

Welcome to the 17th annual conference on
Health Research in East London
What's new and how to get involved

Frank Röhricht

Medical Director
Research, Innovation &
Medical Education

Karin Albani

Associate Director
Research

What's new? 2018-19...

- Research Champions
- Governance & Ethics Committee for Studies and Evaluations (GECSE)
- Working on a 5-year plan
 - Events & Conferences
 - Support resources (webinars etc.)
 - HEI partner in Bedfordshire

New Grants

- Accessibility and acceptability of perinatal mental health services for women from ethnic minority groups (PAAM)
NIHR HS&DR: 2019-2021; £550k; PI=**Jelena Jovanovic**
- Improving the Accuracy and Efficiency of Autism Assessment for Adults
NIHR RfPB 2019-2021; £300k; PI = **Will Mandy**
- Acceptability, feasibility and co-development of a community based, caregiver support program for parents /carers of children and young people with cerebral palsy
Barts Charity 2020; £50k; PI = **Michelle Heys**

Why get involved?

- Development and evaluation of novel interventions – *Improved health outcomes*
- Service user like being involved – *Improved experience of care*
- Make the Trust a more attractive place to work – *Improved staff experience*
- Helps win new contracts – *Improved value*

Ways for staff to get involved



Did You Know?



The Trust's research Unit for Social and Community Psychiatry is a designated World Health Organization (WHO) Collaborating Centre.



The Unit is one of currently only 14 mental health related WHO Collaborating Centres in Europe and the only one specifically for 'mental health services development' in the world.



ELFT was a 2016 finalist for the HSJ award for Clinical Research Impact for Using DIALOG+ to Improve Patient Outcomes in Community Mental Health Services.



SUGAR (Service User and carer Group Advising on Research) won the Health and Wellbeing award at the National Co-ordinating Centre for Public Engagement's Engage Competition 2014.



ELFT has been awarded a total of over £15m in research grants since 2008.



Clinical research is included in CQC Monitoring and Inspection as part of its framework for a Well Led NHS Trust.



Ways for staff to get involved

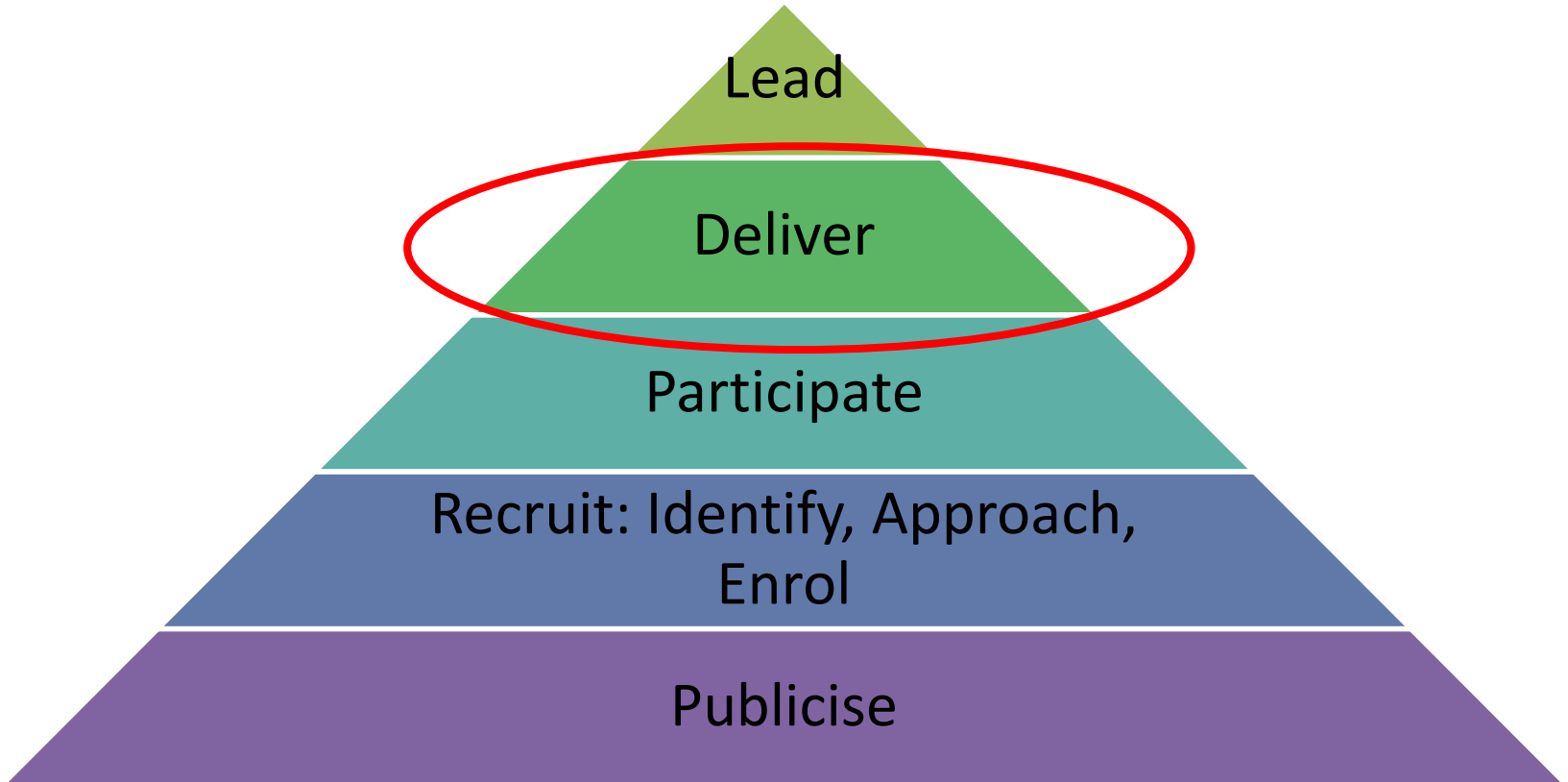


Recruit: Identify, Approach,
Enrol

We want to help you to talk to patients about taking part in research.

Take a look on the Trust intranet for [tools and advice to support you](#) having this conversation and knowing when to have it.

Ways for staff to get involved






Deliver

NHS Staff may be engaged to deliver a novel research treatment to be compared to standard care

- for example, becoming a social contacts coach; delivering a new smoking cessation programme; etc.

Today

- As usual:
 - format of brief presentations on a range of topics
 - researchers from 5 groups, 3 university partners
 - feedback questionnaires
 -  #ELFTResearch
- Some changes:
 - new faces at the helm
 - first time with posters (competition, prizes)
 - longer break in Pathology Museum

Assessing people presenting with self-harm in the emergency department

Rose McCabe & Clara Bergen
Professor of Clinical Communication

rose.mccabe@city.ac.uk

t: @RoseMcCabe2

Every

40

seconds somebody dies by suicide

cause of death
er vehicle
y than
n are

have a
pressive

hopeless. First, they must have a serious desire to die. This usually comes about when people feel they are an intolerable burden on others, while also feeling isolated from people who might provide a sense of belonging. Second, and most important, people must

The self-destructive...
...are two ways...
...develop the ability...
...preservation instinct...
...working up to it. In the...
...attempt is tentative, w...
...mind overdose. It is onl...
...attempts that the actio...
The other is to becom...
...painful or scary experie...
...police who have been sh...
...colleagues injured or kil...
...become inured to the ide...
Both groups also have a h...
...suicide rate. Similarly, do...
...who witness pain, injury a...
...more likely to be able to co...
...is significantly higher than...
...population. Joiner describe...
...“steeliness” in the face of...
...would intimidate most peop...
Another group that displa...
...people with anorexia. Joiner...
...heightened suicide rate in his...
...Why people die by suicide (Har...
...Press, 2005), but it wasn't un...
...grasped the importance of th...
...That realization began to de...
...during a seminar in which...
...graduate students, Jill...
Tracy Wise, was...
...risk of...



Contact before death

- 1 in 4 have contact with mental health specialists in year before death
- 1 in 2 have contact with primary care in month before death
- 43% attended the ED at least once in the year before death
 - Of these, 28% attended ED >3 times
- Assessments have additional potential to be therapeutic

RESEARCH ARTICLE

Open Access

How do healthcare professionals interview patients to assess suicide risk?



Rose McCabe^{1*} , Imren Sterno², Stefan Priebe³, Rebecca Barnes⁴ and Richard Byng⁵

Abstract

Background: There is little evidence on how professionals communicate to assess suicide risk. This study analysed how professionals interview patients about suicidal ideation in clinical practice.

Methods: Three hundred nineteen video-recorded outpatient visits in U.K. secondary mental health care were screened. 83 exchanges about suicidal ideation were identified in 77 visits. A convenience sample of 6 cases in 46 primary care visits was also analysed. Depressive symptoms were assessed. Questions and responses were qualitatively analysed using conversation analysis. χ^2 tested whether questions were influenced by severity of depression or influenced patients' responses.

Assessments in the emergency department

- People who harm themselves (overdose, cutting) or who feel suicidal are triaged in the main ED and then (usually) seen by liaison practitioners
- Videos of practitioner-patient meetings (assessments) – around 1 hour long
- Practitioners work in pairs
- Interviews with patients
- Interviews with carers
- Interviews with staff – liaison & main ED

45 participants

- Mean age: **35.5**
- **31** women and **14** men
- **43** of White British ethnicity
- **16** were employed and **7** were students
- **12** live alone
- **19** left school at 16 years
- **30** ED and **15** AMU
- **>21** were known to the Liaison team

Staff perspective on the assessment

- The objectives of the assessment:
 - 1. To ensure patient safety:
- *“In my mind, is this patient safe to go home”*
 - 2. To identify if the patient’s current care needs to be changed or upgraded
 - 3. To offer patient centred care:
- *“It depends on the patient. We ask ‘what do you want’ and what the question is they want answered.”*
- Who should be coming to A&E?
- Frequent attenders, people with PD



WHY

- *“Why did you self-harm?”*
- **Clinician:**
 - Asks patient to account for event
- **Patient:**
 - Responds with disengagement, uncertainty, or crying



WHAT

- *“What were your thoughts at that time?”*
- **Clinician:**
 - Asks patient to describe their thoughts during event
- **Patient:**
 - Responds with engagement, answers, eye contact

AGREEMENT/ DISAGREEMENT ALIGNMENT/ MISALIGNMENT

IN RESPONSE TO QUESTIONS

- Agreement/alignment with the question is
 - Fast
 - Direct
- Disagreement/misalignment with the question is
 - Delayed
 - Indirect
 - Hedged

Patient 01

Pro: **What did you think** when you went to bed. What- [1 sec] What did you think might happen or-

Pat: **I just- I just thought I wouldn't wake up** again. Yeah.

Pro: And at that point **did you hope you wouldn't wake up?**

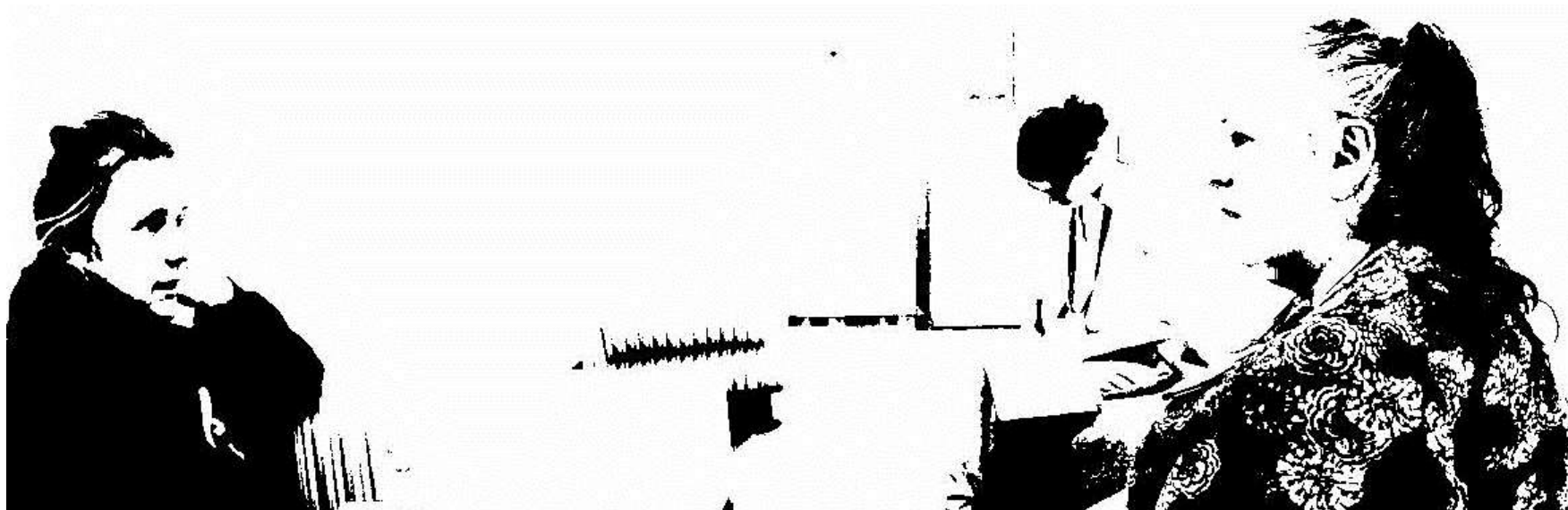
Pat: I did and I didn't.

Pro: Okay?

Pat: It's very tough to describe like [1 sec] **I didn't want to wake up** to go back to being so anxious and so stressed again.

Pro: Mhm?

Pat: um **But I wanted to wake up** because I don't- I didn't want to leave my family. I didn't want to leave my sister, I didn't want to leave my dogs- any of my animals really.



Patient 02

Pro: Can you put into words **why you cut yourself** on your wrists last night?

Pat: [2 sec] Because there like- there's no help? Uh no escape?

Pro: Okay. [2 sec] Alright. [1 sec] Mhm?

Pat: Like right now, I just want to run out the door, run down the road,

Pro: Mhm. [3 sec] And,

Pat: **[crying, 42 sec]**



Patient 03

Pro: Are you able to tell us what happened? Why- **Why did you self-harm?**

Pat: Um [3 sec] I don't know.

Pro: Hm?

Pat: **I don't really know.**

Pro: You don't know. That's okay.

...

Pro: And if someone asked you **why did you cut your arm** what would you say.

Pat: I don't know.

...

Pro: So you- Just to ask- **At that time did you think of** ending your life or?

Pat: Yeah.

Pro: You did. So in terms of that what- what did you do to- [1 sec]

Pat: I think, **what I was thinking was that** I thought I needed to self-harm so I wouldn't do it.

Patient 03

Pro: Are you able to tell us what happened? Why- **Why did you self-harm?**

Pat: Um [3 sec] I don't know.

Pro: Hm?

Pat: **I don't really know.**

Pro: You don't know. That's okay.



Patient 03

...

Pro: So you- Just to ask- **At that time did you think of** ending your life or?

Pat: Yeah.

Pro: You did. So in terms of that what- what did you do to- [1 sec]

Pat: I think, **what I was thinking was that** I thought I needed to self-harm so I wouldn't do it.



Patient interviews

“I realized I had people to talk to? I mean- I’m- You know yourself and I always thought that I couldn’t speak to (partner) for example and I realized that I could. So it wasn’t actually them giving me a leaflet on depression it was that sort of- I knew that I had someone or somewhere to go to. And I didn’t have that- I wasn’t disconnected as much as I was... and she was like “there is help out there... it was making sure that I knew that I could actually speak to somebody. That’s why I’ve been a lot better since then.”

Conclusions

- ‘Why’ questions put people on the defensive and lead to disengagement or if answered, patient becomes distressed = interactional moments when rapport breaks down
- ‘What’ questions (what were your thoughts? What were you thinking when...?) are responded to, provide information about the person’s rationale and state of mind



ASsuRED is a five year programme of research that aims to develop and test a new intervention for people who present in Emergency Departments having harmed themselves, which began in May 2019.

Overview of ASsuRED

- ASsuRED aims to reduce self-harm & reduce the risk of suicide by developing a bespoke intervention for the NHS.
- We will develop and test a brief, low cost, psychological intervention for routine contacts in the ED to reduce future self-harm, delivered by specialist mental health practitioners in existing psychiatric liaison teams.
- Therapeutic engagement, safety plan & follow-up contact
- Started May 1st 2019 - 5 year programme
- Are you a liaison practitioner interested in co-creation workshops on the intervention? Please get in touch

- Thanks to Matt Lomas, Penny Xanthopoulou
- McCabe R, Sterno I, Priebe S, Barnes R, Byng R. How do healthcare professionals interview patients to assess suicide risk?. BMC psychiatry. 2017 Dec;17(1):122.
- McCabe R, Garside R, Backhouse A, Xanthopoulou P. Effectiveness of brief psychological interventions for suicidal presentations: a systematic review. BMC psychiatry. 2018 Dec;18(1):120.

rose.mccabe@city.ac.uk

Using routine data to model associations between depression and A&E use in patients with Type 2 diabetes mellitus

Dr Amy Ronaldson, PhD
Centre for Psychiatry
Wolfson Institute of Preventive Medicine

The logo for NEON, where the letter 'O' is replaced by a stylized black and white illustration of a baby's face.

Nurture Early for Optimal Nutrition

A participatory approach to improve infant nutrition and complimentary feeding practices in British Bangladeshi families

Dr Michelle Heys, Associate Professor UCL, Consultant Paediatrician and ACD, ELFT

on behalf of the NEON team lead by Professor Monica Lakhanpaul, Principal Investigator

**National Institute
Health Research**

Collaboration for Leadership in
Applied Health Research and Care

North Thames



Acknowledgements



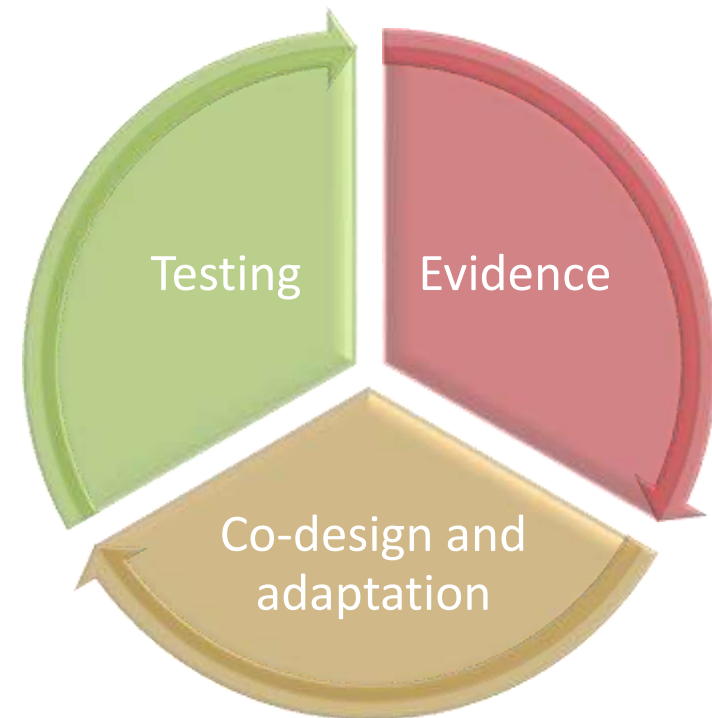
Nurture Early for Optimal Nutrition

- Prof Monica Lakhanpaul
- Lorna Benton
- Oliver Lloyd- Houdley
- Jennifer Martin
- Logan Manikam
- Edward Fottrell
- Georgia Black
- Atul Singhal
- Anthony Costello
- Tower Hamlets Community Facilitators
- Tower Hamlets Community Researchers
- Tower Hamlets Local Authority , Health visitors and Children's centres

- NEON aims and activities
- Premise
 - Why complimentary feeding?
 - Why Tower Hamlet's Bangladeshi community?
 - Why participatory learning action (PLA) group approach?
- NEON study activities
 - Evidence
 - Co-development
 - testing
- NEON study findings and learnings
- Next steps

Nurture Early for Optimal Nutrition

- Aiming to optimise complementary feeding and care practices in Bangladeshi infants (aged < 24 months)
- Co-designing a community facilitator-led adapted **Participatory Learning and Action (PLA)** group intervention.
- Community based participatory research process



Community engaged across all 3 phases

NEON – study premise

1. Complementary feeding practices are important
2. Bangladeshi community of TH are a high risk population
3. PLA approach likely appropriate methodological approach through which to achieve our aims.



... when “breast milk alone is no longer sufficient to meet the nutritional requirements of infants, and therefore other foods and liquids are needed, along with breast milk” (WHO)



MAKWANPUR TRIAL, NEPAL

1 local woman facilitator per cluster
Not a health worker

“It’s not a drug. It’s not a vaccine. It’s women, working together, solving problems, saving lives”

Richard Horton, Editor of The Lancet

49% reduction in maternal mortality

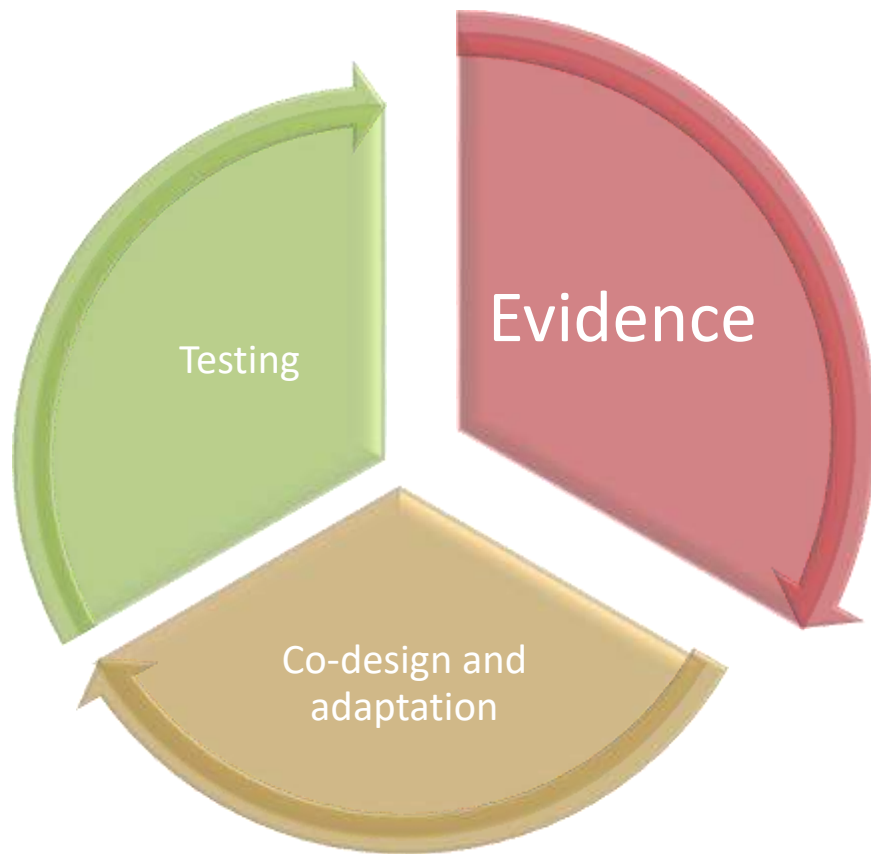
33% reduction in newborn mortality

7 cRCT; 4 LMIC

2004

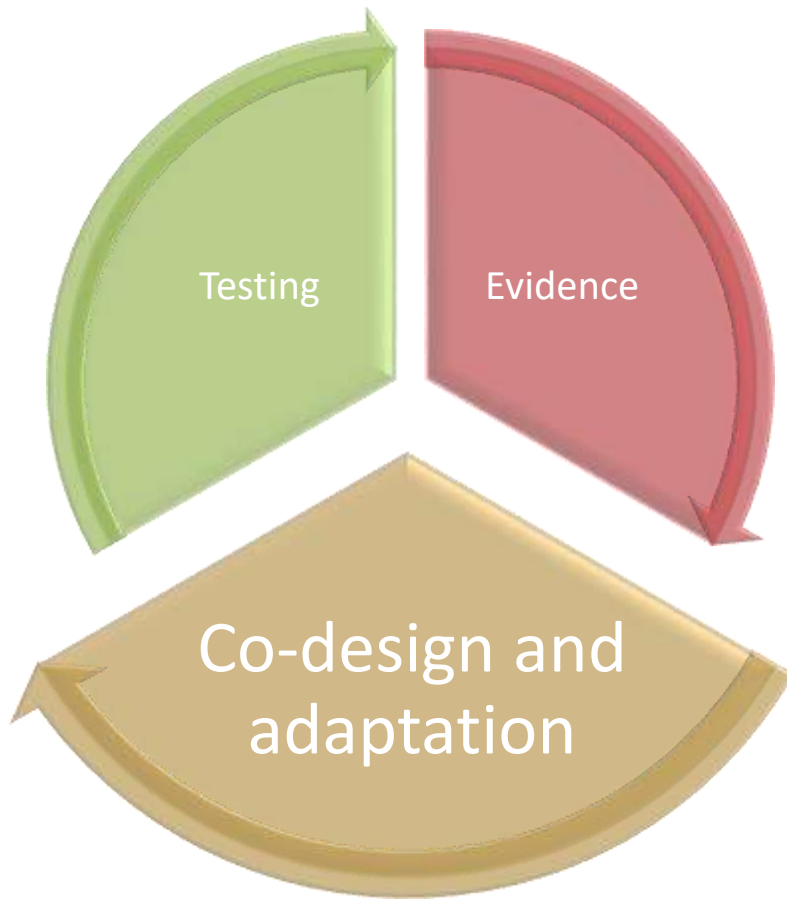
Photo credit: Tom Kelly, Save the Children Fund
Slide credit: Audrey Prost, IGH

NEON study activities - Evidence



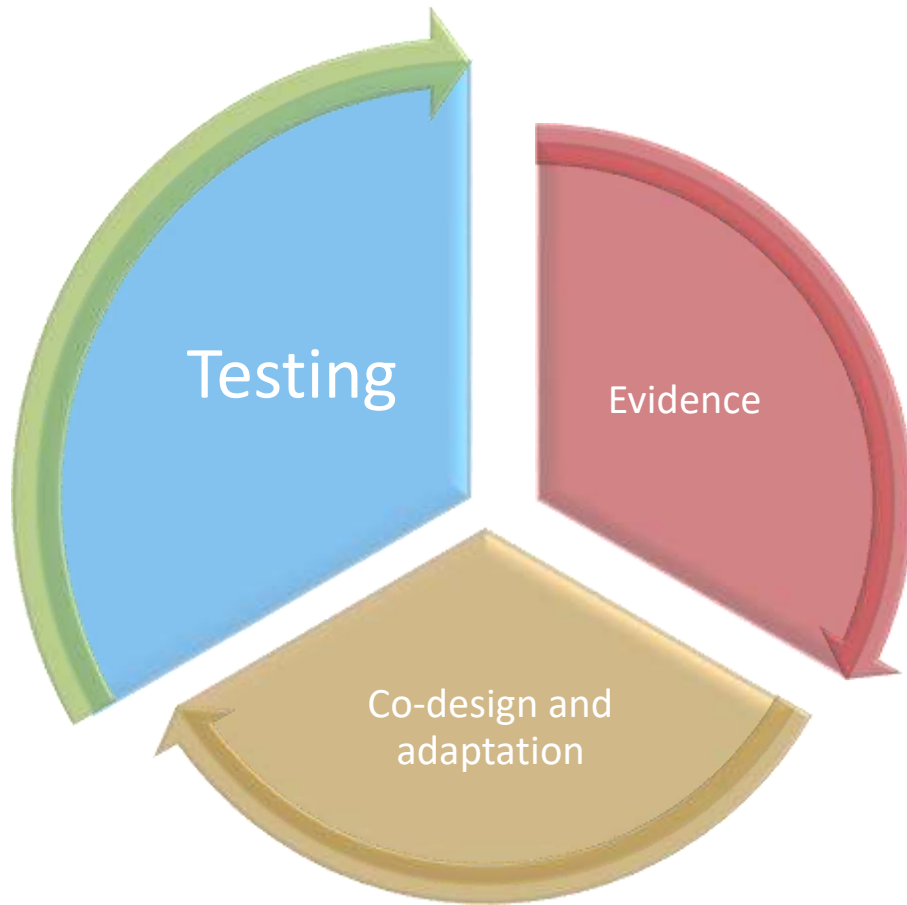
- What does the existing evidence suggest?
 - 4 Systematic literature reviews
- Qualitative study (Community facilitator-led research process in THs)
 - N= 145
 - Health professional study
 - Community study
 - Community members
 - Key informants
 - Family study
 - Pregnant women; Mothers; Fathers ; Grandmothers; Grandfathers
- PhD study - Interviews with PLA experts

NEON study activities – Co-design and adaptation



- Community based participatory action research process
- Stakeholder workshops (THs and Newham)
- Formative data from evidence phase informing co-design and adaptation of PLA group approach
- Iterative process
- Workshops including intervention design exercises, participatory discussion, and roll-play and testing
- Development of NEON intervention tool kit

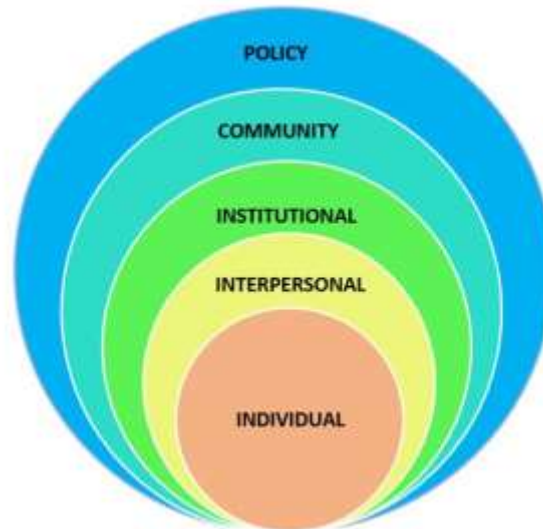
NEON study activities – Testing



- Assessed feasibility of key educational and delivery components of an adapted NEON PLA group intervention
- Trained 5 local women PLA group facilitators – 3 day training
- 4 PLA groups at 4 host community venues
- Total of 28 participants – Bangladeshi carers – mothers, grandmothers and Aunts
- Participatory group sessions – tailored discussion in Bengali, Sylheti and English
- Facilitator and participant-led discussion + group identification, prioritisation and problem solving exercises
- Data collection to assess feasibility



Modifiable infant feeding and care practices



Society and culture

- Chubby equals healthy
- Anxiety and social visits

Physical and local environment

- Physical space for play
- Fast food outlets
- Advertising
- Household environment

Information and awareness

- Engaging with health services
- Balancing cultures
- Parent style

Wider determinants & contributing factors

tailored communication & discussion

non-stigmatising approach

safe space

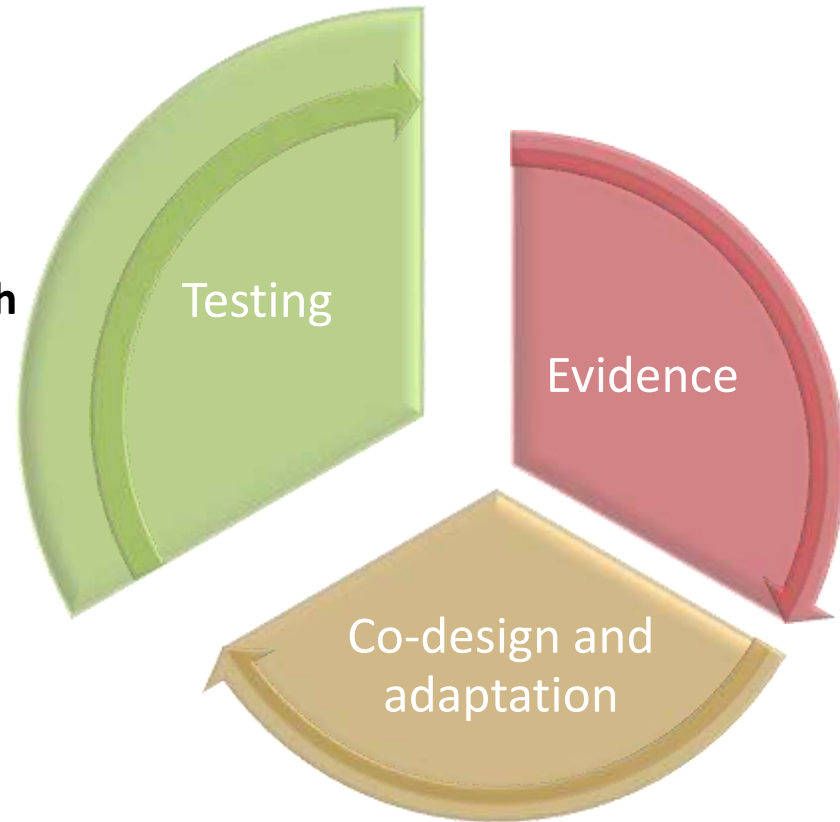
adaptable approach

led to changes in practices and sharing of messages

Visual component highly engaging and influential

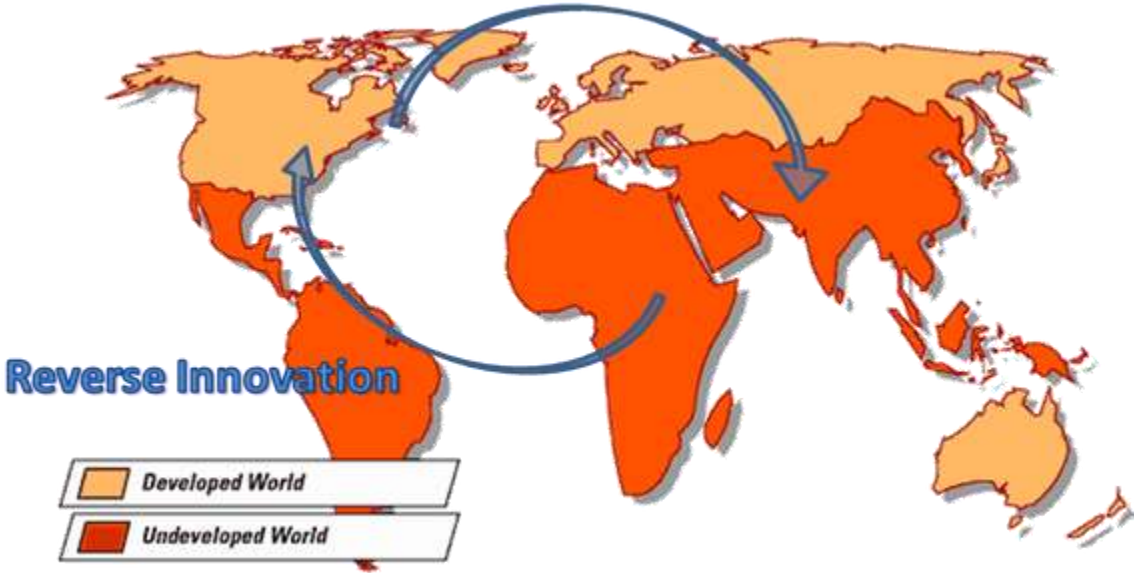
Content, materials and delivery repetitive

Challenges in maintaining fidelity



Community engaged across all 3 phases

Traditional Innovation



Reverse Innovation

- Developed World
- Undeveloped World

Next steps

- Full intervention co-development
- Formal randomised pilot – Newham & Tower Hamlets
- Reverse innovation of community engagement and caregiver groups for neurodisability



A twin study exploring the association between childhood emotional and behaviour problems and specific psychotic experiences in a community sample of adolescents

Dr Sania Shakoor

Centre for Psychiatry, Wolfson Institute of Preventive Medicine
Barts & The London School of Medicine & Dentistry
Queen Mary, University of London

Shakoor, S., McGuire, P., Cardno, A. G., Freeman, D., & Ronald, A. (2018). A twin study exploring the association between childhood emotional and behaviour problems and specific psychotic experiences in a community sample of adolescents. *Journal of Child Psychology and Psychiatry*, 59(5), 565-573.

Background

- **Continuum** (Johns & van Os, 2001, Wigman et al 2011)
- **Risk of developing emotional and psychotic disorders** (McGrath et al 2016)
- **Environmental and genetic risk factors**
- **Suggestions of aetiological parallels with general childhood emotional and behaviour problems**

Research aims and methodology

Aims

- Examine if childhood emotional and behaviour problems are associated with specific psychotic experiences
- Estimate the extent to which genetic and environmental factors influence the association between emotional and behaviour problems and psychotic experiences

Methodology

- Twins Early Development Study (Howarth et al 2013)
- Emotional and behaviour problems: Age 7 and 12
- Psychotic experiences: Age 16
- Twin study design

Findings

Phenotypic analyses

	Emotional and behaviour problems	
	Age-7	Age-12
	r (CI)	r (CI)
Psychotic experiences		
Paranoia	0.13 (0.10, 0.16)	0.17 (0.14, 0.20)
Hallucinations	0.10 (0.07, 0.14)	0.13 (0.10, 0.16)
Cognitive disorganisation	0.16 (0.13, 0.19)	0.22 (0.19, 0.25)
Grandiosity	0.04 (0.01, 0.07)	0.03 (-0.01, 0.06)
Anhedonia	0.06 (0.03, 0.09)	0.12 (0.08, 0.15)
Parent-rated negative symptoms	0.34 (0.31, 0.37)	0.42 (0.39, 0.45)

Note: Correlations were performed using one random member of each twin pair using standardised age and sex regressed residuals. r = Pearson's correlation, CI= confidence intervals.

Univariate twin model-fitting analyses

	Parameter estimates		
	A (CI)	C (CI)	E (CI)
Paranoia	.52 (.49, .55)	-	.48 (.45, .51)
Cognitive disorganisation	.45 (.42, .48)	-	.55 (.52, .58)
Parent-rated negative symptoms	.57 (.50, .64)	.26 (.19, .32)	.17 (.16, .18)
Emotional and behaviour problems: Age-7	.63 (.55, .72)	.12 (.03, .20)	.25 (.23, .27)
Emotional and behaviour problems: Age-12	.50 (.43, .58)	.30 (.23, .37)	.20 (.18, .22)

Note: A=Genetic influences, C= Common environmental influences, E= Unique environmental influences, CI= confidence intervals.

Findings

Multivariate Cholesky decomposition

- Paranoia
 - 4% of variances was explained by emotional and behaviour problems via genetic influences
 - 0% via unique environmental influences
- Cognitive disorganisation
 - 8% of variances via genetic influences
 - 1% via unique environmental influences
- Parent rated negative symptoms
 - 3% of variances via genetic influences
 - 28% via common environmental influences

Conclusions

- Modest associations with psychotic experiences
- Genetically mediated mechanisms - Pleiotropic genetic effects
- Psychotic experiences not merely an extension
- Genetic and environmental influences independent of general childhood emotional and behaviour problems
- New aetiological influences come into play in adolescence
- Attention to other risk factors

Personality Disorder in Custody: Delivering Support and Enabling Change

Robin Brook Centre, St Bartholomew's Hospital, West Smithfield London,
United Kingdom.

ELFT Research Conference 2019

Dr Landon Kuester
Dr Mark Freestone (PI)
Prof Kamaldeep Bhui

Large Scale Genetic Analyses To Uncover Risk Mechanisms in Mental Illness

Andrew McQuillin
Division of Psychiatry UCL

Making carer involvement in hospital mental healthcare happen: a study in East London

Dr. Eleni Petkari



What do we need to consider?

Expected benefits and barriers

- Family involvement improves engagement with mental health treatment and outcomes
- Implementation is poor (on average 20% of patients)
- The way in which carers are involved is inconsistent
- ***Which clinical procedures can maximise family involvement during hospital care?***
- Development and feasibility study of an intervention to involve carers in hospital treatment

Co-production approach



How should the interventions be?

- One session (max 60 mins)
- Within **seven days** of admission
- Structured procedures to approach patients and obtain consent
- Looking forward: discussing current situation, information needs and ways of working together

Results

- Carers were involved for 45% of our patients (against a routine practice average of 20%)
- 71 staff trained in East London
- Only 23 staff members delivered the intervention to 31 patient and their carers
- 52% were organised in the first three days
- Average length of session – 29 mins

Participant feedback

“What you’ve devised is quite good and it opens it up in a more informal not necessarily clinical environment, that both parties can express themselves enough without the anxiety” (Clinician – P09)

“It’s a good meeting. It’s a good way to let parents or friends know um about what’s going on coz sometimes it’s difficult to call your parents or your family or whatever and tell them what’s going on. So it was a good way to have a nurse there to explain it as well.” (Patient – SU3)

“I’m quite impressed just really appreciate that you’re taking the time to do it really coz that’s of my experience and maybe [area name] is different or I think it’s quite unusual. I just wish other hospitals in other parts of the country would do something similar really.” (Carer - C16)

Barriers for implementation

- Carer involvement is pushed behind other priorities
- Patient's capacity and willingness to consent is variable
- Carers not always able to attend within working hours

Does this work in practice?

- Carer involvement is harder than we often think but it is worth it!
- Next steps: Currently testing an online training and procedures for carer involvement in transition to community care

Useful links

https://clahrc-norththames.nihr.ac.uk/mental_health_theme/involvement-of-carers-in-acute-treatment-of-patients-with-psychosis/

Family involvement in the treatment of patients with psychosis
CLAHRC North Thames

https://clahrc-norththames.nihr.ac.uk/wp-content/uploads/2017/02/NIHR_CLAHRC_North-Thames_Carers-involvement-BITEfinalv2-1.pdf

Break

- Follow signs to the Barts Pathology Museum
- Check out the entries in our Poster Competition
- Meet our research partners:
 - NIHR Clinical Research Network: North Thames
 - Noclор Research Support Services
 - Research Design Service London
 - Service User & Carer Research Group
 - SUGAR: Service User and carer Group Advising on Research

Please return by 4:00pm to hear about more
Health Research in East London

Communication and Understanding of Mild Cognitive Impairment Diagnoses

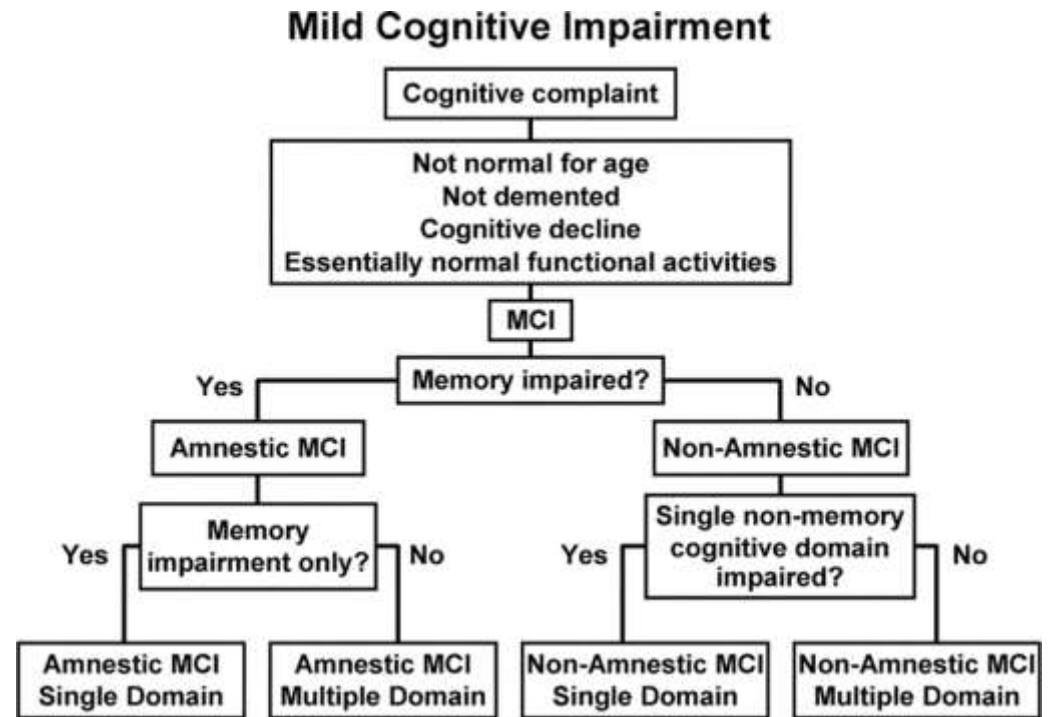
Dr Cate Bailey, Fellow in Medical
Medication (QMUL), ST6 in Old Age and
General Adult Psychiatry (ELFT), with
thanks and on behalf of:

- Dr Jemima Dooley
- Professor Rose McCabe
- Professor Nick Bass
- Dr Penny Xanthopoulou

2nd October 2019

MCI

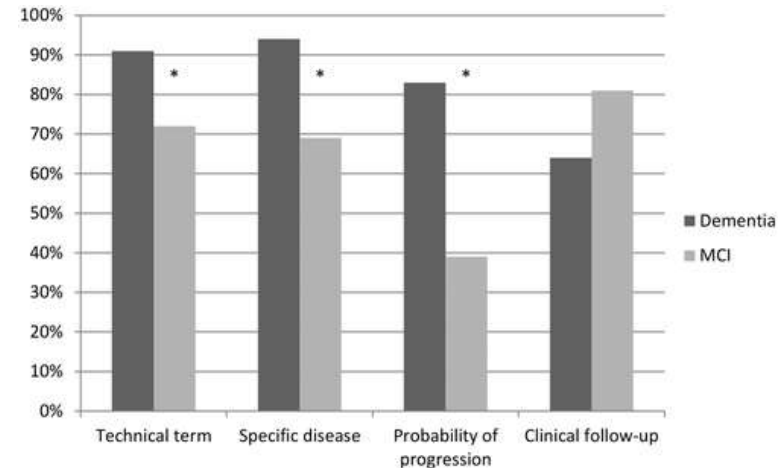
- Somewhere between normal ageing and dementia (see debate of “intermediate” vs “transitional”)
- *Objective and subjective evidence of memory loss, in the context of essentially normal mental status and preserved functional independence, and not reaching the threshold of dementia*
- Aetiologically and prognostically heterogeneous
- Estimated 15-20% prevalence of MCI in the over 60s and a rate of progression to dementia from 8-15% per year (Peterson, 2016)
- Possibility of modifiable risk factors (Cooper et al, 2015)



(Hunderfund et al, 2006)

What patients, relatives and doctors say

- Patients and relatives (Gomersall et al, 2016):
 - Mixture of worry and relief, good to have a name but don't really know what it means
 - *"He (the doctor) says 'no love' he says 'no' he says 'I think you've got a touch of Alzheimer's'. (long pause) 'Ooh, what's that? Have I got to take tablets?'"* (woman, 76, with MCI)
- 54 specialist Danish physicians (Nielsen et al, 2018)
- Doctors (Bailey et al, 2016):
 - *"Sometimes I think a diagnosis of MCI can be difficult to explain because people can catch the wrong end of the stick. They think it's completely normal and you're having to explain that as a diagnostic entity itself it has a lot of uncertainty around it."* - P2



Methods & Analysis

- Part of the ShareD Study
- Video recordings of diagnostic feedback across 9 UK based DMCs (rural and urban)
- Patients and companions asked “Did the doctor give a name (or diagnosis) to your memory problem? If so, what?”
- Doctors also completed a form indicating person’s diagnosis → MCI or VCI videos analysed
- Conversation Analysis; in-depth, qualitative method to micro-analyse communication
- Practices coded quantitatively and Fisher’s exact used for relationship between practices and understanding

Results

- 12 doctors from 6 memory clinics
- 215 patients recruited to Shared overall
 - 101: diagnoses of dementia
 - 47: diagnoses of MCI or VCI
 - 21: diagnoses of depression or anxiety
 - 34: referred for further testing
 - 22: no diagnosis
- 43 videos analysed in MCI/VCI data set, mean ACE III score of 83

Results: Categories

- MCI or VCI named:
 - Named in 79%
- Explanation for symptoms:
 - Vascular conditions (49%)
 - Stage between ageing and dementia (30%)
 - Impairment caused by mood or alcoholism (21%)

Extract 2

DR: so we are on a spectrum of normal (0.2) memory and then with age we forget so there's some age related changes and then eventually there is dementia. But in between that age related change and dementia there's a grey sort of area where (0.2) you have what we call as mild (0.2) cognitive impairment.

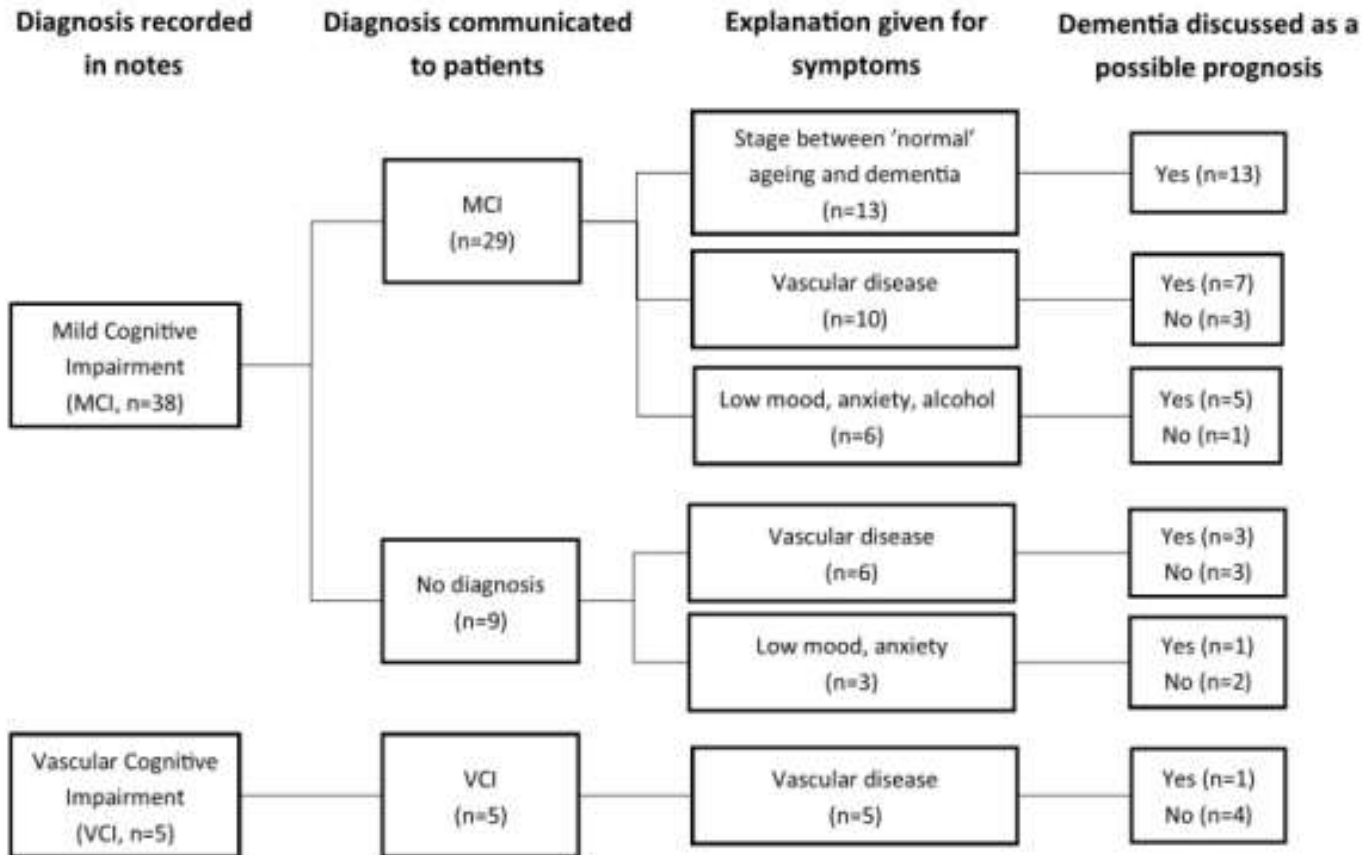
Extract 4

DR: Um, really that's a posh way of saying (0.4) you know age related (0.4) brain change (0.4)

DR: Um (0.4) and I think that wh- what we would put your memory problems down to is (0.4) mild cognitive impairment or age.

DR: Stress and (0.4) anxieties play a massive role in that because, (0.4) if you (0.4) have to make a lot of effort to remember things the more preoccupied you are with other things the harder that effort becomes.

Results



Results: Prognosis

- Prognostic discussions:
 - In all but one meeting, but...
 - Only 54% included explicit indication that dementia is a possibility
 - 47% implied the condition could get worse but did not mention dementia
 - In 30% of the total meetings doctors stated that they expected the condition would ***not*** get worse
 - No association between mentioning dementia with whether a diagnosis was named (Fisher's .26) or the explanation given to the patient (.15)

Extract 6

DR: you know we could be seeing the very early signs of something like a (0.2) a vascular dementia

Extract 8

DR: and the brain's a bit like that you know once a certain amount of change has happened it can't (0.2) get older [if you] know

PT: [mm]

DR: what I mean

PT: ye[ah]

DR: [th]e change [is] already there

PT: [yeah]

PT: yeah

DR: and so generally (0.4) you know (0.2) things should settle down and stay (.) pretty much (0.4) at the level that they're at now

Results: Treatment

- 88% of consultations included discussions about lifestyle modifications such as stopping smoking, increasing exercise or social activities
- Medication to prevent progression discussed in 16% (starting or continuing cardiovascular medications, medication for anxiety, reduce high doses of medication)
- 19% directed towards research

Results: Understanding

- 43% patients, 63% companions reported same diagnosis or explanation as the doctor
- “No problem” and “not dementia” frequently reported by patients
- Both patients and companions more likely to report MCI or VCI as their diagnosis if these diagnoses were named (Fisher’s .12, .00)
- Significant association between prognostic discussions including dementia and patient & companion recalling the MCI/VCI diagnosis (Fisher’s .0004, .018)

What does it all mean?

- The subtypes/categories doctors use don't seem to be related to whether dementia is discussed within prognosis
- Nearly half (47%) of prognostic discussions do not refer to dementia – implications for future planning
- Recall is helped by specifically mentioning dementia
- A lot of patients come away thinking nothing is wrong

Limitations

- Diagnoses not verified (based on doctor's report)
- Didn't capture doctors' beliefs about subtype and prognosis
- Small numbers

What can we learn?

- If it's MCI, say it, write it down
- Mention dementia as a possibility (? Ethical imperative?)
- Refer people for research!
- Reversible risk factors – what about diabetes? (see review by Cooper et al, 2015)

Further Information:

- Camden and Islington Research Ethics Committee approved the study (REF: 13/LO/1309).
- Part of an NIHR RfPB funded study exploring communication in memory clinics (ShareD, 'Shared decision making in mild to moderate dementia' PB-PG-1111-26063).
- This presentation describes independent research funded by the National Institute for Health Research (NIHR). The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health and Social Care.
- Contacts:
 - Dr Cate Bailey: cate.bailey@nhs.net @_parapraxis_
 - Dr Jemima Dooley: @DrMimaDooley
 - Dr Nick Bass: n.bass@ucl.ac.uk
 - Professor Rose McCabe: @RoseMcCabe2
- References:
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PRIDE

Research Project

Adrian Curwen, Jane Fernandes, Racheal Howison, Paul Binfield,
Winnie Chow and Domenico Giacco.

2019

The PRIDE Project

- PRIDE = Participation; Recovery; Involvement; Development; Experience.
- Funded by the Centre for Public Engagement, Queen Mary University of London, based at East London Foundation Trust.

The PRIDE Project

Our Purpose

To measure and evaluate the outcomes of People Participation activities for recovery.

Methodology

There was specific training adapted and modified with Service User participation.

Researchers with lived experience were trained in and delivered Quantitative and Qualitative Interviews.

Training received by Service User Researchers

The Differences Between the Interview Methods Used.

Quantitative Interviewing: Neutral; Standardised; No need to prompt or improvise.

Qualitative Interviewing: Looking into subjective experiences; knowing when to probe and to establish a rapport with interviewee; aims to go below the surface and learn from the interviewee. Flexibility, rapport with interviewee, active listening and an awareness of not asking leading questions.

We learnt the role of a researcher: To show genuine interest and attention; make clear there are no wrong or right answers; be mindful of tone of voice and body language; allow participant time to reply and handle irrelevant/distracting information.

Training received by Service User Researchers

- We learnt to transcribe qualitative interviews.
- We learnt to code transcripts and identify themes.
- We were taught to use specialist software to collate and analyse quantitative data.
- We learnt about ethical issues and challenging circumstances.

PRIDE Qualitative Study

Research Findings

We interviewed 15 people involved for at least one year in People Participation to explore their experiences.

- 46.7% female
- 46.7% under 44 years of age
- Wide spread of ethnic groups (33% White; 27% Black African/Caribbean; 20% Mixed Ethnic Group; 13% Asian; One participant preferred not to define her/his ethnic group.)
- Eight participants were older than 44 years of age (53.3%) and two reported to have a learning disability (13%).

PRIDE Qualitative Study

Research Findings

Why did participants join People Participation activities?

To give back to the service

“I felt a sort of passion in wanting to help improve things. I felt sort of like a need to pay back some of the really great sort of professionals I met across the years who’d helped me out”.

To influence changes for the better within services

“I’ve had quite a few staff remark to me that I’ve changed their attitude of service users and service user involvement in peer support and that sort of thing. So I think I’ve changed some attitude there”.

Curiosity

“So really it was the PPL lead... and she came along and, I’m not even sure how it happened, but I got involved and I started enjoying it. It was hard at first, especially talking to many people. Very scary and very shaky, but she kind of made it a lot better. She’s really good at her job. She really looked after me, you know, and I feel there’s been progress since I first started.”

Social aspect – meeting like-minded people

“I come to the meetings and I look forward to coming... because it’s a change from that routine of hanging around with people (and) doing things that are not going to help them in their mental state.”

PRIDE Qualitative Study

Research Findings

What were the benefits and (positive or negative) experiences for recovery by being involved in People Participation?

Improvement in self-confidence and motivation

“It helped me achieve a sense of well-being, it’s educated me, it’s made me more self-aware, it’s helped me just become a person that could, a normal person, normal as in the sense that like a person that can be in the community and have a mental health problem but still carry on and live a normal life.....”

Sharing experiences with like minded people

“You get to connect with people and it’s so lovely when people come up to you and say “I love coming here because you are here as well” and, you know, that sort of thing. Just to be you.”

Better understanding of services

“When going inside the service that I did stay in it was kind of nice to see the day-to-day running so I guess that kind of give me another dimension to what I knew about that service...”

“It’s changed my views of services in ELFT and it’s changed my view that services are changing towards a more patient focussed and listening more to the service users. I think, I mean in the past with psychiatric services, there wasn’t such a focus on recovery. It was more a focus on containment”

PRIDE Qualitative Study

Research Findings

What were the benefits and (positive or negative) experiences for recovery by being involved in People Participation?

Facing and overcoming fears, independence

“It is always good to learn about things that you actually fear.”

“One of my things is the fear of... being discharged and being left on your own. But now I don’t fear that because I know there’s always access to everything, you know, and if you are having problems, you talk.”

Sense of achievement, feeling valued

“You are important actually... You do learn if you’re given a question your answer is important.”

“So it opens doors. You meet people you normally wouldn’t have met. You know, when you give yourself to something, it is not about rising to this or being big at this or doing, earning x amount of money. For me it was, you know, just one step at a time and I enjoy it now.”

Giving back feels good

“It’s helped with my recovery greatly. Sort of helping other people and feeling productive and putting a positive end to a negative set of experiences. It’s all, sort of, been great.”

PRIDE Qualitative Study

Research Findings

What were the benefits and (positive or negative) experiences for recovery by being involved in People Participation?

Having a voice and improving services

“It made me more empowered because I was sitting on panels and I was having a say of who comes in and who doesn’t come in”

“Getting involved... taking part, having a say, being listed to, being educated...”

Better coping mechanisms

“It’s helped me because it’s made me think about what are the good things in life and what are the bad things in life and what’s going to keep me well and safe and keep me from going back to hospital again.”

PRIDE Qualitative Study

Research Findings

What skills were refreshed or gained by taking part in People Participation activities?

Listening skills/interpersonal skills

“I’ve learnt so much from going to the meetings, you know, talking and listening to other people, so I’ve learnt a lot, and I’ve got sort of self-respect and my say back, which I didn’t have before”

General communication skills

“It trains you to develop your skills set. That was very attractive to me.”

Public speaking skills - giving training to staff

“I think being able to express yourself, especially when I do talks with new nurses or new social therapists, they really want to hear the service user’s view and see the other side. Not just the things they are trained in. Not just the things that are passed down, but the service user’s view is the reality. The fact that I was a patient made my views more important.”

“I’ve had quite a few staff remark to me that I’ve changed their attitude of service users and service user involvement in peer support and that sort of thing. So I think I’ve changed some attitude there.”

PRIDE Qualitative Study

Research Findings

What were the participants' experience of the support provided?

Trust/Availability

"Yes, she has been really good. I've needed to lean on her quite a bit. Especially when writing any script or doing any talk, the fact that she's there makes it much easier. I can get all the information that I need and she really supports me. She does a wonderful job. She has great qualities, you know. So I wouldn't be able to do the stuff I've done without her."

"Our People Participation Lead is probably the best one and I wouldn't want anyone else. I can talk to her about anything. She is down to earth, human. She's a lovely lady and I can go to her whenever I like."

Being a companion

Facing fears - pushing personal boundaries

"I set myself boundaries because I guess we all live in our own safety nets when you have mental illness. She actually makes me go to the edge and sometimes over. And when I do that, I feel, you know, like, 'wow, I'm so glad I did that. Can I do that? I can really do that' you know."

Keeping updated on training, events and opportunities

Support with personal issues

PRIDE Qualitative Study

Research Findings

What were the participants' experience of the support provided?

Genuinely caring – seeing service users as people and not just a job

“People Participation Leads should be on ward rounds. You can talk to People Participation Leads about things you wouldn't talk to a doctor about.”

What aspects of this initiative could be improved/suggestions for improvement?

More involvement from young people

Change in staff attitudes – especially on interview panels not seeing service user involvement as valid

Better financial incentive

Better payment system – getting paid on time, less form filling

Financial recognition of travel time involved for service users from Luton and Beds who attend events in London, recognition of childcare issues and that some service users are parents

Moving-on support system like careers advice

Having a People Participation web page with info on events, training, different mental health conditions, common medication side-effects, sign-posting to other support services, etc

Does not need improving!

PRIDE Qualitative Study

Research Findings

“Whoever is listening to this, just know one thing – People Participation has pulled me out of a very big hole which is now filled with cement and I don’t go back there now... I’m moving forward. I feel like a human being now, not an animal.”

“As far as this Trust is concerned, we seem to have pretty well nailed People Participation, I think. I don’t know where we stand nationally in terms of participation, but we are damn good at it and I think we could teach those other Trusts.”

The PRIDE Academic Paper

**‘Exploring experiences of People Participation activities in a British National Health Service Trust:
A service user-led research project.’**

(Published January, 2019)

“One important output is that its findings were among the first ones providing insights on experience of People Participation activities in NHS Trusts.

This is a still understudied topic and the paper is the first contribution to the scientific literature.”



<https://rdcu.be/bnjoh>

Volunteering via smart-phone for people with psychosis

Dr Mariana Pinto da Costa



Queen Mary
University of London

East London
NHS Foundation Trust



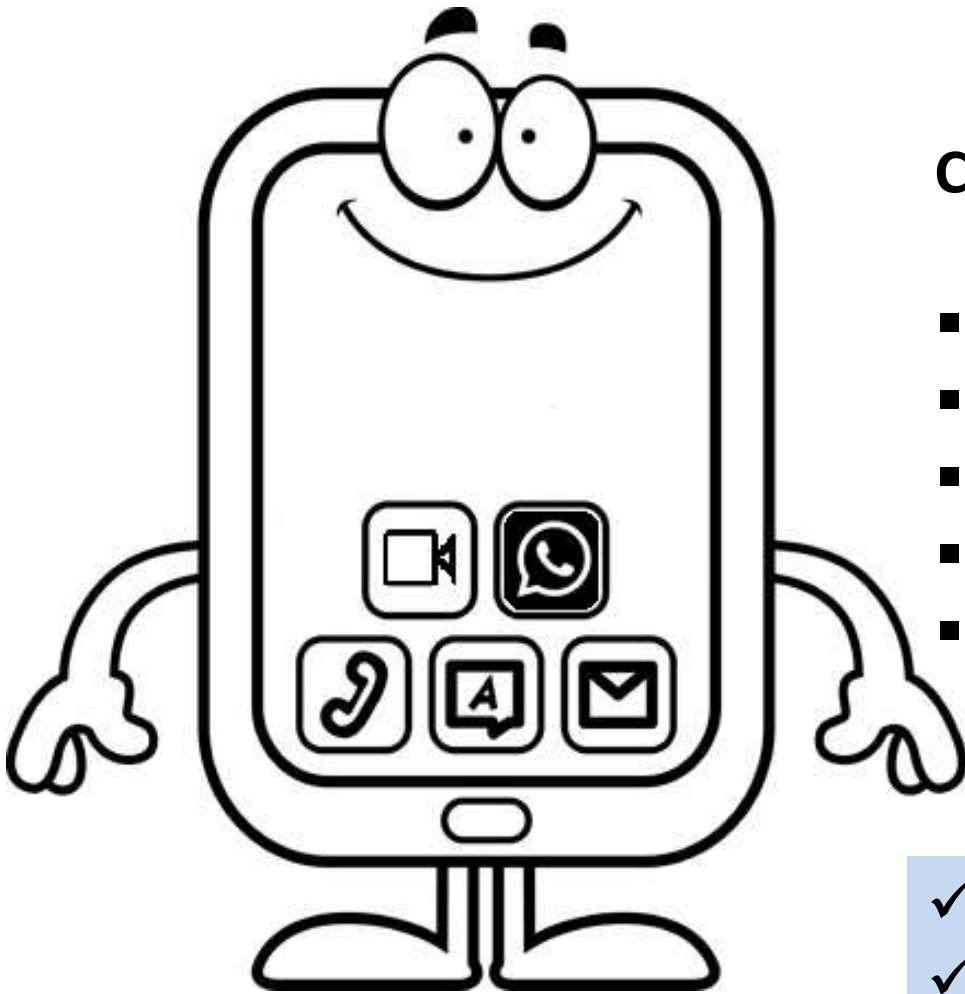


PHONE PAL &



Befriending
Networks

The Intervention



Communicate for 12 weeks via

- Audio phone calls
- Video calls
- Text messages
- WhatsApp messages
- E-mails

- ✓ We give you a smart-phone
- ✓ We will monitor your communication & step count



Social Psychiatry

@QMULSocialPsych

Follow



Would YOU like to take part in the Phone Pal study? We are looking for VOLUNTEERS to speak with people with psychosis over a smart-phone. Check out more information here 📞 & please share! #volunteering #digitalmentalhealth

PHONE PAL

The Phone pal study will connect people.

Would you like to be in contact with a patient with psychosis over a smart-phone?

We invite

- You to volunteer to speak over the smart-phone that we offer, with a patient with psychosis for up to 12 weeks.
- You may be flexible in your communication, although you may find it helpful to communicate

Why should I participate?

- You will be matched to a patient with psychosis, with whom you can speak over the smart-phone. This should make them more connected and feeling better, and possibly yourself as well.
- You will receive £10 for each interview (at the beginning and after the 12 weeks).
- You will receive a Volunteer certificate at the end of this study.
- You can keep the smart-phone at the end of the study.

To find out more about the study and how you will be reimbursed for your time

contact:
mariana.pintodacosta@qmul.ac.uk
Tel: 020 7540 4380 (ext 2320)

27 Retweets 22 Likes



East London NHS FT, Noclor Research NHS, CLAHRC North Thames and 7 others

5

27

22

Volunteers for study



Social Psychiatry

@QMULSocialPsych

Follow



Our Mariana Pinto da Costa has been recruiting volunteers from across the country 🇬🇧 for her Phone Pal study! 🚚🚐 Can you guess a place by its picture? 🔍 This is where she has been:

[#volunteering](#) [#digitalmentalhealth](#) [#PhD](#)



5:33 AM - 27 Mar 2019

5 Retweets 14 Likes



Doctoral College, East London NHS FT, Noclor Research NHS and 7 others

1 5 14



Tue 26/03/2019 21:37

To: Mariana Pinto Da Costa

Caixa de Entrada

Hi Mariana,

I have seen your request for volunteers to talk to people with psychosis via smartphones. Are you recruiting people from within the UK only, or is it possible to be involved from elsewhere? I am based in New Zealand.

Best wishes,

Phone Pal Inquiry



Sun 17/03/2019 20:58

To: Mariana Pinto Da Costa

Caixa de Entrada

Hello Mariana,

I am currently a master's student at McGill University in Canada. Would it be possible to volunteer for this study?

Thank you,

Participants

Patients

Volunteers

Gender

Age

Ethnicity

Nationality

Employment

Living

Conclusions

- ✓ Feasible
- ✓ Enjoy it
- ✓ Benefit



Thanks!



Questions?

mariana.pintodacosta@qmul.ac.uk

Can a brief training improve attitudes when working with Personality Disorder?

Using a Mentalization-Based Treatment approach in
teaching trainee psychiatrists

Dr Patrick Grove

Principal Clinical Psychologist/Operational Lead

Deancross: Tower Hamlets Personality Disorder Service

Background

- Pejorative attitudes of clinicians towards people with Personality Disorder (PD) diagnosis have been widely described and are a major service challenge.
 - **Service user experience** relates to staff attitude towards PD:
 - Service users are acutely aware of pejorative attitudes from staff and feel rejected and disbelieved by clinicians (Bilderbeck et al., 2014).
 - Can lead to more negativity in nurses' responses (Gallop et al., 1989)
 - **Staff experience** is that it can be difficult to know how to manage individuals with PD diagnosis:
 - Staff find Service users more difficult to deal with (Cleary et al., 2002).
 - Staff burnout associated with PD presentations (Crawford et al., 2009)

Background

- Psychiatric trainees are a key professional group working with PD.
- While recent research indicates trainings based on psychological models have led to improvements in staff attitudes, a study that focused on trainee psychiatrists had a small study population.
- Our group* aimed to evaluate if a brief training informed by Mentalization-Based Treatment (Bateman & Fonagy, 2016; MBT) to improve attitudes of trainee psychiatrists in working with patients with PD.
 - *Grove, Lee, Garrett, Kanter-Bax, Whitehurst, Bhui

Method

- 49 trainee psychiatrists completed an Attitudes to Personality Disorder Questionnaire (APDQ)
- Repeated measures before and after 2x3hr teaching:
 - L 1 On Personality Disorder from a psychiatric perspective.
 - Lecture 2 On understanding PD through MBT, and including role play.
- A group discussion was also held after the teaching to collect data on participant experience.

Role Playing a Scenario from A&E

Recognising mentalizing problems

If you don't admit me, then I know you don't care

I just cut myself – I'm fine now. I want to go home

I need my medication increased now or I'll just OD again

You've never been through this, there's no point talking to you



Trainee practises mentalizing stance

I'll try to explain where I'm coming from...

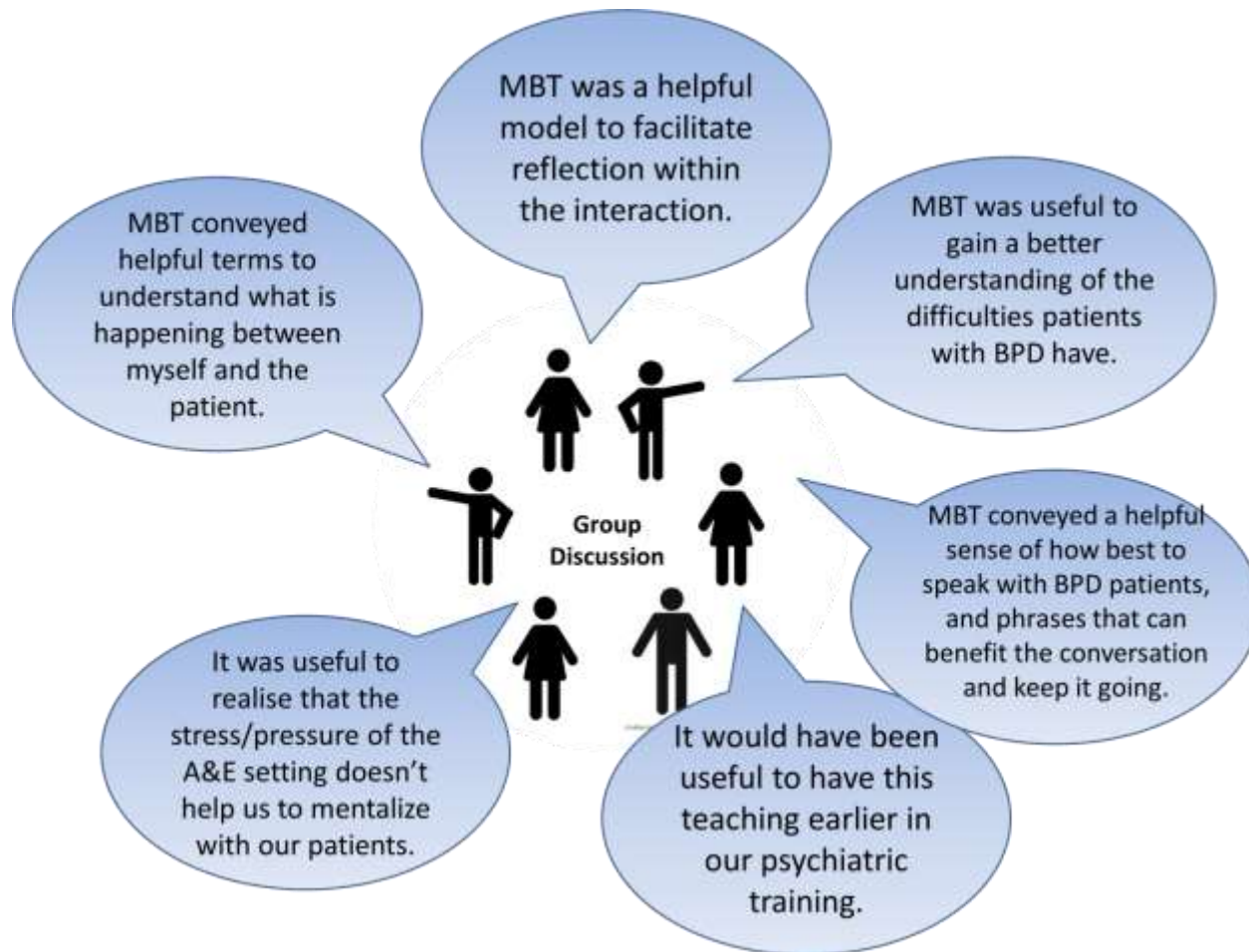
Did I do something which made you want to leave?

Can we pause a second? I'm concerned about what you're saying and want to make sure I understand properly

I'd like it if we can talk it through and perhaps we can plan together?



Participant Feedback



Results

- There was a significant improvement on composite scores of attitude with a more moderate effect size, Wilcoxon Signed Rank Test ($Z = 3.961$, $p < 0.001$, $r = 0.40$).
- Typically, in studies designed to improve attitudes reveal small effect sizes, therefore a more moderate effect size is considerable.
- The group discussion indicated that the trainees found most useful the practical section of the training which focused on the challenges of clinical encounters and appropriate clinician responses.

Conclusions / Recommendations

- A brief MBT-informed teaching significantly improved attitudes of trainee psychiatrists towards people with personality disorder diagnosis.
- This form of training could be widely implemented given it that it is resource- and time-light.
 - Nationally in MRCPPsych trainings
 - Locally within ELFT and across professions/services
 - Teaching could be co-ordinated locally by existed MBT PD Services

Conclusions / Recommendations

- Improvements in Patient Experience:
 - Implementation within ELFT to improve staff attitudes could improve patient experience for people with Personality Disorder diagnosis across ELFT.
- Improvements in Staff Experience:
 - The increased skills and confidence reported by the trainee psychiatrists should translate into offering better care to people with Personality Disorder, and improve staff experience.

Acknowledgements/Citations

- **Acknowledgements**

- Centre for Understanding of Personality Disorder (CUSP).
- Deancross: Tower Hamlets Personality Disorder Service
 - Tennyson Lee, Chris Garrett, Orestis Kanter-Bax, Tom Whitehurst, Prof Kam Bhui.

- **Citations**

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De-escalation in mental health settings

Dr Mary Lavelle
City, University of London

Mary.lavelle@city.ac.uk

De-escalation

“The use of techniques (including verbal and non-verbal communication skills) aimed at defusing anger and averting aggression”

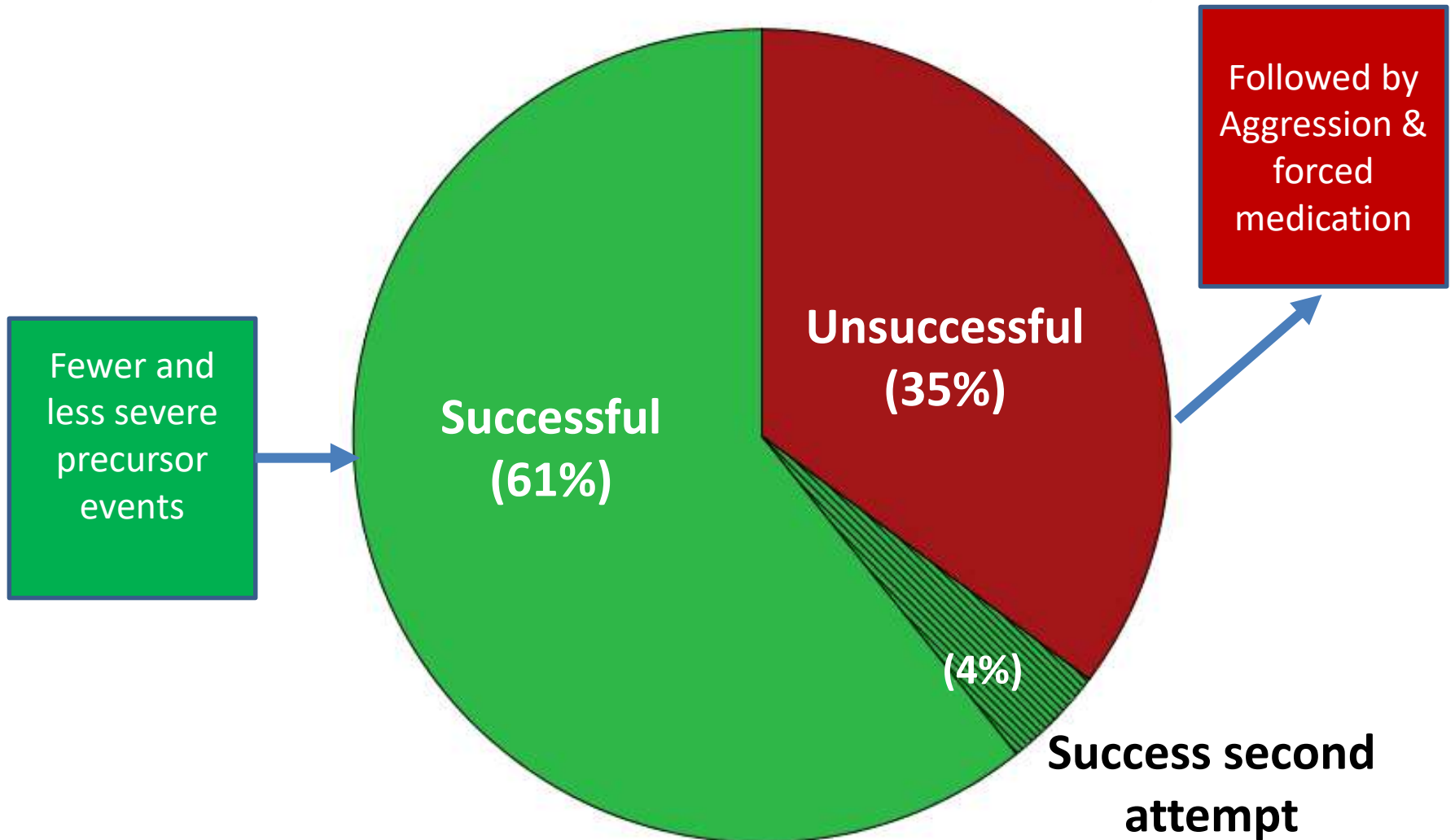
(NICE, 2015)



De-escalation

- Recommended first line of intervention
- Safer alternative to more coercive containment methods – restraint, seclusion
- However, little research evidence
- Mandatory training, no agreed best practice

De-escalation Success

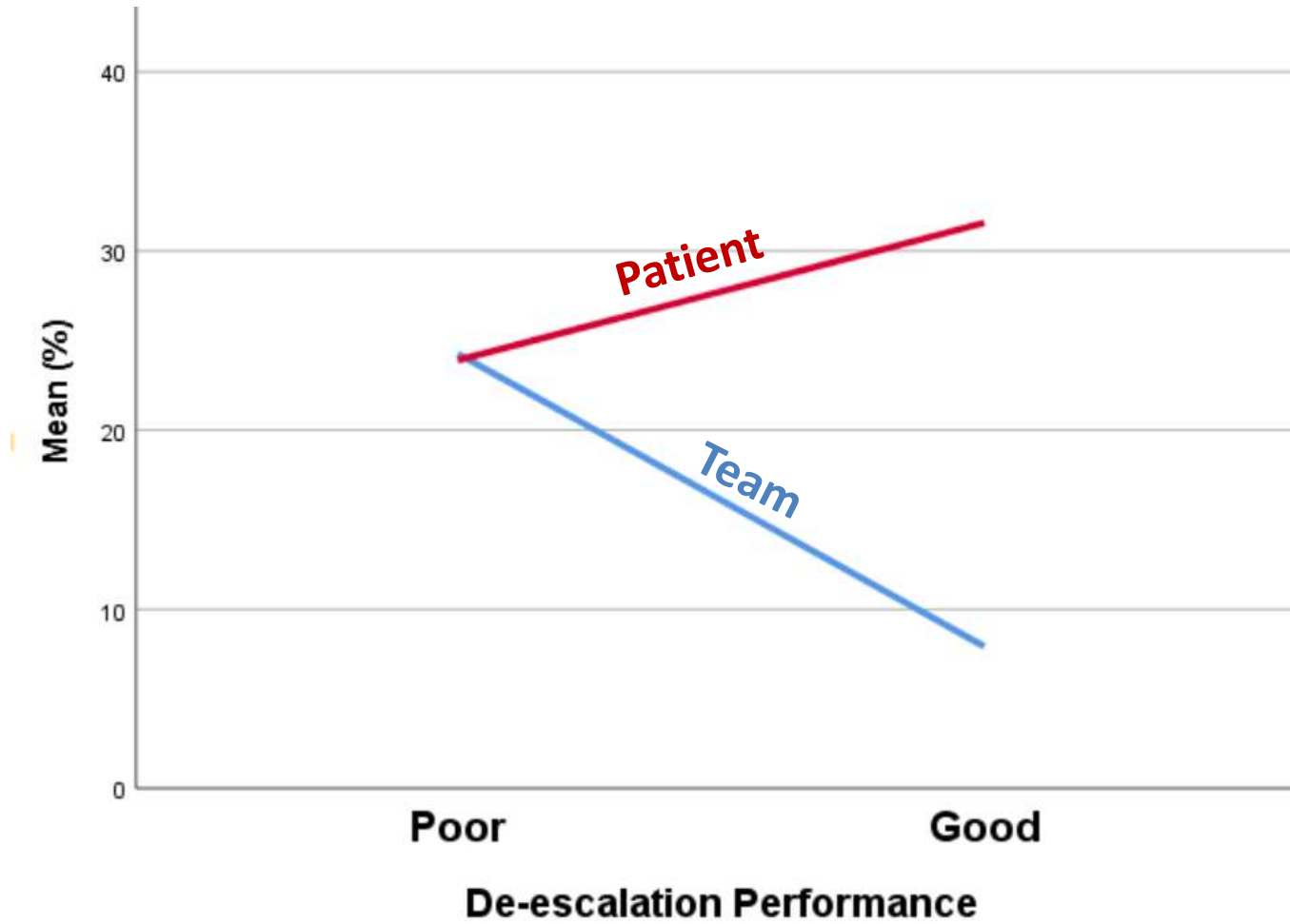


How do staff de-escalate?

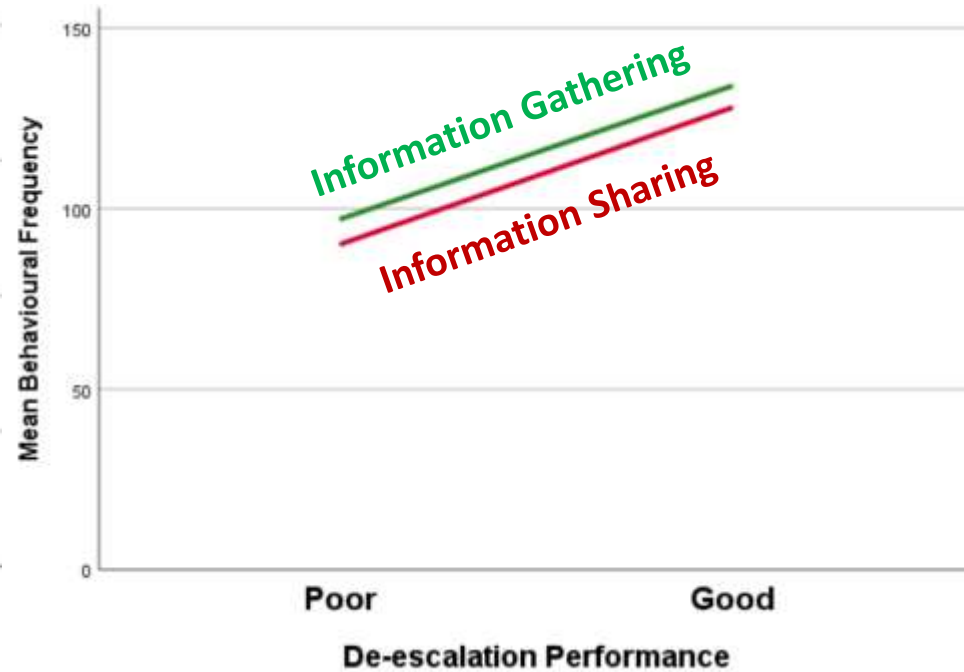
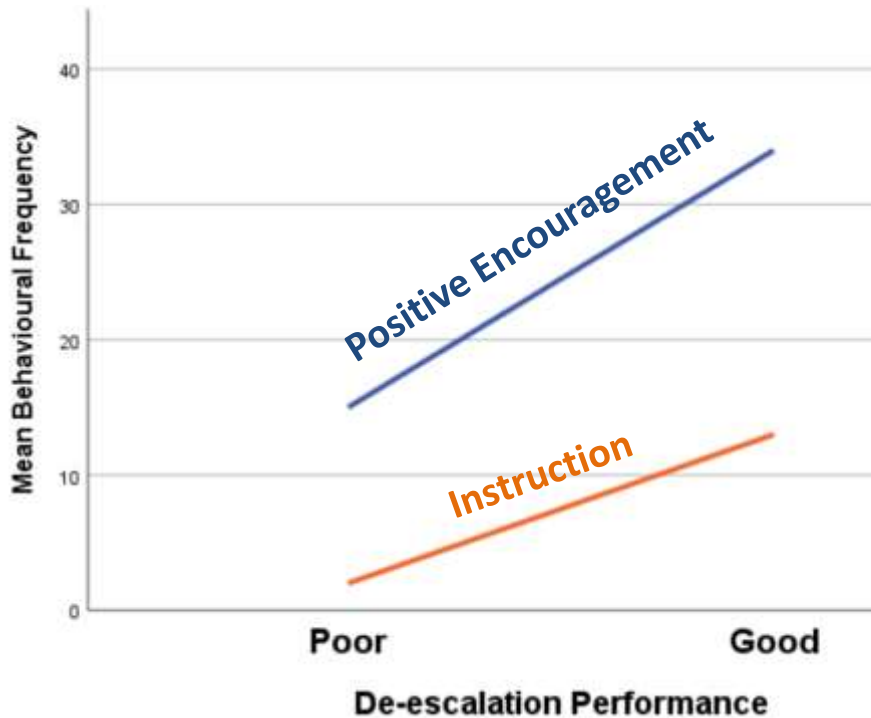
Observational analysis of simulated de-escalation scenarios ($n=10$)

- De-escalation performance observer rated
 - De-escalation Aggressive Behaviour Scale (DABS, Nau et al., 2009)
- Staff behaviour annotated
 - Temporal Observational Analysis of Teamwork Framework (TOAsT, Lavelle et al., 2020).

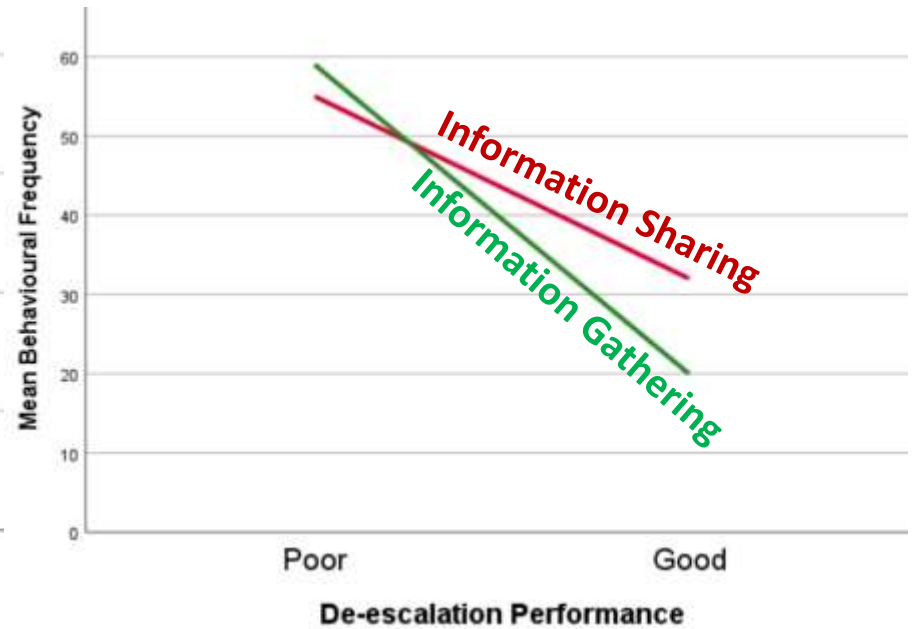
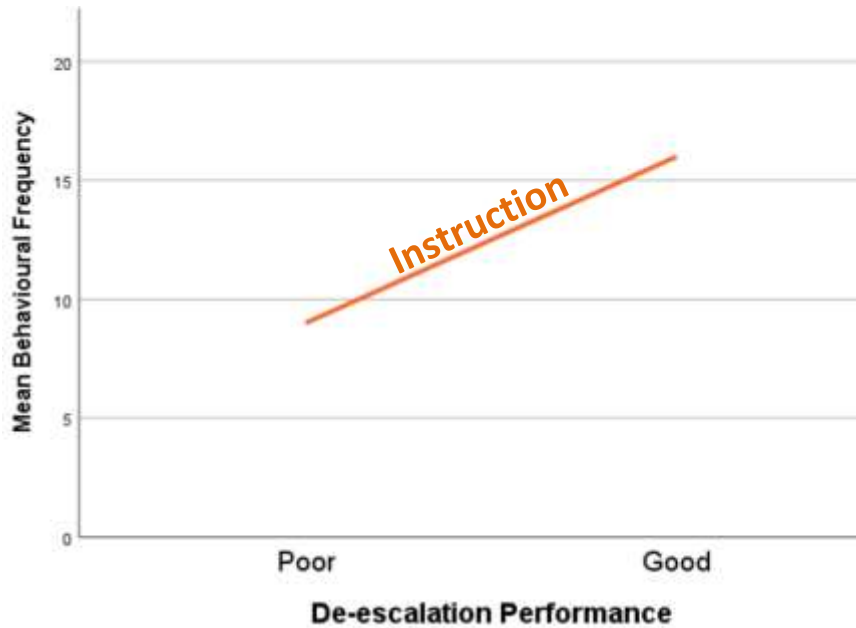
Communication Overall



Communication with Patient



Communication with Team



Summary

- Effective teams may employ implicit, nonverbal communication not captured in current analysis
- Simulation not real life – success difficult to evaluate
- Potential to examine behavioural predictors of successful de-escalation in real world settings





Thank you!

Collaborators:

Dr Janet E. Anderson

Dr Gabriel B. Reedy

Can Psychosis be Treated Without or with Minimal Antipsychotics?

Dr Ruth Cooper

Unit for Social and Community Psychiatry
Queen Mary University of London/East
London NHS Foundation Trust

Background

- Antipsychotics are the main treatment for psychosis.
- Adverse effects but benefits may outweigh risks.
- But up to 40% of people stop taking antipsychotics.
- No formal NICE guideline for treatment without antipsychotics.

2.2 People who choose not to take antipsychotic medication

What is the clinical and cost effectiveness of psychological intervention alone, compared with treatment as usual, in people with psychosis or schizophrenia who choose not to take antipsychotic medication?

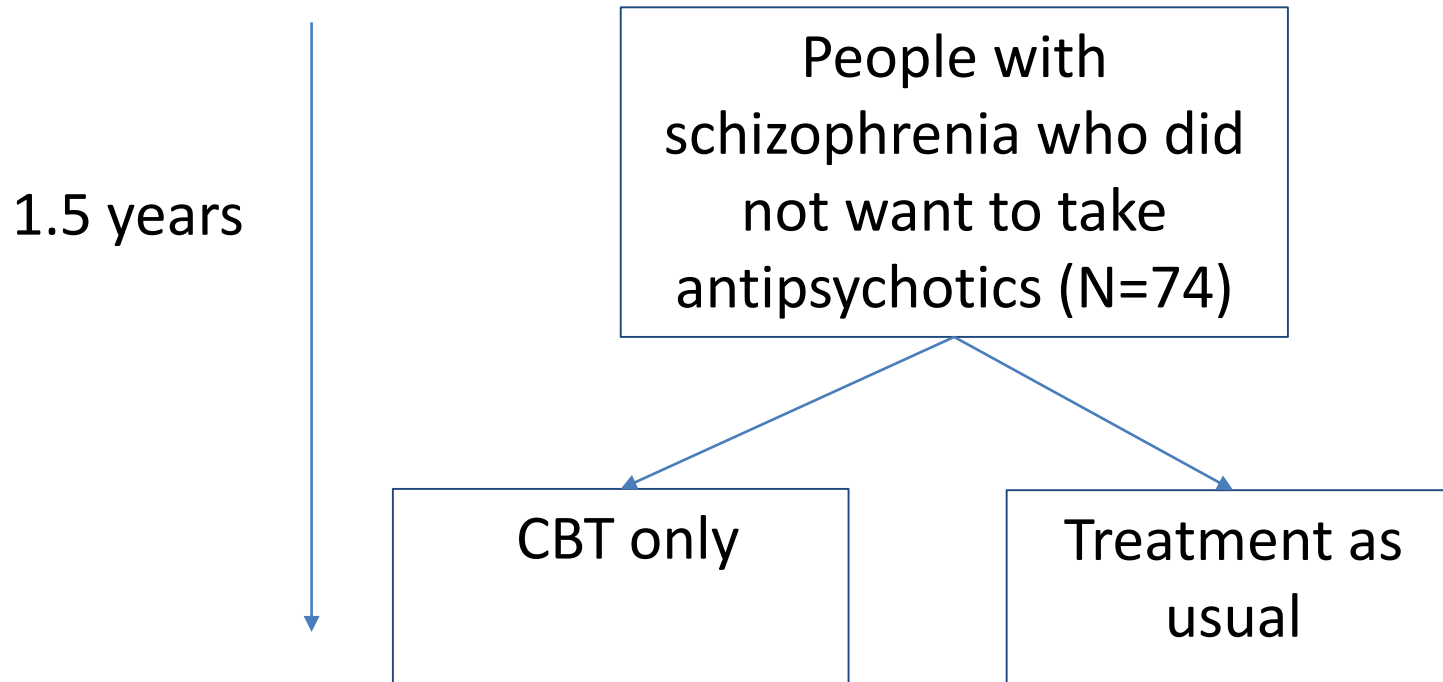
Method

- **Can psychosis or schizophrenia be treated with psychosocial methods without antipsychotics or with minimal antipsychotics?**
- Systematic review
- Psychosocial methods e.g. talking therapy, peer support

Results

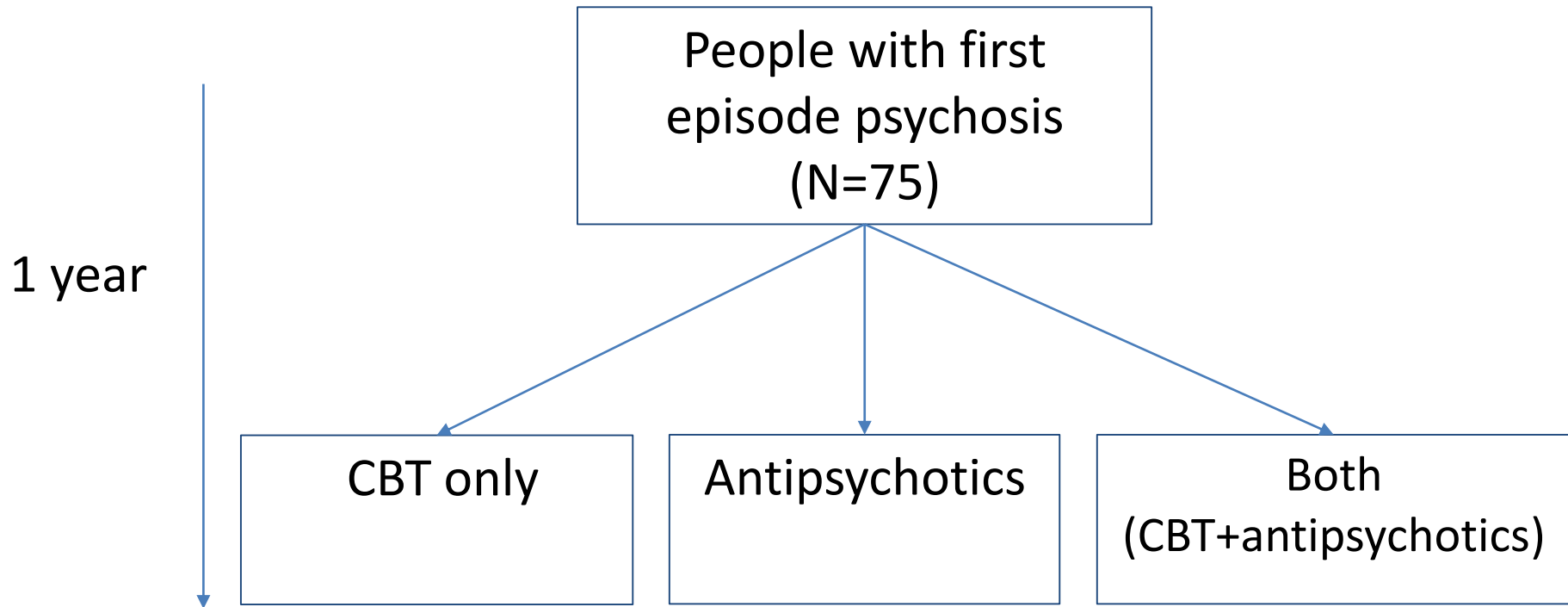
- 9 psychosocial treatments
 - 5 without antipsychotics e.g. CBT, psychoanalysis
 - 4 minimal antipsychotics e.g. Soteria, Open Dialogue
- Compared to control (generally antipsychotics) for relapse, symptoms, function.
- Majority of studies reported no difference.
- But
 - Poor study quality
 - Little recent research – only 3 trials in the last 20 years.
 - Interpret results with caution!

Cognitive Behavioural Therapy



- CBT - lower symptoms and better functioning than people who had usual treatment.

Cognitive Behavioural Therapy



- CBT vs. AP: no difference in symptoms or function
- Both: improved symptoms

Conclusion

- Evidence base for psychosocial treatments without or with minimal antipsychotics is encouraging but under-researched
- Recommendations cannot be made.
- More high quality RCTs are required to meet the request made by NICE.

Acknowledgements

Professor Stefan Priebe, Professor Joanna Moncrieff,
Neelam Laxhman, Dr Nadia Crellin

Contact

Ruth.cooper3@nhs.net

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Closing Remarks

Frank Röhrich

Reminders

- Please complete feed back questionnaires
- Slides will be uploaded to the conference webpage
- For more on health research in East London
www.elft.nhs.uk/research

Poster Competition

- New for 2019
- Representing all innovation work, including service evaluations
- Awards for:
 - Best Poster
 - Best Example of Clinical Impact
 - Best Example of PPI Engagement

....and the winners are....

Thanks to

- All patients, carers and staff who supported research
- Kam Bhui and Rose McCabe for chairing
- All speakers for their presentations
- Our poster judging panel of Vicky Bird, Mark Freestone, and Mary Lavelle
- Our research partners for staffing information stalls
- Doris Holloway and Sharmin Khonij for organising
- Our volunteer stewards for guiding everyone
- All of you for attending!

Finally, please note for next year:

***Health Research
in East London***

When?

Wednesday, 7 October 2020!

Where?

Robin Brook Centre