Thinking about mental capacity & multiple exclusion homelessness

Emerging research findings from expert interviews

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Jess Harris, King's College London, on behalf of the study team

NIHR | Policy Research Unit in Health and Social Care Workforce

King's College London

Today: discussing emerging findings from first phase of study

- Study outline
- Definitions: MEH & MCA
- What prompted the study?
- Methods: what we're doing
- Findings: snapshot of challenges in current practice
- Question: is capacity being used as an off-switch for support?
- Over to you for discussion, comments, experiences, etc

Study outline

Title: **Use of the Mental Capacity Act 2005 (MCA) with people experiencing multiple exclusion homelessness (MEH) in England** (project page)

Dates: 2023 – 2026 (2.5 years)

Funder: National Institute for Health and Care Research (NIHR) Health and Social Care Delivery Research (HSDR) Programme: Award ID: NIHR154668 (NIHR Project Page)

Purpose: **explore health and social care practitioner approaches to mental capacity assessments with people experiencing multiple exclusion homelessness. Use findings to inform co-production of an MEH assessment tool for practitioners and pilot it:**

- **Does the tool improve capacity assessments (approach and outcomes)?**
- **Does this improve understanding, support, outcomes for individuals experiencing MEH?** (*Limitation*: not longitudinal study).

Definition: what is Multiple Exclusion Homelessness (MEH)?

Why is homelessness a health and social care, not just a housing issue?

- When **people die while homeless, mean age: 45 years men; 43 years women** (ONS 2021); almost 1/3 deaths from causes amenable to health care (Aldridge et al. 2019).
- Focus on **multiple exclusion homelessness (MEH) captures overlap between repeat and chronic homelessness and other forms of severe and multiple disadvantage**, including experience of: adverse childhood experiences, other trauma, 'institutional care', substance use, domestic and sexual violence and abuse, participation in 'street culture' activities (Fitzpatrick et al. 2011).
- Past negative experiences of statutory services and of stigma / discrimination contribute to service mistrust and **deter people from seeking and accepting help**, **increasing inequalities and exclusion**.
- **Factors and risks which contribute to people both *becoming* and *remaining* homeless**, especially 'street homeless', also **contribute to concerns about mental capacity, including executive function** (ability to follow through on a decision): **mental illness, self-neglect, acquired brain injury, autistic spectrum disorder, learning disabilities, substance use, cognitive impairments**.
- **Any of these factors might indicate we should explore** if there is any long- or short-term or intermittent **impairment in someone's decision making**, **particularly if they are at risk and are not accepting support**.

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Definition: what is Mental Capacity Act 2005 (MCA)?

Mental Capacity Act 2005 applies to England and Wales:

- **Aim**: to **empower us to make decisions for ourselves wherever possible** and protect us if we lack capacity to make a decision; places our best interests at heart of decision-making about us.
- **Application**: enables practitioners to decide whether a person's consent or refusal to treatment, care or support should be taken at face value: **is this person able to make this decision?**
- **Who can assess capacity?** As the significance (and risks) of a decision increases, the assessment, decision-making and recording processes should become more detailed.
- **Five principles**:
  1. Begin by **assuming people have capacity**
  2. People must be helped to make decisions
  3. **Unwise decisions** do not necessarily mean lack of capacity
  4. Decisions must be in the **person's best interests**
  5. Decisions must be as **least restrictive** of the person's 'rights and freedom of action' as possible
- **What decisions might prompt concerns about mental capacity in MEH populations:** seeking or refusing health treatment (and remaining to receive it), accepting care and support, including accommodation, saying 'no' to unwanted associates, managing money (eg, prioritising substance use over adequate nutrition)...

Why are we researching MEH and mental capacity?

- **No prior research**, but analysis of **Safeguarding Adults Reviews** (SARs) shows **assessments not always done, done well, or documented for this population.** Our research on MEH and safeguarding found **'presumption of capacity'** and **freedom to make 'unwise decisions'** were at times given as reasons not to safeguard someone experiencing homelessness and self-neglect.
- **Concern:** someone unable to make a capacitous decision to reject services may not receive support in their best interests, that could reduce their risk of harm. Intervention under the MCA may not be considered, even where risk of people dying on the street.

Is there risk of welfare over-reach for individuals already traumatised by coercive institutional experiences?

A critical and delicate balance

Is there risk of welfare neglect for individuals already facing inequalities and exclusion?

Mixed methods / six work packages

1. Evidence review
2. Interviews with national experts

Quantitative: national survey

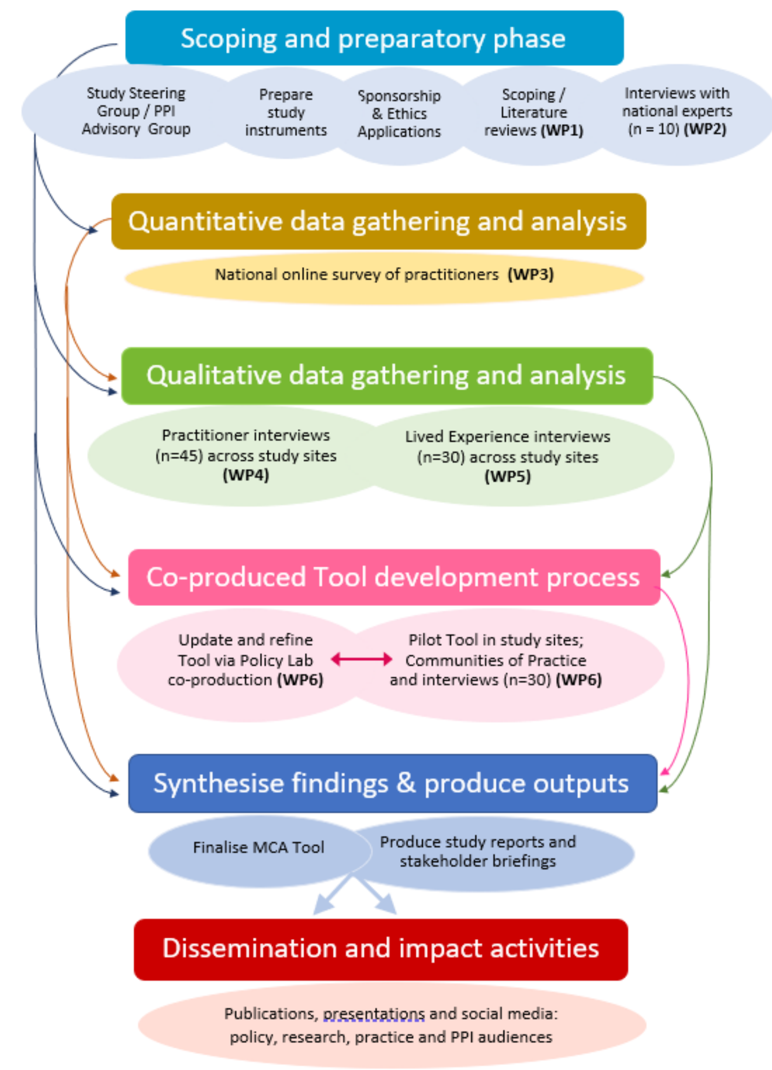
3. Online survey of practitioners here

Qualitative: fieldwork in three study sites

4. Interviews with practitioners
5. Interviews with people with lived experience of MEH

Co-produce updated MCA Assessment Tool & Guidance

6. Use findings to draft tool; pilot in sites; publish (free / online)



Expert interviews: generating context & questions

13 one-to-one semi-structured interviews; Jan – Mar 2024, online:

- Participants: social work; occupational therapy; speech and language therapy; health (psychiatry; general practice; emergency medicine; inclusion health); neuropsychology; police; homelessness outreach and law.
- Most are undertaking and/or overseeing capacity assessments; others offered distinct practitioner perspectives on working with people experiencing MEH.
- Informed the survey questions and findings will be built on in fieldwork phase.

Findings

Challenges in current practice raised by interviewees

Findings: challenges of considering & conducting assessments (1/9)

Some practitioner attitudes

- **Some preconceptions around homelessness and stigmatizing attitudes; seeing visible substance use as the (sole) cause of any social care and/or health needs; contributes to failure to identify needs relating to self-neglect, mental illness or cognitive impairments, or to fully consider and assess mental capacity:**

*'One of the big things is getting over **individuals'** [practitioner] **personal prejudices or judgement calls**, and them being able to look behind the immediate presenting factor to what might be the root causes'* SM3

*'A **lack of understanding that there's issues underneath the substance misuse**, or what's driving those, or whether people are able to control those'* SM7

*'**That's what a mentally ill homeless person looks like** because he's unkempt, he's got a really long beard, he's got loads of layers of clothing on. Homeless people don't look like that … you go into a day centre in London people are shaving, they're using the washing machines … **There's this merging between a homeless person who's self-neglecting and just thinking … that's what homeless people look like**'* SM1

Findings: challenges of considering & conducting assessments (2/9)

A stretched workforce

- **At times, a lack of skills, knowledge and confidence, but also a lack of time:**

*‘**It’s a confidence issue, it’s a training issue**, it’s a knowledge issue, **but also it’s an overworked issue**, so **people are just so inundated by the level of work, and they won’t have time**’* **JH3**

*‘Looking after people with very complex needs who may not comply with treatment is not seen as rewarding, and **may be seen as a low value activity** … **We're so busy, I don’t feel terribly bad if they decide to go**’* **JH2**

- **Practitioner attitudes may be due to numbness or burnout, so choose to step away from difficult and complex cases rather than show tenacity:**

*‘**People** **[practitioners]** **that are jaded** actually, so rather than values, more actually aspects of **burnout**’* **JH2**

*‘Colleagues who are not homeless specialists say, “**Oh, homelessness is a choice**” … This sort of casualness, **this numbness** … as human beings we don't want to think about how awful it must be … that's how we keep ourselves sane’* **SM5**

Findings: challenges of considering & conducting assessments (3/9)

Interrogating concepts of 'choices' and decision making

- Why would someone refuse care or treatment or accommodation? Is that 'choice' sufficient to prompt a capacity assessment? Streets may seem a better option than the accommodation / service options, given people's past experiences and current needs:

*'**Nobody is 'choosing' to live on the streets**, very few'* **JH3**

*'**Maybe living on the streets is preferable** to living in a hostel'* **JH5**

*'**When you're thinking about substance misuse and** some of the debates that we enter into, particularly around **"Well that's just a poor life decision, that's their life decision"** … they're **not really having the understanding of what might have happened to that person** for them to have come to that point'* **SM2**

'People are very well aware of the positive symptoms [of **schizophrenia**] … [but] *some **people present with a more negative symptom picture** which is lack of agency, poverty of speech, inability to get your thoughts together, where **you're more likely just to say yes or no answers or just tell people to go away because you can't cope with the interaction, and those are the people who I think are more likely to be deemed as making a 'lifestyle choice',** not wanting people to be engaged when **actually the rationale behind it is a mental illness.**'* **SM1**

Findings: challenges of considering & conducting assessments (4/9)

Understanding the impact of past and ongoing trauma within MEH

- **What are professional approaches to trauma and its impact on mental capacity:**

*'**Trauma is the central feature**, whether it be a long time ago or current, **the more you're in this community the more trauma occurs** … Another night out on the streets, another rape, another beating'* **SM6**

*'**Whenever we see 'schizophrenia' and 'emotionally unstable personality disorder' … I do think, right** … **we have a person, who we know from the information has been traumatised**, that is neglected, at the margins of society, living in poverty from pretty much birth … a perfectly physically evidenced result of abuse and trauma, the brain has changed, we've got the cortisol going, the amygdala is on fire … I do **look for other reasons as to what may explain the behaviour** … what's gone on across this person's life?'* **JH6**

*'Capacity is taken away by something that supersedes their essential ambition or their desire … **"They're making the decision to take drugs" … I don't think associated trauma**, historic trauma whether it be adverse childhood experiences, sexual abuse etc, **whatever it is that is making people self-medicate pain, I don't think that that is necessarily a choice**.'* **JH3**

Findings: challenges of considering & conducting assessments (5/9)

Complexities and uncertainties in the assessment process

- **Assessing fluctuating capacity and executive function contribute to uncertainty:**

*'The problem is there's law, and then there's human beings … **We don't know enough about the science of what brains do** … everything I've read about fluctuating capacity doesn't hit home … **if it's more than 50% of the time that someone's fluctuating, then they lack capacity? I don't know, how do you decide?** … Sometimes it looks like people have decided not to do something, but they just can't do it'* **JH5**

- **'Masking' of needs may be due to environment, or uneven abilities/impairments:**

*'The thing that **we find really frustrating** is: **"Well, this person is eating their three meals a day, they've showered"** … **That lack of awareness of how artificial environments are, when you assess someone's capacity or someone's function** … **This person was laying in their faeces and urine before coming into hospital … we know exactly what's going to happen as soon as they leave** … We see with **people with traumatic brain injuries and with alcohol-related brain injuries** … quite good language memory and language abilities, so **they can mask quite well'*** **SM7**

Findings: challenges of considering & conducting assessments (6/9)

Accessing information from across the system

- **Lack of access to client/patient information across sectors and organisations creates challenges where information systems are not integrated/accessible.**
- **In 'acute on chronic' cases, paramedics may be assessing an acute case without the chronic history, so any assessment of wider risks is difficult: more likely to find capacity and step away, not knowing the long-term behaviour pattern:**

Unless you really understand the context of the risk, it's very hard to risk assess*, which is really what capacity, at that point, is'* **SM5**

'I'd say ***the biggest challenge is the incomplete information****'* **JH2**

Findings: challenges of considering & conducting assessments (7/9)

Resource constraints within and across systems

- Resource context may affect assessments and pre-determine the outcome because of lack of service / support options if there is a finding of incapacity:

*‘**People should not be coming to a different conclusion based on there not being a provision available** to them, **but … if there isn’t anything for that person then what can you do?’*** **JH6**

*‘ **“They have capacity, I can’t do anything about it”** is just, you know, **it’s a part of our absolutely stretched system** … it feels safer to say “Oh, it’s because they’ve chosen not to’* **JH5**

*‘Everybody is so protective of their budgets … **if there is anything borderline, they may say, “No, somebody doesn’t lack capacity”, because they haven’t got resources** within their own teams’* **SM3**

Findings: challenges of considering & conducting assessments (8/9)

Moving forwards, what would help to ensure 'good' capacity assessments with people experiencing MEH?

'I would like actually for there to be ***some guidance for organisations about really what type of qualifications and / or experience people should be having*** *to make those decisions'* **JH5**

- **Suggestions from expert interviews; we have put to current national survey:** *(Over 90% survey respondents so far say these five factors are a priority (Note: % may change)*
  - **Multi-disciplinary team input**
  - **Access to expert supervision / guidance**
  - **Access to information from other services**
  - **Access to cognitive / neuropsychological assessments**
  - **Advocacy for individuals being assessed**
- **Survey asks practitioners what else is important…**

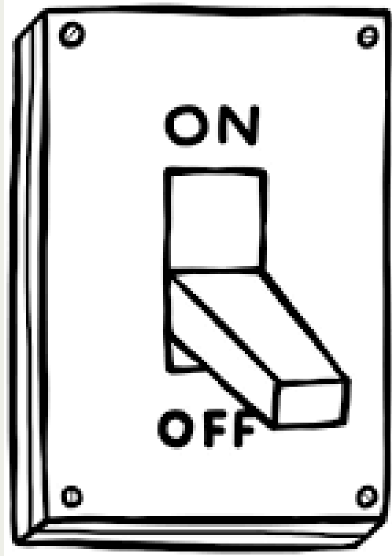
Findings: how does MCA fit with supporting MEH health/social care? (9/9)

- **Some reflected that MCA's underpinning spirit of empowerment that focuses on a single decision at a point in time, plus the unclear responses to addiction, can contribute to a poor fit with understanding and responding to the health, care and support needs of MEH populations:**

'When the Act was written, ***it wasn't imagined that we'd be trying to do these really complex legal processes in these really muddy, messy situations*** *… It would be very clear, and you would say to your client* [with learning disabilities] *'We're worried about whether you can decide whether to … get married or whatever, and we're going to have a conversation' …* ***With our*** **[MEH]** ***population, we're doing it in reverse … This person hasn't had enough support, this person has had presumptions made that they're doing fine, when they're not****, for lots of complicated reasons…'* **JH5**

'For a non-medical professional ***it's very easy to look in and say, "Of course she*** **[using substances]** ***doesn't have mental capacity"****, because there's 'making unwise decisions'* ***and then there's not being able to do anything else*** *… That's not within quite the rigid psychiatric boundaries of MCA and so* ***there is no way she'd ever be assessed as lacking capacity, but I can't see how she has got capacity****…'* **SM3**

Question: is finding of capacity being used as off switch for support?



Whilst we do try to improve understanding and assessment of mental capacity for this population, **does practitioner engagement end when, for example, there is a finding of capacity in a decision to reject care, support, treatment or accommodation**, despite high levels of risk to an individual experiencing MEH?

Back to national debates we need about the critical and delicate balance:

welfare over-reach vs. welfare neglect

Next steps in this study

- **Please contribute to our short online survey for health, social care and homelessness practitioners here**
- **Next study webinar will share the survey findings and continue this discussion**
(future events in this series listed here)

Your thoughts & experiences?

Thanks: To our research participants and Lived Experience Advisory Group for their time and insights.

Research Team: Jess Harris, Stephen Martineau, Kritika Samsi, Alex Ruck Keene KC (Hon) (King's College London), Michelle Cornes (University of Salford), Bruno Ornelas (Collaborative Safeguarding Hub), Stan Burridge (Lived Experience Lead), Sam Dorney-Smith, (Pathway homeless health charity), Nathan Davies (University College London).

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Contact: jess.harris@kcl.ac.uk

KING'S College LONDON