



NIHR | Applied Research Collaboration
East of England

NIHR ARC EAST OF ENGLAND SHOWCASE 2023

[#ARCEoEShowcase](#)

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

Session four:

Engaging with communities

Chairs: [Dr Elspeth Mathie](#) and [Prof. Fiona Poland](#)
Theme Leads, Inclusive Involvement in Research
for Practice Led Health and Social Care

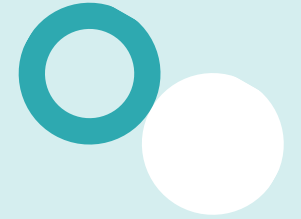
Access to HealthCare

Gypsies, Roma and Travellers



Sally Burrows, Sherrie Smith, Prof. Ewen Speed





NIHR Applied Research Collaboration East of England

Inclusive Involvement in Research

“Nothing about us without us”

Finding ways to hear from people who are under-represented and under-served



Prioritising an ethics of participation Travelling Communities and Healthcare Workers

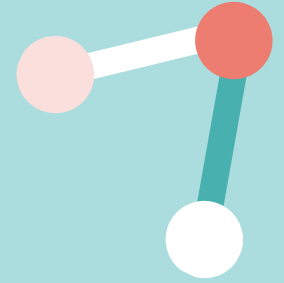
- Finding out what matters to Travelling communities and if/ how they want issues addressed
- Working with local organisations already supporting Gypsies, Roma and Travellers
- Talking with health professionals and organisations regionally and nationally

Cultural Competency

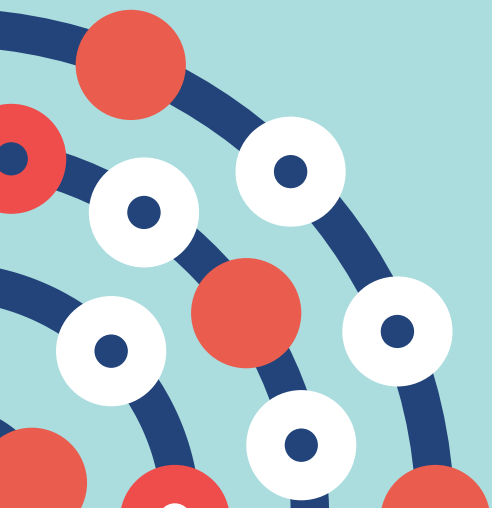
- To engage with people you need sensitivity and understanding of their different life experiences.
- Assume nothing - as an outsider, you can't guess all those things or really understand why someone would choose to live that life
- We need academics that are supportive and tolerant and used to working with different people.

Inclusive research leads to better research and greater impact

- Better questions
- Better research samples
- Better methods
- Better interview quality
- Better understanding of data
- Better outcomes for participants, for knowledge, for understanding of all stakeholders



Prioritising an Ethics of Participation



Sally Burrows, Researcher
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Sherrie Smith, Director of Gypsy and Traveller
Essex sherrie.gatessex@gmail.com

Prof Ewen Speed, Principle Investigator
esspeed@essex.ac.uk



Evaluation of British Islamic medical association (BIMA) intervention for bowel cancer screening in the Muslim community



Delivery and evaluation in Luton and Peterborough

- **Intervention:** (a one-hour educational session delivered by a health professional from BIMA educational session) delivered in mosques across Luton and Peterborough
- **Evaluation:** aimed to recruit 300 participants across Luton and Peterborough. Asked participants to self-report use of cancer screening (before, immediately after and 6-12 months after attending the intervention session)
- Survey looked at knowledge, awareness and attitudes to screening, accessibility and acceptability of the intervention
- Focus groups with participants and interviews with health professionals to find out how the session went

Barriers to bowel cancer screening in Muslim communities

Bowel screening uptake is approximately 28% lower in people of South Asian ethnicity, compared to the general population

Issues around fatalism, misconceptions, fake news, services not sensitive to needs, inequity of resources, uncertainty over religious proscription, low (health) literacy/SES

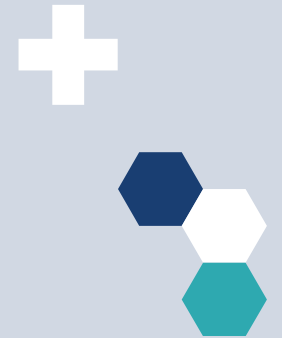


BIMA: National, democratic, professional association of British Muslim healthcare professionals with 4,000+ members. Volunteer led, funded, and delivered

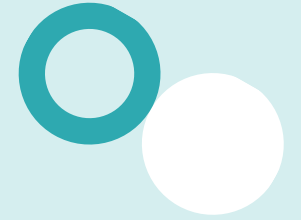
‘Faith-placed’ intervention – light touch - using adapted CRUK materials

Fieldwork reflection from our research and evaluation in Luton and Peterborough

- Awareness of research in different cultures
- Challenges in data collection
- Ways to work around the challenges



Awareness of research in different cultures:

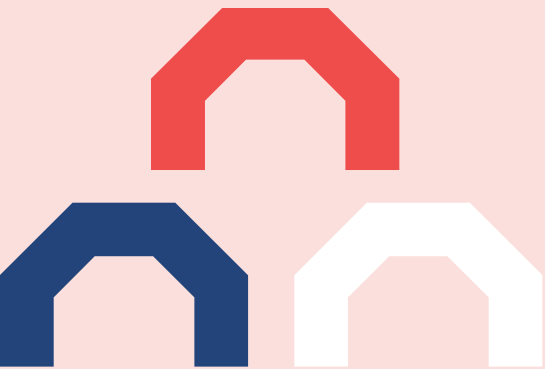
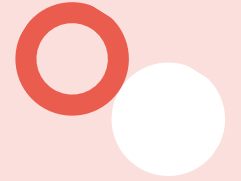


- Different levels of awareness of research, what it entails, and why it is important.
- Being comfortable and familiar giving data and personal details



Challenges in data collection:

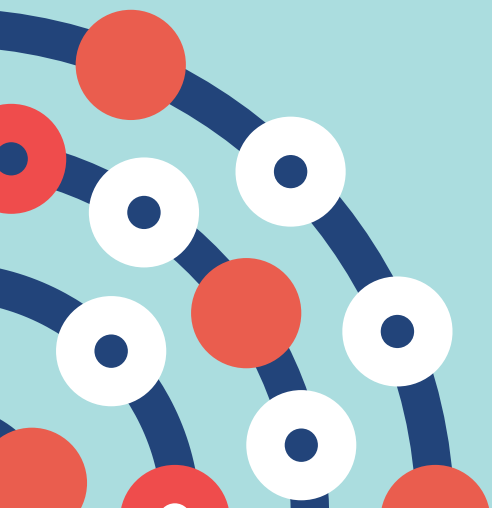
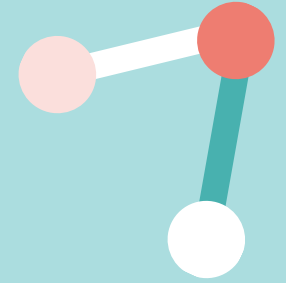
- Recruiting participants and follow-up contact
- Filling-out questionnaires (worked in group settings but not individual ones)
- Language barriers



Ways to work around the challenges:

A bridge that we have to cross.:

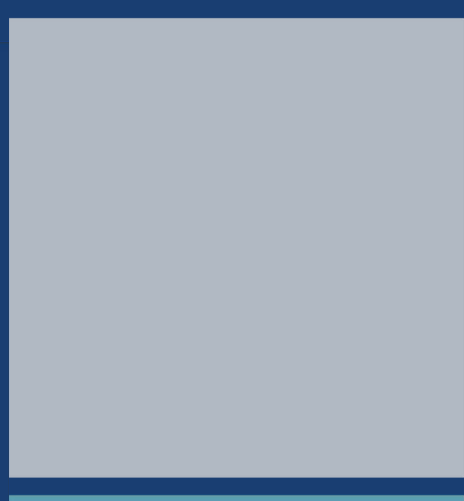
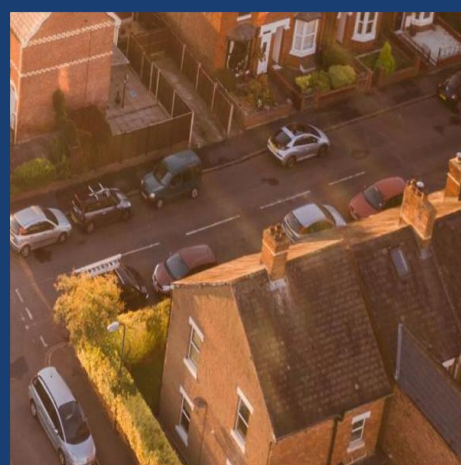
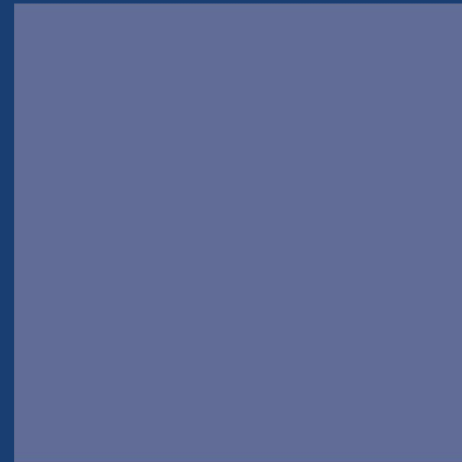
- Reaching out
- Working with community gatekeepers, particularly clinicians.
- Conducting research in culturally appropriate settings
- Investing time and money in building relationships and resources for translation.
- Providing opportunities to get involved in research.



Partners:

- Bedfordshire Luton and Milton Keynes (BLMK) Cancer Action Group
- Peterborough City Council
- Luton Borough Council
- Cambridge and Peterborough CCG
- BLMK CCG
- BLMK Cancer Alliance
- Luton Council of Mosques
- Midlands and East Screening Hub
- Public Health England
- NHS England and NHS Improvement
- BIMA (Dr Salman Waqar)
- PPI Representatives





Reflecting on how we work with communities

Bryony Porter & Debbie Drew

Populations-in-Focus Approach

- Some of our work has focused on working with specific areas of the region
- Working with communities that are varied; coastal, rural, diverse, socioeconomics
- Previously underserved by research



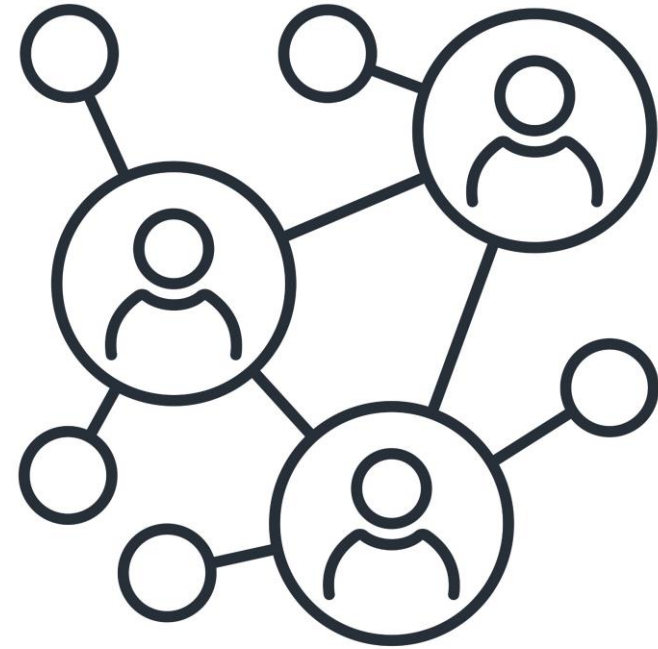
Review of the Populations-in-Focus Approach


- To explore how this approach has been going, we interviewed 11 researchers and 9 community partners
- Involved with the ARC through a local charity, public contributor, local authorities, NHS primary care, an ICS representative or through Healthwatch.



Engaging with communities and collaboration

- Engagement was varied across the ARC research themes
- Working with communities and organisations in these areas has supported a deeper understanding
- Providing a focus and opportunity to develop locally relevant research





Each area has its own nuances and as ICBs or ICSs we're very much championing that sort of placed based approach or that hyperlocal approach to reducing inequalities.

I think that the other work you do around it, like engagement co-production, needs to model that approach, so I think it's good to have that local research.

Community Partner



I think the biggest outcome was just the relationship everyone built together. It really felt like we had created a bit of a sort of network.

To this day I still have a really good personal relationship with the local authority on the back of doing that work, as well as with the University and the community organisation as well. So, building that network I think was a great outcome.

Community Partner



Debbie Drew

Public Contributor

What are your reflections about how the ARC is involved with communities?

Considerations for engagement

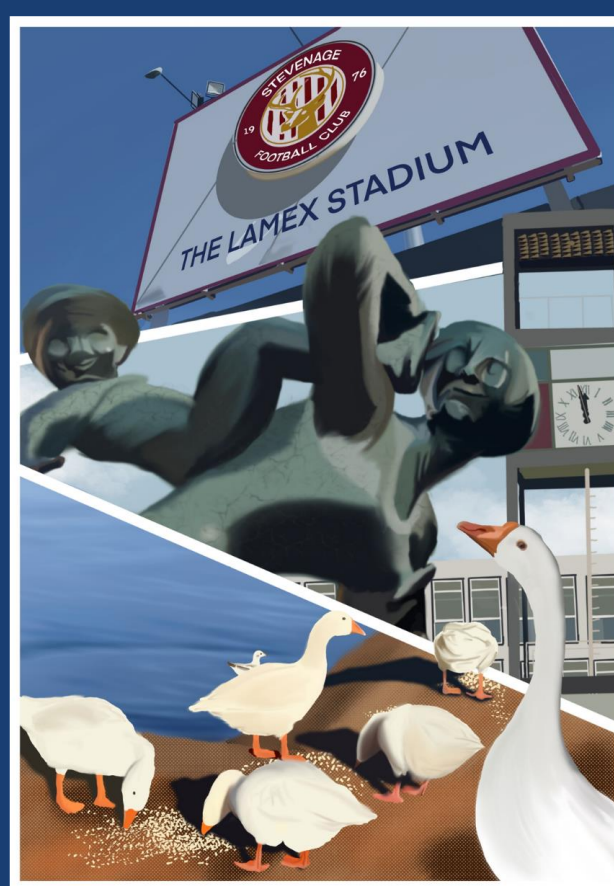
- The ARC Structure gives time to develop relationships with communities
- Aligning with local and national priorities encouraged investment of effort, resource and commitment
- The approach doesn't necessarily fit with university research agendas
- Invisible work - People are often going above and beyond when involved



Reflections for improvement



- The terminology of ‘population-in-focus’ is inaccessible and meaningless to anyone outside of ARC. Suggestions included to change the term to *place-based*.
- Share the learning from populations-in-focus projects and focus on what difference it has made in the community.
- Be more explicit about what inequalities the work is addressing to demonstrate the meaningful outcomes of the work.
- Support some central coordination of engagement and support the researchers in being able to make those links in the communities and vice versa.



Contact:

Bryony.porter@cpft.nhs.uk



Session five:

Increasing skills for undertaking
research in the region

Chair: **Dr Christine Hill**
Deputy Director and ARC Fellowship Lead

Developing Research in Social Care

My experience of the ARC East of
England Fellowship programme

Deborah Sheppard
Programme Manager,
Hertfordshire County Council



- How did I hear about the ARC Metal Health Fellowship?
- Why did I apply?
- What was the application process like?

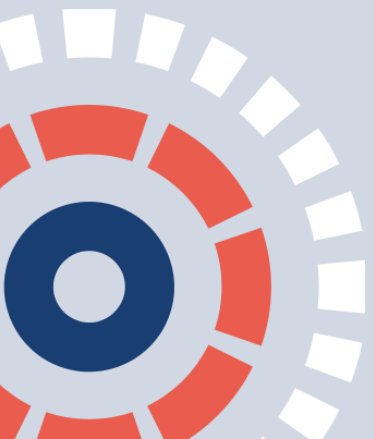


- A year of monthly workshops and bi monthly action learning sets

Research methods and design, ethics, critical evaluation, system approach and boundary spanning etc

- Culmination in showcase event to present poster and share topic, methods, findings
- Further series of Implementation workshops

Implementation science, project management in practice, stakeholder engagement, behaviour change etc



- Invitation to join Supervisor's Applied Social Science Group events and learning experiences
- Access to wider research community to support with practice based challenges
- Mutual support and collaboration



- Increased confidence in local and national policy and practice discussions
- Development of local 'reading group' between social care and mental health professionals to review new research and implement change
- New and sustainable skills and knowledge to apply to my Local Authority role
- Strengthening evaluation of and utilising research in practice based development
- Becoming an ambassador for evidence informed practice
- Keen to pursue future opportunities



Thank you!



How the ARC fellowship shaped my career



Allison Bentley

20th September 2023

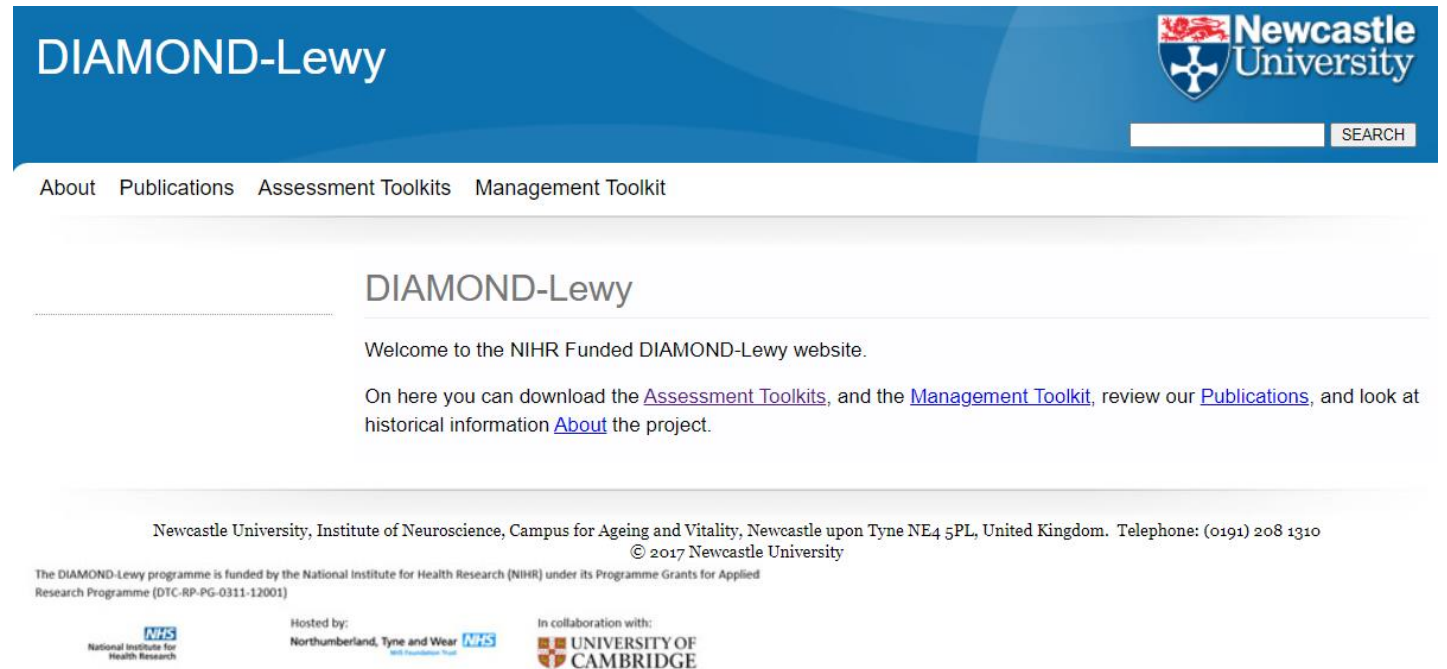


Background

- Community nurse
 - District nurse
 - Community matron
 - Palliative care nurse
 - Parkinson's nurse
 - Research nurse



Dementia research nurse NIHR funded project DIAMOND-Lewy



DIAMOND-Lewy

Newcastle University

SEARCH

About Publications Assessment Toolkits Management Toolkit

DIAMOND-Lewy

Welcome to the NIHR Funded DIAMOND-Lewy website.

On here you can download the [Assessment Toolkits](#), and the [Management Toolkit](#), review our [Publications](#), and look at historical information [About](#) the project.

Newcastle University, Institute of Neuroscience, Campus for Ageing and Vitality, Newcastle upon Tyne NE4 5PL, United Kingdom. Telephone: (0191) 208 1310
© 2017 Newcastle University

The DIAMOND-Lewy programme is funded by the National Institute for Health Research (NIHR) under its Programme Grants for Applied Research Programme (DTC-RP-PG-0311-12001)

NIHR National Institute for Health Research

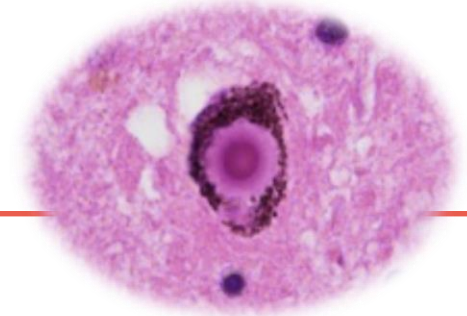
Hosted by: Northumberland, Tyne and Wear NBS

In collaboration with: UNIVERSITY OF CAMBRIDGE

<https://research.ncl.ac.uk/diamondlewy/>

Lewy body dementia

- Includes dementia with Lewy bodies (dementia first) and dementia in Parkinson's disease (“one year rule”)
- Age related dementia. Characterised by presence of certain symptoms and appearance of Lewy bodies in the brain
- Lewy bodies are small ‘clumps’ of protein that develop inside nerve cells
- Common in pathological series, up to 15-20% dementia. Underdiagnosed clinically, but by how much is unclear
- Relatively little known or studied in comparison to Alzheimer's disease



Research idea forms 2014-2016

Working clinically with people with Lewy body dementia +

Completing a notes review for the DIAMOND-Lewy study

Noticed patients had many debilitating physical symptoms compared to the other dementias.

Got me thinking?

How is this problem affecting patients and family carers?

What are the experiences of living with the physical symptoms of Lewy body dementia?



ARC fellowship 2016

- One day a week funding for time to complete the research
- Monthly training and meeting other fellows.
- Support from supervisors to write proposal
- Support from CPFT service user and carer involvement in research group. Brought together 4 family carers
 - Design, interview topic, information sheets, poster, analysis, dissemination plans.
- Ethics Committee
- Completed 12 semi structured interviews.
- Together we managed to reach preliminary analysis stage within the year

ARC fellowship opened doors

Grants

Alzheimer's Society Dissemination Grant 2017

- Dissemination grants provide funding for researchers who wish to disseminate the findings of a completed research programme or project.
- Joint application with family carer.
- £2500
- Presented poster at Alzheimer's Society conference

British Geriatric Society Nursing Grant 2018

Alzheimer's Research UK – Travel grant 2019



Dissemination

Nursing
Older People 



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[Clinical articles](#) | [CPD articles](#) | [Test your knowledge](#) | [Practice question](#)

How to inform service users quickly in dementia care

Chris Carling

Allison Bentley

Posted 02 October 2018 - 12:13

Nurses and people living with dementia can work together to conduct simple, research studies that inform services

ARC research led to other questions

Open Access Research

BMJ Open Mortality in dementia with Lewy bodies compared with Alzheimer's dementia: a retrospective naturalistic cohort study

Annabel Price,^{1,2} Redwan Farooq,³ Jin-Min Yuan,³ Vandana B Menon,⁴ Rudolf N Cardinal,^{1,2} John T O'Brien^{1,2}

ABSTRACT
Objectives To use routine clinical data to investigate survival in dementia with Lewy bodies (DLB) compared with Alzheimer's dementia (AD). DLB is the second most common dementia subtype after AD, accounting for around 7% of dementia diagnoses in secondary care, though studies suggest that it is underdiagnosed by up to 50%. Most previous studies of DLB have been based on select research cohorts, so little is known about the outcome of the disease in routine healthcare settings.
Setting Cambridgeshire & Peterborough NHS Foundation Trust, a mental health trust providing secondary mental health care in England.

Strengths and limitations of this study

- ▶ Large clinical cohort of dementia with Lewy bodies cases.
- ▶ Study design reflecting clinical conditions.
- ▶ Cases identified by treating clinician diagnosis; therefore, undiagnosed/wrongly diagnosed cases may have been missed.
- ▶ Possibility of bias introduced by secondary care study setting.

To cite: Price A, Farooq R, Yuan J-M, et al. Mortality in dementia with Lewy bodies compared with Alzheimer's dementia: a retrospective naturalistic cohort study. *BMJ Open* 2017;7:e017504. doi:10.1136/bmjopen-2017-017504

▶ Prepublication history for this paper is available online. To view these files please visit the journal online (<http://dx.doi.org/10.1136/bmjopen-2017-017504>)

$$\begin{matrix} + \\ \text{Clinical} \\ \text{Experience} \\ + \\ \text{Patients and} \\ \text{families tell us} \\ = \end{matrix}$$

In palliative care why is dementia taken as one group when different types such as LBD may have different needs?



ARC fellowship – platform for PhD

Experiences of living and dying with Lewy body dementia: A longitudinal narrative study

- Service user and carer involvement group
- Experienced centred narrative research
- 3 interviews with couples over 6 months
- One interview was life story work
- Narrative research helps to explore the character of different health experiences and encounters
- Gives voice for people living with Lewy body
- Makes visible gaps



ARC fellowship – start of a career pathway

- Research associate - Cambridge University
- Palliative and end of life care group in Cambridge (PELiCam)
- Department of Public Health and Primary Care
- Working on palliative care projects with community nurses and GPs
- NIHR funded post to develop projects and seek external funding

<https://www.phpc.cam.ac.uk/pcu/research/research-groups/end-of-life-care/>



To summarise

- ARC fellowship enabled me to:
 - Develop research skills and confidence
 - Work collaboratively with people living with Lewy body dementia and family carers
 - Opened doors to further research funding.
 - Gave idea for a PhD project
 - Started a process that allowed me to enter an academic career, which can be particularly challenging within the community nursing profession.

Thank you

Dr Allison Bentley

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Session six:

The journey of our research

Chair: **Prof Kathryn Almack**
Theme Lead, Ageing and Multi-morbidity



The journey of the DACHA study (**C**LAHRC to the **A**RC)

Claire Goodman
University of Hertfordshire



Presentation



Why involving care homes in health and care research matters



The national CLAHRC/ARC care home network



Better Together



The DACHA study



Outputs and impact

Care Homes

- Divided from the NHS..... **but** key partner
- 11,000 care homes >65s : 5,000 different providers.
- No centralised system of control or voice
- Under-valued, under resourced, misunderstood



CLAHRC to ARC : Local and National Care Home focus

- East of England research workshops CLAHRC funded studies
- National network: Researchers, Clinicians care home providers and dementia charities
- Reducing duplication and fragmentation
- Resource
 - 3 Summary Reports
 - 3 face to face London meetings
 - Capacity building and research priority setting
 - Briefing.....

NIHR | National Institute
for Health Research

CLAHRC Care Homes Research:
National Work Stream
November 2019
Summary Report



Collaboration led to.....

- Less duplication & exposure to different methods
- Pandemic response
- Grant capture
- Capacity building (Dementia research)
- Dissemination on new ways of working

Top Tips for Tricky Times: Helping care home residents with dementia to use video to communicate with their families

- 1) Image and sound:** Using video (e.g. Skype, Zoom, FaceTime, WhatsApp) can work well. It helps residents with dementia to connect with family – the extra clues of body language help the conversation.
- 2) Reducing isolation:** It can help residents feel more connected, less lonely.
- 3) Support and timing:** Residents will need support to use the technology. You may not have enough time to do this – allocate staff set times to support different residents.

Top Tips for Tricky Times: Hydration and Covid-19

- 1) Remember:** Routine tests for dehydration (such as dry mouth or skin, dark coloured urine) do not work in older people living in care homes, so offering drinks is generally the best way of preventing dehydration.
- 2) Timing:** Offer lots of drinks earlier in the day, including one before breakfast, with breakfast, and two morning rounds of drinks.
- 3) Frequency:** If using small cups, glasses or mugs, offer drinks more often and if drinks are not finished, offer more drinks more often.
- 4) Avoid missing drinks rounds and ensure all residents are offered drinks during each round.**
- 5) Encourage drinking in a social, pleasant environment as it is more enjoyable.**
- 6) Variety:** Offer a variety of drinks, including hot milky drinks and fruit juice so drinking is more enjoyable. Offer foods high in fluid content such as soup, jellies or ice-lollies.
- 7) Find out resident's preferences for drinks types and presentation, and record in resident's individual hydration care plan. (Alcohol can be offered unless this is not advised.)**

Initiate: Do not rely on residents asking for, or helping themselves to drinks, offer them.

Medication: Provide a generous drink with medications.

Using Online Consultations to Facilitate Health and Social Care Delivery During COVID-19: An Interview Study of Care Home Staff

> Res Involv Engagem. 2021 Mar 20;7(1):18. doi: 10.1186/s13000-021-00557-7

A realist evaluation of a collaborative model to support research co-production in long-term settings in England: the ExCHANGE protocol

K Wilkinson ¹, J Day ², J Thompson-Coon ², V Goodwin ², K Liabo ², G Coxon ³, G Co C Marriott ⁵, I A Lang ²

Affiliations + expand
PMID: 33743827 PMCID: PMC7980357 DOI: 10.1186/s40900-021-00257-2

CHAPPI: Care Home Activity Providers facilitating Public Involvement in research as meaningful activity for care home residents



Developing resources And minimum data set for Care Homes' Adoption



DEVELOPING A MINIMUM DATASET FOR OLDER ADULT CARE HOMES IN THE UK: THE DACHA STUDY

Study
Deliverables for
working in and
with care
homes

Guidance on resident assessment, outcome measurement and implementation of innovation

New methods to support staff and resident engagement in research

Trial repository for secondary data analysis
(currently 6000+ older people, 340 care homes)

Prototype MDS tested in three Integrated Care Systems (ICS)

Recommendations on implementation of MDS for social care

REVIEW

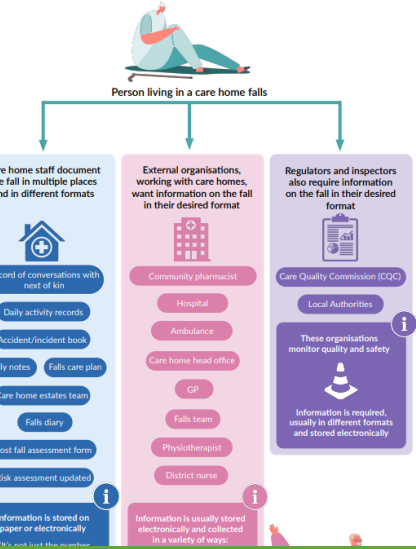
Outcome measures from international older adult care home intervention research: a scoping review

SARAH KELLY^{1,2}, ANDY COWAN¹, GIZDEM AKDUR³, LISA IRVINE³, GUY PERYER^{4,5}, SILJE WELSH⁶, STACEY RAND⁷, IAIN A. LANG^{8,9}, ANN-MARIE TOWERS^{10,11}, KAREN SPILSBURY^{12,13}, ANNE KILLETT^{14,5}, ADAM LEE GORDON^{14,15}, BARBARA HANRATTY^{16,17}, LIZ JONES¹⁸, JULIENNE MEYER^{18,19}, CLAIRE GOODMAN^{1,5}, JENNIFER KIRSTY BURTON²⁰

Visual Summary



Where is information recorded when a person in an English care home falls?
 Data about people living and dying in care homes are collected, stored and used in multiple places to inform quality of care. However, this same information is often re-recorded in different ways, by various organisations, and there is limited sharing between them - which can be costly on time and resources.



Suddenly social care data matters! So let's future proof it properly

July 7th, 2021 | Categories: DACHA Blog

<http://dachastudy.com>



A Visual Guide

Developing a minimum data set for older adults in care homes in the UK: Key principles

Population Health Sciences Institute, Newcastle University, Newcastle upon Tyne, UK
 Institute of Cardiovascular and Medical Sciences, University of Glasgow, Glasgow, UK
 University of Hertfordshire, Hatfield, UK
 University of Nottingham Royal Derby Hospital, Derby, UK
 School of Health Care, University of Leeds, Leeds, UK
 Correspondence to: Barbara Hanratty, Barbara.hanratty@newcastle.ac.uk
 Cite this as: BMJ 2020;369:m2463
 Published: 24 June 2020

Using linked health and social care data to understand service delivery and planning and improve outcomes

Keywords: Older people, long-term care, social care, data
Key Points:
 • The COVID-19 pandemic has highlighted the need for reliable, routinely collected, shared care data.
 • Existing linked data sets are not comprehensive enough to accurately predict demand for long-term care in England.
 • The DACHA study will pilot linking health and social care data for service planning and delivery.
 Adult social care provides short or long-term support with many essential activities of daily living, such as washing.

social care amongst older adults (age 75 and over) and build a predictive risk model forecasting future service use.
 The Northwest London Discover Database, which is used in the research [2], links data from primary, secondary and tertiary care, community and mental health care, emergency departments and social care. The linked data contain rich information of participants' sociodemographic characteristics and health conditions. However, its power to accurately predict demand and access to adult social care is limited by a lack of data on key indicators, such as availability of informal support (whether or not the person lived alone was missing for 82% of the sample), the individual's socioeconomic status and if they were funding their own social care. Unsurprisingly, the study found that individuals were more likely to receive long-term, publicly funded adult social care if they were older, lived in areas with higher socioeconomic deprivation and had a pre-existing mental health or neurological condition (which are likely to be associated with loss of function and independence in old age). The lack of

Covid-19 and lack of linked datasets for care homes

The pandemic has shed harsh light on the need for a live minimum dataset

Barbara Hanratty,¹ Jennifer Kirsty Burton,² Claire Goodman,³ Adam L Gordon,⁴ Karen Spilsbury⁵

Residents of care homes are centre stage in the covid-19 pandemic for all the wrong reasons. Home to vulnerable people with complex needs, these settings should have been an obvious focus and priority in pandemic planning.¹ Almost half of newly admitted residents in the UK are transferred from hospitals, creating a resident population with wide ranging needs spread across 450 000 beds in almost 11 000 homes.^{2,3} This is more than double the number of beds in NHS hospitals,⁴ but unlike NHS facilities most homes are privately owned, with residents responsible for some or all of the costs of their care. In the UK, minutes suggest that the Health and Safety Commission placed a spotlight on the sector, and the lack of

was introduced in England to generate data on care home bed occupancy and staffing.^{1,5}
 To date there has been no national, systematic approach in the UK to develop care home datasets or to exploit their full potential to enhance residents' care. We are collaborating on a study to design, develop, and implement a minimum dataset for UK care homes such as that developed in the US for the Centers for Medicare and Medicaid Services.^{1,6} The learning from covid-19 will directly inform this work, and we intend that any minimum dataset built for UK care homes should be a resource to support residents' care and not just a tool for regulation or cost containment.

Musa et al. BMC Geriatrics (2022) 22:33
<https://doi.org/10.1186/s12872-021-02705-w>

BMC Geriatrics

RESEARCH Open Access

The uptake and use of a minimum data set (MDS) for older people living and dying in care homes: a realist review

Massirufulay Kpehe Musa¹, Gizdem Akdur², Sarah Brand³, Anne Killett⁴, Karen Spilsbury^{4,5}, Guy Peryer⁶, Jennifer Kirsty Burton^{7,8}, Adam Lee Gordon^{7,8}, Barbara Hanratty^{7,8}, Ann-Marie Towers^{11,9}, Lisa Irvine¹⁰, Sarah Kelly¹³, Liz Jones¹⁴, Julienne Meyer¹⁵ and Claire Goodman^{1,16}

Abstract
Background: Care homes provide long term care for older people. Countries with standardised approaches to residents' assessment, care planning and review (known as minimum data sets (MDS)) use the aggregate data to guide resource allocation, monitor quality, and for research. Less is known about how an MDS affects how staff assess, provide and review residents' everyday care. The review aimed to develop a theory-driven understanding of how care home staff can effectively implement and use MDS to plan and deliver care for residents.

QUALITATIVE PAPER

Contextual factors influencing complex intervention research processes in care homes: a systematic review and framework synthesis

GUY PERYER^{1,2}, SARAH KELLY^{3,4}, JESSICA BLAKE⁵, JENNIFER K. BURTON⁶, LISA IRVINE⁵, ANDY COWAN³, GIZDEM AKDUR⁵, ANNE KILLETT^{1,2}, SARAH L. BRAND^{7,8}, MASSIRUFULAY KPEHE MUSA⁵, JULIENNE MEYER⁹, ADAM L. GORDON^{10,11}, CLAIRE GOODMAN^{5,2}

¹School of Health Sciences, University of East Anglia, Norwich Research Park, Norwich NR4 7TJ, UK
²NiHR Applied Research Collaboration, East of England, England, UK
³Cambridge Public Health, University of Cambridge, East Forvie Site, Cambridge CB2 0SZ, UK
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⁵Centre for Research in Public Health and Community Care, University of Hertfordshire, Hatfield, UK
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Developing a minimum data set for older adult care homes in the UK: exploring the concept and defining early core principles

Jennifer Kirsty Burton, Arne Timon Wolters, Ann-Marie Towers, Liz Jones, Julienne Meyer, Adam Lee Gordon, Lisa Irvine, Barbara Hanratty, Karen Spilsbury, Guy Peryer, Stacey Rand, Anne Killett, Gizdem Akdur, Stephen Allan, Priti Biswas, Claire Goodman

Reforms to social care in response to the COVID-19 pandemic, in the UK and internationally, place data at the heart of proposed innovations and solutions. The principles are not well established of what constitutes core, or minimum, data to support care home residents. Often, what is included privileges data on resident health over day-to-day care priorities and quality of life. This Personal View argues for evidence-based principles on which to base the development of a minimum data set (MDS) for care homes. Co-produced work involving care home staff and older people and stakeholders is required to define and agree the format, content, structure, and operationalisation of the minimum data set, and its usability. Care home staff who collect the data need to benefit from the MDS and see value in its use, and residents must derive benefit from data collection and synthesis.



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 Institute of Cardiovascular and Medical Sciences, University of Glasgow, Glasgow Royal Infirmary, Glasgow, UK (J K Burton PhD); Improvements in Health Services Unit, The Health Foundation, London, UK (A T Wolters MSc); Centre for Health Services Studies (A M Towers MSc) and Personalised Care Research Unit

Irvine et al. Trials (2021) 22:157
<https://doi.org/10.1186/s13061-021-03107-w>

STUDY PROTOCOL Open Access

Protocol for the development of a repository of individual participant data from randomised controlled trials conducted in adult care homes (the Virtual International Care Homes Trials Archive (VICTHA))

Lisa Irvine¹, Jennifer Kirsty Burton², Myzoon Ali³, Terence J. Quinn⁴ and Claire Goodman^{1,5}

Abstract
Background: Approximately 418,000 people live in care homes in the UK, yet accessible, robust data on care home populations and organisation are lacking. This hampers our ability to plan, allocate resources or prevent risk. Large randomised controlled trials (RCTs) conducted in care homes offer a potential solution. The value of detailed data



Developing resources And minimum data set for Care Homes' Adoption

DACHA WEBINAR SERIES



13th



12:00 TO 13:30



Online

NIHR | Applied Research Collaboration
East of England

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Summary

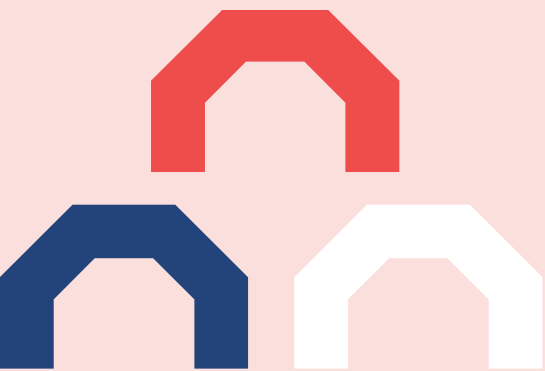
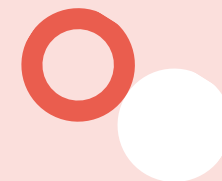
- Addressed underserved area of research with care homes' interests and needs at the centre
- Encouraged collaboration and priority setting
- Built capacity and grant capture
- Infrastructure of support, expertise and interest nested within national ARC theme for ageing and dementia
- Care homes valued research partners



Thank you!

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ARC Care Home network: Krystal Warmoth
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Optimising digital health tools for sleep and fatigue in NHS ambulance staff: from SleepSmart to CATNAPS



Dr Chiara Lombardo & Professor Kristy Sanderson
Mental Health over the Life Course Theme, UEA



Plan of presentation

- My research journey
- Why sleep in the ambulance sector
- From SleepSmart to CATNAPS
- Preventative approaches to sleep management at work

My Research Journey

- Public Mental Health Researcher
- How can MH services can be improved for the benefits of patients, their families and friend and staff? *CLAHRC EoE*
- How structural inequalities impact the mental health of individuals and the communities where they live? *MHF*
- What mechanisms can we put in place to improve work conditions in the emergency sector? *UEA*

Why the Ambulance Sector?



Increased risk of a range of poorer health outcomes

Increased risk of suicide in comparison to both the general workforce (x2-x4) and other emergency service occupations

Perform consistently worse than other health sectors on staff experience including engagement, sickness absenteeism, morale



From SleepSmart to CATNAPS

Scope of the Study

First study in UK looking at sleep quality and fatigue in ambulance staff using clinically relevant measures in one Trust

Headline results

Data collected from 689 staff
60% reported clinically important levels of mental and physical fatigue, 75% reported poor sleep quality

Fatigued staff were more likely to report being injured and to feeling unsafe at scene

No NHS ambulance trust in England had a fatigue management policy

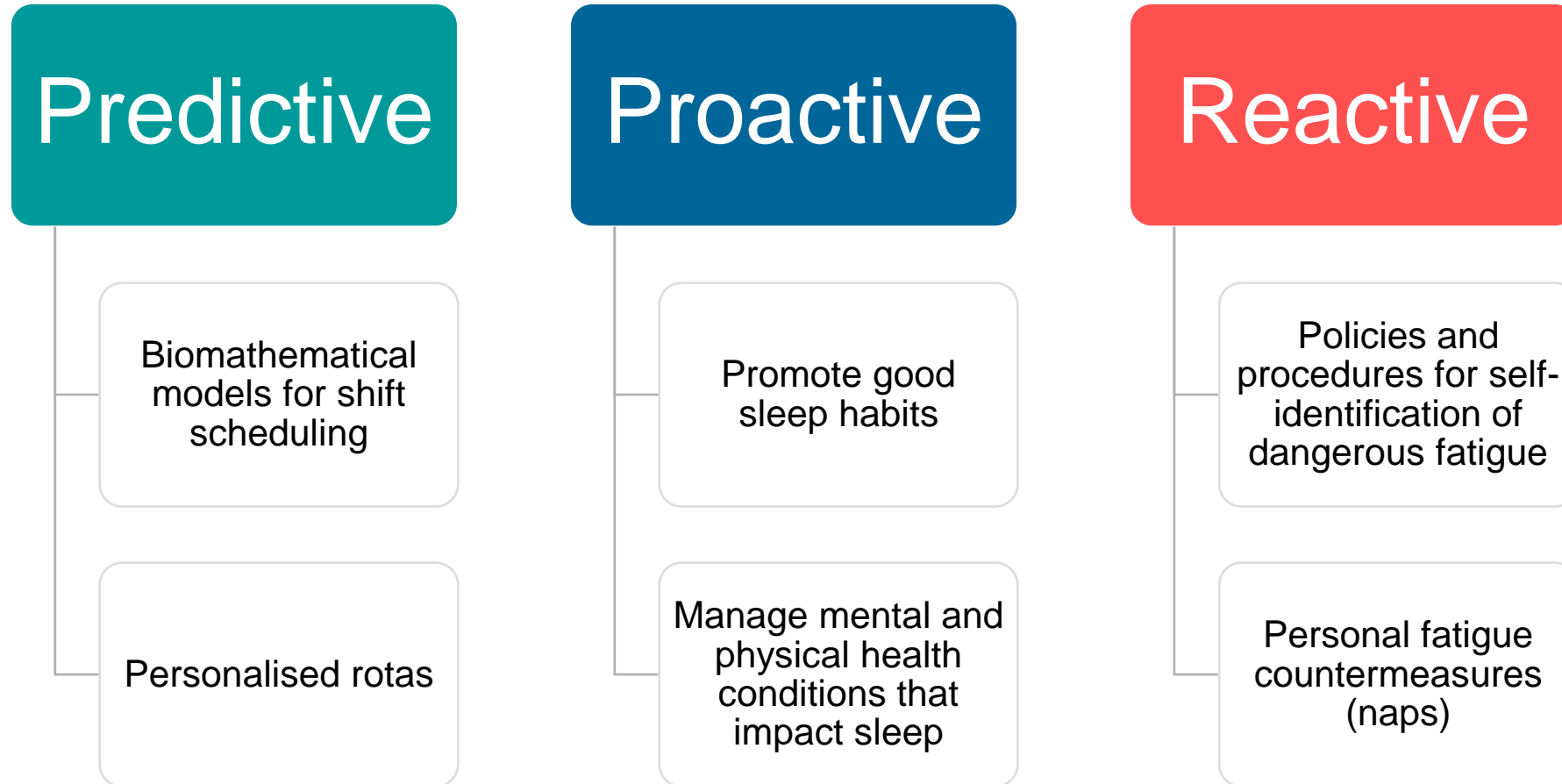
Next steps

Develop new national study

Coproduce and implement a fatigue and risk framework with stakeholders involved in managing sleep and fatigue

Focus on public health approaches

Public health approach to sleep health: examples



CATNAPS: building a coalition of the willing



*Fatigue Risk Management Systems

CATNAPS: how can we make a difference?

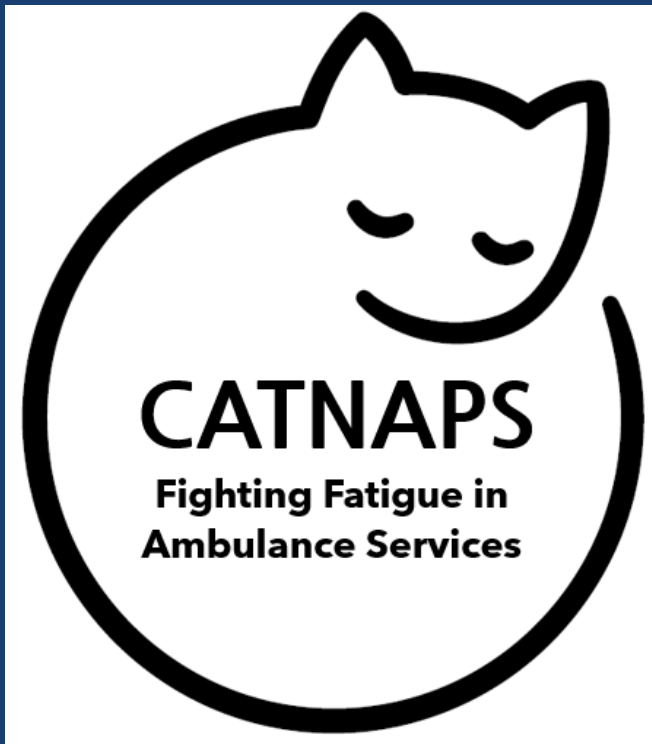


Identify best practice in fatigue management

Identify what is currently done in NHS ambulance

How to make change happen

Design an implementation strategy based on what staff and patients have told us will help make strategies fit for purpose for ambulance sector and for different staff/settings, feasibility test

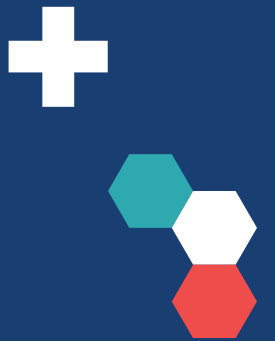


If you'd like to stay in touch with the study please do contact us:

catnaps.study@uea.ac.uk

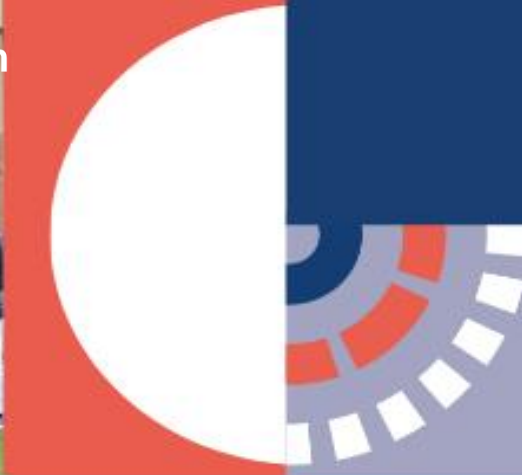
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