Engaging scientific authority for participatory decision-making: How a rare disorder community uses a social platform

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The public participates in policy-making but faces challenges

Institutional policies directly impact lives.Typically, policy-making tends to value expert insights over people's experiences

Not considering people's inputs might yield policies that fail to address public needs

Official platforms often limit participation to consultation (Arnstein's ladder)

Our Goal: Design platforms that can facilitate public participation in policy making

Research Question: What strategies do people use when attempting to participate in policy-making processes using social platforms?

Approach: Study how a community uses a social platform to engage with institutional experts

The ALS community is motivated to participate in policy-making

Amyotrophic lateral sclerosis (ALS)–also known as Lou Gehrig's disease–is a rare neurodegenerative disorder that affects nerve cells in the brain and spinal cord which impacts physical function.

- Fatal, no cure, limited treatment options
- Treatments approved only via institutional processes & policies

- People organize on official platforms and social platforms to engage with regulators (like FDA)

- Increased funding for drug development via the Ice Bucket Challenge
- Prior success influencing institutional policies (ACT for ALS)

The ALS community is motivated to improve access to treatments and organizes on social media to advocate for its needs.

Patient communities demonstrate a new approach to citizen science

Traditional citizen science work has two separate forms (Ottinger, 2017, The Routledge Handbook of the Political Economy of Science, Chapter 26):

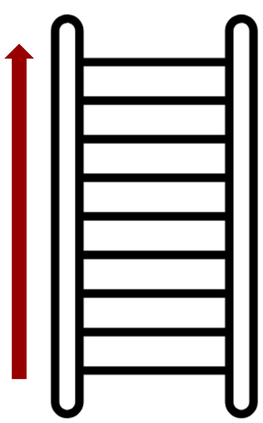
Social movement-based citizen science

- Communities define questions based on local problems
- Community volunteers gather data based on their priorities
- Community volunteers explicitly aim to change real-world situations

Scientific authority-driven citizen science

- Scientists establish research questions based on "scientifically-important" topics
- Volunteers collect data following experts' protocols
- Scientists and volunteers focuses on expanding scientific knowledge

Arnstein's ladder is a concept that shows different levels of citizen participation in decision-making processes



- Citizen Control
- Delegated Power
- Partnership

Degree of citizen power → People and authorities share decision-making via negotiated agreements and joint committees

- Placation
- Consultation
- Informing

Degree of tokenism → People share their opinion without assurance that it will be considered by authorities

- Therapy
- Manipulation

Non-participation → People attend pseudo-participatory programs that might wear down opposition

Participation via social media: Stance & engagement on X

Platform

Posts include images, videos

Community members interact with each other

Community responds rapidly to institutional decisions

Method

Coding based on Hyland's linguistic model of stance and engagement

Digital ethnography to capture contextual aspects of linguistic strategies

Inductive coding based on contextual insights

Words/Phrases	Category
'Some', 'likely'	Hedge
'Clearly'	Booster
'Should be approved', 'need to do', 'approve it'	Directive
'I', 'me'	Self-mention
'Dying patients'	Attitude Marker

Category	Goal: What it does
Stance	
Hedge	Indicates the speaker's tentative commitment
Booster	Expresses the speaker's certainty
Attitude Marker	Indicates the speaker's affective attitude
Self-mention	Explicitly references the speaker's presence
Engagement	
Reader Pronoun	Brings the reader into the discourse
Directive	Gives direct instructions or commands
Rhetorical Question	Implicitly convey a statement and can attempt to persuade, make arguments, criticize, and express sarcasm or irony
Appeal to Shared Knowledge	Constructs inclusion by making the reader recognize something familiar through mentions of: - Institutional Processes: Understanding of institutions' inner workings - Scientific Knowledge: Understanding of scientific principles - Specific Drug/Trial: Awareness of a specific drug or trial

Findings

The ALS community…

- Attempts to establish partnerships with the FDA by presenting themselves as informed and credible stakeholders
- Demonstrates possessing scientific knowledge of ALS and institutional processes
- Presents its views as representative of broader collective interests
- Shares their lived experience as a form of evidence for their arguments

Next steps & implications for designing structured, collaborative participatory platforms:

- Investigate other strategies of participation in institutional policy-making across official channels designed for public participation and other social platforms
- Design platforms based on 1) How institutions integrate public input in their policy decisions; and 2) Various strategies that people use to engage in policy-making processes

Submitted paper can be found here

Cognitive Profiles Using Fine-Finger Performance on a Web-Based Task for Touchscreens

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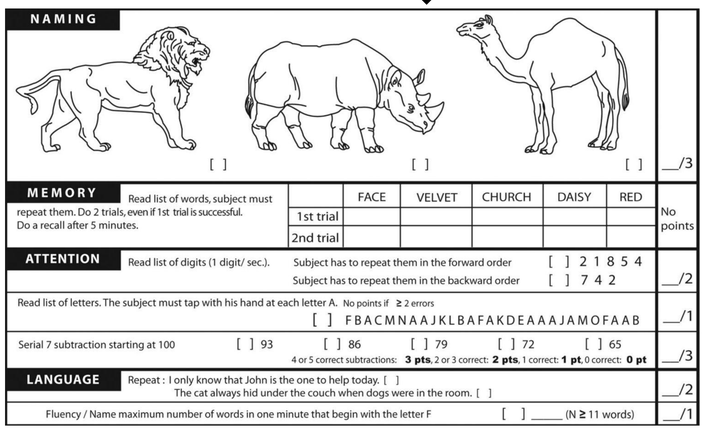
Screening tests–like Montreal Cognitive Assessment (MoCA)–produce basic summative scores and require trained expert time

Typically takes 12 minutes to complete

Instructions to perform MoCA tasks → Patient performs tasks → Examiner gives a score for each task → Sum of scores is final MoCA score

Expert needed for all steps

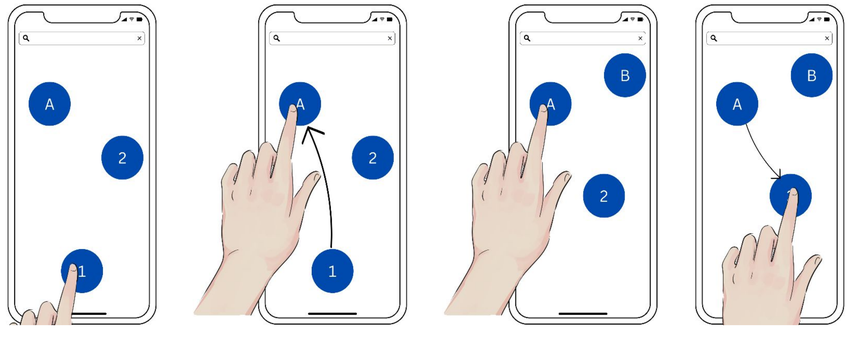


Interpretation	Score Range
Normal Cognition	26 - 30
Mild Cognitive Impairment	18 - 25
Moderate Cognitive Impairment	10 - 17
Severe Cognitive Impairment	0 - 10

Touchscreen-based tasks can highlight varying cognitive performance using fine-finger tracking and do not require expert presence

Automated instructions → Patient independently performs tasks → Automated feature computation → An understanding of cognitive performance

No need for experts



User starts by placing finger on dot labeled ‘1’

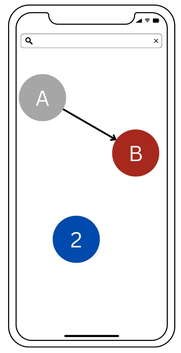
User drags their finger to the dot labeled ‘A’

Dots labeled 1 and 2 are replaced by 2 and B in new positions

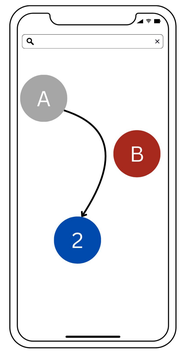
User drags their finger to the next dot - alternating between letters and numbers

Different stages of error processing provide measures of cognitive performance

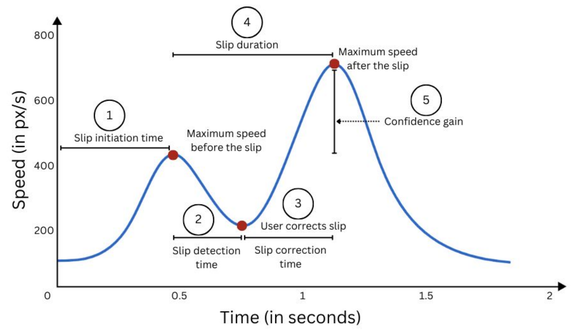
Mistakes occurs when the user enters the wrong circle



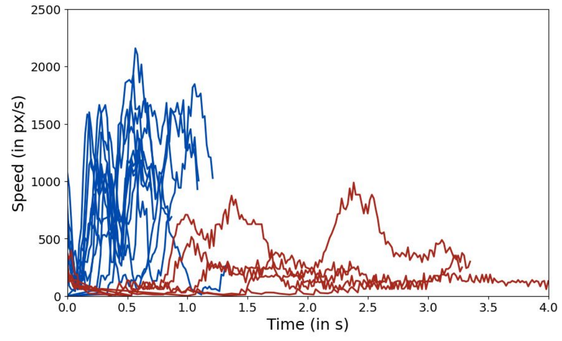
Slips occurs when a user moving in the wrong direction starts moving in the correct direction



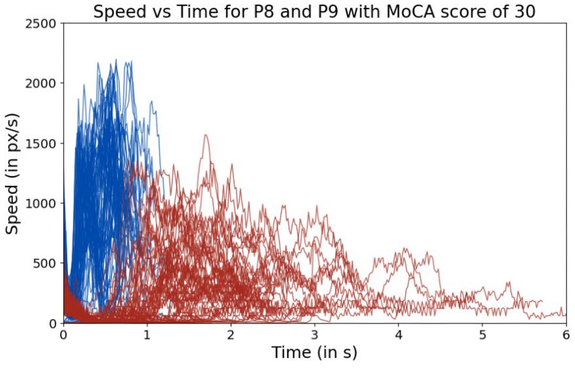
Different stages of error processing like **slip identification and correction** is tracked by analyzing change in speed

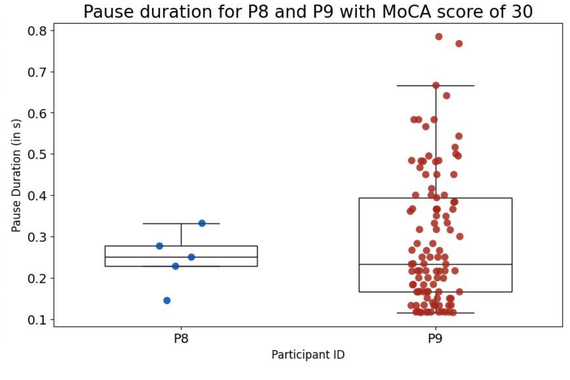


People with MoCA score = 26 moved slower and for longer duration while people with MoCA score = 30 moved faster and for shorter duration



Participants with same scores on MoCA used **different strategies**





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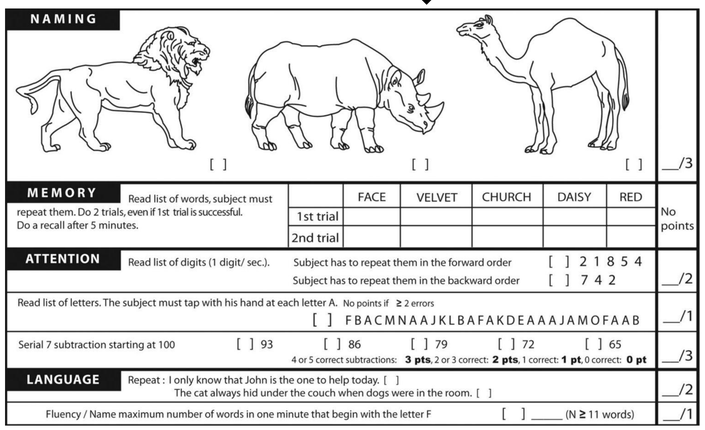

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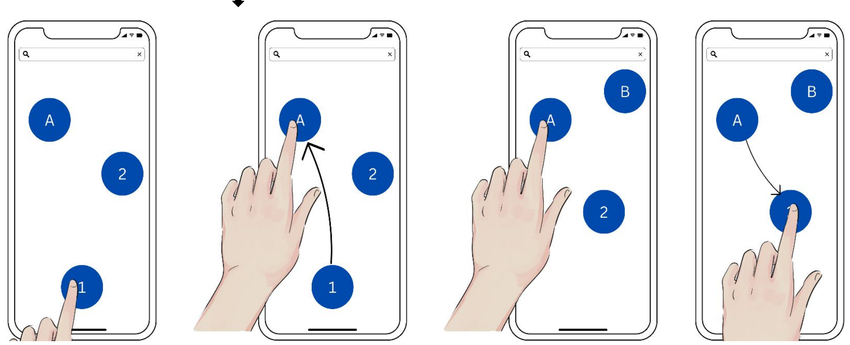

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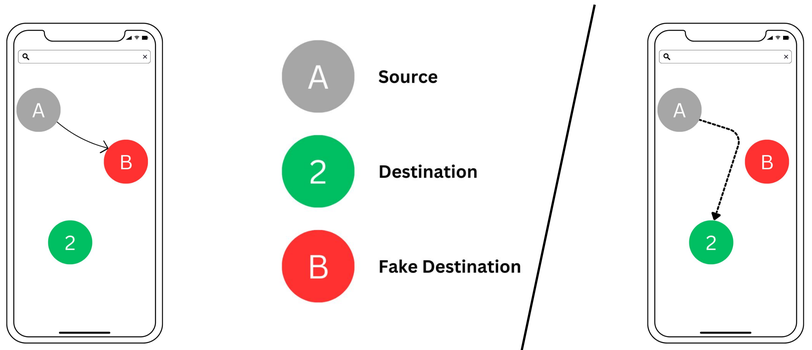

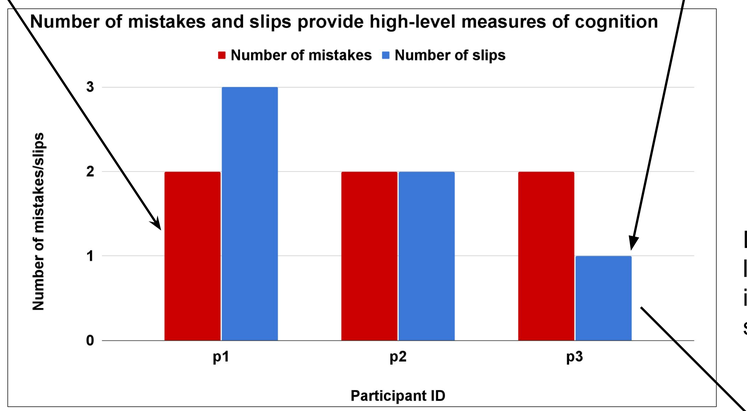

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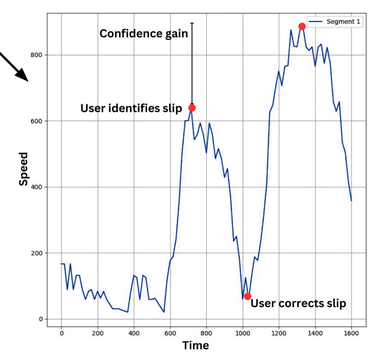

Confidence gain is the difference between the maximum speed before and after a slip