Development of the Mental Capacity Assessment Support Toolkit (MCAST)

Mark Jayes
Highly Specialist Speech and Language Therapist
NIHR/HEE Clinical Doctoral Research Fellow
Background: mental capacity

- The ability to make an **informed decision**
- **Mental Capacity Act (2005)**: framework for assessing decision-making ability and making decisions on behalf of others

Two stage test:
- **Impairment/disturbance** of mind or brain
- Functional assessment of **decision-making**: ability to understand, retain, weigh up information and communicate a decision

- **26% medical inpatients** may lack capacity
Background: patients with communication difficulties

- **More likely** to need capacity assessment

- **Two** of four abilities tested in MCA functional assessment involve **communication** skills

- MCA requires **adjustments** to assessment:
  ‘A person is not to be treated as unable to make a decision **unless all practicable steps** to help him to do so have been taken without success’

- Hospital staff may not **recognise** or know how to **support** communication difficulties
Problems with capacity assessment

- Assessment is subjective, complex
- Current practice is inadequate
- Inaccurate assessment risks excluding people from decision-making / asking people to make uninformed decisions
- Tools and resources need to be developed to make assessment easier and better
This research project

- Developing a **toolkit** to support **multidisciplinary** staff to assess **mental capacity for hospital patients**
- Focus on patients who have had a **stroke** or have **dementia** and have **communication difficulties**
- **User-centred** design process
- **Collaboration** between researchers, hospital staff, experts and service users
The Mental Capacity Assessment Support Toolkit (MCAST)

- **3 components**
  - 1. Support tool
  - 2. Communication screen
  - 3. Resource pack

- **Paper and digital formats**
Accessible information guidelines

- Guidelines for different groups
- **My focus:** people with aphasia, people with dementia
- Guidelines published by charities
- Based on **expert** opinion
- Often created in partnership with service-users
Accessible information guidelines for people with aphasia

Aphasia

- difficulty using language
- caused by stroke, brain injury, brain tumour
- can affect speaking, understanding, reading, writing
- different severities / patterns of difficulty

Guidance reviewed:

- Connect (2007) 9
- Stroke Association (2012) 10
- NIHR Stroke Research Network (2014) 11
Accessible information guidelines for people with aphasia

- Guidelines provide specific **content** and **design** principles for written information
- Some **inconsistencies** / contradictions
- Common principles:
  - **Simplified language**: everyday words, short sentences, one idea per sentence, simple grammar (no passives!)
  - **Highlight** important information: boxes, headings, **bold**
  - **Large, clear fonts**: sans serif, 14+, lower case, don’t **underline**, use dark font on white
  - **Break up text**: use bullet points, plenty of white space
  - **Clear visual images** to support key words / ideas
Dementia and communication

- difficulty using language
- impact of changes in thinking skills
- can affect speaking, understanding, reading, writing
- different patterns of difficulty
- variability: good days and bad days
- difficulties increase over time
Accessible information guidelines for people with dementia

Dementia Engagement and Empowerment Project (DEEP) 2013 ¹²

- One idea at a time, in a logical order
- Simple language: avoid jargon, one topic per sentence
- Contextualise information: add quotes / examples
- Highlight important information: use text boxes
- Sans serif font: 12+ (ideally 14); avoid italics
- Break up text: use white space, bullets, bold headings.
- Use relevant clear pictures, diagrams, photographs
- Avoid illustrations: ambiguous / patronising?
Example: Stroke Association

Language is talking and understanding.

“hello”
Example: Stroke Association

Driving after stroke

A blue badge can help
The brain controls everything we do
movement
emotions
communication
thinking
The brain needs blood
Blood keeps the brain working
The blood supply can stop
Then the brain is damaged
This can happen suddenly
This is called a stroke
Dear

You are invited to another research meeting.

When?
Wednesday 26th August 2015, 11.00 - 12.30pm.

Where?
The Innovation Centre,
217 Portobello,
Sheffield,
S1 4DP.

The Innovation Centre is marked with X on the map:
Example: MCAST Resource pack

- Photographs and simplified language related to discharge / treatment decisions

“PEG tube” → “A small **tube** that goes into your **stomach**. We can put **food** and **drink** through the tube”
Accessible information: effectiveness

People with aphasia

- Lack of high quality evidence that methods work
- Using simplified language, large clear fonts, spacing and highlighting may make info easier to read and understand
- People with mild to moderate difficulties benefit most
- Evidence for use of visual images is weaker

People with dementia

- No published evidence for effectiveness?
Accessible information: user preferences

Aphasia
- People with aphasia tend to appreciate use of “aphasia-friendly” content and design
- But be careful with visual images!

Dementia
- No published evidence re preferences?
Accessible information: take home messages

- Use simplified **language**, clear large **font**, plenty of white **space**, **highlight** key information
- Check **reading level**: use Flesch-Kincaid Readability checker on Microsoft, aim for 5 or below
- **Photographs** may be the best visual images
- Involve **target users** in design process
- Ask recipients what they **prefer**
- One size does not fit all: provide **different formats**?

**Useful resource**: Consent Support Tool ¹³
References

3. Mental Capacity Act 2005 Section1(3).


References

Thanks for listening
Any questions?

mark.jayes@sheffield.ac.uk

@MCAsupporttool

Supervisors: Dr Rebecca Palmer, Professor Pam Enderby

This is a summary of independent research funded by Health Education England (HEE)’s and the National Institute for Health Research (NIHR)’s Integrated Clinical Academic Programme. The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health.