

# Dr Zoe Swithenbank

'Treatment pathways for Co-occurring Mental Health & Alcohol Problems'

2.30pm – 3.30pm



## Improving treatment pathways for people with co-occurring mental health and alcohol problems

## **Dr Zoe Swithenbank**

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#### FUNDED BY

## **NIHR** National Institute for Health and Care Research



# Who am I?

- Lived / living experience
- Rethink involvement
- Researcher

# What is the problem?

- People with a mental health problem are more likely to drink at harmful and dependent levels, compared to those without.
- Both heavy drinking and mental ill-health alone are associated with a range of adverse health outcomes, however, experiencing these issues concurrently means people are even more likely to develop physical diseases that are attributed to alcohol.
- We need to better understand how we can prevent the premature mortality experienced by those with co-occurring mental health and alcohol use disorders.
- This is particularly important given that this population has been underserved in research and they often do not receive coordinated support to address their needs.



- Alcohol use can delay someone seeking help for a mental heath problem, due to them coping by 'self medicating'
- Alcohol use can provide a barrier to someone starting mental health treatment, if they don't meet the eligibility criteria
  - Told to reduce drinking before they can be seen by services
- Hazardous and harmful drinkers are more likely to drop out of IAPT services (Buckman et al., 2018)
  - Even though they have equal treatment outcomes if they adhere to treatment
- Someone with serious mental health problems may not be seen by addiction services if substance use is thought to be a consequence of their mental health problem/their needs are 'too complex'



# Mental health and Alcohol treatment Pathways (MAP Project)

- 1. To identify and engage with public contributors for a PPI group with lived experience of co-occurring mental health and alcohol use disorders, working with underserved communities who will receive training and capacity building in line with their needs and the project aims.
- 2. To identify and develop a national stakeholder group with negotiated structure and terms of reference.
- 3. To investigate the feasibility of using suitable national linked data sources to conduct epidemiological analyses around treatment pathways and physical outcomes for people with co-occurring mental health and alcohol use disorders.
- 4. To conduct a realist synthesis of two secondary data sources to understand the extent to which current guidance on care for people with co-occurring mental health and alcohol use disorders is being followed and any barriers to implementation.

#### **PROGRAMME DEVELOPMENT GRANT**

DWP 1: Training and capacity building of people with lived experience of co-occurring mental health and alcohol use disorders

DWP2: Identifying and developing a national stakeholder group with negotiated structure and terms of reference

DWP 3: Investigating suitable national linked data sources to conduct epidemiological analyses around treatment pathways and physical outcomes for people with cooccurring mental health and alcohol use disorders

DWP 4: Preliminary analyses to understand the extent to which current guidance on care for people with co-occurring mental health and alcohol use disorders is being followed and any barriers to implementation **PROGRAMME GRANT** 

PGWP1: Epidemiological analyses to understand which interventions and treatment pathways for people with cooccurring mental health and alcohol use disorders are associated with better outcomes

PGWP 2: Development of updated national i) clinical and ii) service user guidance for better care of people with co-occurring mental health problems and alcohol use disorders

PGWP3: Feasibility study involving implementation of the clinical and service user guidance in the Lancashire and South Cumbria Integrated Care System

PGWP4: Process evaluation of the interventions at an ICS level

#### **PROGRAMME OUTCOMES**

Novel and important epidemiological data on physical health outcomes for patients with cooccurring mental health and alcohol use disorders and data on which treatment pathways are associated with better outcomes

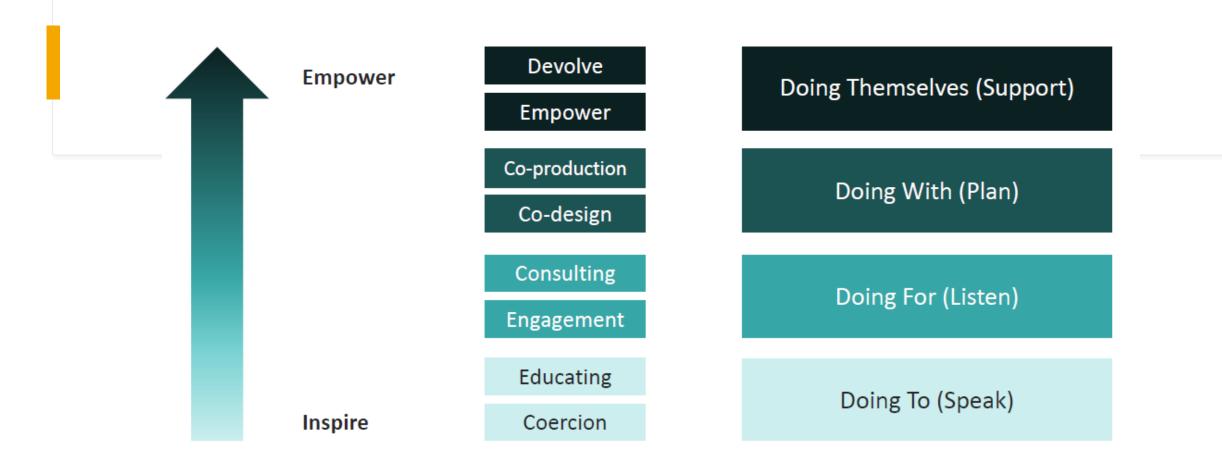
Updated and more specific national clinical and service user guidance developed using codesign methods and ready to implement across England

Outcomes and learning from implementation of the interventions at a regional ICS level, providing a template for other regions

## What is PPI?

## Research being carried out '<u>with</u>' or '<u>by</u>' members of the public rather than 'to', 'about' or 'for' them

- Patient and public involvement (PPI) in research refers to an active partnership between patients and/or members of the public and researchers.
- Involvement is distinct from participation in research:
- Patients and the public you actively involve are contributing to the research process as advisers and possibly also as co-researchers.
- Researchers and clinicians may not have first-hand experience of the illness, disease or health condition that they wish to research. PPI can therefore provide researchers with insights into what it is like to live with a particular disease, illness or health condition, and these insights can help to make health research more relevant to the needs of patients, carers and service users.



# Ladder of involvement

# Who?

### • Who are patients and the public?

- people who use, or have used, health or social care services
- informal (unpaid) carers and family members
- parents
- members of the general public
- organisations who represent patients and users of a service
- patient support groups
- charities that represent specific health conditions
- individuals with an interest in the topic being researched
- people with lived or living experience

# Why?

"No matter how complicated the research, or how brilliant the researcher, patients and the public always offer unique, invaluable insights. Their advice when designing, implementing and evaluating research invariably makes studies more effective, more credible and often more cost efficient as well."

Professor Dame Sally Davies, Chief Medical Officer (Foreword in Staley, 2009)

- **Democratic principles** (transparency, accountability, empowerment & influence for change)
- Research quality and relevance:
  - Provide a different perspective
  - Improve quality
  - Ensure relevance

### Funding and research organisations

# Benefits

#### For researchers:

- Widens horizons
- Improved research relevance
- New connections in the wider community
- Impact in policy and practice
- Accessible and innovative research outputs
- Increased credibility among stakeholders
- Development of new research methods

#### For public:

- Widens horizons
- Influence on academic practice and priorities
- New working relationships with researchers
- Impact in policy and practice
- Opportunity to have voice heard
- Participants feel valued and respected
- Increased confidence and skills
- Improved experience in research

# Challenges

#### For researchers:

- Time commitments
- Unfamiliarity with methods, language and approaches
- Lack of training in safeguarding or relationship management
- Avoiding tokenism in recruitment
- Loss of control over research activities
- Demonstrating impact in context of conventional academic publication metrics
- Difficulty applying for grants where methods are unconventional
- Budgeting for external costs
- Lived vs living experience
- Ethics
- Maintaining contact when projects end

#### For public:

- Time commitments
- Unfamiliarity with methods, language and approaches
- Risks to wellbeing if experience is stressful or creates triggers
- Lack of meaningful involvement or perception of tokenism
- Lack of sustained involvement, especially at the end of research phase
- Stigma due to disclosure
- Intimidating or unfamiliar environments
- Financial implications if costs not covered

## How?

## Five Key Stages:

- design of the research
- development of the grant application
- undertaking/management of the research
- analysis of data
- dissemination of research findings.

## Ways to work with people:

- Steering groups / committees / reference group
- Expert by experience panel
- Workshops / conferences open to public
- Co-researchers / peer researchers / coapplicants
- Development of study tools
- Analysis workshops
- Presenting findings how and where?

## The MAP Project - What we've done:

- Workshops to establish the problem and treatment pathways
- Co-investigator with lived experience
- Group established with 6 members plus PPI co-investigator (Phil)
- Monthly meetings held (usually online) decided by the group
- Paid involvement
- Three away days which focused on different aspects of treatment, as decided by the group.
- Evaluation underway

# Workshops:

- Two online workshops were held with 25 public representatives with lived experience of co-occurring mental health and AUDs and professionals who work with them (e.g. health professionals).
- Seven people attended workshop 1 with 18 attending the second. Snowball sampling was used to engage attendees.
- All attendees were offered a £50 voucher as a thank you for their participation in the workshops.



# What are the different treatment pathways?

The current NICE guidelines describe three treatment models for co-occurring problems:

Serial - one service at a time

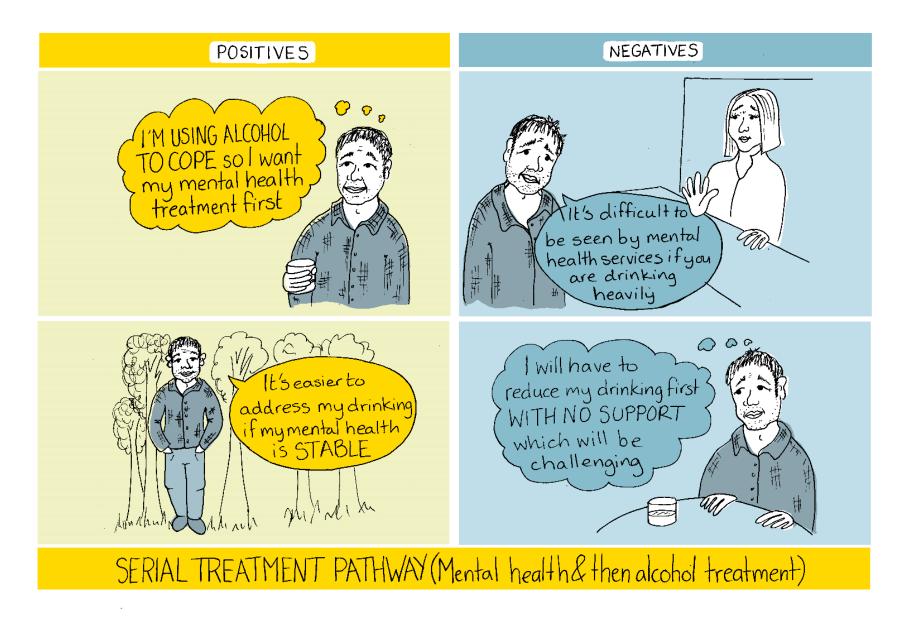


Parallel - both services at the same time

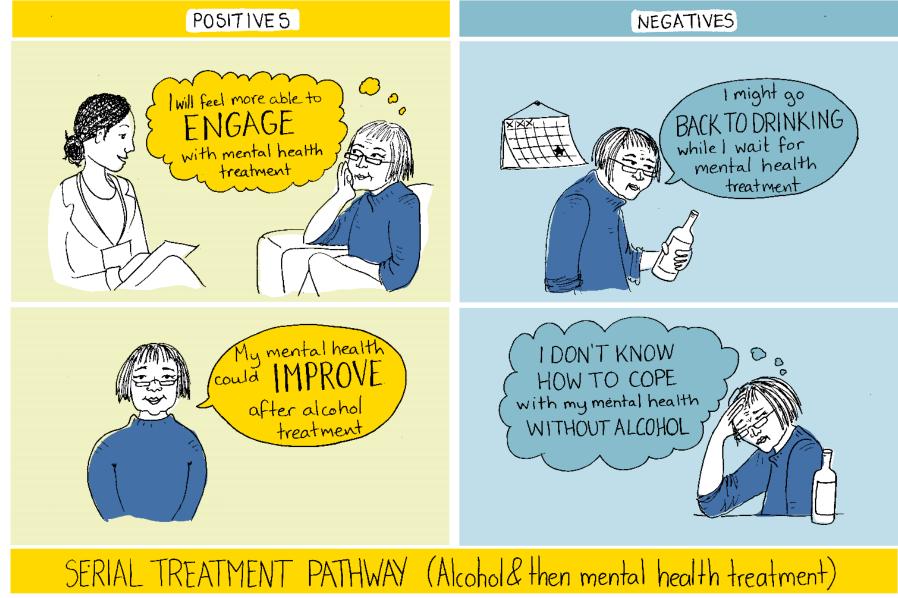


**Integrated** - mental health and alcohol/drug needs are addressed at the same time as part of an integrated package of care. Does not have to be delivered in the same location/by same person

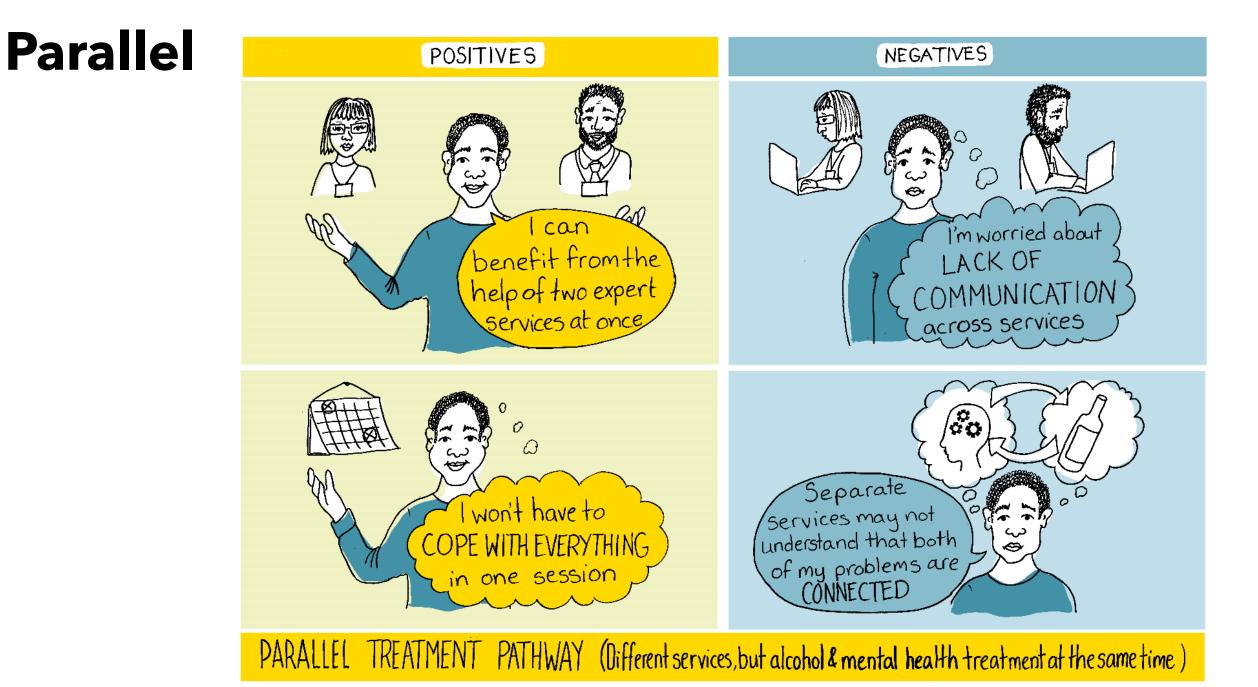
## Serial (Mental Health and then Alcohol treatment)

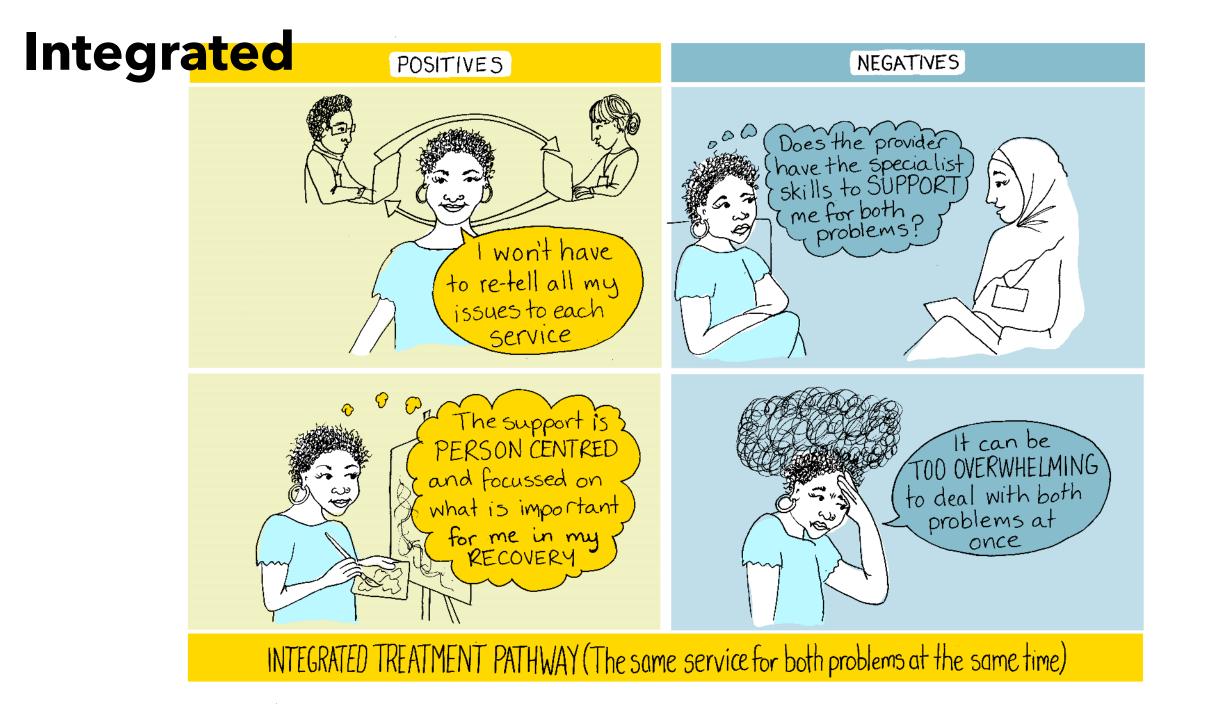


# Serial (Alcohol then mental health treatment)



\* Over 75% of workshop attendees thought that this was most common treatment pathway





# How we have involved the PPI group:

- Phil is a co-applicant on the grant and has been involved from the beginning in defining and shaping the project.
- As well as our monthly meetings, we have tried to embed PPI throughout the project.
- Attended and took part in national stakeholder meetings.
- Attended and took part in data workshops.
- Helped to define and prioritise the research questions and how we use data.
- Raised some key issues and areas we need to research to address.



# What issues have been raised by our PPI group?

- Many barriers, including long wait lists, confusing pathways, issues around diagnosis and 'suitability' for treatment, time limited treatment options, and inconsistencies across services.
- The group were more likely to recommend non statutory services, e.g. voluntary and community groups, for several reasons:
  - Challenges to accessing NHS or other formal services.
  - 'Other' groups and services were seen as more welcoming, easier to access and offered more immediate support.
  - Importance of social connection and community.
  - Value of peer support and lived experience sharing and learning from people who had 'been there' is beneficial.
  - Additional barriers for those in work, due to limited opening hours, expectations of engagement and lack of flexibility

## Overarching issues across the work packages



#### Social aspects:

Connection

Relationships within and between organisations

Therapeutic relationships, feeling safe and feeling heard (stigma, barriers to support, no wrong door)

Need for additional support (often voluntary) to address need for connection and community



#### **Communication:**

Within and between organisations

Clear and understandable comms with people accessing services

Data collection, linkage and information sharing (barriers to care coordination and in understanding how treatment pathways work)

Referral pathways (also to the VS and to other sources of support such as housing, physical health, employment) and how can this be captured in the data



#### **Other Support:**

Third and voluntary sector - what do they do and how

How can we gather data on this aspect?

Importance of voluntary sector and how to better support / work with them (often reliant on individuals and good relationships rather than clear and explicit pathways) and social prescribing

Holistic support and wider treatment / support needs (housing etc)

Recovery support within SU services (linked to communication and social aspects)



# **Conclusions and implications**

There should be more acknowledgement within services of alcohol use as a coping response and of the mental health consequences of heavy alcohol use.

We need to better understand how current services interact, and how this can be improved, given integrated treatment programmes may not be a realistic option for everyone.

There is opportunity to know more about what treatment pathways are associated with better outcomes using novel linkages e.g. using drug and alcohol service data.

Our work will prioritise public involvement in developing the hypotheses we test and in understanding the findings from public records data.

# Future plans and outcomes

- Novel and important epidemiological data on physical health outcomes for patients with cooccurring mental health and alcohol use disorders and data on which treatment pathways are associated with better outcomes
- Updated and more specific national clinical and service user guidance developed using co-design methods and ready to implement across England
- Outcomes and learning from implementation of the interventions at a regional Integrated Care System (ICS) level, providing a template for other regions







# Thank you to the public contributors and the following organisations who have supported this work:

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