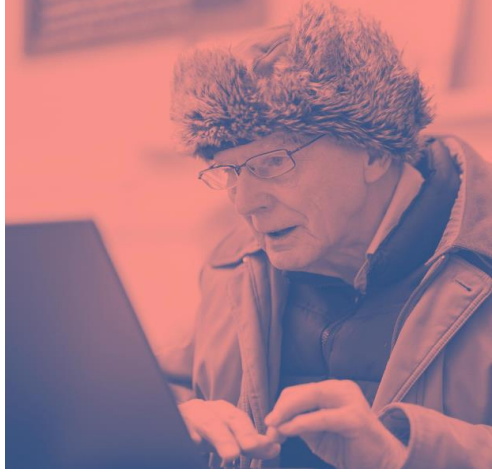
NIHR | Applied Research Collaboration East of England

# NIHR ARC EAST OF ENGLAND SHOWCASE 2023

#ARCEoEShowcase







# ARC East of England Showcase

## Morning

| | |
|---|---|
| 10:00 - 10:10 | Welcome and Introductions |
| 10:10 - 10:45 | **Session 1:** Living well in the East of England |
| 10:45 - 11:20 | **Session 2:** Working with young people in the region |
| 11:20 - 11:55 | **Session 3:** Getting research into everyday practice |
| 11:55 - 12:00 | Closing the morning session |
| **12:00 - 14:00** | **The Zoom link will remain active during this period** |

# ARC East of England Showcase

## Afternoon

| | |
|---|---|
| 14:00 - 14:05 | Welcome back |
| 14:05 - 14:50 | **Session 4:** Engaging with communities |
| 14:50 - 15:25 | **Session 5:** Increasing skills for undertaking research in the region |
| 15:25 - 16:00 | **Session 6:** The journey of our research |
| 16:00 | Closing remarks |

# ARC East of England Showcase

## Annual Summary 2022/ 2023


Our Annual Summary 2022/ 2023 is available **online on the ARC East of England's arc-eoe.nihr.ac.uk > latest news.**

To receive a **physical copy, please contact the ARC Office (ARCOffice@cpft.nhs.uk).**

NIHR | Applied Research Collaboration East of England

# Session one:

## Living Well in the East of England

**Chair:** Dr Adam Wagner
Theme Lead, Health Economics and Prioritisation

NIHR | Applied Research Collaboration East of England

# Carer Support Nurse pilot


Prof Morag Farquhar
School of Health Sciences, UEA
Karen Murphy
East Coast Community Healthcare

Dr Carole Gardener (UEA)
Prof Alison Leary (London South Bank Uni)
Roberta Lovick (PPI)
Dr Adam P Wagner (UEA)
Dr Jennifer Lynch (University of Herts)
Dr Guy Peryer (UEA)
Prof Susanne Lindqvist (UEA)


# Who are unpaid/family carers?

- *“Lay people in a close supportive role who share the illness experience of the patient and who undertake vital care work and emotion management”*

(NICE, 2004)

# Who are unpaid/family carers?

- *"Lay people in a close supportive role who share the illness experience of the patient and who undertake vital care work and emotion management"*

(NICE, 2004)

- Family/ friends/ neighbours
- Often older with own health problems

# Importance of carers

- Support patients with single or multiple physical/ mental health conditions
- Enabling them to stay in their place of choice

# Importance of carers

- Support patients with single or multiple physical/ mental health conditions
- Enabling them to stay in their place of choice
- Reduce formal care costs
  - Nationally: £132 billion/year
  - Norfolk & Waveney estimate: £573million - £2.17billion/year
  - Set to increase as population demands for care increase...

# Caring role is complex

- **Multi-faceted role…**
  - managing (complex) symptoms
  - personal care
  - care management
  - practical support
  - emotional support
  - overnight vigilance
- **Changing role**
- **Can be a carer to multiple people**
- **May not be geographically close**

# Carers' health-related support needs

- **Health-related education needs**: may need specialist knowledge & skills, but often lack training (Xiang et al., 2022)

- **Caring role negatively impacts carers'...**
  - physical & psychological health
  - mortality
- **Put own health second:**
  - prioritise the patient
  - ambivalence
  - reality of caring role (time)

# Carers' health-related support needs

- **Health-related education needs**: may need specialist knowledge & skills, but often lack training (Xiang et al., 2022)

- **Caring role negatively impacts carers'...**
  - physical & psychological health
  - mortality
- **Put own health second:**
  - prioritise the patient
  - ambivalence
  - reality of caring role (time)

- **N&W ICS carers:** *higher than national average LTCs, arthritis/back/joints, & mental health conditions*

# Threats to carer sustainability

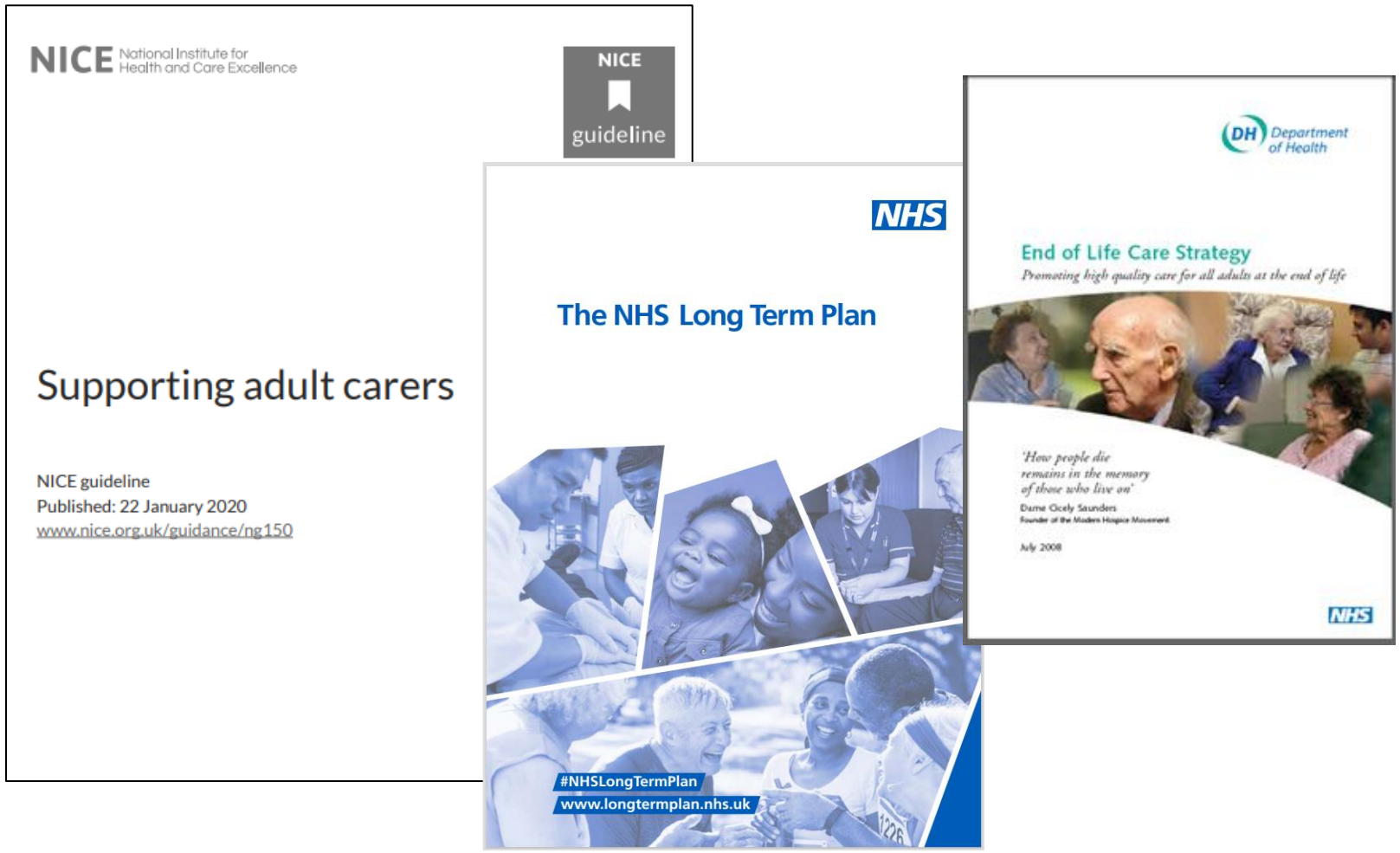
- Carer role is characterised by **uncertainty & unpredictability**
- Carers **rarely acknowledged & largely unsupported** by clinicians
- **Threatens carer health & patient support**...
- ...leading to **patient/carer crises**

# Threats to carer sustainability

- Carer role is characterised by **uncertainty & unpredictability**
- Carers **rarely acknowledged & largely unsupported** by clinicians
- **Threatens carer health & patient support**...
- ...leading to **patient/carer crises**

- **Supporting the carer actually supports two people – the carer & the patient**

# Health policy rhetoric




- **Carers should be supported...**
- but little guidance on how

# Our solution – Carer Support Nurse

- Targeting nursing skills within existing structures, but across systems

- Two evidence-based prerequisites:
  - 1) dedicated to carers
  - 2) a nursing role

Farquhar & Moore, 2017

# Our solution – Carer Support Nurse

- Targeting nursing skills within existing structures, but across systems

- Two evidence-based prerequisites:
  - 1) dedicated to carers
  - 2) a nursing role

- Differentiated from, & complementing, existing services

Farquhar & Moore, 2017

# Our solution – Carer Support Nurse

- **Collaboration between East Coast Community Healthcare (ECCH) & University of East Anglia (UEA)**

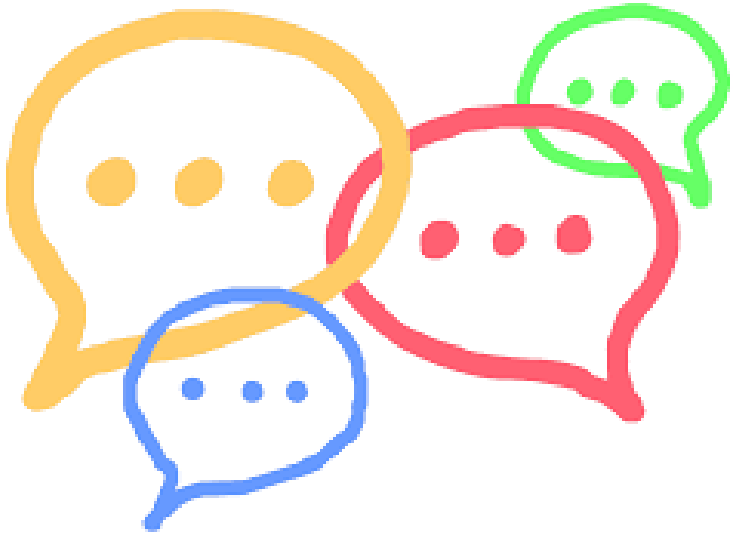

# Our solution – Carer Support Nurse

- **Collaboration between East Coast Community Healthcare (ECCH) & University of East Anglia (UEA)**



- **Health care & academia working together** to develop:
  - an **evidence-based role**
  - delivering **evidence-based nursing practice**

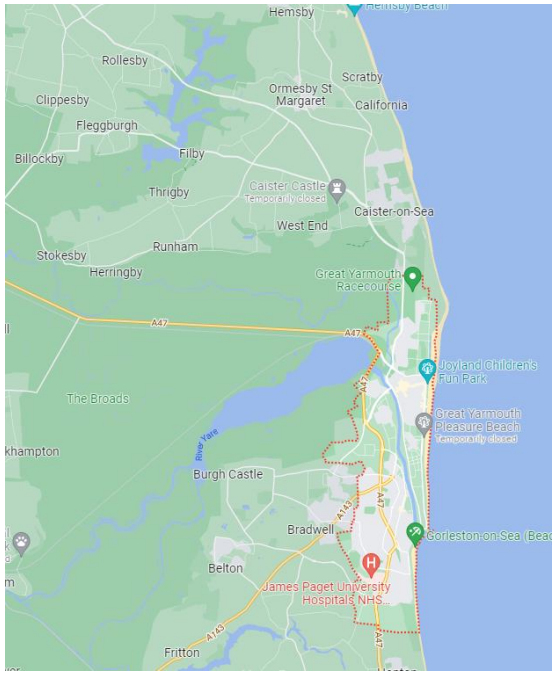
# Developing the role – worked with...



- **70+ stakeholders**
  - **Regionally:**
    - Health care (including workforce leads)
    - Social care
    - Voluntary sector
  - **National leaders in carer support:** NHS England, Queens Nursing Institute, Adult Social Care, Carers UK
- **100+ carers & patients**
- **Universal enthusiasm**

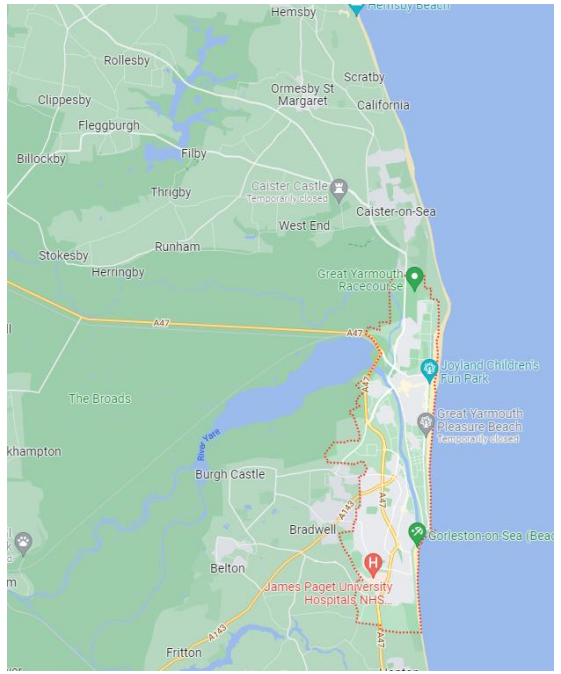
# Carers in Gt Yarmouth area

- Confirmed national evidence
- Told us they often **feel their needs are not met** but instead can feel….
  - **assumptions** are made about how they are coping
  - abandoned, or **passed around**, by services
  - underappreciated and **overlooked**



# Carers in Gt Yarmouth area

- Welcomed the new Carer Support Nurse role – felt it could….
  - create a **space for their needs to be discussed**
  - provide opportunities to talk to a professional **who understands** how difficult it can be for carers to open up about their own needs
  - **fill gaps** in existing carer support



# Carer Support Nurse: Five evidence-based principles

1) **community-based**
2) **cross-sector working** e.g. receiving/making referrals across health/ social care/ voluntary sector
3) **deliver person-centred care to carers with complex needs** (complementing social care assessment & practice)
4) **attend to marginalised communities**
5) **be educational – to carers & other healthcare professionals** (raising awareness of carers & modelling best practice)

# Carer Support Nurse at ECCH

- **Karen Murphy**
- **Gt Yarmouth & Northern Villages 'Primary Care Home Team'**
  - supports a cluster of GP practices in Gt Yarmouth & Waveney
  - **Award-winning evidence-based role** based on demand & intended outcomes, valuing the practice of nursing
- **Current funding (Band 7 role):**
  - Norfolk & Waveney ICB
  - *Pilot role funding ends Oct '23*

# Evaluation of the pilot

- **Led by UEA – 3 stages**
  - **Funded by** Health Education England (East of England)
  - **Supported by:**
    - NIHR Applied Research Collaboration (East of England)
    - UEA Health & Social Care Partners
  - **Collaborators:**
    - London South Bank University
    - University of Hertfordshire
    - Carer Public Involvement Group (PPI)

# Evaluation of the pilot

- **Led by UEA – 3 stages – completes autumn 2023**
  - **Funded by** Health Education England (East of England)
  - **Supported by:**
    - NIHR Applied Research Collaboration (East of England)
    - UEA Health & Social Care Partners
  - **Collaborators:**
    - London South Bank University
    - University of Hertfordshire
    - Carer Public Involvement Group (PPI)

# Evaluation of the pilot

- **Led by UEA – 3 stages – completes autumn 2023**
  - **Funded by** Health Education England (East of England)
  - **Supported by:**
    - NIHR Applied Research Collaboration (East of England)
    - UEA Health & Social Care Partners
  - **Collaborators:**
    - London South Bank University
    - University of Hertfordshire
    - Carer Public Involvement Group (PPI)
- **Value & impact of CSN role:**
  - Role activity & views of carers, patients, & health/social care/voluntary sector

# Role activity

- **100+ referrals; triage system & waiting list**
- **Home visits + follow up phone calls/visits**

- **Carer acknowledgement & listening**
- **Person-centred assessment & solutions –** using evidence-based intervention *(CSNAT-I)*
  - Opening up conversations about what is important to the carer & their unmet support needs
  - Enabling solutions – responding together to physical, social & emotional concerns

# Role activity

- **100+ referrals; triage system & waiting list**
- **Home visits + follow up phone calls/visits**

- **Carer acknowledgement & listening**
- **Person-centred assessment & solutions –** using evidence-based intervention *(CSNAT-I)*
  - Opening up conversations about what is important to the carer & their unmet support needs
  - Enabling solutions – responding together to physical, social & emotional concerns

- **Health screening & coaching**
- **Upskilling**
- **Assessing risk of carer breakdown/ crisis management**
- **Safeguarding concerns**

# Role activity: *"Super-connector"*

**Extensive interprofessional inter-sector working e.g.,**

- Health care:
  - Primary & community care
  - Mental health trust
  - Wellbeing service
- Social care
  - Norfolk County Council
  - Gt Yarmouth Borough Council
- Vol. sector: carer/patient support groups
- Emergency services: fire & police

# Carer feedback

- **Overwhelmingly positive**

- **Particularly value opening up conversations**
  - Sharing experiences of being a carer
  - Discussing difficult issues & feelings

# Carer feedback

- **Overwhelmingly positive**
- **Particularly value opening up conversations**
  - Sharing experiences of being a carer
  - Discussing difficult issues & feelings
- **Practical support** put in place
- **Welcome the opportunity to re-engage** if needed

# “Susie” – carer to her mother [C-240]

- *“It allowed me to be her daughter for the last three days of her life. [...] when you’re caring for somebody, [...] liaising with healthcare professionals, [...] dealing with her needs, you become sort of a bit like a robot [...] If it hadn’t been for [Karen] coming in when she did, I don’t know what I would have done [...] I was on my knees [...] She’s just very kind, very natural. [...] There was no sort of ‘I’m the nurse here to tell you what you’ve got to do & you do it’... it was, ‘I’m here, what help do you need?’”*
- *“..when she said ‘Right, we’ve got somebody coming in to sit with your mum tonight’, I went ‘Wow!’ [...] I was able to get a bit of sleep, be more with my mum, sit with my mum, & just not have to worry ‘will she be alright?’ all night”*
- [Susie went on to described a series of other actions Karen took]
- *“she made [...] a big difference to [...] my family’s situation”*
- *“if you want any more proof that this scheme works, there’s your proof”*

# Unsolicited feedback
# East Norfolk Medical Practice

*"We have been very fortunate to work with Karen and so far,* ***the difference she is making to our patients is incredible****. In fact, since December last year, Karen has seen 45 carers via various referral routes which is the* ***highest number of engagements for carer support over all the GYNV practice areas****, so this is very positive that we are going in the right direction to ensure that unpaid carers are supported and, Karen says we have only just scratched the surface"*

# Regional winner –
# NHS Parliamentary Awards 2023
# Nursing & Midwifery

## Carer Support Nurse

**East**

The Carer Support Nurse service assists unpaid carers to look after their health and wellbeing, and to boost their skills and confidence to care. The pilot scheme was launched to address this 'gap' in healthcare provision following endorsement from 100+ carers and patients and 70+ stakeholders and groups from health, social care and voluntary sectors.

Nominated by: Brandon Lewis MP

# Shortlisted for RCNi Award 2023
## Innovations category


1 of 75 finalists from 900+ applications; final outcome November

# What next?

**Evaluation completes – autumn**

# What next?

**Evaluation completes – autumn**

**Role funding ends mid-October**

- **Continued funding would ensure continuity of current provision prior to winter pressures** and...
  - prevent loss of opportunity of move to a sustainable role
  - prevent loss of developed skills
  - prevent loss of established networks *(super-connector)*

- **Enhanced funding (e.g., team approach)** would enable geographic spread and/or enhanced carer support (i.e., longer-term support)

# Thank you!

east coast community healthcare

University of East Anglia

NHS England

NIHR | Applied Research Collaboration East of England

University of East Anglia HEALTH & SOCIAL CARE PARTNERS

**All pilot participants:**
**carers, patients & health/ social/ voluntary sector stakeholders**

# Referral criteria

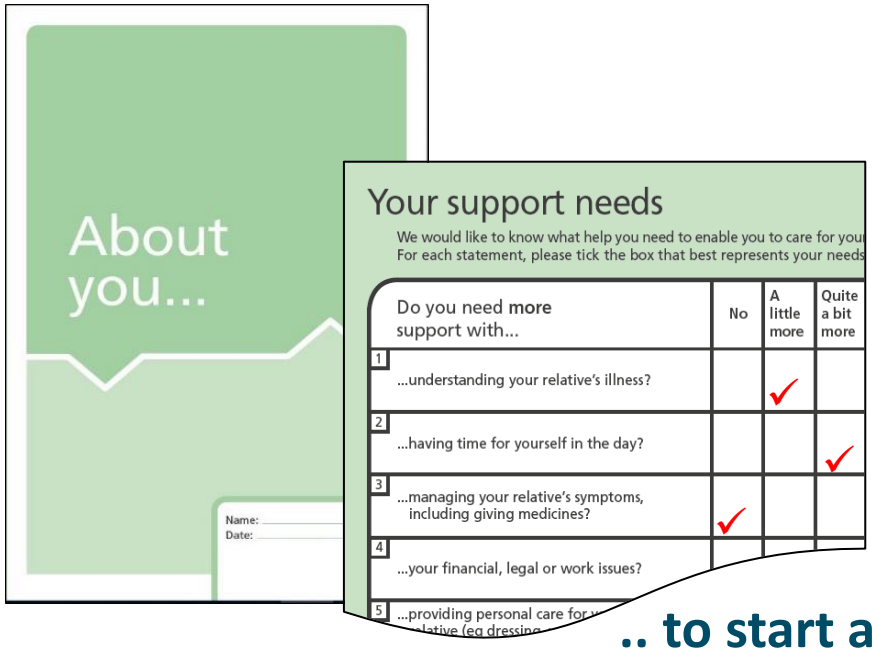
- Carers living within **Gt Yarmouth & Northern Villages**, who have:
  - **complex support needs relating to (or impacting on) their own health or wellbeing, or their skills or confidence to care**

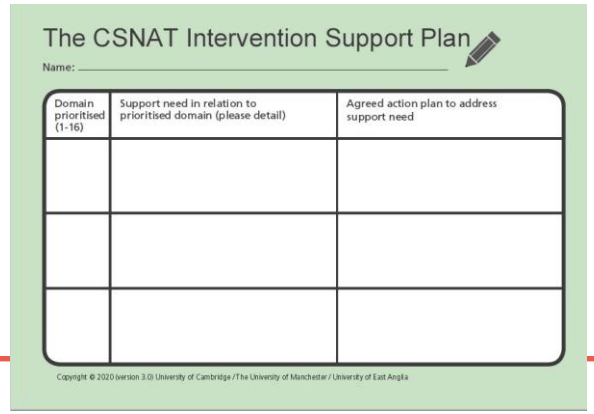
  ...or...
  - **unresolved health-related support needs that cannot be met by their usual health care team**

- The **complexity lies with, or relates to, the carer** rather than the patient

# CSNAT Intervention

Carer Support Needs Assessment Tool Intervention




**.. to start a conversation to gain tailored support**

https://csnat.org/

NIHR | Applied Research Collaboration East of England

# Regional Inequalities in health in the United Kingdom

***Godsfavour Ilori***
*Doctoral Researcher (Health Economics)*

# Introduction

- Geographical variation in health outcomes.
- Significant and urgent challenge for policy makers.
- Despite great health achievements over the years, regional health disparities still persist.
- Human and financial cost (£30 billion a year lost productivity).
- Eleven and nine geographical regions.

# Research Questions

- What lies behind the differences in health outcomes across regions in the UK?
- Does the neigbourhood environment contribute to hypertension and CKD disparities in England?
- What are the underlying sources of CKD disparities between coastal and non-coastal areas in the East of England region?

# Method Overview

- The use of objective health measures.
- United Kingdom Household Longitudinal Study (UKHLS).
- Linked UKHLS at the small area level with the English Indices of Deprivation (EID2010).
- Oaxaca Blinder decomposition analysis: Explains differences in the outcome variable between two groups.

# Outcome variables

- Nurse measured indicator

I. Body Mass Index; Lower or higher BMI signifies poor health.

II. Systolic blood pressure; Higher values of 140mmHg or over signifies high blood pressure.

- Blood based biomarker

I. Cholesterol ratio; total cholesterol/HDL cholesterol. Higher ratio means a higher risk of heart disease.

II. Estimated glomerular filtration rate; Rate of 89mL or below signifies a risk of CKD.

# Covariates

- Demographics e.g., age and gender.
- Neighbourhood-level characteristics e.g., air quality, road distance to a GP, income deprivation etc.
- Socioeconomic status e.g., household income, education, job status etc.
- Lifestyle factors e.g., physical activity, smoking status, alcohol consumption etc.

# Preliminary Results

- London has a better health outcome compared to the rest of the regions.
- There are evidence regional differences in all the health measures.
- Job status, education, and alcohol consumption are the reoccurring factors contributing to regional gap in the health outcomes.
- The neighbourhood-level factors significantly contributes to regional disparities in both hypertension and CKD in England.
- There are coastal and inland disparities in CKD in the EoE region with age and household income contributing the highest to these disparities.

# Policy Implications

- The individual-level characteristics contributes to regional disparities in health outcomes in England and the whole UK.
- The neighbourhood environment also plays a crucial role towards regional disparities in hypertension and CKD in England.
- Interventions focusing on the older population and levelling the average job pay of the coastal area population with their inland neighbours will reduce CKD disparities in the EoE region.

# Acknowledgement


- NIHR ARC East of England.
- Faculty of Medicine and Health Sciences, UEA.
- Supervisors.

# Thank you for listening!

Email: g.Ilori@uea.ac.uk

Twitter or X: @GE_Ilori

LinkedIn: Godsfavour Ilori

NIHR | Applied Research Collaboration East of England

# Session two:

## Working with young people in the region

**Chair:** Dr Louca-Mai Brady
Senior Research Fellow, University of Hertfordshire

NIHR | Applied Research Collaboration East of England

# Enhancing collaboration between the health and education systems to increase access to parent-led CBT for child anxiety: the **'Working on Worries'** implementation project

***Dr Tim Clarke***

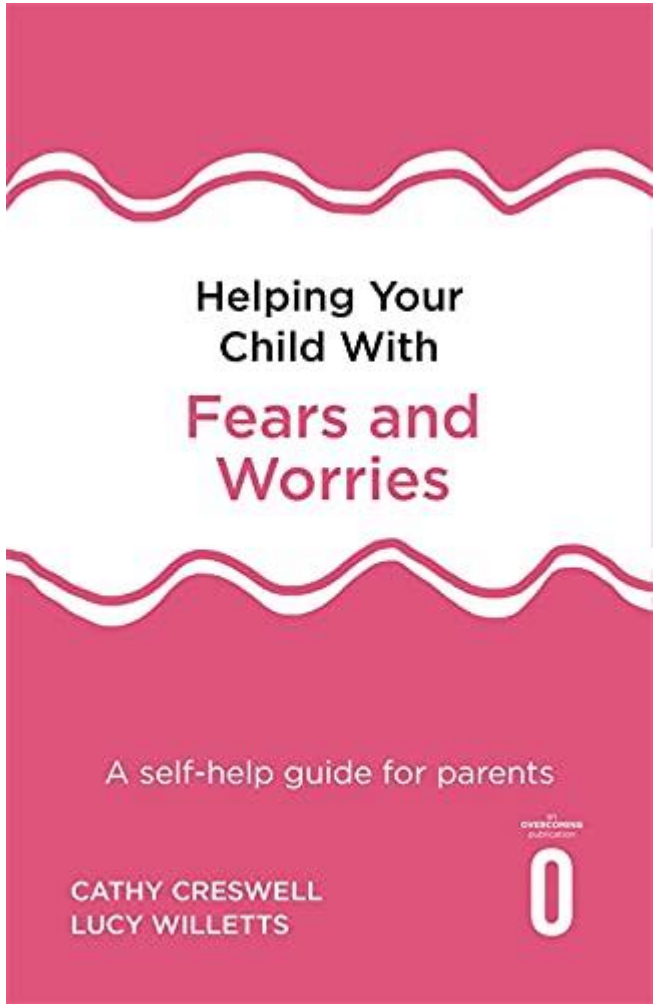
Principal Research Clinical Psychologist and NHSE / N&W ICB CYP MH Clinical Advisor

# Background

- Childhood anxiety disorders are common and are associated with increased risk of negative educational, social and health outcomes.
- While, there are evidence-based treatments for childhood anxiety disorders, most families are currently unable to access them. Reardon et al. (2020), reported that less than 3% of children identified as meeting diagnostic criteria for an anxiety disorder via school-based screening had accessed evidence-based treatment.
- Already high demand for child and adolescent mental health services has increased further in the wake of the COVID-19 pandemic, exacerbating existing capacity issues.
- Novel approaches are needed if we are to provide more children experiencing anxiety difficulties with timely access to evidence-based treatment.

# Parent-led CBT

- Parent-led cognitive behavioural therapy (CBT) for child anxiety is a brief, manualised, evidence-based intervention.
- The approach involves the practitioner working with a child's parent/carer to support them to implement CBT strategies in their child's day-to-day life.
- Evidence suggests that the intervention can be successfully delivered by novice therapists without previous CBT training.
- The intervention was select by the NIHR MHIN as a target for expanded implementation.



# Parent-led CBT

**Helping Your Child with Fears and Worries (HYC)**

- Self-help guide book 4 in-person sessions of up to 60 minutes
- 2 telephone sessions of up to 20 minutes
- Individual & Face-to-Face

**Online Support & Intervention (OSI)**

- 8 online modules lasting 30 minutes each
- Home tasks from each module
- Weekly telephone session after each module

# Nebula Federation Pilot

NIHR | Applied Research Collaboration East of England

## IMPLEMENT-TEAM: PARENT-DELIVERED CBT FOR ANXIETY IN PRIMARY SCHOOLS

"They are now much more confident and more independent. They have managed all of the tasks that we set out, which at the time seemed like a mountain to climb. As a result of achieving the goal set out they are really happy and much more independent. They are now able to be themselves for short periods and happy to go to their friends without me always being by their side" [Anon, Parent]


**Authors & Affiliations**

Dr Tim Clarke: Norfolk & Suffolk NHS Foundation Trust
Natalie Brown: Nebula Federation
Katie Thompson: Ormiston Families
Dr Brioney Gee: Norfolk & Suffolk NHS Foundation Trust
Dr Jon Wilson: Norfolk & Suffolk NHS Foundation Trust
Julie Young: University of East Anglia



This project is supported by the NIHR ARC EoE. The views expressed are those of the authors and not necessarily those of the NIHR or the DoHSC

**Acknowledgements**

We would also like to thank the UEA Health and Social Care Partners (Mark Hitchcock); ARC EoE; Mike Cook; John Gabbay and Andre Le May; Nebula Federation staff - Natalie Brown, Jenni Porter, Ashley Best-White and the pastoral staff that delivered the intervention (Amy, Alice, Danielle). Thanks to the parents/carers and children that participated in this project too. We also thanks Prof. Cathy Creswell and her team for their ongoing support and allowing us to use their training slides for this project.


### INTRODUCTION

Lifetime prevalence of anxiety disorders are common (NHS Digital, 2021) and increasing where the onset is often thought to start before the age of 12 in 50% of cases (Kessler., et al, 2005). It is estimated that anxiety prevalence in children is 6.5% and associated with many negative outcomes, such as poor school attendance, poor school performance, reduced life satisfaction etc. (Polanczyk et al., 2015). Furthermore, families and children often experience difficulties in accessing mental health services and receiving timely support due to increased demand and capacity issues. One study suggests that of 65% of families who sought support for child anxiety only 2% accessed an evidence-based treatment (i.e. Cognitive Behavioural Therapy; Reardon et al., 2019)

**Parent-Delivered CBT** (Creswell et al., 2017) is an evidence-based brief CBT based intervention that can be delivered with the parent/carer by a range of professionals with good effect.

It is a good solution to increase the uptake of anxiety treatments across different settings.

### OBJECTIVE

To pilot the implementation of Parent-Delivered CBT for Child anxiety through training Primary school pastoral staff to deliver it.

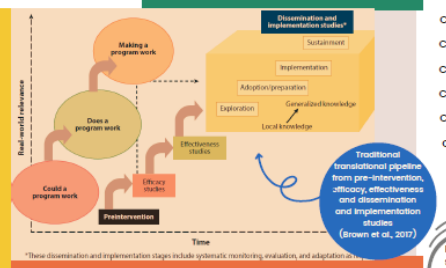
### DESIGN & METHOD

This was a mixed methods implementation case-series design with pre-post clinical outcomes and post within-site implementation outcomes.

**Implementation Strategy:**
Our strategy was informed by the Exploration, Preparation, Implementation and Sustainment (EPIS) framework (Aarons et al., 2011), Normalisation Process Theory (May et al., 2015) and the PARiHS (Promoting Action on Research Implementation in Health Services; Kitson et al., 2008) Framework. We developed optimised implementation facilitators across inner and outer contexts through:

- Leadership agreement and buy-in
- Resources
- Training and supervision
- Clear outcome collection plan
- Monitoring fidelity / adherence
- Forming an bridging 'partnership'

**Methods:**
- Clinical outcomes
- Goal based outcomes
- Surveys
- Focus Group / After Action Review
- Implementation Outcomes




### RESULTS/ FINDINGS

**Participants were** 12 parents/carers-child and 5 pastoral staff facilitators. All children were identified as having anxiety difficulties with 8 of the 12 being in the raised or clinical range for anxiety.

Goal based outcomes (GBO; Law & Jacob., 2015), the Revised Children's Anxiety and Depression Scale (RCADS; Corpito et al, 2015) and the Child Anxiety Impact Scale (Langley et al., 2004) were administered for most at baseline, final and review session. A Parent survey was also completed by 7 parents.

Implementation success was measured by assessing adherence to the training / manual; an after actin review / focus group, a facilitator survey and the Normalisation Process Theory Toolkit (May et al., 2015) measure NoMad (Finch et al., 2015) was used to assess implementation factors

### ANALYSIS

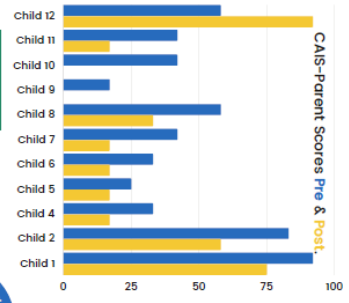
Differences in pre-post Clinical outcomes measures were analysed by calculating t-tests, effect sizes and reliable change.. Qualitative survey data was thematically analysed and implementation outcomes using the NPT tool examined visually.

### CLINICAL OUTCOMES

There was no significant change in RCADS scores with a small effect. In general though RCADS anxiety scores improved and there were less children in the clinical range following intervention.

In the 11 cases with paired scores the CAIS-P examining the impact of anxiety on a child's life scores decreased in 10 cases where this was significant with LARGE effects (see below)

For GBOs all 12 families moved towards at lest one of their goals with 8 of the 12 reaching reliable change.

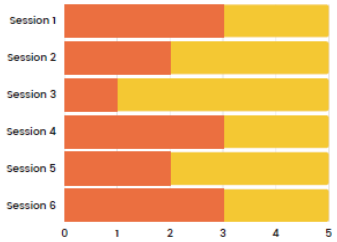



### PARENT QUALITATIVE SURVEY THEMES

Parents initially felt ambivalent but were pleased to be offered some support. **Engagement and relationship** with their facilitator was an important facilitator and relationships were generally perceived positively with facilitators identified as **engaging and empathic**. They generally found the intervention **easy to follow and acceptable**. Most felt it had a **positive overall effect and made a difference to the child and family**

### IMPLEMENTATION OUTCOMES

Facilitators were either **FULLY** or **MOSTLY** adherent to all sessions. None were partial or non-adherent. Session 4 with step by step plans required flexibility to suit individual needs. See Below.




The Normalisation Process Theory NoMAD tool suggested that the staff delivering the intervention felt it was now **familiar**, a **normal part of their work or would become a normal part of their work**. The **understood what was expected** of them, recognised its **value** and had a **shared understanding**.. They felt it was a legitimate part of their work, that the **organisation was driving this forward** and that they would like to **continue using it**. They felt that were **skilled enough and had adequate training and support and were keen to learn and improve**. Areas for implementation improvement were to **find additional time to integrate** in to practice and modify to fit with their other duties as well as further **understand how this intervention differs from others**.

Survey results support these findings where facilitators talked positively about the intervention, felt **confident** using it, felt it was **acceptable** and would like to continue to **sustain** its use. They agreed that some **flexibility** in session durations was required to suit the school context and timetable and are keen to trial other formats such as group and face-face sessions too. The felt for most it was overall **very effective** and had made a difference to the families, child and school. There was a sense that they also wanted to intervene **earlier as a preventative intervention**. There was agreement that the **leadership** provided by the pastoral manager and school leadership team was key to implementation as was **training, supervision and working across agencies**.

### CONCLUSION & CLINICAL RECOMENDATIONS

Parent-delivered CBT can successfully be delivered by Primary school pastoral staff and it is an acceptable, clinically useful and helpful approach. Pastoral staff with comprehensive training, supervision, resources and 'time' can implement this intervention with good adherence. Considering implementation factors and a strategy is key to ensuring that this intervention is optimised and sustained. Implementation facilitators include training, flex of session durations to fit a school context, links with external mental health services and good internal leadership, staff dedication and integration in to their workload.

# Working on Worries

NIHR | Applied Research Collaboration East of England

# Project aims

The aim of the Working on Worries project is to enhance collaborations across the health and education systems in Norfolk & Waveney in order to improve access to Parent-led CBT for child anxiety .

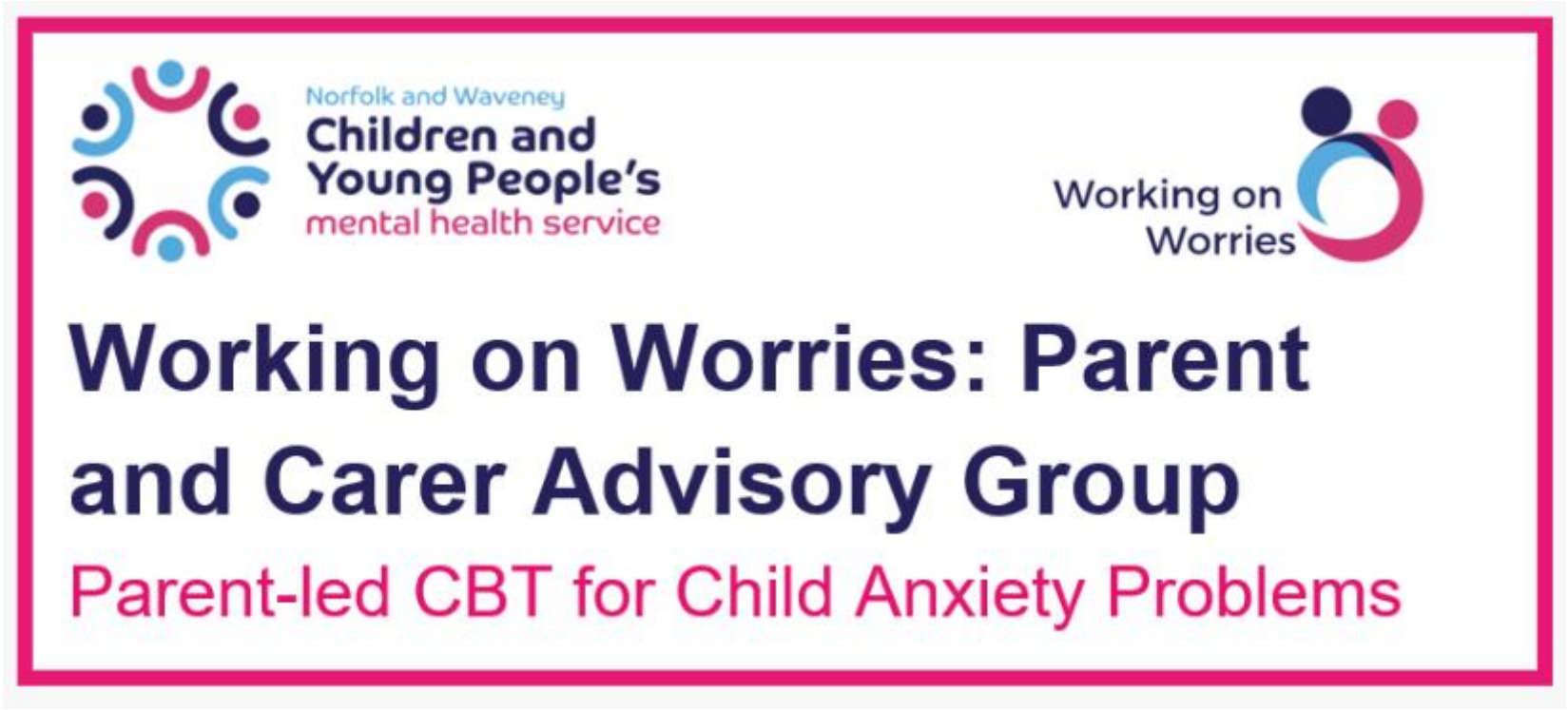
Focusing on schools in areas of Norfolk and Waveney with highest need, we aim to support the local mental health system to provide training and ongoing collaborative learning to primary school pastoral support staff to enable them to deliver Parent-led CBT for child anxiety to families within their school communities.

We aim to using implementation science to optimise delivery and sustainability, and are evaluating the process and outcomes to inform future implementation and facilitate shared learning.

# Implementation plan

- Identify practitioners in the region who are currently trained to deliver parent-led CBT for child anxiety to receive further '**train the trainer**' training to enable them to train and support school staff to deliver the intervention.
- Work with public health colleagues to **identify schools** with high deprivation/mental health needs and those not currently covered by MHSTs.
- **Invite schools to participate** and identify an implementation lead and school staff to be trained.
- Co-produce a tailored **implementation plan** with each school.
- Provide identified school staff with **training** to deliver parent-led CBT and establish Collaborative Learning and Support Sessions (CLaSS) to provide **ongoing support**.
- School staff **deliver the intervention** to families within their school communities who might not otherwise have access to it.

# PPI


Norfolk and Waveney
Children and Young People's mental health service
Working on Worries
Working on Worries: Parent and Carer Advisory Group
Parent-led CBT for Child Anxiety Problems

# Progress to date

**Train the trainer**

- 21 CYP mental health professionals have been trained to train school staff in parent-led CBT for child anxiety and have begun providing ongoing support through Collaborative Learning and Support Sessions (CLaSS).

**Wave 1 (March 2023)**

- 48 staff from 35 primary schools attended
- Have begun delivering the intervention to families

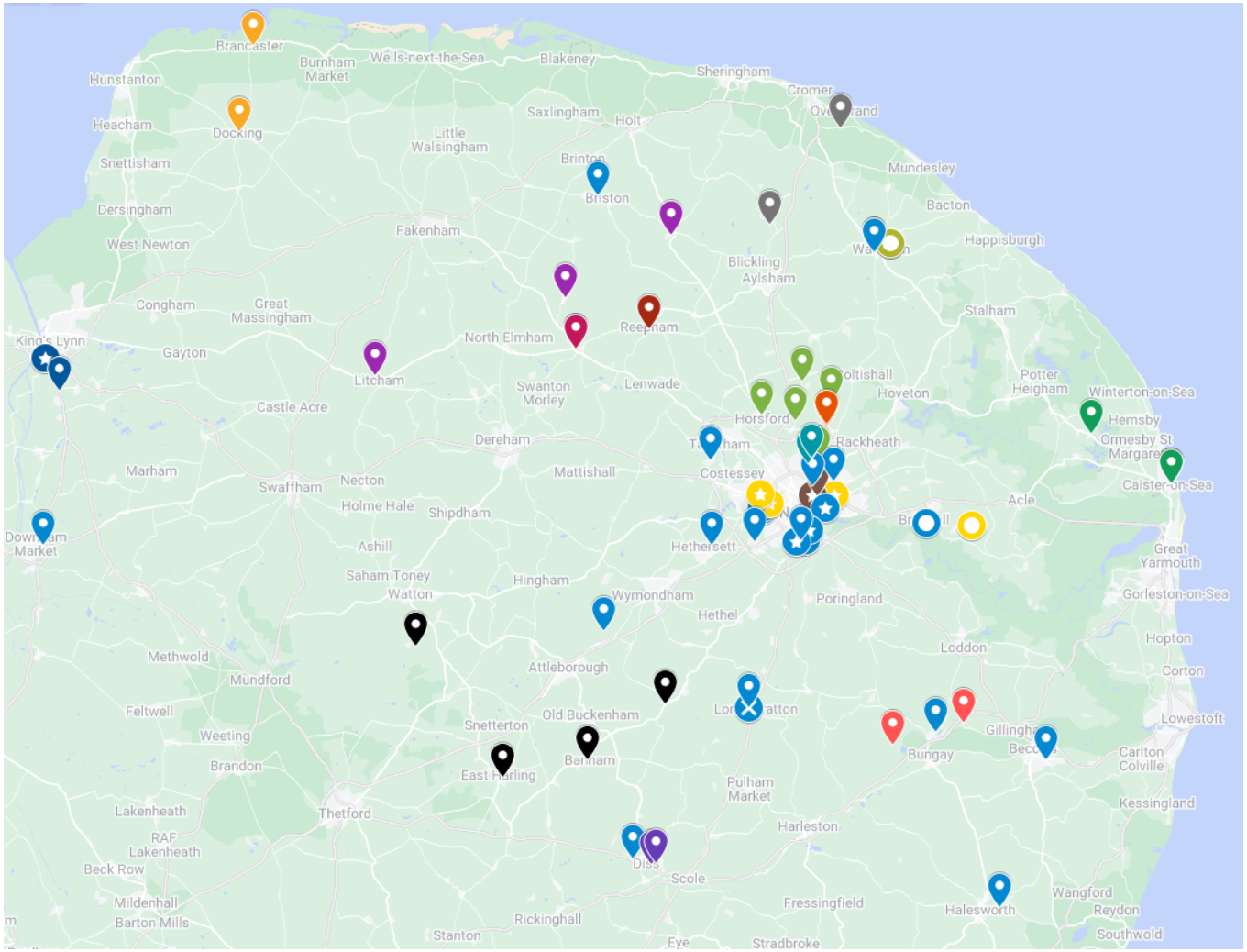
**Wave 2 (July 2023)**

- 39 staff from 27 primary schools attended
- Will begin delivering the intervention in September

This equates to 13% of all Norfolk & Waveney primary schools (16% of non-MHST)

We are now recruiting for a third wave of training to be held in October, which is anticipated to bring another 20-30 school staff on board.

# Progress to date




- 39 OSI cases across 14 schools between May and end of Summer term.
- 9 known cases of HYC to date.

# Evaluation

We are collecting a wide range of data using mixed methods to enable us to assess implementation outcomes, evaluate the implementation process and identifying barriers and facilitators of implementation.

Our choice of implementation outcomes is informed by Proctor et al.'s (2009, 2011) taxonomy and framework of implementation outcomes: acceptability, adoption, appropriateness, feasibility, fidelity, implementation cost, penetration, and sustainability.

Evaluation of the implementation process is focused on understanding the barriers and facilitators of implementation to allow us to optimising future

Implementation of parent-led CBT for anxiety within primary schools, support sustainment of this model of delivery in Norfolk and Waveney, and share learning nationally.

# Training Feedback

**Trainer the Trainer**

Attendees enjoyed the training and noted that Chloe was a fantastic facilitator

The resources shared were helpful.

The training was interactive and attendees enjoyed the discussions that were had.

Some attendees commented that an overview of the project at the beginning of the day would have been useful rather than towards the end of the day.

Due to attendees experience they felt confident with Parent-led CBT but highlighted how it would be useful to focus on implications of the project specifically including the CLaSS sessions and how these will be facilitated.

Attendees found the activities were helpful and relevant, helping to make the training interactive and engaging.

# Training Feedback

**Wave 1**

Chloe was very positively received. Attendees commented on how knowledgeable and passionate she was and praised her for her clear delivery and regular checking of everyone's understanding.

Attendees appreciated the resources provided and were grateful for the opportunity to explore the OSI platform.

While attendees appreciated the mix of groupwork and facilitator-led training, there were some comments that too much time was given to the group activities.

Overall, attendees felt there was too much content for 2 days of training, but expressed excitement about implementing the intervention nonetheless.

# Training Feedback

**Wave 2 – HYC**

Attendees commented that the trainers were engaging and clear, though some felt that the trainers weren't completely confident with some of the content.

Attendees enjoyed the practical activities and groupwork, several comments suggest people would enjoy more of these practical elements (e.g. working through Handout 2).

Someone commented that it was beneficial to have a trainer from a school background present and suggested that more "school-based trainers" would be helpful.

In general, attendees struggled with the research evidence portion of the training, feeling that the beginning of Day 1 was difficult to understand and felt like a bit of a slog. Day 2 was received with much more positivity.

# Training Feedback

**Wave 2 – OSI**

The OSI training was perceived as being clear and well-structured with good use of breakout rooms to facilitate discussion and consolidate learning (though one comment said it was difficult to see the activities/questions when in a breakout room).

Attendees valued the opportunity to use the demo OSI platform, though some would have appreciated more time with it and the chance to see some example parent data. There was also a desire to have access to the parent portal and child app as attendees are concerned about supporting families with these without themselves having had access to them.

Some attendees felt that the training and activities were a bit rushed and would have appreciated more time, with one comment saying it was difficult to maintain concentration when accessing the session from within school.

# Lightning Report

**Executive Summary**

1. Time was highlighted most consistently as a factor that has acted as a barrier to school staff implementing the intervention within their setting. Having dedicated time for the implementation of Parent-led CBT is valuable, this is facilitated by having senior leadership support.

2. Challenges of getting parental engagement are highlighted, including difficulties when parents are separated and only one parent is engaged with the intervention.

3. School staff reported that they liked having one to one meetings via Teams to discuss a school specific implementation plan and having a copy of this plan sent to them. The questions during the implementation planning meeting provided useful prompts to ensure schools had thought about the different elements to implementing parent-led CBT within their setting.

# Plans for Extension & Expansion

We have been able to secure additional funding from the ICB and MHST Programme to extend and expand the WoW project. This will consist of two separate programmes:

**Programme 1:** This extension of the WoW project will focus on widening the reach of the current model. It includes funding for Wave 2.2 activity, but will also involve further training which will include school staff from MHST schools.

**Programme 2:** This programme seeks to expand the WoW project to include the training of existing CWPs and EMHPs in the delivery of OSI.
Both programmes are set to run until December 2024.

# Acknowledgments

**Project Co-leads:** Dr Tim Clarke, Dr Bonnie Teague & Dr Jonathon Wilson

**Project Co-ordinator:** Dr Ella Mickleburgh; **Project Assistant Psychologist:** Luke Wrigley

**PPI lead:** Rachel McGuire; **School lead:** Natalie Brown

With thanks to our funders Norfolk and Waveney Integrated Care Board and NIHR Mental Health Implementation Network.

NIHR | Applied Research Collaboration East of England

# Involving young people in research: The CADRE case study and the CA:RING community

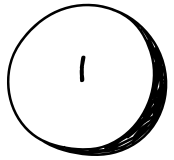
Dr Alisa Anokhina & Dr Anna Moore

*Cambridgeshire and Peterborough NHS Foundation Trust*

*University of Cambridge*

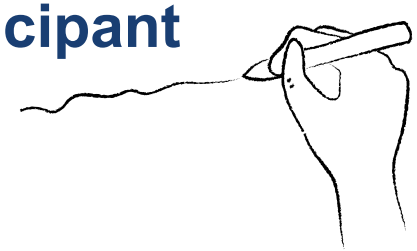
*20th September 2023*

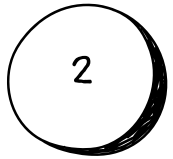
# Overview




## The CADRE case study

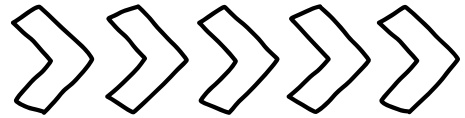
- **Aims:** Understand how to create a linked, multi-agency Trusted Research Environment (TRE) for healthcare research
- **Design:** series of workshops with young people & parents/carers
- **Outcomes & participant experiences**






## Creating CA:RING

- **Aims:** create a diverse and sustainable PPI community to support healthcare research for CYP
- **Set-up work**
- **Community approach & structure**
- **Next steps**

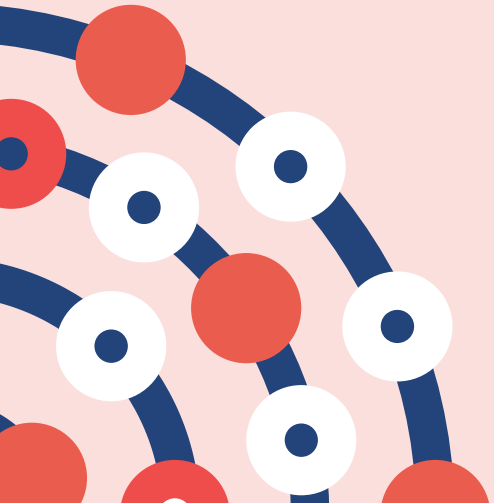


NIHR | Applied Research Collaboration East of England

cadre
Children + Adolescents Data Resource

# The CADRE case study

*Children + Adolescents Data Resource*



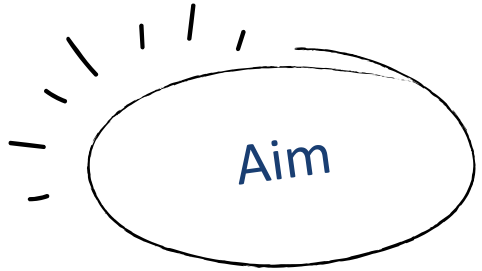
*Full DARE UK report can be found here:*

*FAIR TREATMENT: Federated Analytics and Artificial Intelligence Research across Trusted Research Environments for Child and Adolescent Mental Health*

## Background

- Development of a **Trusted Research Environment** (TRE): linked data from health records, social care, education

- Use case: “Timely” project (PI: Moore) – develop a **digital tool** to identify young people struggling with **mental health earlier** & receive timely support




**Understand under what conditions such a TRE would be acceptable to the public**

**(e.g. security or governance arrangements, public involvement)**

# Design

Participants

Focus on diverse recruitment via third sector orgs

**11-15yrs** N=8

**16-24yrs** N=11

**Parents** N=11

**Questionnaire to test our materials**

N=51

Workshops

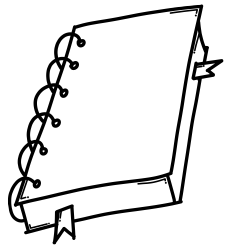
- Is linking CYP data **acceptable** for research?
- **Governance**: who should have access and under what conditions
- **Create** information materials
- **Revise** information materials
- Findings & **feedback** session

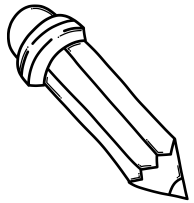
# Outcomes

Generally positive about the potential of linked data for research (even if sensitive)

Early identification tools can stop young people “falling through the gaps”

BUT

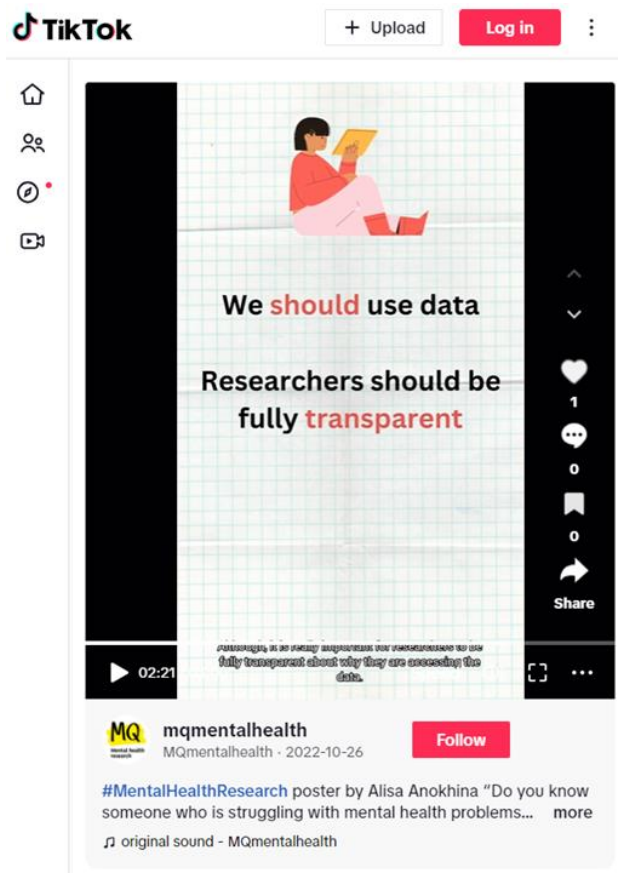




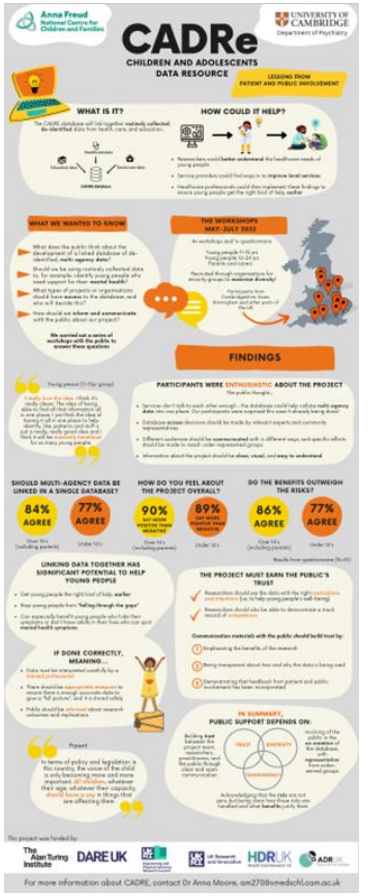
- Build trust with the public: transparency about how data is used, include in decision-making and TRE management
- Trusted researchers only, as decided by Data Access Committee (even commercial orgs, under the right conditions)
- Research outcomes need to be communicated effectively to professionals and the public
- Broader concerns about systemic issues of discrimination, data misuse

# Dissemination

- **Reading pack for participants** summarising aims, findings & our interpretation
- **Feedback session** to ‘sense check’ findings (manuscript in preparation for journal publication)
- “Plain English” **summary poster** published on DARE UK blog
- **TikTok video** for MQ Mental Health Science Festival




TikTok video




DARE UK poster

# Participant experiences

"A mix of backgrounds and ages. A safe space where people can ask and add without facing resistance, reflective of diversity."

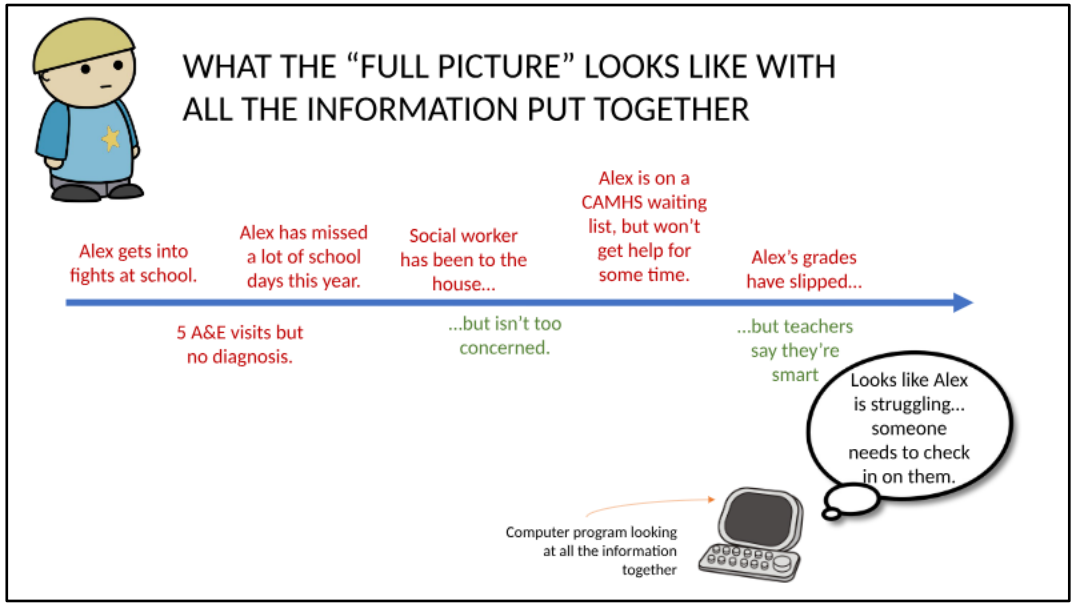
"I felt that the organisers of the group as well as participants listened to one another effectively."

"I got to interact with people who share my concerns/needs."

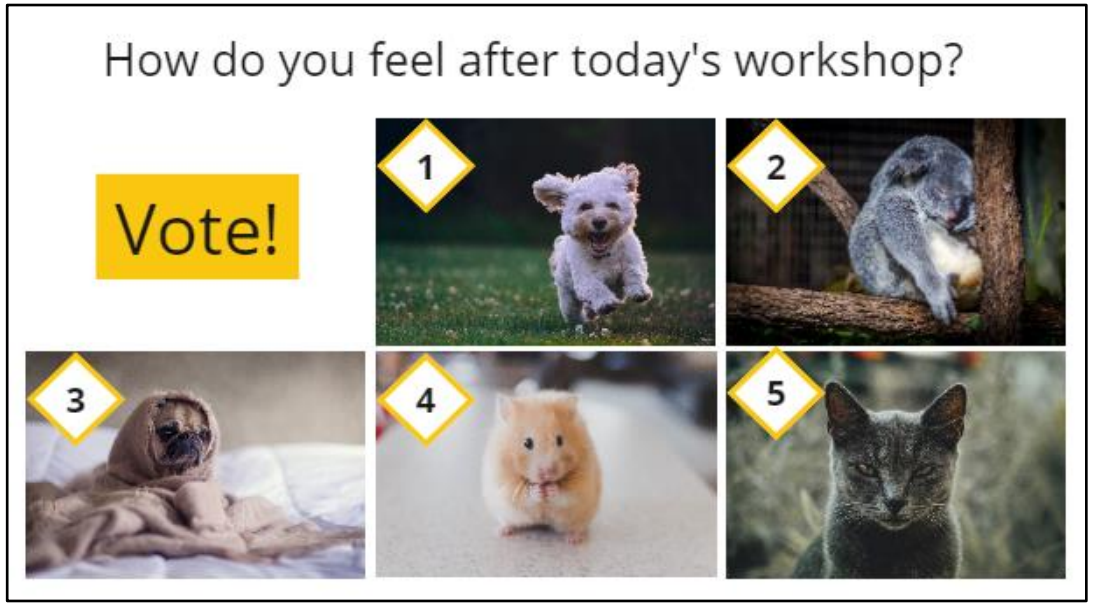
- The space felt **comfortable** and **safe**
- Many **diverse backgrounds** represented
- Facilitators **friendly** and **respectful**
- Workshops should be **closer together** + **more video** content. Mixed opinion of online format.

"I think that it's the same with any online interactions you don't have that same rapport with people that you do when you're face to face."

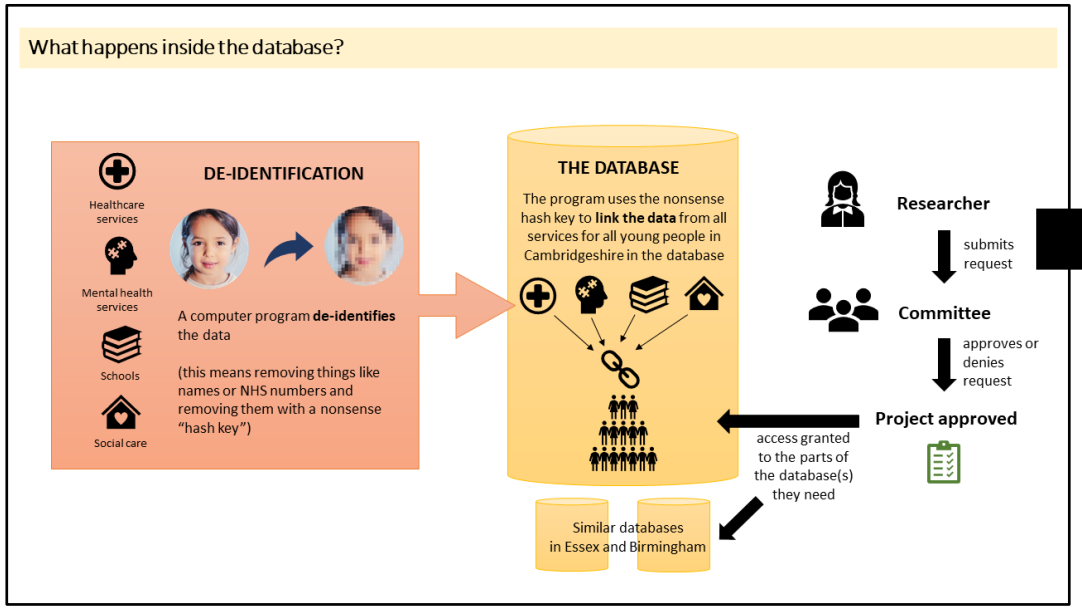
"Having the workshop online helped me engage with the project more as I would have been unable to attend in person."

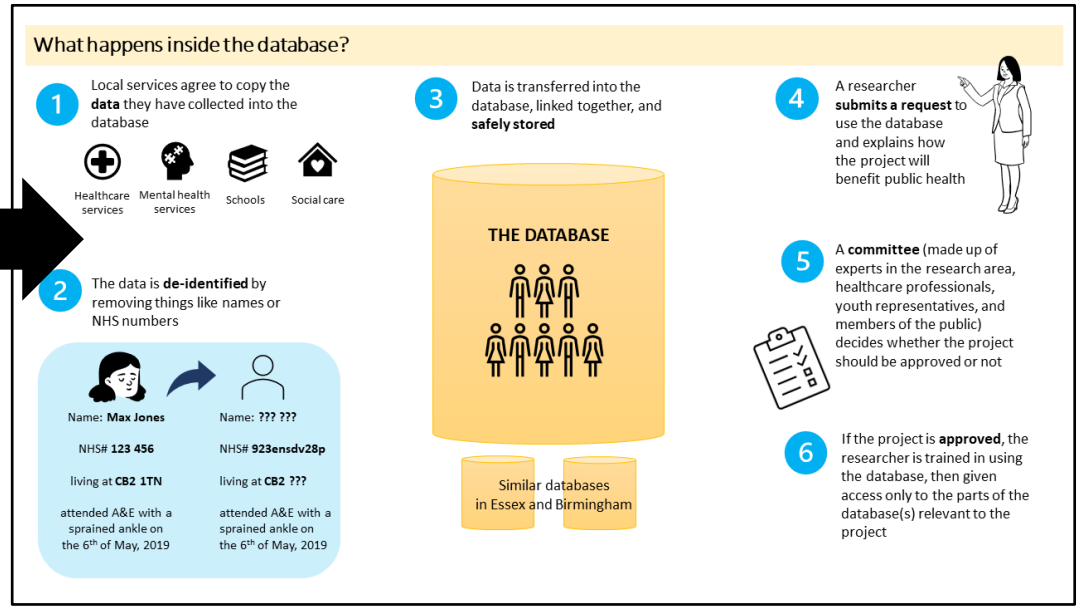



*Example slide*




*Example slide*




*Example of diagram revisions based on participant feedback*

NIHR | Applied Research Collaboration East of England

# Creating CA:RING

*Children and Adolescents:*

*Research Involvement for the Next Generation*

# Background

- Recruitment efforts from CADRE workshops resulted in **190 sign-ups**
- Recruitment strategy meant a reasonably **diverse** group
- Participants interested in hearing about other **opportunities for involvement** in research

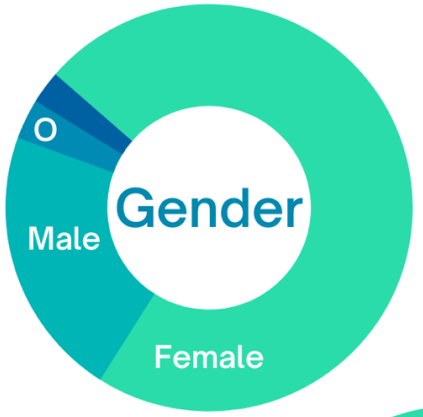
# Aim

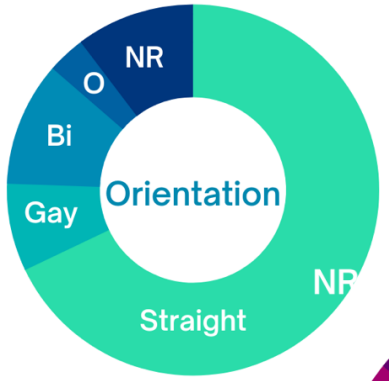
The aim is to evolve this set-up work into a **diverse, sustainable PPI community** of young people, parents and guardians

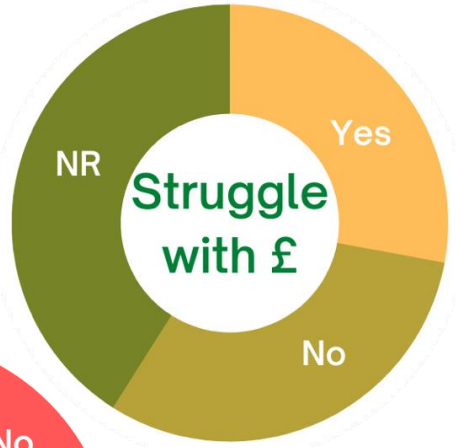
TO

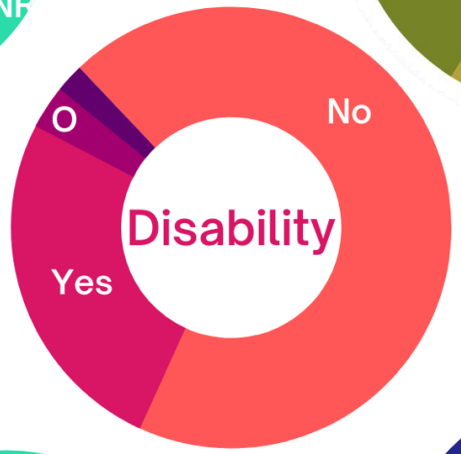
→ Support high-quality public involvement in research & innovation projects for CYP health

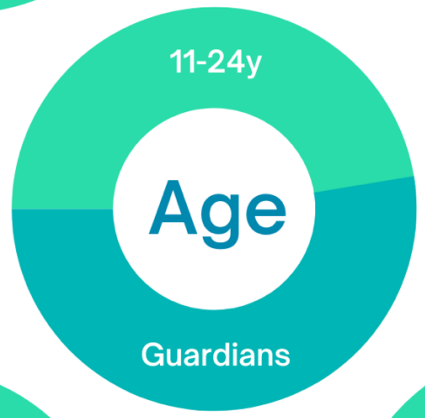
→ Ensure positive experiences for both participants & researchers

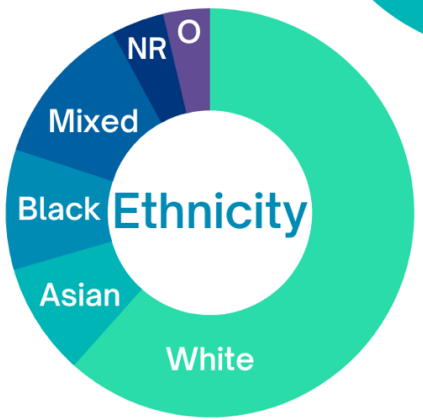


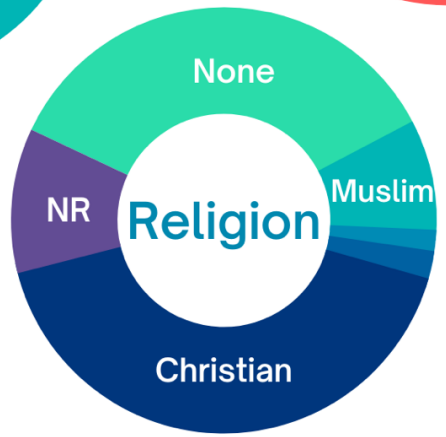



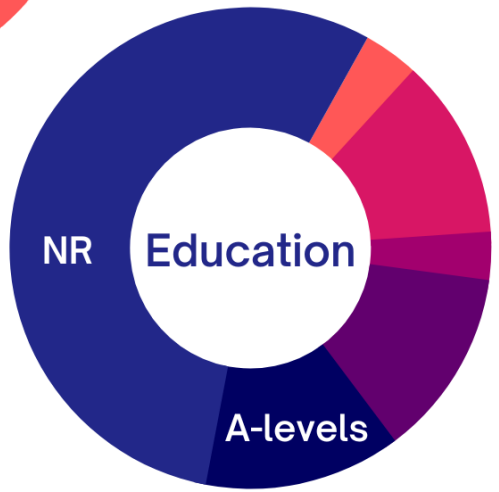




**CA:RING**

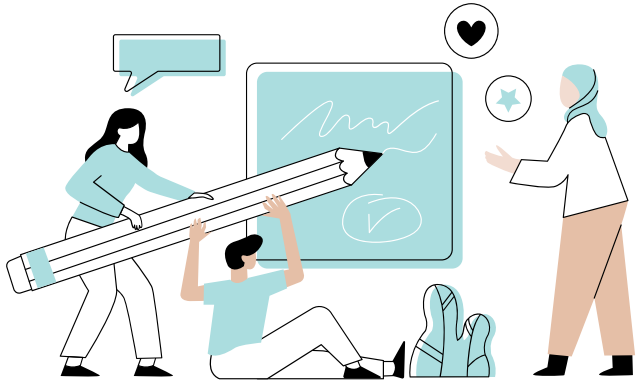
190+ members of the public

*Currently recruiting more participants to address 'gaps'*

NIHR | Applied Research Collaboration East of England

*NR: no response,*
*O: other*

# SET UP WORK



1. **Knowledge-sharing interviews** with 6 YPAGs (report with recommendations in progress)
2. Community **structure** and **approach**
3. **Questionnaire** to understand **researcher needs** Link here
4. **Impact assessment** strategy
5. **Infrastructure** data protection, safeguarding, governance
6. Fortnightly **working group** (incl. public reps)
7. Advisory Group **recruitment** materials and strategy
8. **Website** (launching soon) ca-ring.co.uk

# STRUCTURE

RESEARCHERS

## CA:RING

All public representatives

**Young People's** Advisory Group (N=20)

**Parents/Carers** Advisory Group (N=20)

STEERING GROUP

WORKING GROUP

# Recruitment

## What is Patient and Public Involvement?

Patient and Public Involvement (or "PPI") is about anyone who helps doctors or researchers make their research better. It's not the same as being a "participant" in a clinical study! For example, when doing "PPI" people can:

- Explain to researchers what is important to young people and what kinds of things researchers should study
- Check study documents and make sure they "make sense" and are written in plain language
- Help researchers find study participants
- Help researchers explain their study results and what they mean


## How much of my time will this take up?

To start, the Advisory Group will meet **every 2 weeks** to "create" the community together. After this, we will meet **once a month**.

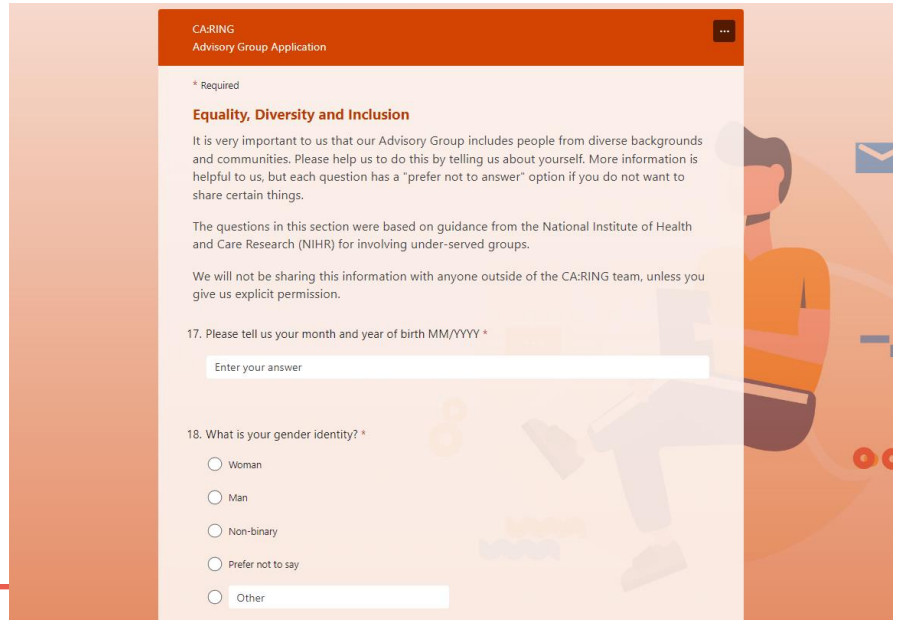
We will do things like:

- Learn more about how research works
- Do fun activities together
- Work with visiting researchers to help them

All of our meetings will be taking place online, so you won't need to travel or be in a room with lots of people you don't know.

## What's in it for me?

- An opportunity to really make a difference to research and young people's health and well-being
- Learn something new and pick up new skills (for fun, or to enhance your UCAS or CV)
- Become part of a community and meet new people
- Use your experiences to make research involvement better for others
- Get paid for your time and effort (£15 an hour if you're under 18, or £25 if you're over)




NIHR | Applied Research Collaboration East of England

# Building capacity

## Let's look at an example

Let's say a university researcher has been working with a group of teachers, psychologists and young people to come up with a new approach to **help students manage exam stress**.

They want to know if their programme actually "**works**".

## What the researchers do

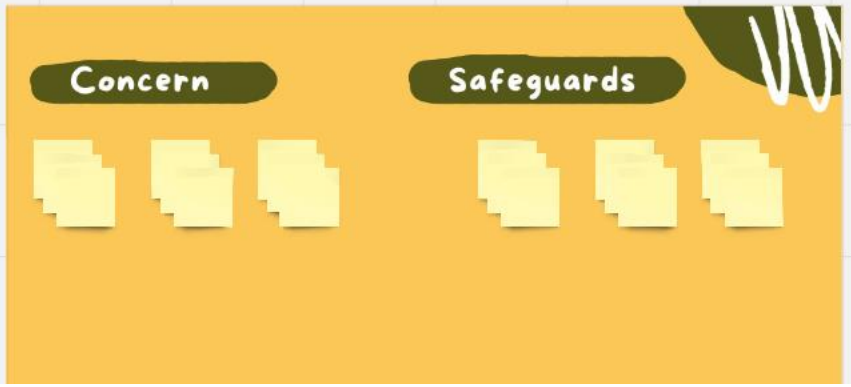
| 1 | 2 | 3 | 4 |
|---|---|---|---|
| Write a **study plan** explaining how they will test their anti-stress programme | **Recruit** participants for their study | Run **statistical analyses** on their findings to find out if their anti-stress programme made a difference | Publish their findings in a **scientific journal** |
| Help the researchers write information about the study in **plain English** and make sure it doesn't have any confusing jargon | Explain to the researchers where they can advertise their study to make sure that **students would see it** | Help researchers **interpret** what they found. If the programme didn't work, what might have been the reasons? | **Write a "plain English" version** of the findings and share it with other students or parents |

## What the PPI advisers do

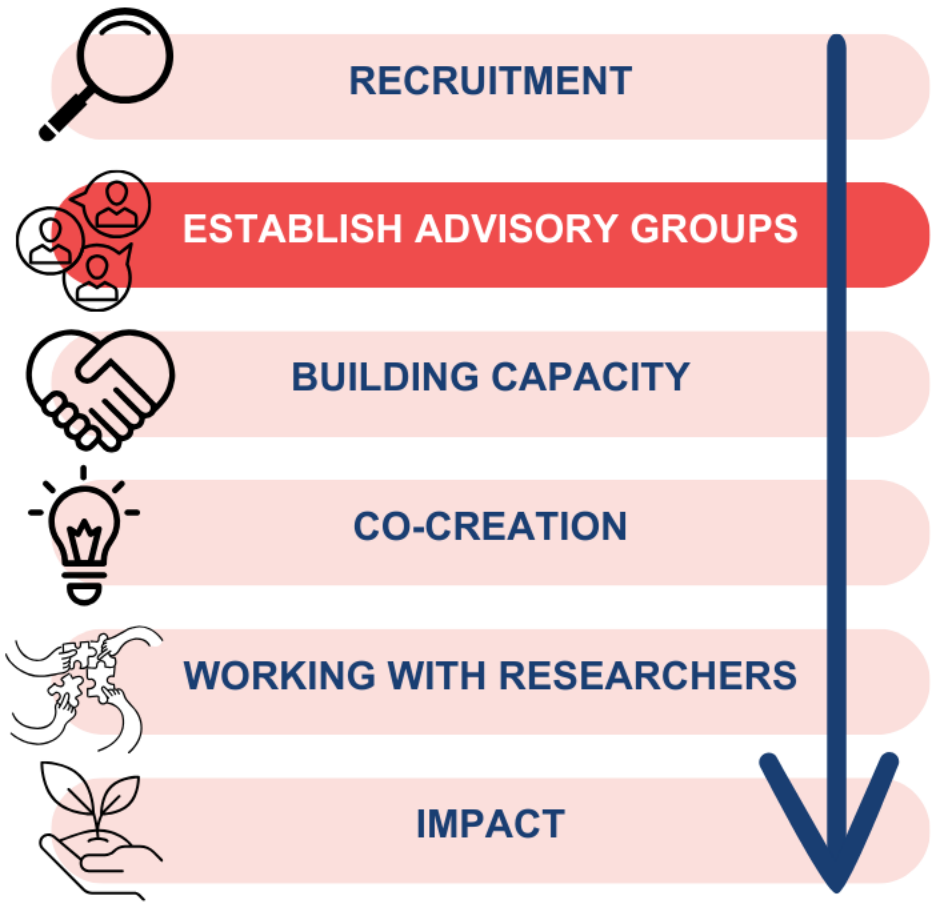
# Co-creation

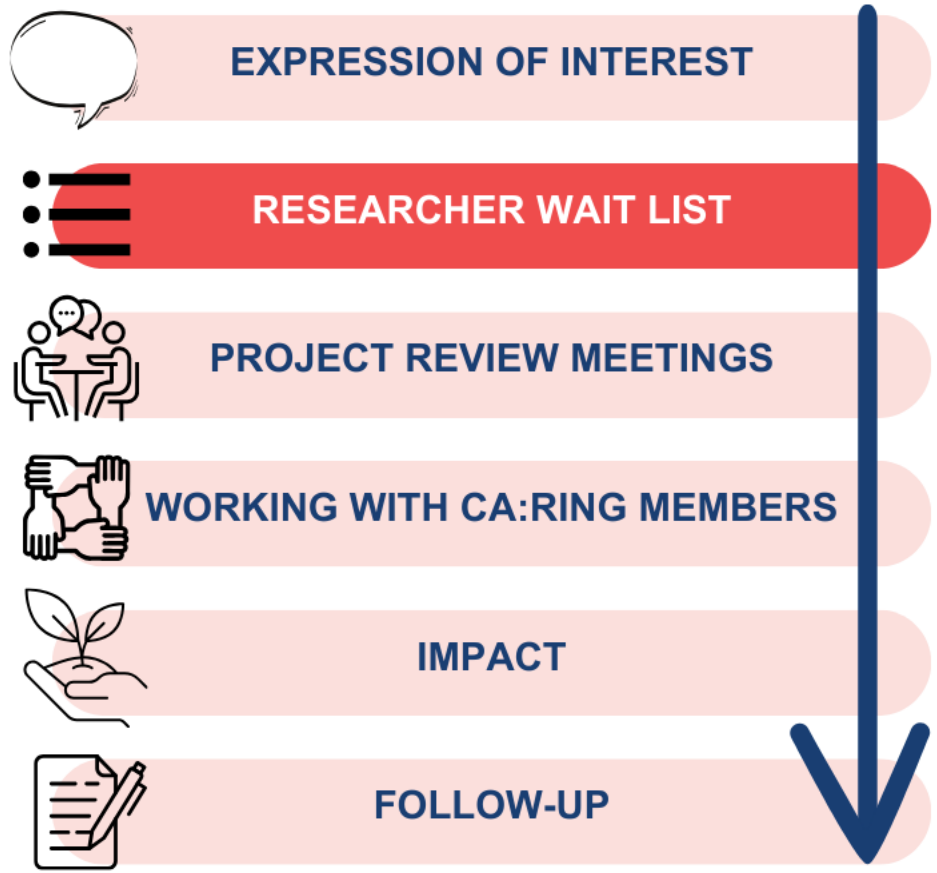

Frame 8


Frame 9



# APPROACH


RECRUITMENT
ESTABLISH ADVISORY GROUPS
BUILDING CAPACITY
CO-CREATION
WORKING WITH RESEARCHERS
IMPACT


EXPRESSION OF INTEREST
RESEARCHER WAIT LIST
PROJECT REVIEW MEETINGS
WORKING WITH CA:RING MEMBERS
IMPACT
FOLLOW-UP

caring@annafreud.org

Researcher expression of interest form (Link; in beta!)

*ca-ring.co.uk (in construction; check back soon!)*

NIHR | Applied Research Collaboration East of England

# Thank you

*Dr Alisa Anokhina: aa2350@cam.ac.uk*

*Dr Anna Moore: am2708@medschl.cam.ac.uk*

NIHR | Applied Research Collaboration East of England

# Session three:

## Getting research into everyday practice

**Chair:** Dr Sarah Robinson
Director, Eastern Academic Health Science Network

NIHR | Applied Research Collaboration East of England

# Opioid Deprescribing Toolkit Project

Sophie Knight, Principal Advisor

Amy Chapman, Advisor

# Our partners

NIHR | Applied Research Collaboration East of England

NHS
Norfolk and Waveney
Integrated Care Board

Patient Safety Collaborative

UEA
University of East Anglia

UNIVERSITY OF LEICESTER

# From Insight to Implementation:

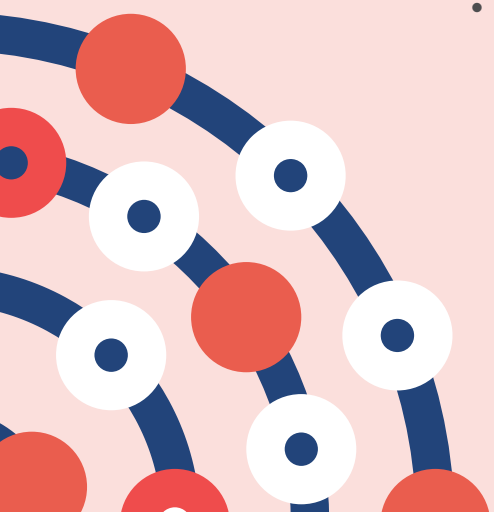



| Insight | Idea | Implementation | Impact |
|---|---|---|---|
| Research led to a developed toolkit (the 'intervention') with six components as an evidenced approach to opioid tapering / deprescribing | If we operationalise and implement the toolkit for prescribers, can we reduce opioid prescribing and in so doing, the risk of harm for people living with pain | Can we produce implementation strategies to address the six toolkit components, how can we best do this… develop our implementation pathway | Measurement of the impact - the implementation outcomes |

NIHR | Applied Research Collaboration East of England

# Introduction

- Public Health England reported that in the year 2017 to 2018, 5.6 million people were prescribed opioids and over half a million of these people had been continuously prescribed for three years or more
- Great Yarmouth and Waveney CCG were the 8th highest prescribers of opioid analgesics of all CCGs in England*
- Great Yarmouth and Waveney CCG were the PresQIPP Winner - High dose opiate reduction in Great Yarmouth and Waveney 2019 for work making significant reductions using engagement, training, incentives and improved benchmarking



- Building on the evidence and activities:
  - NICE guidance for chronic pain recommended against starting opioid treatment for people with chronic primary pain
  - The Royal College of Anaesthetists states how 'tapering or stopping high dose opioids needs careful planning and collaboration'
  - Previous interventions focused on patient behaviour change and practitioner behaviour change – progress suggested that potentially more was needed

*August 2021 ePACT2 data

NIHR | Applied Research Collaboration East of England

# A toolkit for organisations to support opioid deprescribing

# The toolkit development

The Medicines Optimisation Group East Anglia was supported by (NIHR) East of England ARC to develop an approach to opioid tapering

Research evidence from opioid deprescribing trials

Practice evidence from national survey of opioid deprescribing service managers/commissioners

**Toolkit including six components that are essential to effective organisational level strategy for opioid tapering services**

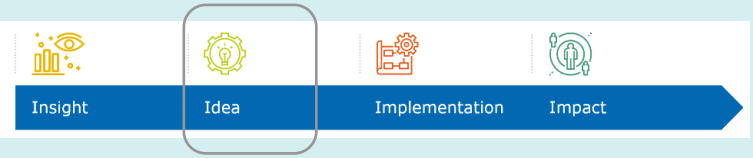
# The six componants

| | |
|---|---|
| Clear expectation that opioid deprescribing is the responsibility of prescribers | There needs to be a **clear expectation that opioid deprescribing is the responsibility of prescribers,** as this makes them more likely to initiate deprescribing discussions with patients |
| What is expected of practitioners and what support is available when the complexity of a patient's situation warrants referral | Programmes need a defined pathway incorporating tapering guidelines, so that practitioners know **what is expected of them and what support is available** when the **complexity of a patient's situation warrants referral** |
| Consistent approach by all members of the healthcare team | There needs to be a **consistent approach by all members of the healthcare team** to achieve more success in supporting patients to taper and stop opioids. |
| Skills to give providers confidence | Prescribers should be equipped with cognitive behavioural intervention **skills to give them the confidence** to initiate and manage tapering discussions |
| Access to psychological and physical support for patients | Programmes should incorporate a pathway that includes **access to psychological and physical support for patients** |
| Align patient: practitioner expectations of tapering | Patients need comprehensive education to **align patient: practitioner expectations of tapering** which supports them to engage and persist with a tapering schedule making the tapering process easier for the prescriber. |

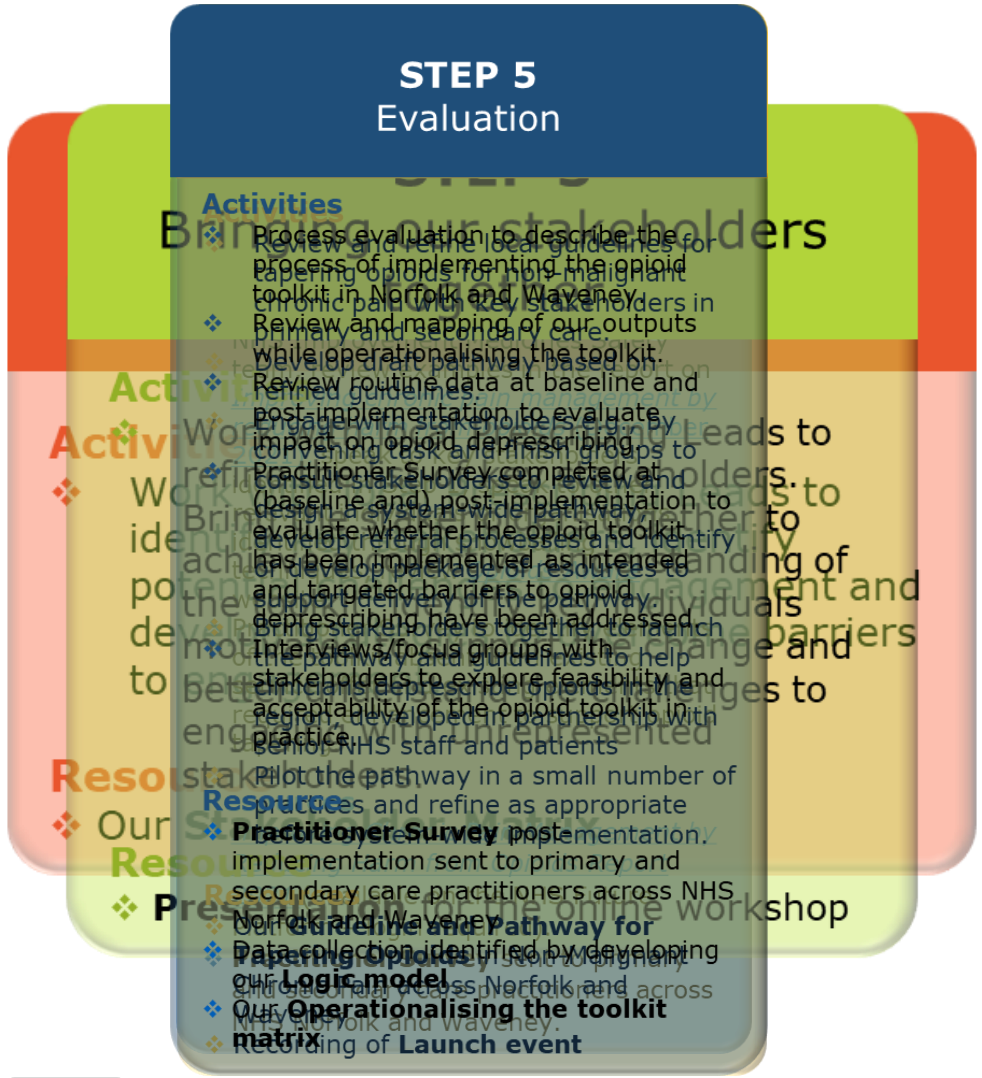
NIHR | Applied Research Collaboration East of England

# Our vision:

To develop a pathway to help prescribers taper patients off analgesia through implementing evidence-based approaches



# Our implementation pathway




Insight | Idea | Implementation | Impact

Eastern AHSN

## Our journey to implement the Opioid Deprescribing Toolkit

**STEP 1**
Identify and engage with key stakeholders

Activities
- Work with local Prescribing Leads to identify key stakeholders, identify potential challenges to engagement and develop strategies to overcome barriers to engagement.

Resource
- Our **Stakeholder Matrix**

**STEP 2**
Gap analysis of local resources or services

Activities
- Desk research: Use multiple approaches to identify resources or services, such as, discussion with NHS England and NHS Improvement Medicines Safety team, review examples in the report on *Improving chronic pain management by reducing harm from opioids (December 2021)*, speak to key stakeholders identified in Step 1, speak to other relevant individuals or organisations identified through snowballing techniques, review *Opioids Aware* website.
- Practitioner Survey conducted at baseline to identify elements of the toolkit absent from existing service offer and existing elements that required enhancement to support opioid tapering.

Resources
- *Improving Chronic Pain Management by Reducing Harm from Opioids Report 2021* (available on the NHS Future Platform – login required).
- **Practitioner Survey** baseline sent to primary and secondary care practitioners across NHS Norfolk and Waveney

**STEP 3**
Bringing our stakeholders together

Activities
- Work with local Prescribing Leads to refine the list of key stakeholders. Bring the stakeholders together to achieve a collective understanding of the toolkit, identify key individuals motivated to support the change and better understand the challenges to engaging with unrepresented stakeholders.

Resource
- **Presentation** for the online workshop

**STEP 4**
Identifying guidelines and developing a pathway

Activities
- Review and refine local guidelines for tapering opioids for non-malignant chronic pain with key stakeholders in primary and secondary care.
- Develop draft pathway based on refined guidelines.
- Engage with stakeholders e.g., by convening task and finish groups to consult stakeholders to review and design a system-wide pathway, develop referral processes and identify or develop package of resources to support delivery of the pathway.
- Bring stakeholders together to launch the pathway and guidelines to help clinicians deprescribe opioids in the region, developed in partnership with senior NHS staff and patients
- Pilot the pathway in a small number of practices and refine as appropriate before system-wide implementation.

Resources
- Our **Guideline and Pathway for Tapering Opioids** in Non-Malignant Chronic Pain across Norfolk and Waveney
- Recording of **Launch event**

**STEP 5**
Evaluation

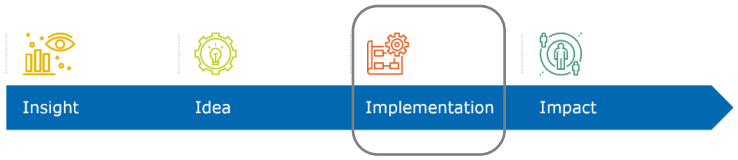
Activities
- Process evaluation to describe the process of implementing the opioid toolkit in Norfolk and Waveney.
- Review and mapping of our outputs while operationalising the toolkit.
- Review routine data at baseline and post-implementation to evaluate impact on opioid deprescribing.
- Practitioner Survey completed at (baseline and) post-implementation to evaluate whether the opioid toolkit has been implemented as intended and targeted barriers to opioid deprescribing have been addressed.
- Interviews/focus groups with stakeholders to explore feasibility and acceptability of the opioid toolkit in practice.

Resource
- **Practitioner Survey** post-implementation sent to primary and secondary care practitioners across NHS Norfolk and Waveney
- Data collection identified by developing our **Logic model**
- Our **Operationalising the toolkit matrix**

NIHR | Applied Research Collaboration East of England

# Key Implementation Strategies

- Identification of clinical leads at ICB-level, and engagement in core project group.
- Development and facilitation of 3 task and finish groups:
  1. Primary care
  2. Secondary care
  3. Patients
- Co-production of a new pathway based on the above groups – ensuring buy-in and engagement.
- Launch event
- Development of implementation resources to ensure ongoing support where needed.
- £ Deprescribing and training in approach included in incentive payment scheme for 24/25 (activity overseen by N&W clinical leads)



# Operationalising the Toolkit

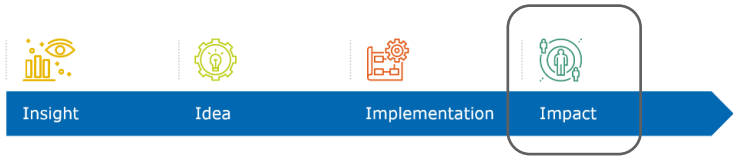
| Intervention / output from the programme | Link: Intervention Pathway | | | Opioid Deprescribing Toolkit<br>Opioid Deprescribing Toolkit Componants | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | | | Clear expectation that opioid deprescribing is the responsibility of prescribers | Programmes need a defined pathway incorporating tapering guidelines | Consistent approach by all members of the health care team | Prescribers should be equipped with skills to give them the confidence | Access to appropriate levels of psychological and physical support for patients | Patients need comprehensive education to align patient – practitioner expectations of tapering |
| | | Activities | Stakeholder identification and engagement | ✓ | | ✓ | | | |
| | | | Gap analysis of local resources or services | ✓ | | | | | |
| | | | Initial Event | ✓ | | | | | |
| | | | Launch event | ✓ | ✓ | ✓ | | | |
| | | | Task and Finish Groups engaging Patients | | | | | ✓ | |
| | | | Task and Finish Groups engaging various secondary and primary care staff | ✓ | ✓ | ✓ | | ✓ | |
| | | Resources | Practitioner Survey | ✓ | ✓ | ✓ | | | |
| | | | Opioid Deprescribing Pathway and Guidelines co-developed | | ✓ | | ✓ | | ✓ |
| | | | Dose equivalence information | | | | ✓ | | |
| | | | Package of approved patient resources | | | | ✓ | ✓ | ✓ |
| | | | Social prescribing contact list created | | | | ✓ | ✓ | ✓ |
| | | | CBT training being reviewed and communicated at ICB and PCN level | | | | ✓ | | ✓ |
| | | | Licenses for PresQIPP training | | | | ✓ | ✓ | |
| | | | Deprescribing will be included in the Incentive Scheme next year A | ✓ | | ✓ | ✓ | ✓ | |
| | | | ARRS Funding Guidance | ✓ | | | | ✓ | |

NIHR | Applied Research Collaboration East of England

# Evaluation

# Evaluation question and measures

- Can the toolkit be implemented in Norfolk and Waveney ICS to achieve reductions in opioid prescribing rates?
    - How the pathway has been implemented and fidelity measures e.g. if the pathway has been delivered as planned
    - Impact on opioid and gabapentinoid deprescribing
    - Staff satisfaction
    - Impact on other service delivery (e.g. other pain medication prescriptions, social prescribing)



# Next Steps

# Next steps

- Continue to promote use of the pathway
- Evaluation activity (which has been pushed back to ensure there is enough time for the pathway and toolkit use to be embedded)
- Submission of manuscript to British Medical Journal planned for December 2023

# Thank you

NIHR | Applied Research Collaboration East of England

# Learning from the Beyond+ Words Project

**Study Team**: Prof. Natalie Pattison, Prof. Jacqueline Kelly, Dr. Helena Wythe, Prof. Julia Jones (University of Hertfordshire), Dr. Raj Attavar, Anne Hunt (Hertfordshire Partnership University NHS Foundation Trust), Louise Jenkins (Hertfordshire County Council)

FUNDED by the Royal College of Nursing Foundation

NHS Hertfordshire Partnership University NHS Foundation Trust

Beyond Words empowering people through pictures

Hertfordshire

University of Hertfordshire UH

RCNFoundation Supporting nursing, improving care

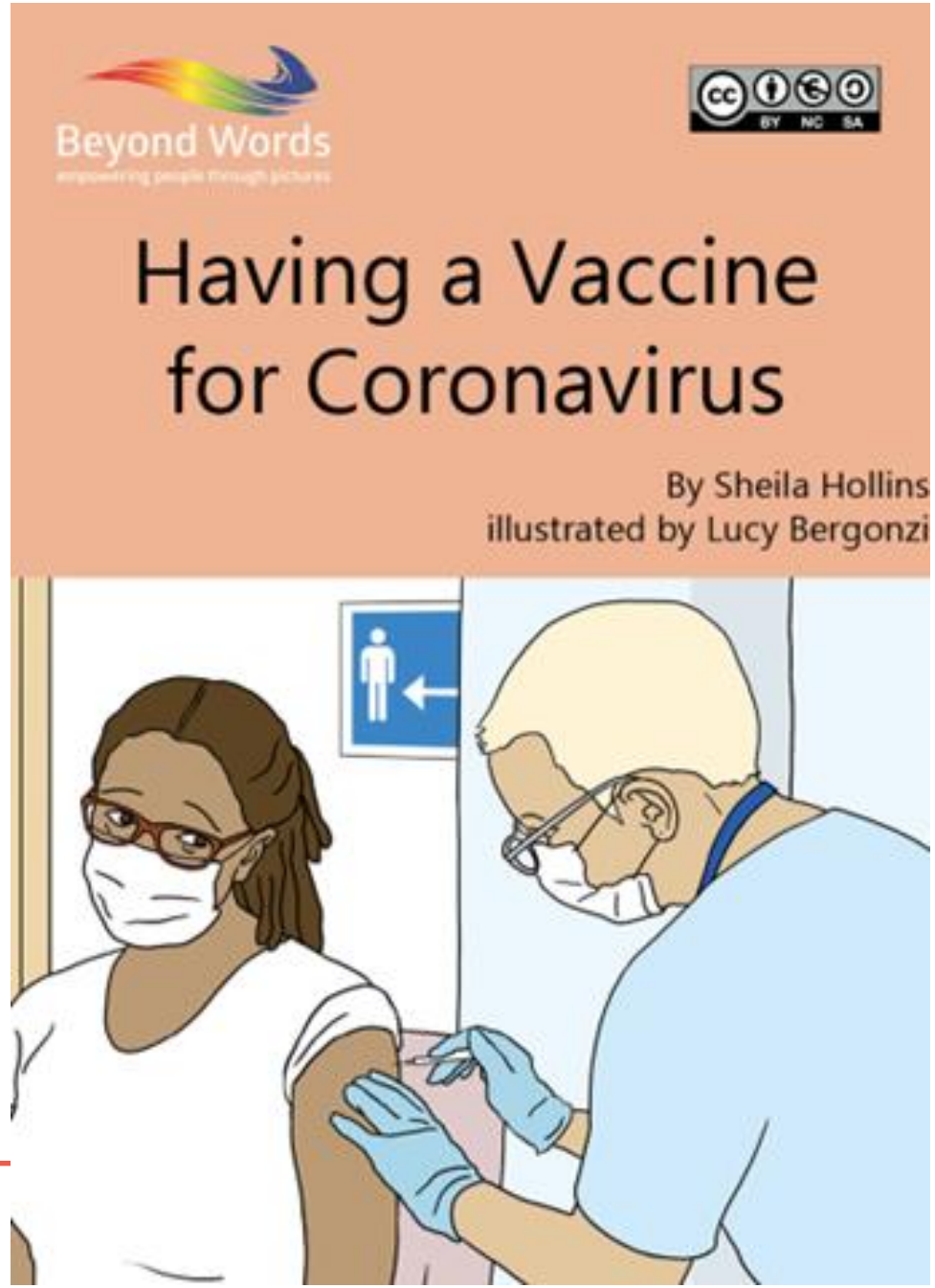
# CAREVIS:Co-creation and Evaluation of a Visual Resource to support COVID-19 Vaccine uptake in people with Intellectual Disabilities

**Background**:

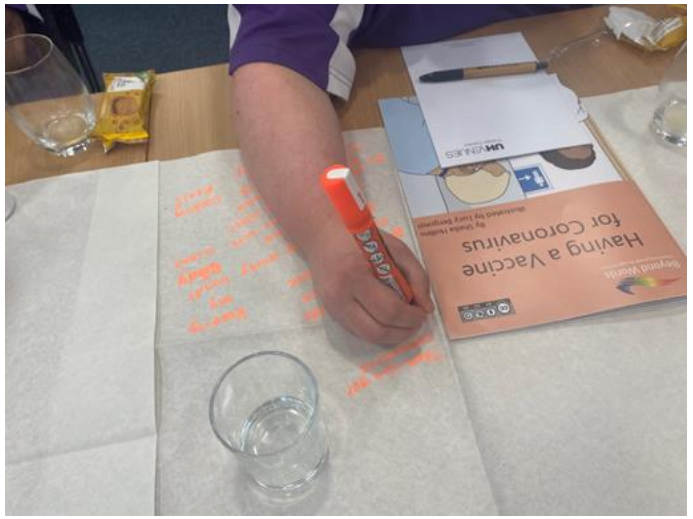
- 1.5 million people in UK with intellectual disability
- Low update of annual health checks and vaccinations
- Much higher mortality rates and shorter life expectancy than general population
- Death rate from COVID-19 in people with a learning disability was 3.6 times higher compared to general population
- Challenges to support uptake of vaccines among this group:
  - Conveying of information about COVID-19 vaccine
  - Needle and vaccine phobias
  - Explaining social distancing requirements

# Collaboration with Books Beyond Words (Charity) and the Purple All Stars (Learning Disability group)

- Visual Resource '**Having a Vaccine for Coronavirus**' co-designed with the Purple All Stars group at Herts County Council.
- Resource produced by charity 'Books Beyond Words'
- Involvement from Experts by Experience
- Evaluated by University of Hertfordshire and partners



# Co-design workshops with the ‘Purple All Stars’ group




# Evaluation: Three work packages

Semi-structured Interviews =35

- people with a mild-moderate learning disability (11), Informal and formal carers (10), health professionals (14).

ii) Mapping of resource distribution, downloads and vaccine uptake data

iii) National online survey

- (n=55 responses [2 people with a learning disability,
  42 health professionals, 8 carers, 3 ‘others’])
- Informed by involvement from Purple All Stars

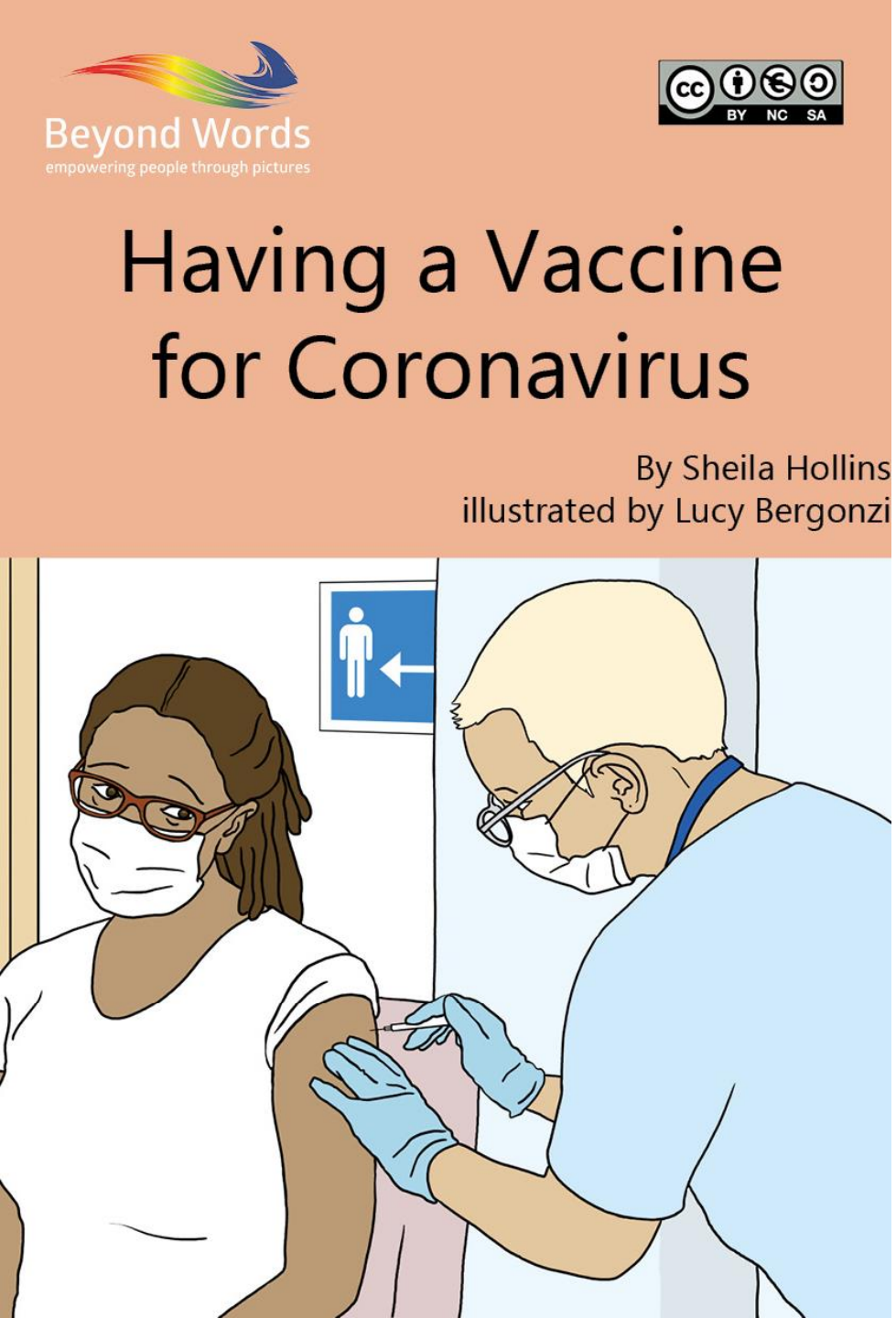
# Findings:

**Vaccine uptake**: Uptake of Covid-19 vaccination higher in the learning disability population in Herts and Essex than adults in general population.

**Download data**: As of March 2022 – 3611 downloads – highest in Feb 2021 (1878)

**Survey:** 8/55 (14%) people had used the resource; one informal carer (1/8), one person with a learning disability (1/2) and six (6/42) health professionals. Mainly used as an e-resource (40%), not printed. Reasons why it had not been used was that people had already received vaccine or they were unaware of the resource.

**Mapping:** Local adjustments made: 'reasonable red flag', reasonable adjustments in settings, using dentists for sedation, needle desensitisation programmes.

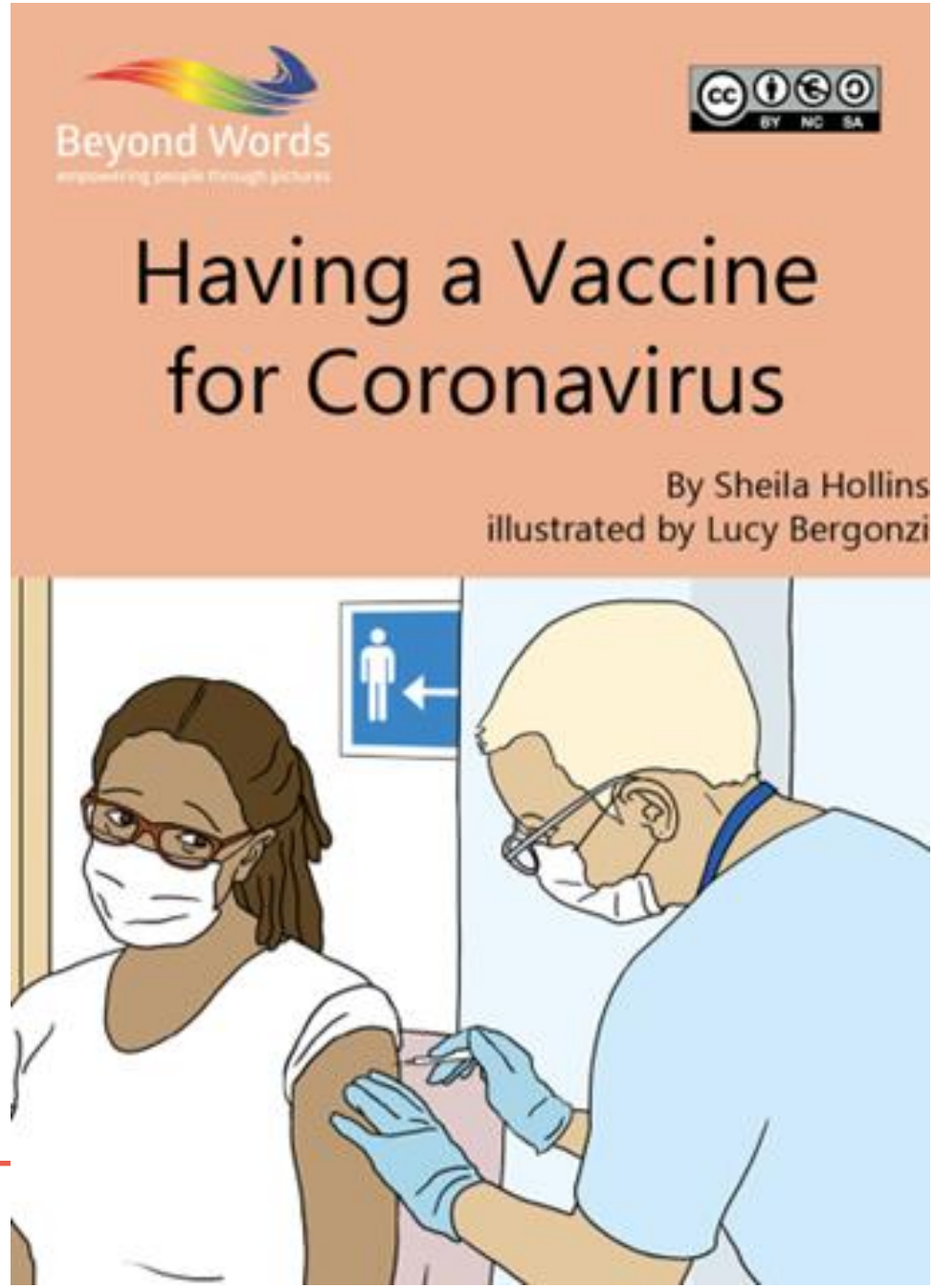



# Examples of revisions suggested for the resource from evaluation

- Consider changing the front image. Showing the needle in the first image was confronting and should appear later in the book.
- Consider adjusting the emotions depicted in the woman being vaccinated to more neutral, impression was that she looked ‘worried’.
- A little more could be shown to depict this was a vaccination centre, could be shown on a sign

# Impact and learning

- Visual Resource '**Having a Vaccine for Coronavirus**' has been revised, based on evaluation
- Findings being published
- BLOG ARC EoE
- Learning shared via Learning Disability and clinical networks (e.g. RADIANT)
- Continued collaboration with partners, including The Purple All Stars group
- Follow-on projects:
- CAREVIS Long-COVID (funded by HPFT)
- Creative Learning Abilities Partnerships (funded by NIHR Programme Development Grant)



# Thank you!

J.Jones26@herts.ac.uk
n.pattison@herts.ac.uk
h.f.wythe@herts.ac.uk

NIHR | Applied Research Collaboration East of England

# NIHR ARC EAST OF ENGLAND SHOWCASE 2023

#ARCEoEShowcase