Adjustment to test, risk and diagnostic disclosures in people with suspected mild cognitive impairment: an observational cohort study

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Presentation

Background: what is MCI/recommended clinical approach

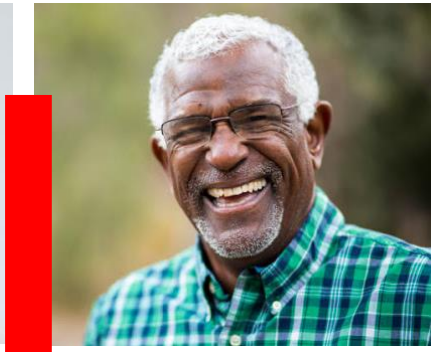
Study: Adjustment to test, risk and diagnostic disclosures in people suspected of having MCI

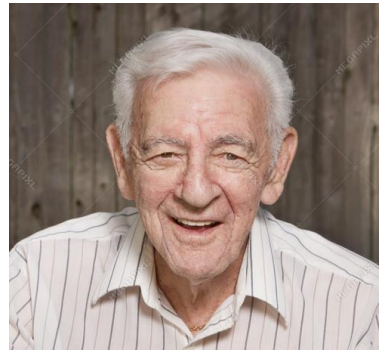
Discussion: Disclosing MCI results

Future directions: Capturing meaningful change in brain health outcomes

Background



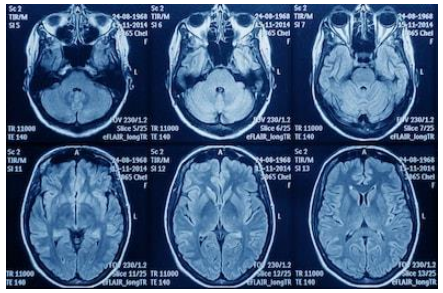


Normal | Preclinical | Prodromal | Dementia

Alzheimer's disease pathology

Biomarker assessment → Functional assessment

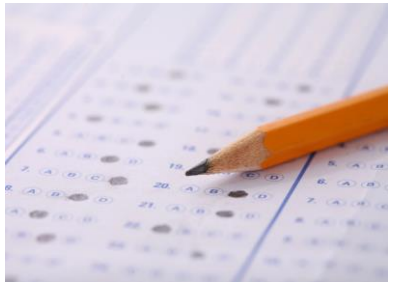



Background

Recommended assessments?

Biomarkers



Neuropsychological testing

Recommended management?

Globally, 13 MCI guidance documents for Clinical Practice Guidelines/Consensus statements (4 guidelines, 9 consensus)

- Risk reduction
- Counseling
- Pharmacologic interventions
- Non-pharmacologic interventions
  - Physical activity,
  - cognitive,
  - dietary and nutritional
  - acupuncture

Chen et al., 2021

4 – China; 2 – UK (Dunne et al., 2021 MCI consensus; O'Brien et a., 2017 [anti-dementia drugs]);
2 – USA; 2 – European; 1 – Singapore; 1 – Canada; 1 – Switzerland (WHO)

Study

The aim of the MCI adjustment study is to identify whether the way clinical information is communicated to individuals with newly identified MCI by clinicians could have:

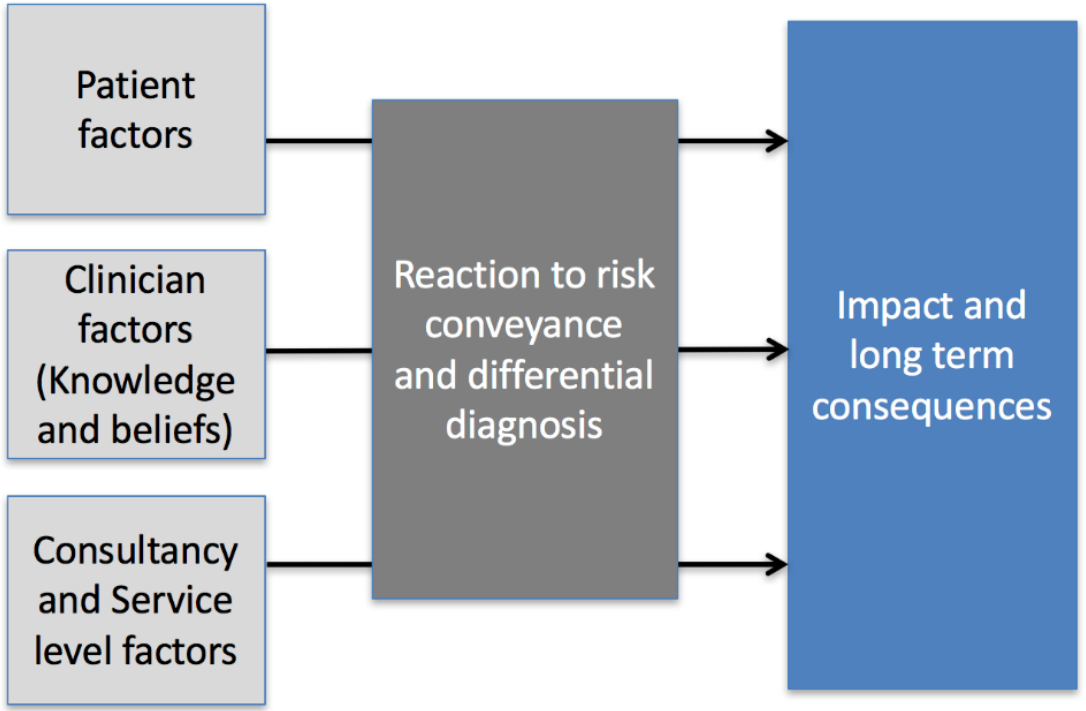
An impact on the individuals' clinical outcomes,

possibly lead to an altered prognosis.

We hypothesise that the way the consultation process is conducted in the context of patient characteristics could have a long-term impact on the patient's cognition and well-being.

Method

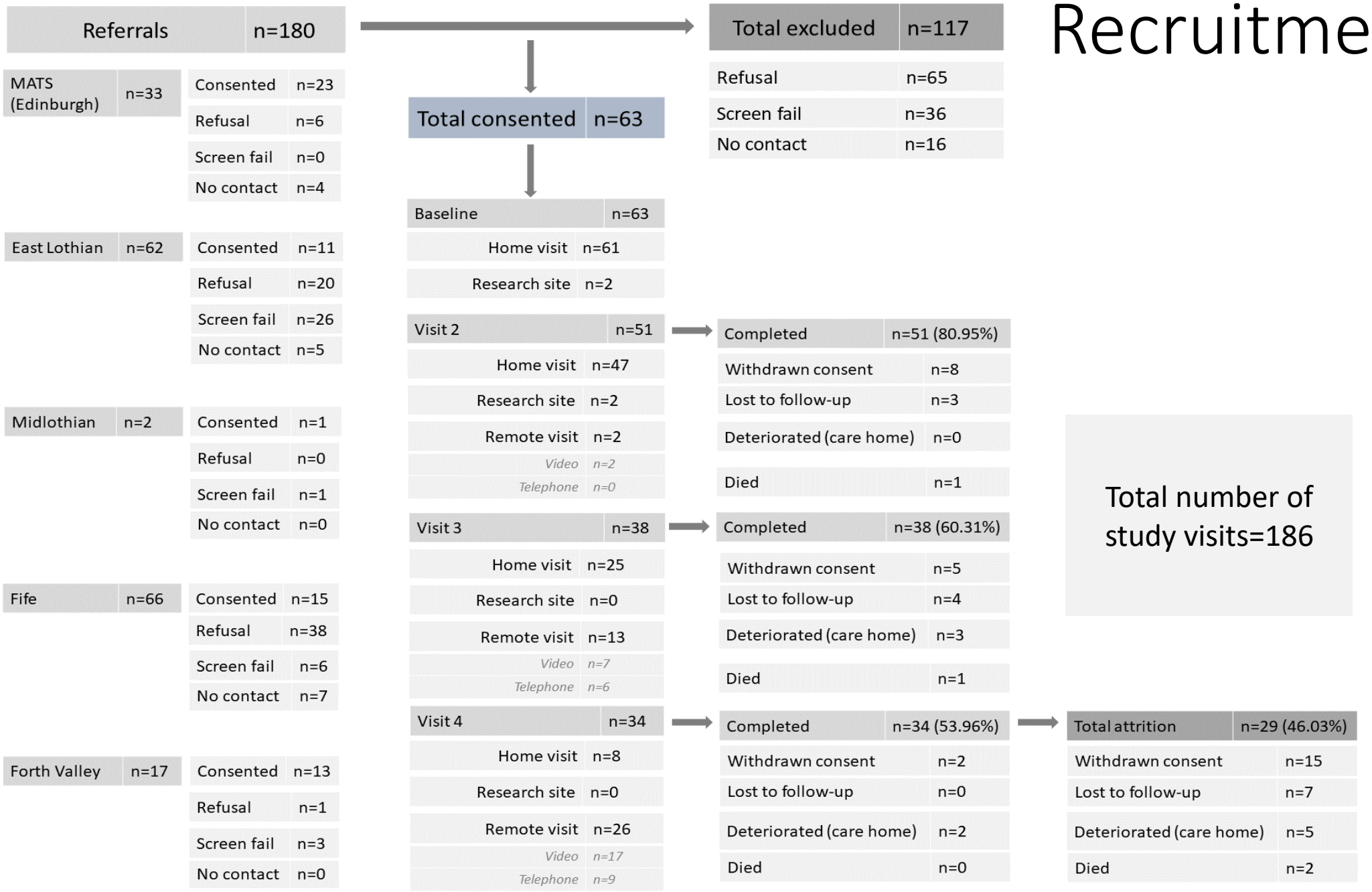
- LCS at five memory assessment services in South-East Scotland, baseline before risk disclosure, three follow-up assessments after risk disclosure over two years.
- Recruitment: 2018 Jul – 2019 July
- Subset of 12 participants interviewed about their experience of risk disclosure at the memory clinic
- Clinicians at each five site also interviewed on their views on MCI



Inclusion criteria

- Referred to one of the memory assessment services enlisted as research sites in this study
- Suspected of having problems **not consistent with dementia**
- Over 60 years old
- Have the capacity to consent

Recruitment



Results: descriptives

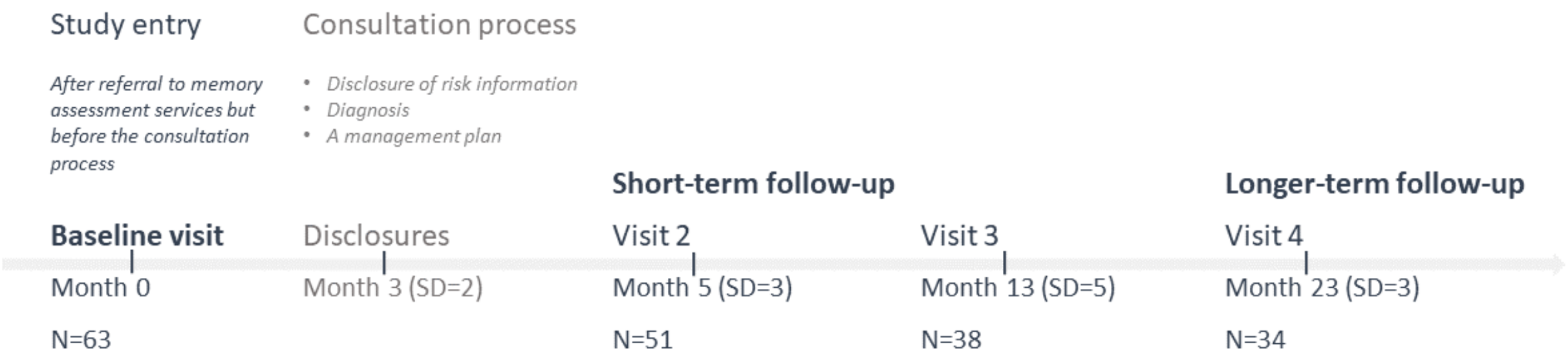
Descriptive characteristics of the study sample		
Number of participants	N=63	
Male	n=25 (39.68%)	
Female	n=38 (60.32%)	
Recruitment site	MATS (Edinburgh)	n=23 (36.51%)
	Fife	n=15 (23.81%)
	Forth Valley	n=13 (20.63%)
	East Lothian	n=11 (17.46%)
	Midlothian	n=1 (1.59%)
Age	Mean=77.24 (SD=6.76)	
Years of education	Mean=12.94 (SD=3.57, mode=10)	
Ethnicity	White	63 (100%)
Annual household income	£0 - £24 000	35 (55.56%)
	£24 001 - £60 000	25 (39.68%)
	More than £60 000	3 (4.76%)
	Refuse to say	0
Marital status	Married/living as a couple	39 (61.90%)
	Widowed	14 (22.22%)
	Divorced/separated	8 (12.70%)
	Never married	2 (3.17%)
Living situation	Living as a couple	35 (55.56%)
	Living alone	19 (30.16%)
	Living with family	9 (14.29%)
Current or past medical history at baseline	Dementia	0
	Arthritis	30 (47.62%)
	Heart conditions	17 (26.98%)
	Depression/anxiety	13 (20.63%)
	Cancer	12 (19.05%)
	Diabetes	11 (17.46%)
Do you have children?	Yes	57 (90.48%)
	No	6 (9.52%)

Disclosure group	Participants
MCI	n=34 (53.97%)
Non-MCI	n=29 (46.03%)
Dementia	*n=8*
Mild Alzheimer's disease	*n=4*
Mild dementia	*n=1*
Discharged with no diagnosis	*n=6*
Progressive memory loss	*n=1*
Subjective Cognitive Decline	*n=1*
Vascular cognitive impairment	*n=1*
Parkinson's disease with Lewy body	*n=1*
Anxiety, dementia	*n=1*
Anxiety	*n=1*
Depression	*n=1*
Attentional issues	*n=1*
Delirium	*n=1*
MND	*n=1*

	Rating of disclosure experience		
	Good	Not good	*Total*
MCI	23	6	*29*
Non-MCI	12	8	*20*
Total	*35 (71.42%)*	*14 (28.57%)*	*49 (100%)*

Average (n=11) and poor (n=3) ratings combined into "Not good"

Results: study timelines



Results: longitudinal trajectories of change

Outcome variables		Baseline	Visit 2	Visit 3	Visit 4
		N=63 Mean (SD)	N=51 5 months (SD=3)	N=38 13 months (SD=5)	N=34 23 months (SD=3)
RBANS *Higher score indicates better cognitive performance (score range 40-160)*		86.95 (SD= 15.67)	86.51 (SD=19.19)	82.11 (SD=17.29)	82.29 (SD=21.11)
STAI *Higher score indicates greater anxiety (score range 40-160)*		81.52 (SD= 17.85)	78.22 (SD=16.74)	80.97 (SD=14.77)	74.09 (SD=22.83)
PGWBI *Higher score indicates better psychological well-being (score range 0-110)*		73.50 (SD=17.96)	77.10 (SD=15.45)	75.47 (SD=16.79)	72.27 (SD=20.87)
PAIS *Higher score indicates worse psychological adjustment to illness (score range 0-102)*		11.55 (SD=6.74)	13.10 (SD=6.79)	16.53 (SD=10.85)	20.26 (SD=10.32)
PDQ *Higher score indicates more perceived deficits (score range 0-80)*		30.89 (SD=11.22)	29.70 (SD=11.52)	33.24 (SD=12.12)	32.82 (SD=12.35)
PSQI *Higher score indicates poorer sleep (score range 0-36)*		13.24 (SD=6.93)	12.04 (SD=6.26)	13.18 (SD=5.61)	13.47 (SD=6.87)
COPE *Higher score indicates greater alignment with*	Positive coping	9.11 (SD=4.62)	8.08 (SD=5.74)		
	Mental disengagement	7.35 (SD=3.98)	5.78 (SD=4.46)		

Results: short and long-term impact

The rating of disclosure experience did not predict any of the clinical outcomes in the short-term follow-up.

Over longer time, rating of disclosure experience as not good had no associations with:

- the RBANS scores in the whole sample (cognition)
- the STAI scores (anxiety – just below sig at 0.057)
- the PGWBI scores (psychological well-being)
- the PSQI scores (sleep)

Over longer time, rating of disclosure experience as not good had associations with:

- the PAIS scores (psych adjustment to illness worsens for those in the not good group)
- the PDQ scores (perceived deficits score is higher for those in the not good dis group)

Results: at study entry

At study entry, the rating of disclosure experience did not have associations with:

- STAI
- PAIS
- PGWBI
- PDQ
- PSQI

At study entry, the rating of disclosure experience had an associations with:

- RBANS

Those who rated their disclosure experience as not good (average or poor) scored 11.34 (SE=5.34) points higher at study entry than those who rated their experience of disclosure as good.

Results: impact of age/sex/education

Age not an important predictor of clinical outcomes among individuals referred to memory assessment services with suspected MCI. **Older age** at study entry was only associated with one outcome**: better psychological adjustment to illness over time**.

Sex differences were in cognitive functioning and sleep but there were no differences in psychological outcomes. **Men had a faster rate of decline in cognitive outcomes and faster rate of decline in sleep** quality.

Higher education was associated with better sleep over time but there were no differences in psychological well-being or cognition over time.

Results: qualitative longitudinal interviews

- In a sub-study, 12 participants were interviewed in-depth about their disclosure experience at the memory assessment service
- An independent researcher blind to the participant's own rating analysed the interview transcripts to give an objective rating of the disclosure

  - All participants who rated their experience as average or poor received either an average or poor rating from the independent rater (n=8).

  - However, n=3 individuals (out of n=4) who rated their experience as good received a rating of average or poor from the independent rater and only n=1 participant who rated their experience as good also received a good rating from the independent rater.

Results: qualitative longitudinal interviews

Consultation process

- *Disclosure of risk information*
- *Diagnosis*
- *A management plan*

	Short-term follow-up	**Medium-term follow-up**	**Longer-term follow-up**
Disclosures	Visit 2	Visit 3	Visit 4
Month 0	Month 2 (SD=1)	Month 7 (SD=2)	Month 20 (SD=5)
	N=12	N=10	N=8

Relief of not having dementia, even in the case of limited understanding of future risk.

Lack of advice and clarity of how to prevent further decline.

Worried about the future perspective, regardless of their rating of disclosure experience,

even though this was particularly dominant in the not good group

All: **Reflective of how they feel** about themselves now

with **worry and uncertainty** about future decline becoming even more prominent across the study sample.

Results: qualitative longitudinal interviews

Participant 7:

"I would say I was elated when I left the service because I was told I didn't have Alzheimer's… or you know, dementia. Later on, I start feeling like I cheated the doctors though. I was told I have a little bit of shrinkage of the brain."

"No, [the consultation process] is not in the past. I'm hanging onto it like an anchor, you know?"

"I do think back to the consultations where I was told I don't have dementia; I am hanging on to it for my dear life that I was told I don't have it [dementia]. I used to have such a good memory, that's why it's terrifying. When I'm calm it's a little easier but I forget little things like names."

Results: clinicians' views on MCI

- Most clinicians interviewed (Total N = 19) considered MCI to have **significant limitations as a diagnostic term**, n=15 use the term in clinical practice with patients.

- Over half of the participants (n = 11/19) reported a **positive response from patients**, with fewer (n = 6/19) saying that they detected **anxiety in some patients about being at risk of developing dementia.**

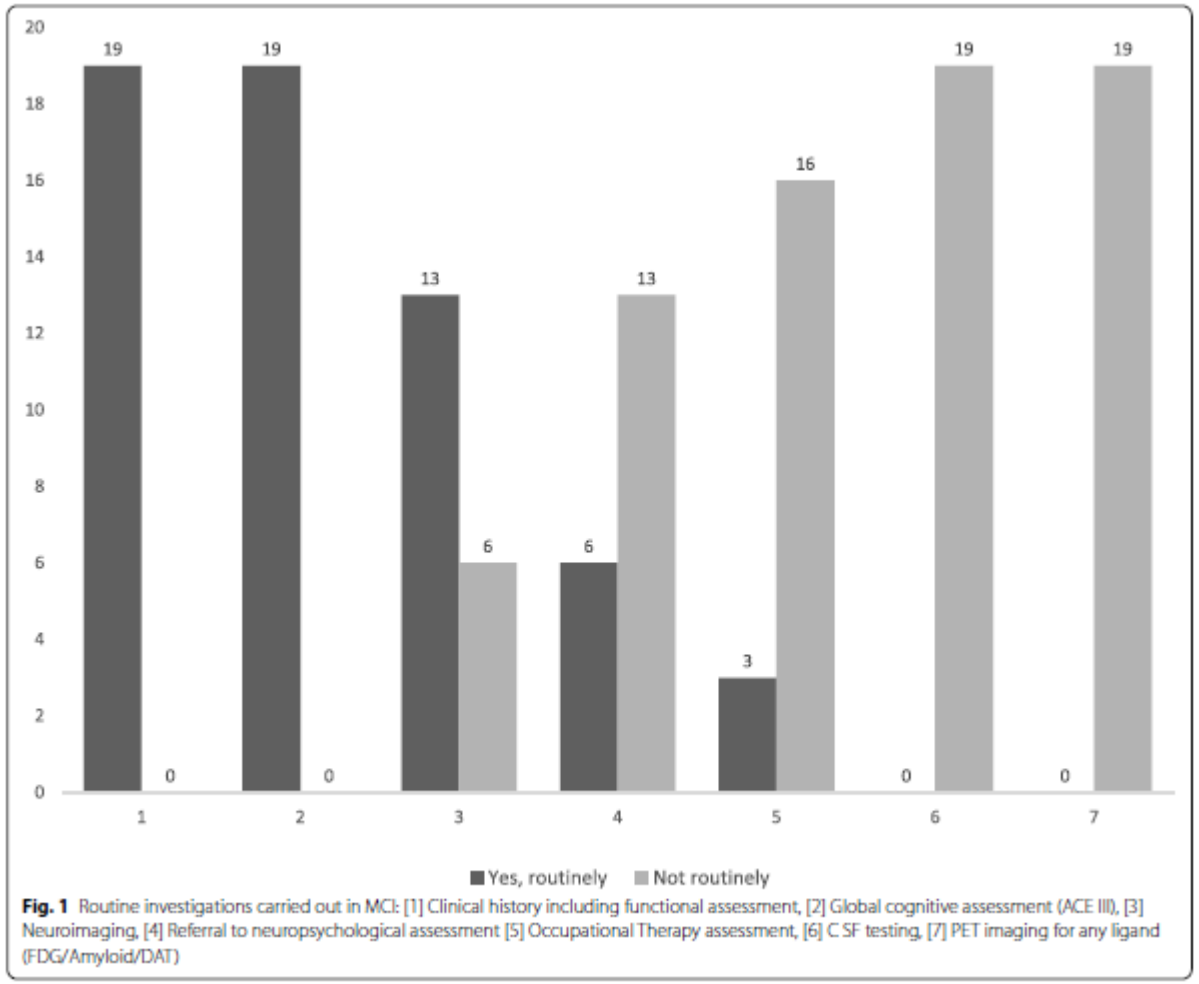


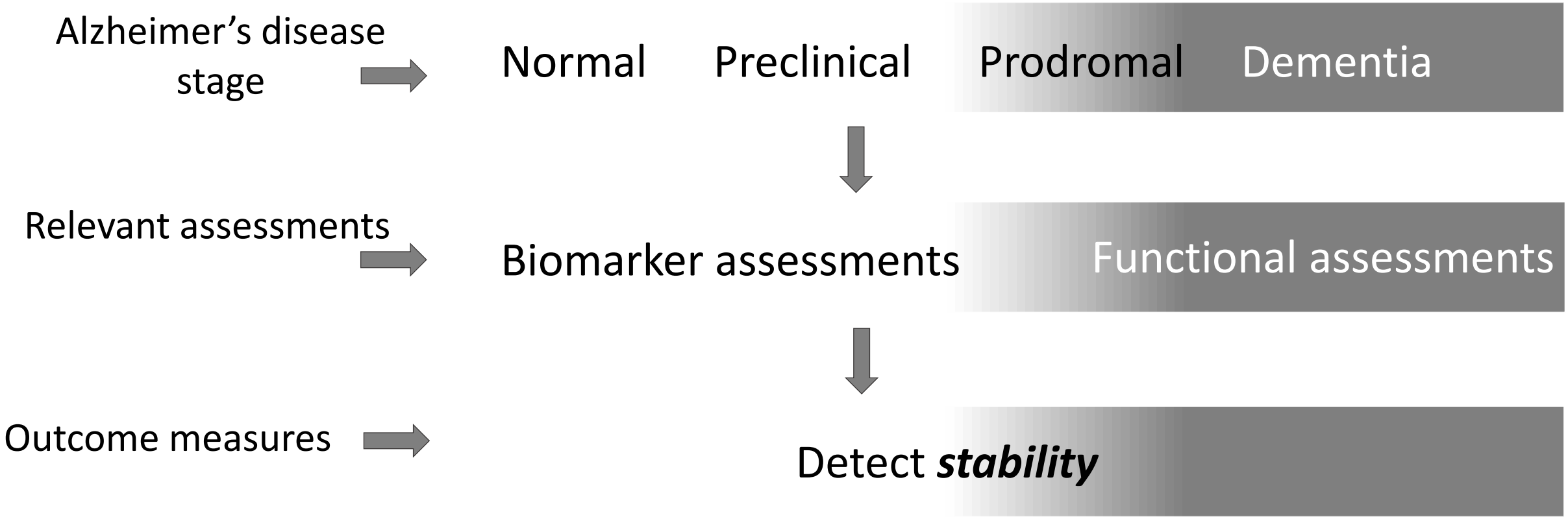
Fig. 1 Routine investigations carried out in MCI: [1] Clinical history including functional assessment, [2] Global cognitive assessment (ACE III), [3] Neuroimaging, [4] Referral to neuropsychological assessment [5] Occupational Therapy assessment, [6] C SF testing, [7] PET imaging for any ligand (FDG/Amyloid/DAT)

Saunders, S., Ritchie, C.W., Russ, T.C., Muniz-Terrera, G., Milne, R. Assessing and disclosing test results for 'mild cognitive impairment': the perspective of old age psychiatrists in Scotland. *BMC Geriatr* **22,** 50 (2022). https://doi.org/10.1186/s12877-021-02693-x

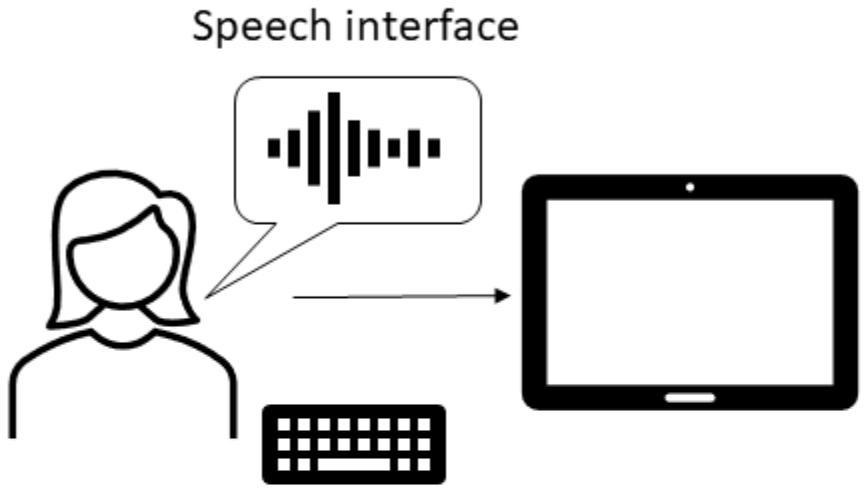
Discussion

- Individuals referred to memory assessment with similar referral info/initial assessment are a **heterogeneous group** (healthy vs MCI; MCI vs dementia; non-neurodegenerative diseases)
- Difficulty with rating of disclosure experience in the study – **lack of clear expectations from the participants.**
- A study by Visser et al. 2022 (unpublished), found 52% (n=55 out of 105) patients attending a memory clinic didn't express a specific motivation for attending the service
- Other studies looking at amyloid disclosure (e.g., AMYPAD) have found amyloid+ associated with minor transient distress (no amyloid disclosure in current study though)

Future directions

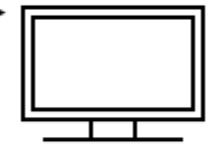


ePSOM = electronic Person Specific Outcome Measure

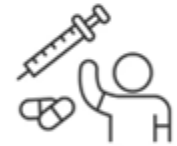


Set specific coaching intervention to maintain 'what matters most'

Set Qualitative Treatment Target and Quantify (score) the outcome



Track changes over time to gauge success of interventions (personalised prevention) and coaching



Use in clinical practice/clinical trials

Clinical practice

Brain health services →

- Pre-treatment assessment:
  "What matters to you about your brain health?" *Free-text answers*

Research

Realistic medicine in Brain Health Study
Contact individuals who completed pre-treatment assessment
↓
ePSOM: Provide free-text what matters answers **and score items**

Summary

Background: what is MCI/recommended clinical approach

MCI is not categorical but on a continuum, opportunity to reduce risk, engage with research

Study: Adjustment to test, risk and diagnostic disclosures in people suspected of having MCI

Individuals referred to memory assessment services with ? MCI

Discussion: Disclosing MCI results

We hypothesised that the way the consultation process is conducted in the context of patient characteristics could have a long-term impact on the patient's cognition and well-being.

Cognition – no;

Psychological outcomes – yes

At study entry, rating of disclosure experience as not good was associated with higher cognitive function – expectations higher?

Future directions: Capturing meaningful change in brain health outcomes

Measure personalised outcomes, tailor intervention accordingly, promote necessary skills

THE UNIVERSITY of EDINBURGH
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Thank you!

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