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**The clinical impact of the Edinburgh Cognitive and Behavioural ALS Screen (ECAS) and neuropsychological intervention in routine ALS care.**

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*Objectives:* The Edinburgh Cognitive and Behavioural ALS Screen (ECAS) is a brief multi-domain assessment designed for people with Amyotrophic Lateral Sclerosis (ALS). This study evaluated the clinical impact of using the ECAS on ALS patients, carers and healthcare professionals. A secondary aim was to evaluate the clinical impact of neuropsychological intervention. *Methods:* A survey of current screening practices in ALS services across the UK was undertaken. In addition comparative case studies, in seven ALS care contexts, was qualitatively explored through interviews with patients, carers and healthcare professionals. *Results:* 22/34 health care services responded to the survey. 95% screen patients for cognitive and behavioural changes and all used the ECAS. Thematic analysis indicated that the ECAS: raises awareness about cognitive and behavioural change between patients, carers and healthcare professionals; validates and/or reassures; identifies changes, aids understanding of the patients' presentation and informs clinical decision-making. The latter includes suitability of interventions, adaptations by the multidisciplinary team, discussions about end-of-life care, referral on to other services, and identifying carers' support needs. A number of indirect economic benefits were described. Clinical neuropsychological intervention was reported to help the multidisciplinary team manage the care particularly of complex cases, the effects on daily life, and stress of patients, carers and families. *Conclusions:* The ECAS has been widely implemented across ALS health care teams in the UK. Screening for cognitive/behavioural deficits and neuropsychological intervention has a positive impact on patients, carers and healthcare professionals and improves the quality of routine clinical care.

**Keywords: Cognition; Neuropsychology: Assessment; Screening**

Word Count 3121 main text

## **Introduction**

Approximately 50% of people with ALS will experience some degree of change in cognition and/or behaviour (Goldstein and Abrahams 2013). These changes have been shown to have consequences for clinical decision-making (Oliver and Turner 2010), patient adherence to life-prolonging interventions (Olney *et al.* 2005; Martin *et al.* 2014;

Govaarts *et al.* 2017), and caregiver burden (Lillo *et al.* 2012, Andrew *et al.* 2017). In the UK, the National Institute for Health and Care Excellence (NICE) recently updated guidelines on the assessment and management of ALS which recommend that the multidisciplinary team should recognise, explore and assess changes in cognition and behaviour (NICE 2016). The Edinburgh Cognitive and Behavioural ALS Screen (ECAS) is a multi-domain brief assessment developed for use by both neuropsychology and non-neuropsychology health professionals and validated against extensive neuropsychological assessment with high sensitivity and specificity (Abrahams *et al.* 2014; Niven *et al.* 2015; Pinto-Grau *et al.* 2017) and good convergent validity with other dementia screening measures (Lulé *et al.* 2014; Mora *et al.* 2018; Poletti *et al.* 2016). It was specifically designed for people with varying motor disability and can be undertaken in written and spoken forms. To date, the ECAS has been translated into 22 languages and is used by researchers and healthcare professionals around the world to screen people with ALS for changes in cognition and behaviour (<https://ecas.psy.ed.ac.uk>). Within the UK, effort has been made to educate ALS healthcare professionals about cognitive and behavioural symptoms and how to use the ECAS. Despite these advances, the clinical impact of implementing neuropsychological assessment and intervention in people with ALS has yet to be determined.

The study aimed to evaluate the clinical impact of assessing cognitive and behavioural change using the ECAS. Specifically we undertook a mixed methods study (surveys and case study interviews) in order to evaluate:

- Current practices in assessing cognitive and behavioural change in ALS and clinical utilisation of the ECAS in the UK;
- The impact of implementing the ECAS on ALS patients, carers and healthcare professionals; and,

A secondary aim was to evaluate the impact of clinical neuropsychological intervention on ALS care which was undertaken using case study interview alone.

## **Materials and methods**

### ***Survey***

To assess current practices, ALS care services across the UK were asked to select an appropriate member of staff to complete a survey. This asked about: which screens for cognition and behaviour were being used; which healthcare professionals administered them; whether or not every patient was offered screening; and, the services patients were referred to if issues were detected (see supplementary materials). Thirty-four UK services (including care centres and other multidisciplinary models) were identified by the Motor Neurone Disease Association as specialising in ALS care and sent an online link to the survey between Jan-Jun 2018. One further invitation to complete the survey was sent by email if no response was received after the initial approach.. The online survey was created using Qualtrics software (Qualtrics, Provo, UT).

### ***Case Studies***

We used comparative case study methods to evaluate the impact of the ECAS and neuropsychological intervention. In our approach, a healthcare context was a ‘case’ and we aimed to explore the impact from a range of viewpoints in each context, including patients, carers and healthcare professionals. Contexts where the use of the ECAS was established were identified in England and Scotland. Purposive, heterogeneous sampling was employed to achieve variation between the seven contexts selected. Key features of variation, which formed the basis of selection, were informed by previous research (Crockford et al. 2017; Hodgins et al. 2018) and clinical experience. A description of each context (labelled A-G) and the key features on which they vary is shown in Table 1. Each health care context was asked to nominate appropriate participants and each of the patients nominated had to have undertaken an ECAS within the last 12 months. The nominated patients had undertaken an ECAS within 1, 2 and 12 months.

Table 2 gives details of the case study participants within each healthcare context.

This study was reviewed by the Department of Psychology, University of Edinburgh Ethics committee, the NHS Research Ethics Service and approved by Research and Development in each of the health boards/trusts where data collection took place. All participants have given written consent to the inclusion of material pertaining to themselves and acknowledged that the data is fully anonymised and cannot be identified.

**[Insert Tables 1 and 2 here]**

Data were collected in semi-structured interviews either by telephone or face-to-face between December 2017 and June 2018. Interviews lasted approximately 45 minutes. Topic guides helped structure the interview and ensure main themes were covered (see supplementary material). Questions were derived from previous research and clinical insight into issues pertinent to screening and intervention in ALS care. One of the authors (FH) transcribed interview audio-recordings verbatim and subsequently checked the transcripts against the audio-recordings. The Framework Analysis method (Ritchie and Spencer 1994) was used to thematically analyse the data. This comprises five stages which were implemented in the following ways. 1. Familiarisation: The data was familiarised through the process of transcribing and checking the transcriptions against the original audio recordings and subsequently reading through the transcripts. 2. Constructing a thematic framework: Through detailed examination of each transcript FH highlighted key concepts and potential themes. These were then organised to produce a hierarchical coding map. The coding was checked and refined following discussion with two other authors (SA and SM) 3. Indexing and sorting: The Framework Matrices function on NVivo 11 (QSR International Pte Ltd, Doncaster, Victoria, Australia) was used to link data (lines of the transcript) to relevant codes. 4. Data summarising and display: The NVivo software aided the organisation and summarisation of data in to rows (each row representing an interviewee) and columns (representing themes). Using NVivo software meant an electronic link between data summaries and the original transcripts was retained. 5. Mapping and interpretation: Data in matrix rows and columns were compared, characteristics and differences between healthcare contexts were identified, and relationships were explored

## **Results**

### ***Survey of current practices in cognitive screening in the UK***

Twenty-two ALS care services responded to the survey, (Non-responding care services included 3 MND care centres, 3 MND care networks/services, 5 community teams, 1 hospice). Figure 1 shows that 95% of services screened patients for cognitive and behavioural change and all those used the ECAS to do so. Less than half of the services offered screening to every patient (45%). A majority of ALS services (90%) reported that they referred patients to clinical neuropsychology or another service (e.g. specialist geriatric service or psychology (clinical) service).

**[Insert Figure 1 here]**

### ***Impact of cognitive and behavioural assessment using the ECAS***

The results of the interviews revealed that the ECAS was reported by participants to have an impact on health professionals, patients and carers in a number of ways which fall under the following overarching themes.

1. *Raises awareness that cognitive and behavioural change can be part of ALS.*  
Patients and carers reported that the process of completing the ECAS ‘raised their awareness of the whole clinical picture’ (*Care Network Coordinator, Context F*) of ALS, including cognitive and behavioural change, and that without this opportunity to be informed, they ‘wouldn’t have even known that it was a factor’ (*Patient, Context D*).
2. *Reassures and/or validates*  
None of the patients participating had cognitive or behavioural problems identified by the ECAS and described it as being ‘reassuring’ to have this confirmed. Healthcare professionals reported that those patients for whom the ECAS identified changes usually found this validating as they may have already noticed some difficulties themselves. Similarly, carers were described as finding the experience validating as the ECAS provided ‘objective rather than subjective’ (*Occupational Therapist, Context G*) evidence of changes and provided an

opportunity for carers to disclose related concerns. Furthermore undertaking the ECAS was reported to provide opportunity for the carer to disclose related concerns.

### 3. *Identifies changes and aids understanding of the patient's presentation*

The ECAS was reported by healthcare professionals to help them identify changes that would otherwise go unnoticed.

There are situations where, maybe because you don't ask the right questions, maybe because you don't listen to the answers...you may underestimate [changes] which an ECAS may then ...pick up on (*Consultant Neurologist, Context C*).

The ECAS was also reported to aid healthcare professionals in distinguishing between Alzheimer's and Frontotemporal dementia in patients with ALS,

We presume they've all got FTD but we've had a few patients who've had Alzheimer's' (*Consultant Neurologist, Context D*)

and to contribute to an assessment of a patient's capacity.

It obviously gives you important insight into things like capacity which clearly is important when you're discussing end-of-life care and other interventions (*Consultant Neurologist, Context C*)

Healthcare professionals also reported using the ECAS results to understand whether cognitive and/or behavioural change could be the underlying cause of a patient's unexpected or difficult-to-manage behaviour.

[There was] a lady with challenging behaviour and increasingly poor communication and it was just very difficult to break down...is it MND, is it the fact that she's in the care home and getting frustrated?...I wasn't quite sure what I was going to find and the ECAS was actually really good...I think it helped us to exclude things that might be responsible Consultant in Palliative Care, Context G).

### 4. *ECAS informs clinical decision-making*



The increased understanding of the patients' presentation was reported to have an effect on a range of issues related to clinical decision-making (see Table 3).

**[Insert Table 3]**

*5. Economic benefits of ECAS*

Two examples of indirect economic benefits to patients and families were mentioned by participants. One was the example of ECAS results being used as evidence of cognitive and/or behavioural change in order to make a stronger case when applying for continuing healthcare funding.

We wouldn't have got the funding if we hadn't have had the ECAS score and it's actually won them the funding' (*Care Coordinator, Context D*).

The second example was that a patient used their ECAS scores as evidence for their employer that they were cognitively fit to continue in their role.

Economic benefits for care teams were also described. As the ECAS could be administered by a trained member of the multidisciplinary team, psychologists could focus their time on intervention work with patients and families. The psychologists were in agreement that the ECAS alone was sufficient for assessing cognitive/behavioural change in most ALS patients and use of the ECAS saved time they would otherwise spend administering a range of cognitive/behavioural assessments.

*6. Possible negative effects and how to minimize them*

Although the patients described the experience of completing the ECAS as 'quite fun' and not stressful, healthcare professionals and patients suggested that some patients could feel anxious about completing the ECAS, concerned about a poor performance, and burdened by news that they have cognitive and/or behavioural difficulties. In addition, it was noted from the patients' responses that they may not have fully understood the potential implications of doing an ECAS before agreeing to do it.

The healthcare professionals were in agreement that the ECAS was not harmful relative to other clinical assessments and interventions. It was even suggested that ‘there may be more harm in not doing it’ as changes in cognition or behaviour pertinent to future interventions or quality of life of the patient and carer may go unnoticed.

However the following themes emerged from health professionals’ responses to minimize any possible negative effects:

- consider the emotional state of the patient and do not ECAS ‘too soon’ after diagnosis;
- explain what the ECAS is, why it is being offered, how the information gathered will be used, and give patients the option to accept or not;
- emphasise what action will be taken if changes in cognition and/or behaviour are identified; and,
- give patients feedback on the ECAS results in a timely, person-centred and meaningful way (i.e. do not use jargon such as ‘cut-off’ or give patients their raw ECAS scores but, rather, explain how the scores may relate to their everyday functioning).

It was considered important to safeguard the interpretation of the ECAS by ensuring that a psychologist has input. Clinical neuropsychologists and clinical psychologists highlighted the potential risks of pathways to screening without input from psychology which included:

- subtle qualitative information about how the patient reacted to the assessment and their general behaviour not being taken into account in interpretation leading to under/overestimation of deficits;
- limited knowledge of how to adjust and interpret scores (or whether an ECAS is appropriate) in cases where patients have e.g. limited education or dyslexia, and, lack of reliability in administration as care team may not use the ECAS on a regular basis and therefore become de-skilled.

### ***Impact of neuropsychological intervention in ALS***

*What is neuropsychological intervention in ALS?*

The clinical neuropsychologists and clinical psychologists who participated in this study described their ALS-related work as involving an initial assessment of the patient, a formulation of the factors (physical, emotional, cognitive, behavioural, developmental) affecting how the patient presents, and, in Contexts A, C, D and E, subsequent intervention. Interventions mentioned by psychologists included:

- behavioural interventions- working with carers to implement strategies for managing challenging behaviour;
- relational/family interventions- facilitating communication between family members to promote understanding and manage stressful situations; and,
- interventions to improve emotional wellbeing and adjustment to living with the disease- e.g. mindfulness, Acceptance and Commitment Therapy, discussion of existential issues and the experience of dying.

#### *Impact of neuropsychological intervention on healthcare professionals*

Clinical neuropsychological (or clinical psychology) input was reported by psychologists and other healthcare professionals to impact directly on healthcare teams in the following ways:

- providing healthcare professionals with an understanding of a patient's cognitive and behavioural status, enabling them to manage the patient more effectively;
- providing support to an MDT, helping healthcare teams manage the stress of caring for patients and families;
- being available for discussion of complex cases and referral for assessment and intervention, if required;
- assisting with explanation of ECAS/other neuropsychological assessment results to patients and carers and how this relates to daily functioning and potential management strategies; and,  
advising on effective strategies for communicating with patients and carers.

## **Discussion**

The study showed that the ECAS has been widely implemented across the UK. Ninety-five percent of ALS care services who responded screen ALS patients for cognitive and behaviour change and all use the ECAS. The patients, carers and health

professionals interviewed described that the process of completing an ECAS raises awareness of cognitive and behaviour change and that these symptoms form part of the whole clinical picture and provides an opportunity to discuss related concerns. It was seen to identify changes which may go unnoticed and aid in the understanding of the patients' presentation, including determining why a patient may be behaving in a particular way and helping to assess capacity to make decisions.. The ECAS was also reported to be used to inform clinical decision-making by identifying changes that may otherwise go unnoticed, tailoring the types of intervention to the individual's cognitive/behavioural problems (such as support with comprehension of guidance), and informing other health professionals on the suitability of interventions such as gastrostomy or non-invasive ventilation. It was also regarded as prompting early discussion of end of life care for those with cognitive/behavioural changes, indicating when referral to other services such as psychiatry is warranted and identifying when a carer may need support. As such administering a cognitive and behavioural screen was seen to improve the overall quality of routine clinical care

The ECAS was also seen to validate both patients and carers experiences and to reassure those patients who were unimpaired. However it should be noted that this theme emerged mainly from a healthcare professionals perspective, which may have been due to the few number of carers and patients interview. Further benefits to patients were economic, such as using ECAS results to secure continuing healthcare funding and provide evidence to employers. In these ways, the ECAS indirectly benefits patients and their families. There were also economic benefits in psychologists' time being saved through use of an efficient screen which can be administered by other trained members of the care team. Psychologists could focus their time on intervention work with patients and families. However, psychologists suggested that the feasibility of this arrangement would depend on the capability of the individual team member to conduct a reliable ECAS and that supervision would still take up some of their time.

It is of note that fewer than half of the services offered screening to every patient (45%); most typically offering screening in cases where cognitive and/or behavioural change was suspected by a clinician. Given that most cognitive impairment in MND is mild and can be masked by physical disability it is possible that impairment may continue to go unrecognized in some people with MND.

Neuropsychological intervention was reported to impact on healthcare by enabling the understanding of patients' cognitive and behavioural issues to help MDT with managing care, facilitating discussion of complex cases, helping the MDT manage stress from patients, carers and families, enabling the understanding of these changes in patients carers and families and how this affects daily life and management and advising on strategies

Some possible negative effects mentioned included anxiety over poor performance, burden of news of cognitive change and lack of understanding the implications of an assessment. In relation to managing these, two key themes emerged. Firstly, the need to incorporate supervision from a clinical neuropsychologist for interpretation of the ECAS in order to ensure the administration and interpretation is reliable and valid. Secondly, issues related to patient welfare including: the need to consider the timing of the administration of the screen in the patient's care pathway; the importance of being transparent about the reasons for, and potential consequences, of screening; and, to consider how and when the patient will receive feedback on their results.

We aimed to explore the impact of the ECAS and separately neuropsychological intervention from a range of perspectives in different healthcare contexts. With regard to the survey data we acknowledge that there is likely to have been a response bias with those who use the ECAS more likely to participate. Although 95% of respondent centres use the ECAS, this equates to 62% of the total who were approached including non-respondents. Furthermore within the time limits of the study, we were able to recruit key healthcare professionals involved in the implementation of the ECAS in each context; however, we were only able to recruit patients in three contexts and carers in two contexts. This led to the majority of our findings being informed by the perspective of healthcare professionals and it is possible that emergent themes would have been enriched with the inclusion of more patients and carers. Further work would benefit from more concentrated efforts to explore the perspectives of patients and carers.

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Data availability statement: The data that support the findings of this study are available from the corresponding author [SA], upon request.

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Table 1. Description of each healthcare context included in the sample.

	<b>Scotland</b>			<b>England</b>			
	<b>Context A</b>	<b>Context B</b>	<b>Context C</b>	<b>Context D</b>	<b>Context E</b>	<b>Context F</b>	<b>Context G</b>
	MND Care	MND Care	MND Care	MND Care	MND Care	Team within	Hospice
	Service in	Service in	Service in	Centre in	Centre in	MND Care	Team,
	West (local)	West (regional)	East	North East	North	Network, South East	South
<b>Psychologist based within multidisciplinary clinic</b>	Yes			Yes			
<b>ECAS usually administered by non-psychology healthcare professional</b>			Yes	Yes		Yes	Yes
<b>Psychologist interprets ECAS</b>	Yes	Yes	Yes		Yes		
<b>Psychologist available for ECAS, further assessment and intervention</b>	Yes	Yes	Yes	Yes	Yes		

Psychologist: Clinical Psychologist or Clinical Neuropsychologist. MND Care centre is defined by the MNDA <https://www.mndassociation.org/getting-support/care-centres/>



Table 2. Case study participants from each healthcare context (A-G).

<b>Context</b>	<b>Participants</b>
A	Clinical Neuropsychologist; Consultant Neurologist
B	Clinical Neuropsychologist; Clinical Psychologist; Consultant Neurologist (the same individual as Context A as they work across both areas)
C	Clinical Nurse Specialist; Clinical Neuropsychologist; Consultant Neurologist; Patient
D	Care Coordinator; Consultant Neurologist; Clinical Neuropsychologist; Patient; Carer
E	Clinical Psychologist; Assistant Psychologist
F	Care Network Coordinator
G	Consultant in Palliative Care; Occupational Therapist; Patient; Carer

Table 3. Impact of the ECAS on clinical decision-making.

<b>Impact of ECAS on clinical decision-making</b>	<b>Example Quotation</b>
Informs healthcare professionals about the suitability of interventions (e.g. gastrostomy, Non-invasive ventilation)	<p>‘... you’re probably being more proactive in terms of getting patients’ opinions of what they want done if there’s evidence of cognitive impairment...if people are likely to have significant behavioural disturbance and are not going to be able to manage to understand what a gastrostomy is or take part in it’</p> <p><i>Consultant Neurologist, Context A &amp; B</i></p>
The type of interventions may be tailored to their cognitive/behavioural status (e.g support with comprehension of guidance)	<p>‘If there [are] mild memory difficulties...we would... highlight that and say that this person might not remember all of their consultations so if you could give them written summaries...or if it’s fluency or language...adapt their communication style, slow things down, don’t overwhelm them with information’</p> <p><i>Clinical Psychologist, Context B</i></p>
Prompts early discussion of end of life care for patients with cognitive/behavioural changes	<p>‘[people are] making very serious decisions quite quickly... we want to make sure they’re making choices that are right for them and that they can make those choices independently so, by finding out their cognitive state, it enables us to support them’</p> <p><i>Consultant Neurologist, Context D</i></p>

Care may be improved if other healthcare professionals are informed of changes in cognition/behaviour and advised on adjustments	‘being able to flag up where someone might be having problems that people aren’t aware of to get them the right support, advice, to help make adjustments, support with decision-making’ - <i>Clinical Psychologist, Context E</i>
Indicates when referral to neuropsychology or psychiatry is necessary	‘If there’s clearly other behavioural issues, we might want to involve psychology or psychiatry services in the community for behavioural management’ <i>Consultant Neurologist, Context A &amp; B</i>
Identifies cases where carer may need additional support, leading to signposting or referral to appropriate services (e.g. GP, counselling, clinical neuropsychology)	‘[A patient] was not really eating and not taking her medication...she was really quite cognitively impaired and that allowed us to get more support ...it alleviated the stress of the family because they were struggling...[it] was causing a lot of friction...We gave them strategies to help them get her to take her medicine and to eat but we also got psychiatric support in to support some of that activity and that .. allowed the family to continue it’ - <i>Clinical Neuropsychologist, Context B</i>

Figure 1. Survey of cognitive and behavioural screening practices in the UK (Jan-Jun 2018).

