p>I'm doing a log of prioritisation with my OT. She (psychologist) helped me with this, so I basically don't overload. I managed large teams in the past and this has been a massive change. I need to remember to keep things simple.' (Participant 3).</p> <p>I get pretty anxious before going in for operations. She (psychologist) talked about mindfulness, and I have looked at that sort of thing. She said we could look into that more moving forward and I think that would be a good life skill for sure. (Participant 4)</p> <p>She has put me forward now to another session with another person... we are coming up with a programme of things to do, working in the areas I was struggling with. (Participant 5)</p> <p>I'm trying to work on the areas I was struggling on, but of course I need guidance, that's why I'm having more sessions. (Participant 5).</p>
	<p>Providing proof</p>	<p>I need to pass this report on to my bosses because its good sort of evidence and documentation why I do need to have my hours reduced. (Participant 1).</p> <p>There's a CT scan on it and everything... I wanted my work to know, just to remind them that this lady has not had a mini stroke but a full-on proper bleed. It's like a hidden disability isn't it. (Participant 1)</p> <p>I wanted some support for work. I wanted it to be recognised'. (Participant 2)</p> <p>I guess what I was looking for was confirmation that what I was experiencing was actually happening and that something could be put in place to manage that.' (Participant 2).</p> <p>They were trying to say there was nothing wrong with me and I was faking injuries.' (Participant 3)</p> <p>She (psychologist) said she would write a report which would be helpful in terms of concrete medical information'. (Participant 4).</p>

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		<p>It was evidence that I know where I am struggling. I understand where I'm struggling but it's evidence to me.' (Participant 5).</p> <p>It's helped me to be honest, I have some tangible proof if I go back to work, or they want me to go back. I can be like; this is what I've had, and this is what I'm struggling with'. (Participant 5).</p> <p>I wanted to prove to myself either I do have cognitive problems, or I don't. (Participant 6).</p> <p>Having that proof, that evidential proof in the report... I'm going to frame it! (Participant 6).</p>
	<p>Learning</p>	<p>I think of life in a totally different way, and I now know that I have got a problem with my memory' (Participant 1)</p> <p>When she summarised it, some areas did fit with Parkinson's, it's how your brain works and probably to be expected. (Participant 2)</p> <p>I know I am weaker than expected in some areas, but I have found out the majority of it was what was expected with my condition. (Participant 2).</p> <p>I know that my injuries caused problems with instant recall. I'm very easily distracted but I do still have ability to recall if I do things slowly and I'm not distracted'. (Participant 3).</p> <p>I take away from it is that my main problems are visual rather than cognitive. (Participant 4).</p> <p>It's made me realise it's not the physical part that makes me tired, it's the mental part like them tests, when I came out, I had to sit down for a good hour before I could actually do anything else because I were that tired. (Participant 5).</p> <p>They have given me sufficient reassurance that like I said, I'm not going mad, and my brain isn't being eaten away and that I should have more confidence in myself and that I know what I am talking about still. (Participant 6).</p> <p>The whole process has definitely helped my perception of myself. That because my MS isn't causing whatever is happening, maybe it's just a confidence thing. (Participant 6).</p>

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Difficulties receiving feedback	Wanting to know more	<p>I didn't really understand the parts of it (assessment), why I was doing bits and bobs. (Participant 1).</p> <p>There were some parts of it around the memory stuff that I was concerned about, where I am in 5<sup>th</sup> percentile in one area and the 50<sup>th</sup> in others. That fluctuation, I would have liked to know more about it, but time was a bit of an issue and I thought about it after the session, when I saw the report.' (Participant 2)</p> <p>I didn't know what pre-morbid functioning meant because morbidity is usually like when you are going to die. (Participant 2).</p> <p>From the feedback session and my overriding feeling when I walked out was that there was a lot I didn't understand. (Participant 2).</p> <p>The whole reason why I did it was to get some practical advice, but I never got that. (Participant 4).</p> <p>It not given me closure that there is nothing I should be worried about because it's given me other questions to ask someone else, but I don't know who that someone else is. (Participant 6).</p> <p>I suppose one area in retrospect that wasn't fulfilled is, what happens now. What I thought was going on in my head isn't, so where does that leave me and what should I do now. (Participant 6).</p>
	Asking questions	<p>I was not prepared for it, and I like to be prepared. Later I thought of things and wish I had written them down like what was the purpose of the test with the blue circles? (Participant 2).</p> <p>She said this score was unusual, but I didn't have questions at the time because all of this was... was sort of coming in (verbal feedback). (Participant 2).</p> <p>I didn't have anything to benchmark it against so I didn't know what sort of questions I should be asking. (Participant 6).</p> <p>I don't know what questions I could or should have been asking. (Participant 6).</p>

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	<p>Readability of report</p>	<p>Some of the academic language was difficult to understand. Explaining tests like this assessment is a rule attainment test blah, blah, blah. That doesn't mean anything to me, I have no idea. (Participant 2)</p> <p>There were some bits that talked about frontal lobe medial retrieval deficits, what does that mean? I have no idea what that means. There is quite a lot of things... on the DKEFS test of verbal fluency she scored within whatever, in phonemic she scored in and in category she scored. So there were things like that.' (Participant 2).</p> <p>Some of it was technical stuff I wouldn't have known anyway. Like, she had put little asterisks where the scores were displayed lower down, but it was partly because I had not been able to make the connection. (Participant 3).</p> <p>The full report which was really more for my care team, that had far more depth and technical stuff that I needed to ask her about to understand.' (Participant 3).</p> <p>The way the report was written was quite jargony. It talked about you are in this percentile or this, and none of it really meant anything to me.' (Participant 4).</p> <p>Most of what the report identified is that I have a lot of visual problems, so reading a report in normal font isn't easy to do. I could have done with large font really. (Participant 4).</p> <p>Some of the terminology used was a little technical' (Participant 6).</p>
<p>Preferences &amp; suggestions</p>	<p>Report summary</p>	<p>The edited version summed it up in a nutshell what happened to me, what the assessment entailed and what the outcome is. These were important bits to me. (Participant 1).</p> <p>All that extra information, it's not useful to me, it brings it all back. Personally, what I needed was the edited version.' (Participant 1)</p> <p>It's quite a long report they get back to you. The introduction and summary were the best bits. It was easier to understand and made more sense than the whole report' (participant 2).</p> <p>I was able to understand far more of the summary report (Participant 3).</p> <p>The summary parts were definitely easier to read (Participant 5).</p>

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	<p>Timing</p>	<p>It's good because you can read it, digest it a bit and then if you have got any concerns you can ask. It's always easier than trying to ring the department, doctors are busy, and you feel it's trivial. That's my personal view anyway. (Participant 1).</p> <p>I got the report two or three weeks after the last appointment, before I had the verbal video link. So, I sort of knew what was coming. It helped me not feel so bad. (Participant 1).</p> <p>It was good to get the letter that followed up. I think if I had the written report first then it would have been really difficult to understand. (Participant 2).</p> <p>She got the report to me the following week, had a week to consider it, then she phoned me last Thursday. It gave me time to read it, digest it and make notes, that really helped because then she was able to answer my questions. (Participant 3).</p> <p>Took me a few days on and off to digest. By doing that it was more constructive because certain things became clearer, and I had time to think about it. I don't think I could have asked questions if I had only just been given the report, it was well timed to get the most out of my feedback session'. (Participant 3).</p> <p>I think it makes sense to get the report first like I did. (Participant 4).</p> <p>It happened really soon after we finished... I think it was only around two weeks wait so I could still remember things (Participant 5).</p> <p>It was all in good timing. I don't think you should get the report before feedback because when you read something you conjecture your own understanding, whereas listening to someone that knows what they are talking about gives it context. (Participant 6).</p>
	<p>Suggested improvements</p>	<p>There's quite a few of them (tests) that don't mean anything to me. If you put in brackets, the blue circle one, I know it makes the report less clinical, but it would be better from the recipient's point of view to know the detail. (Participant 2)</p> <p>It would have been nice to have some more immediate feedback. I wish I understood more about the tests at the time, like why it didn't matter if you guessed it. (Participant 2).</p> <p>The report could have been written in more layman terms, that would have been helpful. (Participant 4).</p>

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		<p>I would have liked a 'what you can do moving forwards' type of paragraph. (Participant 4).</p> <p>In the report it would have been good to have maybe a bibliography or short explanation or reminder of what the tests involved. (Participant 6).</p>
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