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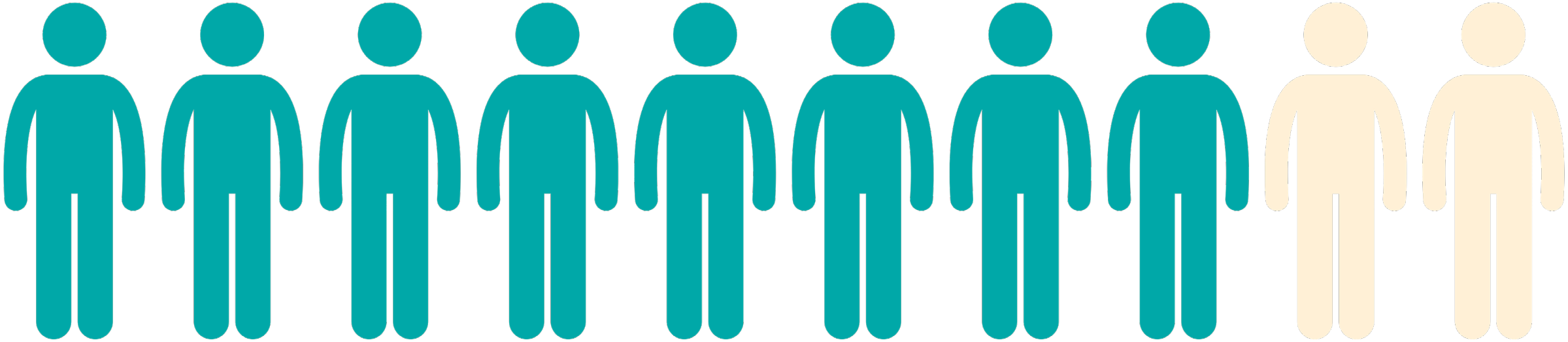
Can Mortality be Predicted for People With Multiple Long-term Conditions - Multimorbidity (MLTC—M)?

Dr Elizabeth Westhead, Dr Felicity Dewhurst, Prof. Barbara Hanratty

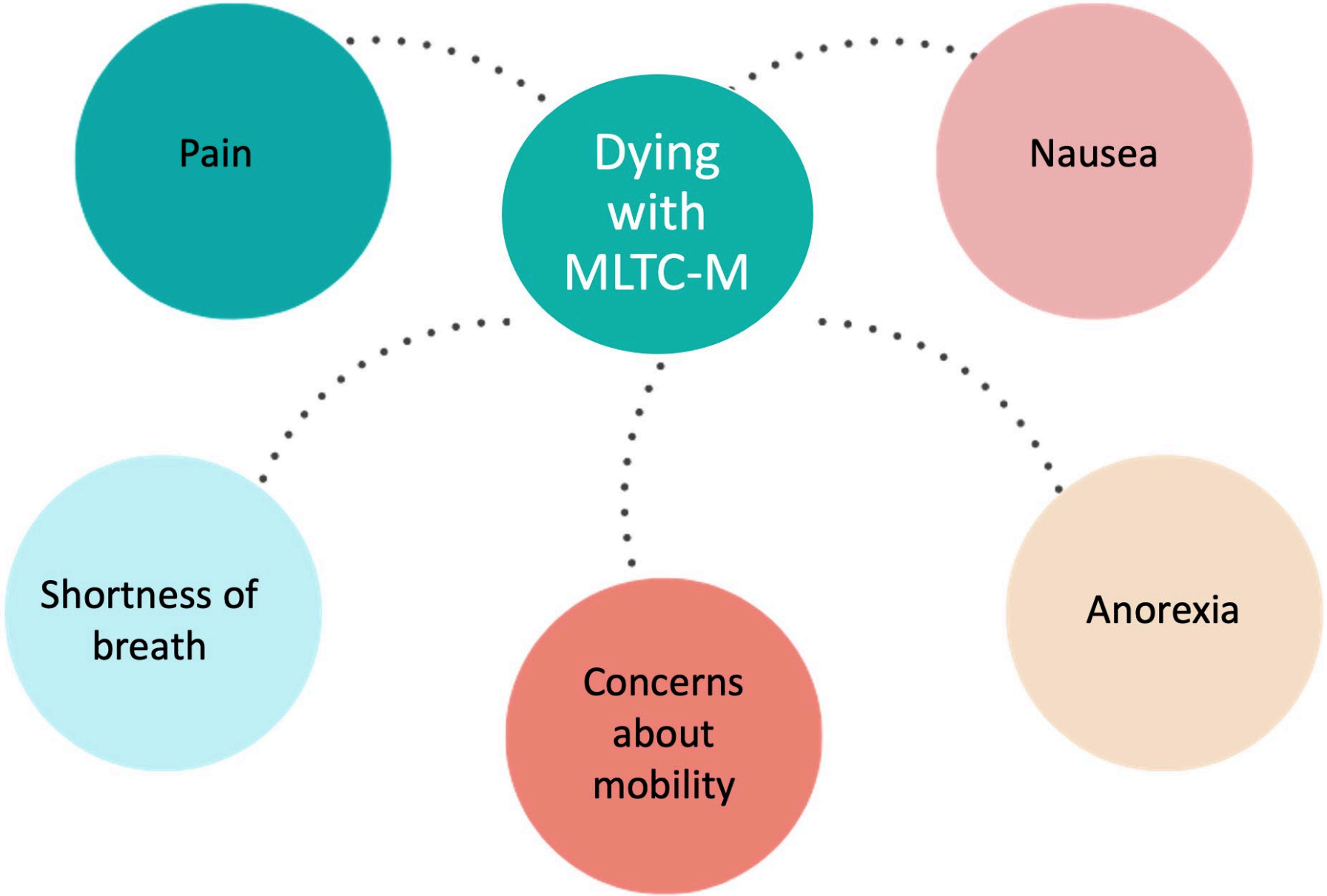
Background

Background

81% of the over 85's have MLTC-M

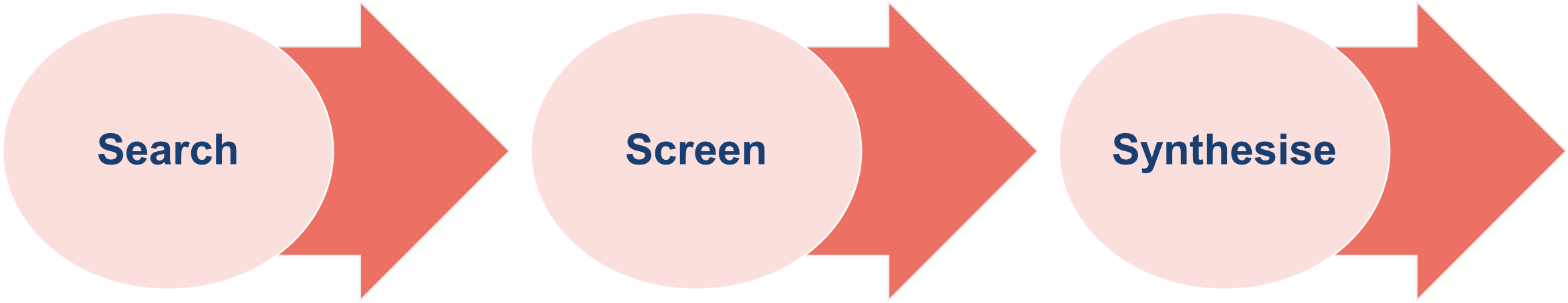


By 2040, most deaths will be in the over 85s

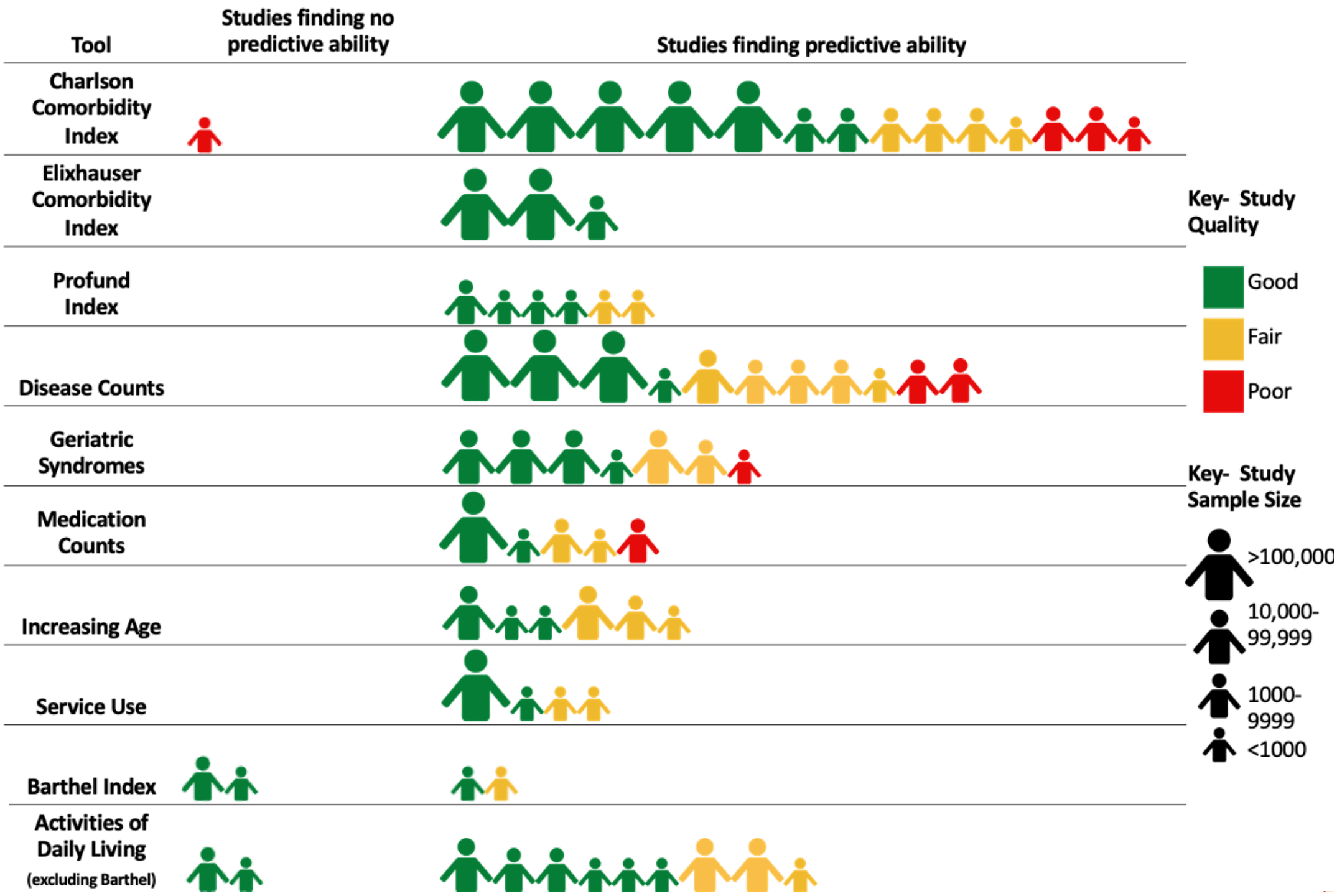

Pain
Dying with MLTC-M
Nausea
Shortness of breath
Concerns about mobility
Anorexia

Aim & Methods

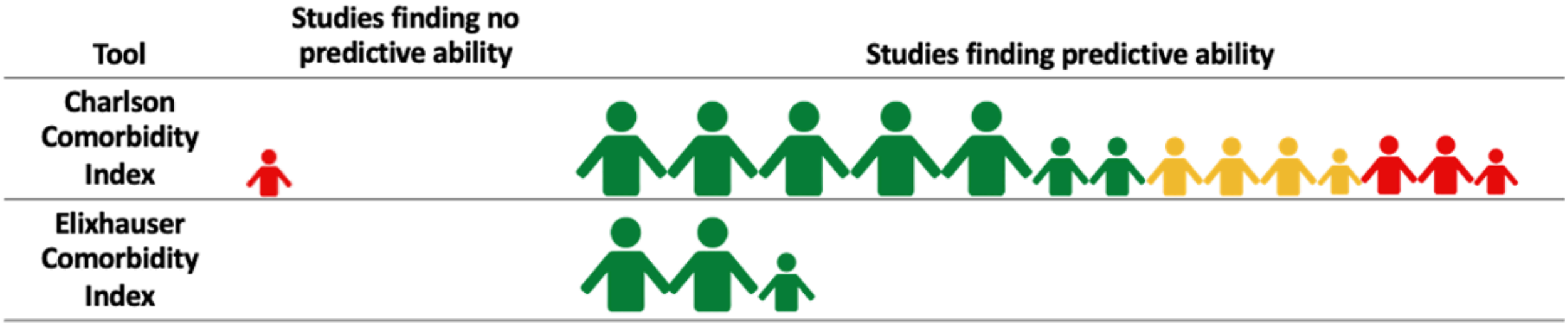
Synthesise the evidence on the ability of currently available tools and approaches to prognosticate at the end-of-life for people with MLTC-M



Findings

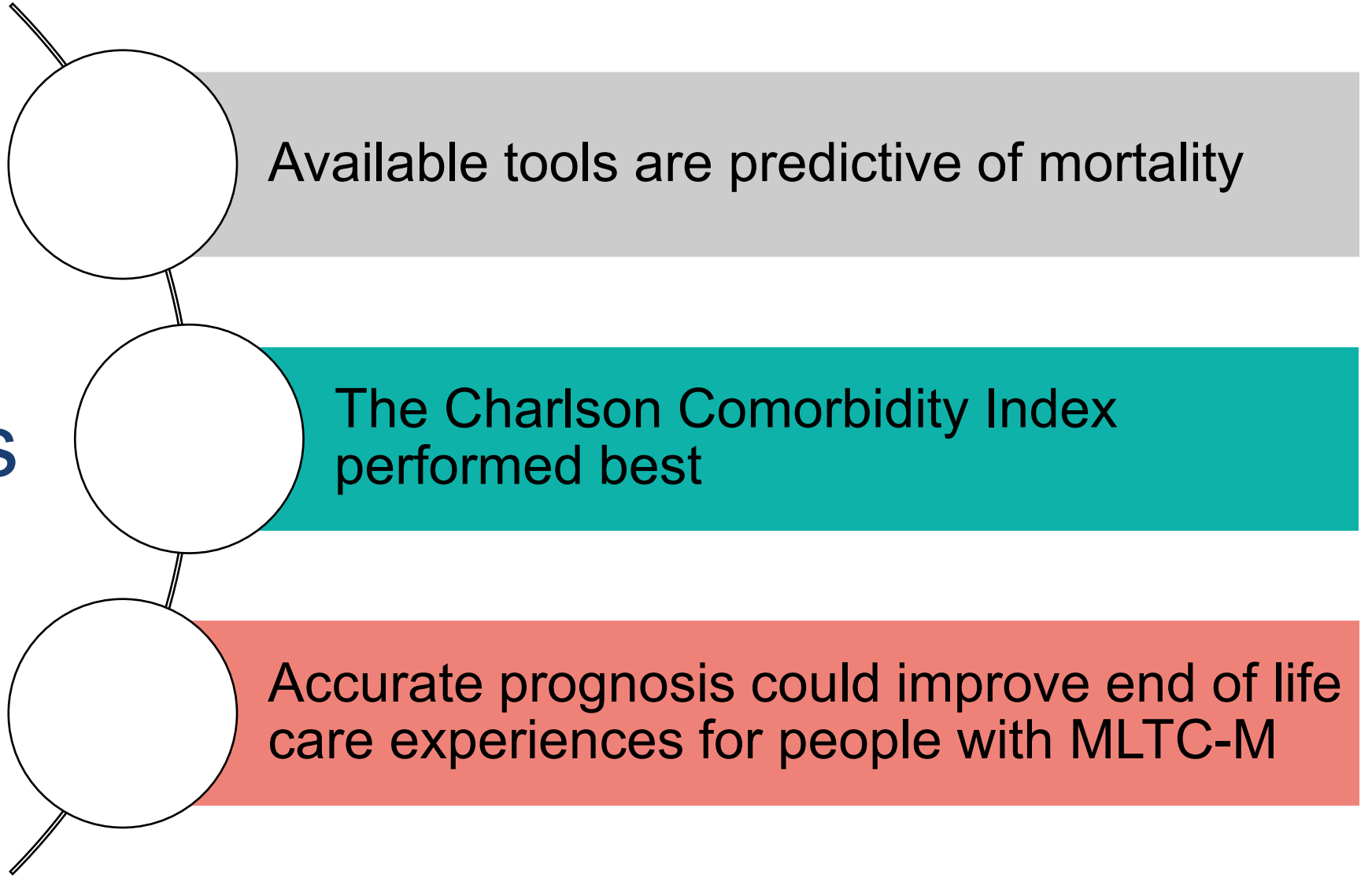

Tool
Studies finding no predictive ability
Studies finding predictive ability
Charlson Comorbidity Index
Elixhauser Comorbidity Index
Profund Index
Disease Counts
Geriatric Syndromes
Medication Counts
Increasing Age
Service Use
Barthel Index
Activities of Daily Living (excluding Barthel)
Key- Study Quality
Good
Fair
Poor
Key- Study Sample Size
>100,000
10,000-99,999
1000-9999
<1000

Weighted Indices



Conclusions

Conclusions



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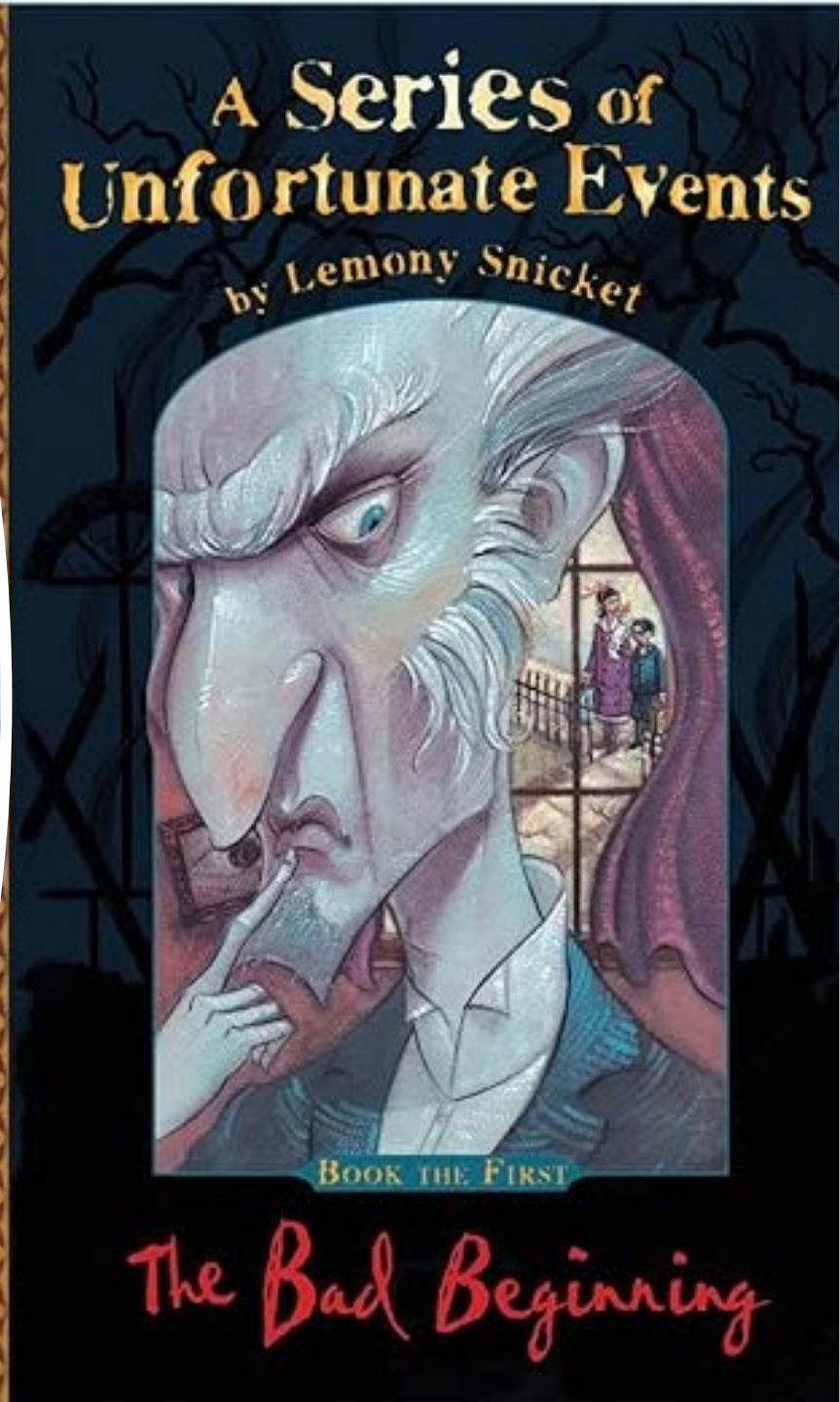
Exploring the factors that influence hope in those with an uncertain prognosis. A qualitative study

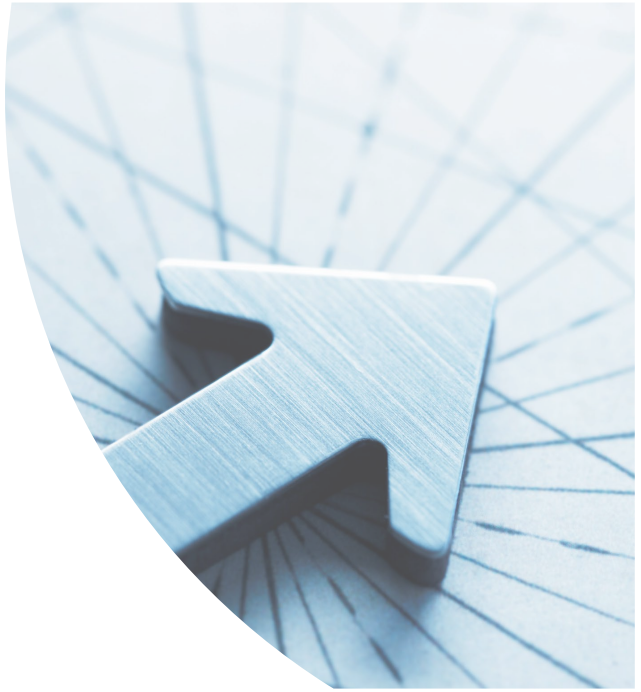
Dr Amy Huggin

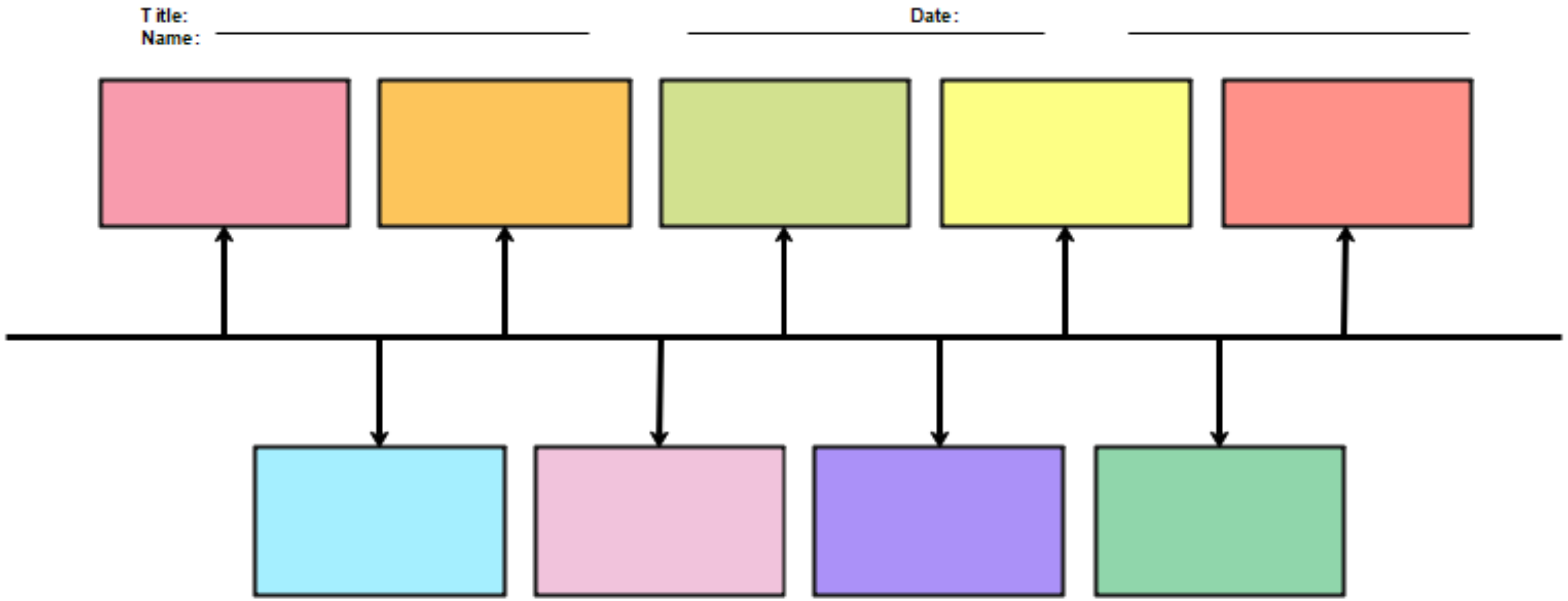
Dissemination Event

16th April 2024

HOW?

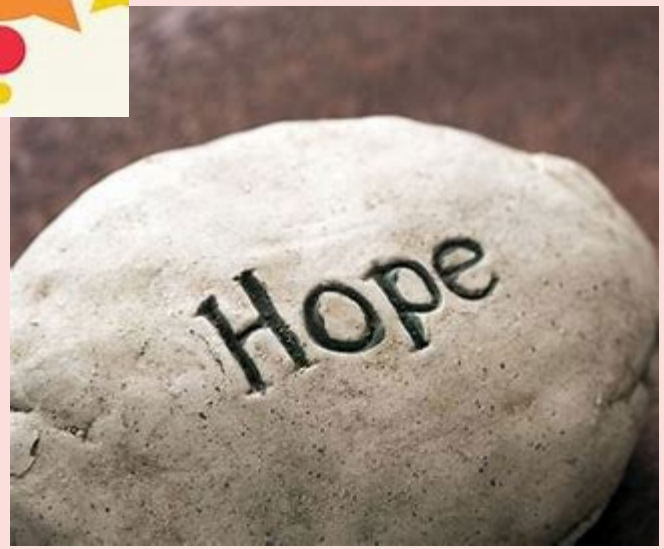

A Series of Unfortunate Events
by Lemony Snicket
Book the First
The Bad Beginning





WHAT?

WHEN?



Thank You

Dr Amy Huggin

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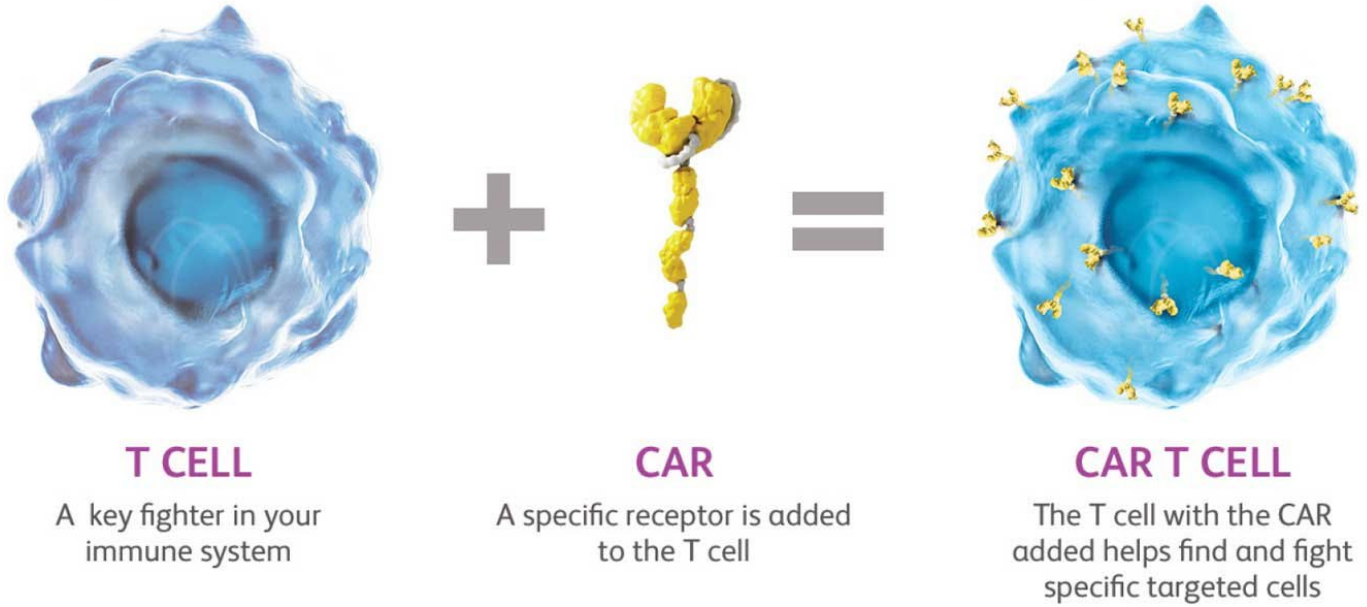
Patient Experiences of CAR-T

Charlotte Stenson

Academic Clinical Fellow in Palliative Medicine
Internal Medicine Trainee



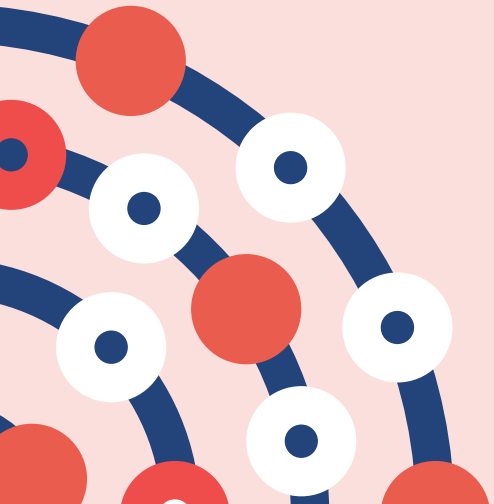
CAR-T therapy, available at: https://www.bms.com/media/media-library/scientific-media-resources/targeting-cancer-with-cell-therapy.html

The Patient Group

High treatment burden

High symptom burden

Median overall survival of 6 months



Crump M, et al. Blood 2017;130:1800–8

What is the patient and carer experience of CAR-T?

Phase 1

qualitative service evaluation

Phase 2

multi-centre longitudinal qualitative study

’The Rollercoaster’

If it comes back in four/five years’ time there will be another trial, then I’ll take that trial, get back in remission for two years, but it’s a vicious circle. (Patient)

Expectations: balancing hope, realism and resignation

I don’t think I had a choice really. . .it was that or you won’t be here much longer. (Patient)

‘a euphoria in having a direction to go in, a positive direction’ (Patient)

Navigating treatment side-effects and impact

A lot of her time has been involved in coming down for blood tests all the time. . ...it feels like she’s having less and less time at home, for me that’s how I see it. (Caregiver)

Coping with uncertainty

It’s just the thought that if I get [into remission] will it be long lasting, will I have to go down another route and can I emotionally cope with that anymore? (Patient)

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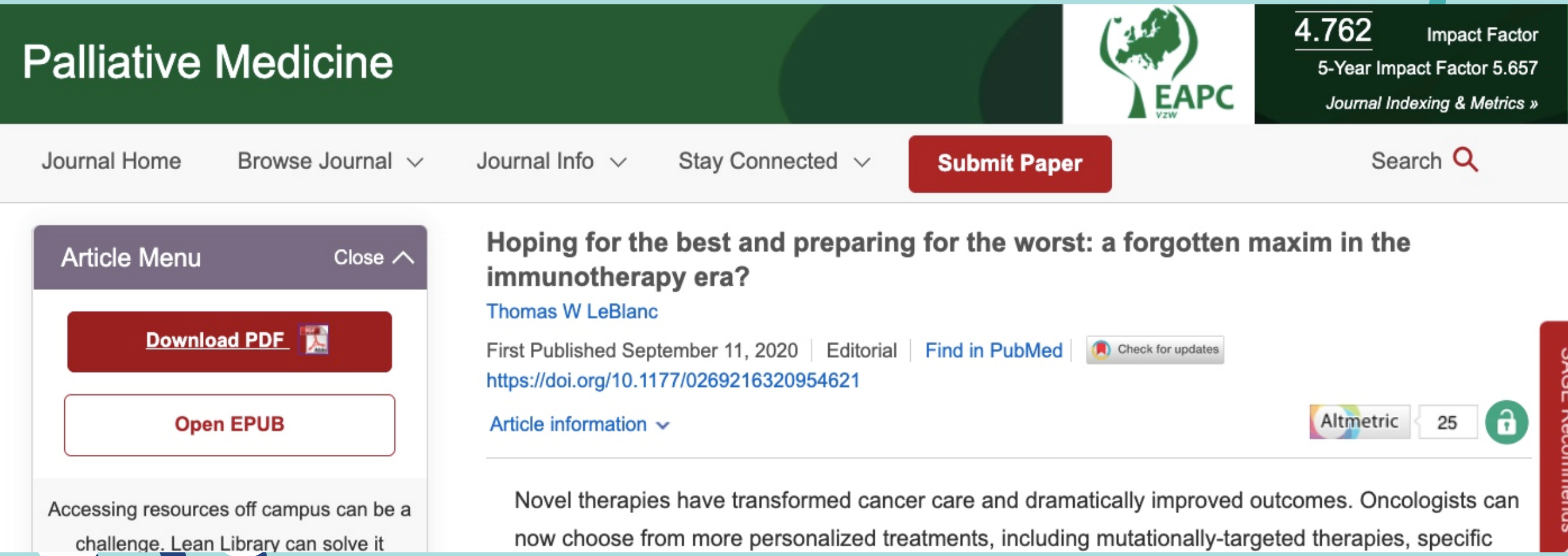
Implications for Palliative Care Services



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Acknowledgements

With thanks to the patients and carers who took part in interviews

Jennifer Vidrine

Felicity Dewhurst

Rachel Stocker

Laura Barnes

Tobias Menne, Wendy Osborne, Hannah Kennedy and the rest of the

Haematology team at the Freeman

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Research In Palliative and End of life care Network: North East (RIPEN NE)

Lucy Robinson

16th April 2024

What matters most?

Exploring the end-of-life care preferences of older people living with frailty

Dr Lucy Robinson

Professor Barbara Hanratty

Dr Katie Frew

Professor Paul Paes

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Preferences

Person Centred Care

Older people

End of life care

Frailty

labor

North East and North Cumbria

Study Aim

To explore how **end of life** health and social care **preferences** develop **over time** for the **oldest old**, and what influences this process.

Methodology

- Constructivist grounded theory

- Primary Care
  - Frailty score
  - No primary diagnosis of cancer

- Longitudinal over 6-18 months

Formulating preferences

It’s just something I never think about, no just go on and get on with life and enjoy it.

Theresa, 90+, severe frailty

Negotiating preference and choice over time

"I think if I got to that stage I don't know that I'd worry too much either way. If I needed permanent hospital care well I would just accept it. I wouldn't have much choice in the matter would I?"

Sally, 90+, moderate frailty, care home resident

Making decisions about death but not dying

"I don't think it's essential to prepare. You know, you can book your funeral if you want to. I've made a will. That's about as far as you can go."

Arthur 85-89, mild frailty

"…but it's difficult to say what one's health is going to be like."

Sally, 90+, moderate frailty, care home resident

Enduring sense of self

"I still enjoy looking on the farm, you know, watching what's going on and not interfering if I can help!"

William, 90+, severe frailty

"Well, our [Daughter] will say, 'Mam, I'll do this. I'll do that,' and honestly, I think to myself I'll give it a go before she comes because I think whey she's working every day as well you know"

Ellie, 85-89, mild to moderate frailty

Conclusions

- Cultural influences and preferences close to death
- Limitations of decision based advance care planning
  - Relationship building
  - Enhancing choice
  - Understanding and maintaining sense of self

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- Older people & Preferences: Centre for better ageing (licence CC0 1.0 Universal)
- End of life care: "Loretta Downs" by On Being is licensed with CC BY-NC-SA 2.0. To view a copy of this license, visit https://creativecommons.org/licenses/by-nc-sa/2.0/
- Frailty: Rockwood et al. A global clinical measure of fitness and frailty in elderly people. CMAJ 2005;173:489-495.

Northumbria University NEWCASTLE

NHS North Tees and Hartlepool NHS Foundation Trust

Discussing preferred place of death during the final hospital admission; exploring the experience of these discussions from the perspective of bereaved informal care givers and staff.

Zoe Booth – Palliative and End of Life Care Lead/PhD student

Supervisors – Dr Joanne Atkinson and Dr Wallace Chan

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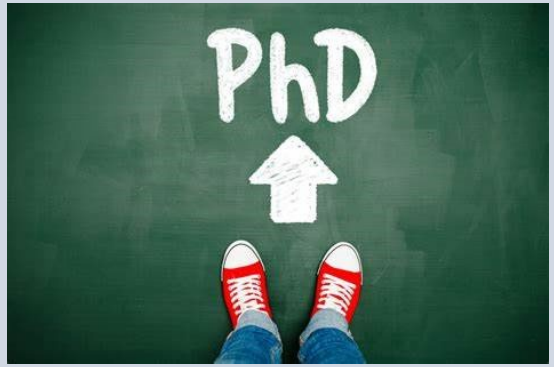
- **2008 – Started specialist palliative care career – interest in choice and options with regards to preferred place of death and achievement of these**
- **2010 – Hospital SPCT - raised interest in 'rapid discharge home from hospital'**
- **2012 – MSc dissertation**

  " Is there evidence which supports the political and strategic claim that home is the preferred place of death for the majority of people reaching the end of their life in hospital?"

  Enough evidence to challenge the assumption that home is best
- **Interest grows in PEOLC discharge from hospital / available options /ethics**
- **2018 – Personal experience**
- **2020 – started part –time PhD**



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Research Aim

Explore the experience of discussing preferred place of death during the final hospital admission, from the perspective of, bereaved informal care givers and staff

Develop theory that may influence clinical care, education, service or strategic improvements and commissioning in this area of end of life care

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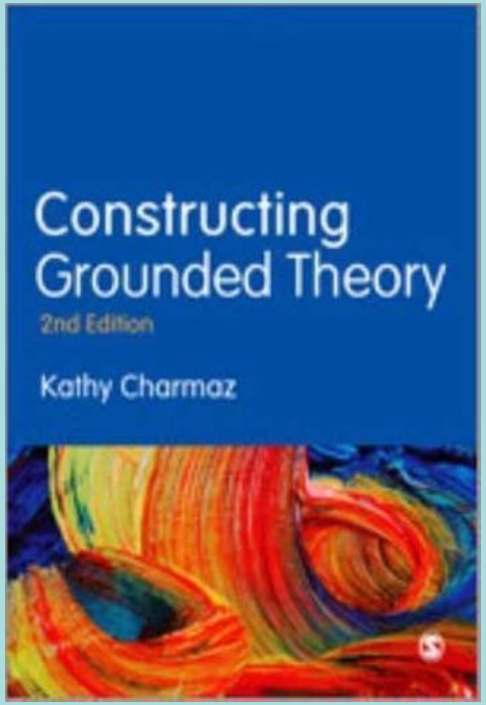
Constructivist Grounded Theory methodology – Charmaz 2014

Ethics

Recruitment

Semi structured interviews



Coding and further interviews through theoretical sampling

Thesis submission April 2026!

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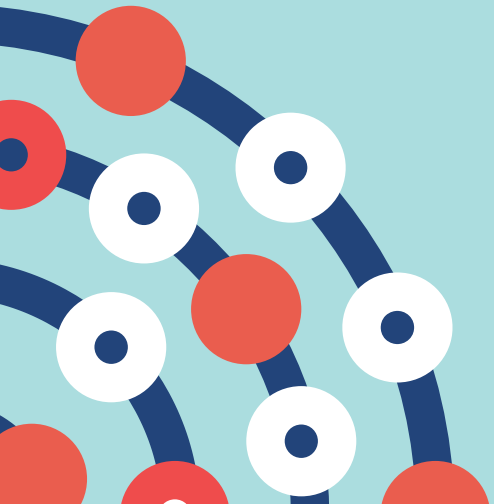
Patient and Public Involvement and Engagement

Founding a PPIE Group for the RIPEN Network



Workstream 5

Patient and public involvement (PPI)

A PPI partner group with representation from diverse faith groups and ethnically minoritised communities will help shape our research, and develop new ways of working that are fit for end-of-life and palliative care.

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NIHR | National Institute for Health and Care Research

Search

People in Research

Home | View Opportunities | Add Opportunity | About Public Involvement | Community Engagement Partnerships

Log in

My Favourite Opportunities (0) | Print

Opportunities for public involvement in NHS, public health and social care research in the United Kingdom.

Find opportunities

I want to get involved

For members of the public who would like to get involved in research.

Add opportunity

I want people involved

For researchers who want to find members of the public to get involved in their research.

There are lots of ways to be part of research

Every day thousands of patients, carers and the public go the extra mile to help make research happen. You could help by taking part in a study or trial, or by working in partnership with researchers to shape what research is done, how it's carried out, and how the results are shared.

Take part in a study or trial

Some studies examine new treatments, while others might involve interviews and surveys. Learn more about being part of a study and find the right study for you.

Work with research teams and organisations to shape research

Use our match-making service – People in Research – to find opportunities to work with research teams and input into how research is carried out.

Suggest a research topic

To make good decisions about what research to fund, we need to know which questions most need answering. This needs your perspective.

Forming a PPIE group for RIPEN

Step 5: engagement

1. Advice about projects already funded.
2. Scoping possibilities for future research attention.

‘Away Day’ to scope research ideas

Meeting researchers to discuss & advise

Step 4: defining the task

Step 3: the call for members - invitation

Intentionally culturally diverse to reduce likelihood of ‘samethink’

Step 2: Understanding the task

Step 1: co-opting two co-chairs

Complementary skills & experience.
Low diversity

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Meet research leads. Welcome additional members with different perspectives. Review ToR

Step 6: review & adjust

Step 5: engagement

Step 4: defining the task

Step 3: the call for members - invitation

Step 2: Understanding the task

Step 1: co-opting two co-chairs

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Our Reflections...

1. We have created a mutually respectful group of people from diverse cultural, employment, age, care-experience and educational backgrounds, that is ready and willing to take on a greater role.
2. There was a ‘learning phase’ during which some members felt impeded by their lack of specialist knowledge of palliative care. Some members would have welcomed a practical orientation with hospice and hospital visits.
3. Members felt that their ideas and perspectives were listened to and valued both by other group members and by research teams.

Our Reflections…

4. The purpose of the group was initially unclear: after being invited to form an ‘umbrella group’ to scope direction and focus of research projects, much of the group’s work was was confined to input on projects already written and funded, or written and seeking funding. This left little scope for co-production.
5. The group held an afternoon to focus on areas for research development: they reached wide-ranging suggestions for broader public engagement, and a variety of research questions about end-of-life care inequities, public understanding of dying, the place of dying in school pupils’ (and their teachers’) education and bereavement-readiness of schools.

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Our Reflections...

Harnessing the insights and perspectives of people served by the services that are investigating how to improve themselves is essential. This is the purpose of PPIE.

However, the tight deadlines for grant applications and the 'steer' of funding calls towards the funders' priorities rather than local needs undermines co-production of locally-relevant research topics or individual projects.

This is a new research network that is learning how to design a research strategy and how to harness public willingness to engage in co-production. That offers us an opportunity to engage public input into the overall strategy as well as into individual projects, and also to observe and learn about public engagement.

Learning about PPI development

- Creating an overarching PPI Group for the Network and not for an individual project required a different approach
- Need for clarity about chair/co-chair/co-ordinator etc.
- Online & hybrid meetings increased inclusion & accessibility
- Importance of creating a safe and collaborative space/ ethos led by the Chair
- Overarching PPI Group has not necessarily resulted in consistent PPI in the individual research projects but has established an expectation & standards
- Co-production needs to be at the heart of everything

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Our Reflections...

6. In the future, group members recommend:
   - More structured induction to the group, the RIPEN/ARC structure, awareness of the time commitment involved. Understanding of the time-line frustrations of bidding for project funding.
   - 'Foundational PPIE' – public engagement to co-produce the overall research vision for the Network, so that projects are envisioned, developed and 'bid-ready' with public/patient/service user/service not-yet-user input from inception
   - Project-specific PPIE – public engagement to co-work with investigation teams, developing the input of the Foundational PPIE co-workers and acting as research collaborators and co-producers for the life of each project

PPIE Ideas Event - Outputs 1

- Multiverse Lab methodology
- Young people: we need CYP's advice about what works to reach them
- Death Cafes
- Community events: arranged in, and by, those communities
- Creation of a drama 'The Thought Police' – what it's permissible/not permissible to talk about

- A 'Death Festival' (established in a few places around the UK)
- could start with a stand in Festivals already arranged? ?Newcastle Mela – we'd need the right cultural links, and to ensure that the stall is staffed by people who can help interpret our intentions.

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PPIE Ideas Event - Outputs 2

Public understanding of dying:

- How do we improve it?
- How does that impact ACP?

Cultural inequities

- What cultural & spiritual needs are there towards, at and after the end of someone's life? How are they addressed from within communities as well as by 'services' ?
- What can service providers learn from community-based support and traditions? Are there gaps? How might those gaps be addressed?

Schools and death/grief:

- Are schools bereavement-ready?
- What are teachers taught about supporting bereaved children in school?
- What are teachers' worries about dealing with bereaved pupils (1 in 24 students, estimate, UK)? Can we work with our PGCE/ B.Ed./ M.Ed providers locally to get better at this?

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Our Reflections...

Mission Statement:

The role of the NIHR Regional PPI Group is to generate curiosity and momentum about the overlooked areas of palliative and end of life care research, and the translation of that research into practice that serves all the residents of our region equitably.

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The RIPEN PPIE Group

Aharon Sandler
Barbara Hanratty
Bryan Vernon
Felicity Shenton
Kathryn Mannix
Khaled Musharraf
Veena Soni
Andy Lie
Bryan Beverley
Fariba Hedayati
Gaby Gitoko
Katie Frew
Olivia Grant

With support from Tom Ewen, Tegan Davison and Anosua Mitra.

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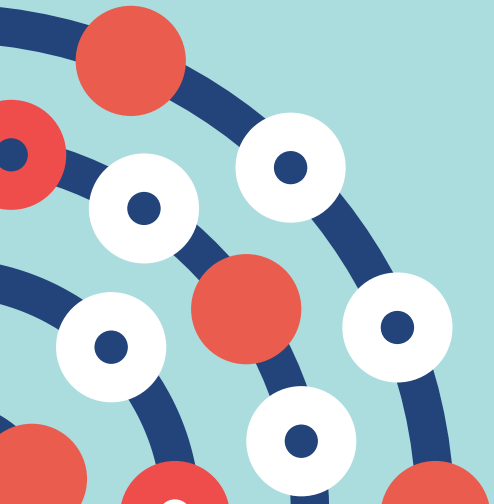

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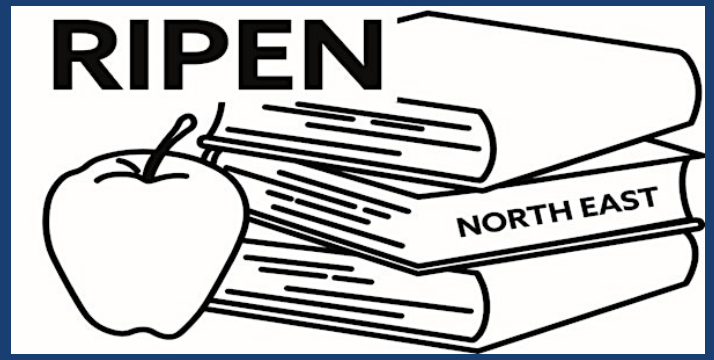
Research **I**n **P**alliative & End-of-life-care **N**etwork (RIPEN) **North East**



Donna Wakefield

16th April 2024

Understanding and addressing **inequalities** in access to **palliative care** for those with **lung disease**; does the inverse care law apply?

Dr Donna Wakefield *Consultant in Palliative Medicine*

FUNDED BY
NIHR | National Institute for Health and Care Research

HULL YORK MEDICAL SCHOOL

NHS North Tees and Hartlepool NHS Foundation Trust

Newcastle University

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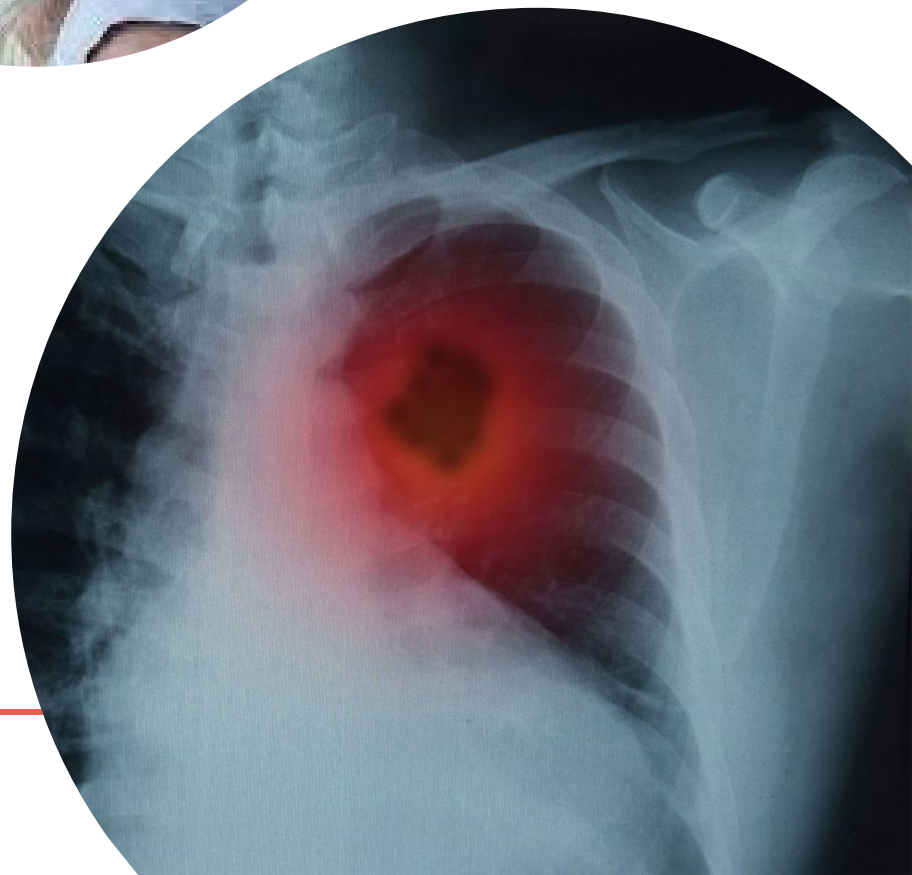
Advanced lung disease

- Lung cancer is the commonest cause of cancer-related deaths in England & Wales (28,570 in 2022)
- Initially planned to focus on lung malignancy (including mesothelioma)- PPI discussion highlighted importance of including non-malignant lung disease.
- COPD mortality, 29,815 deaths in 2022 (5.2% of all deaths).
- Progressive illnesses with a high symptom burden, impacting on QoL

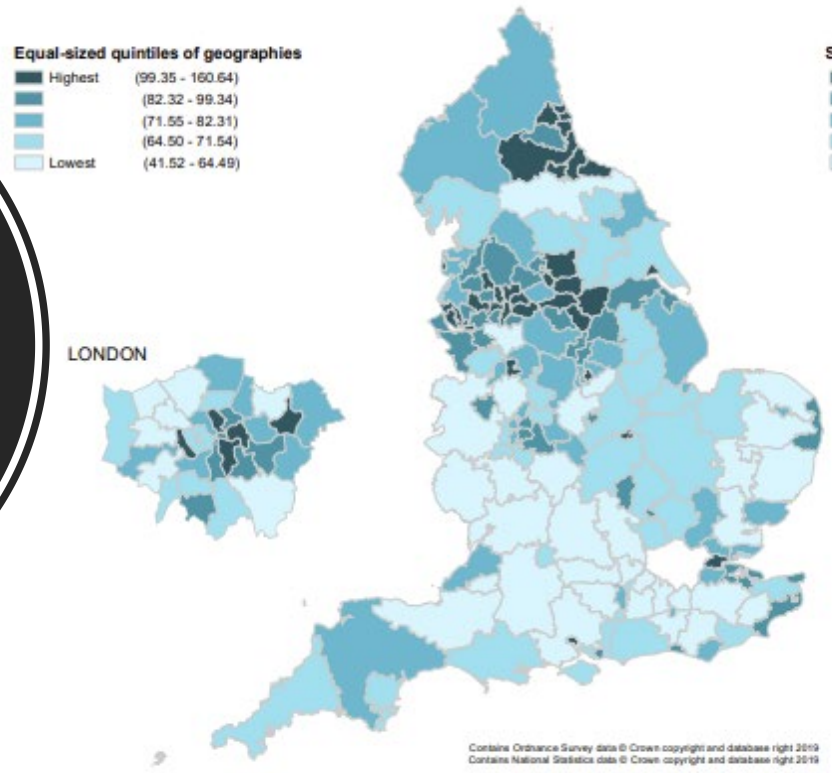


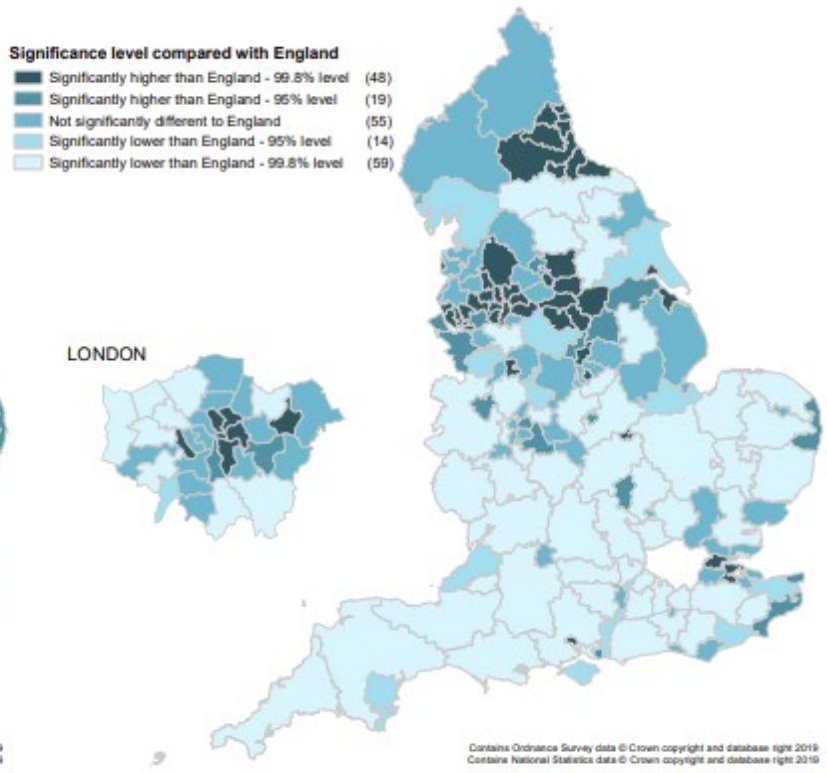
Lung disease-incidence not evenly spread…..

Map 29a: Variation in incidence rate of lung cancer per population by CCG (2015-2017)

Directly standardised rate per 100,000

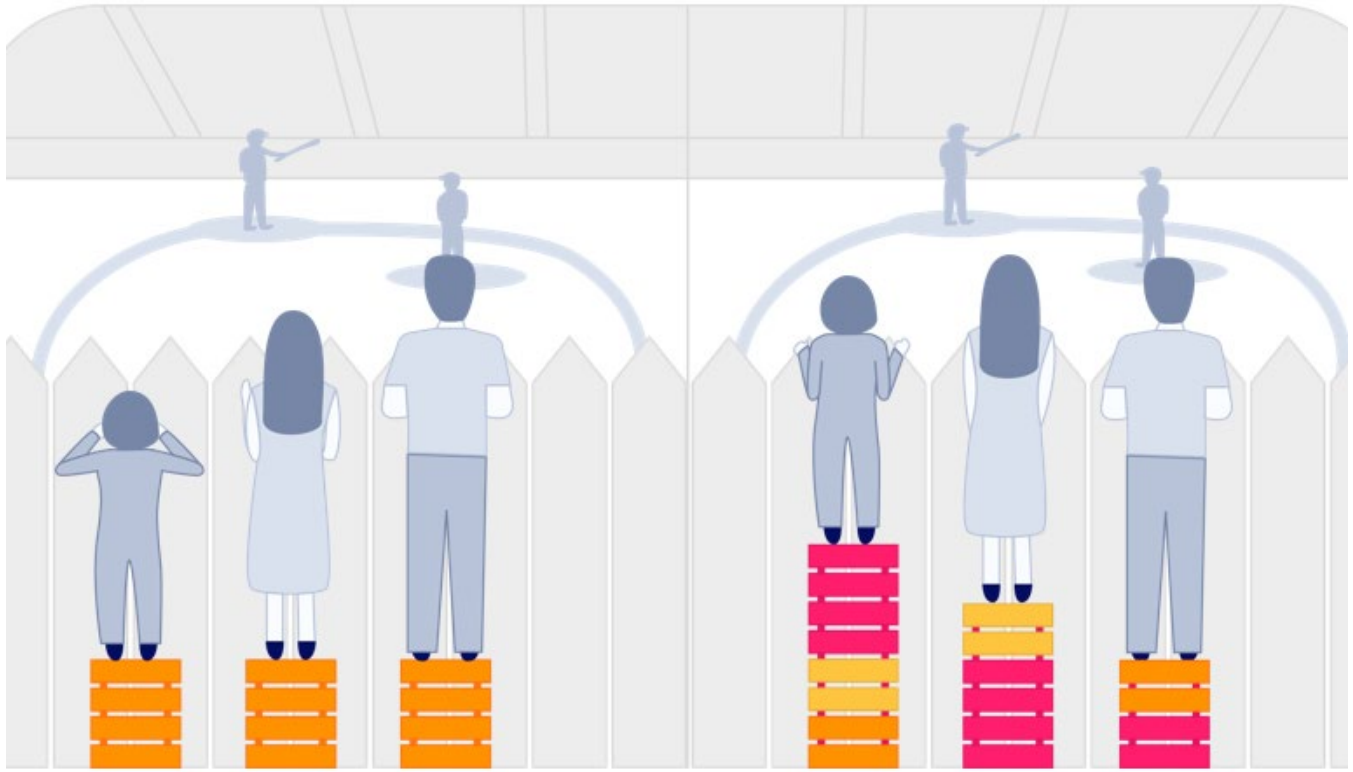
Optimum value: Low





Health inequalities- *the broader picture*

- INEQUALITIES are differences between different groups of people
- INEQUITY makes a judgement that these differences are unjust and unfair.
- Picture on the left represents EQUALITY – everyone gets the same put in…..
- The right represents EQUITY- focuses on getting the same OUTPUT, where people get what they *need* to achieve this.



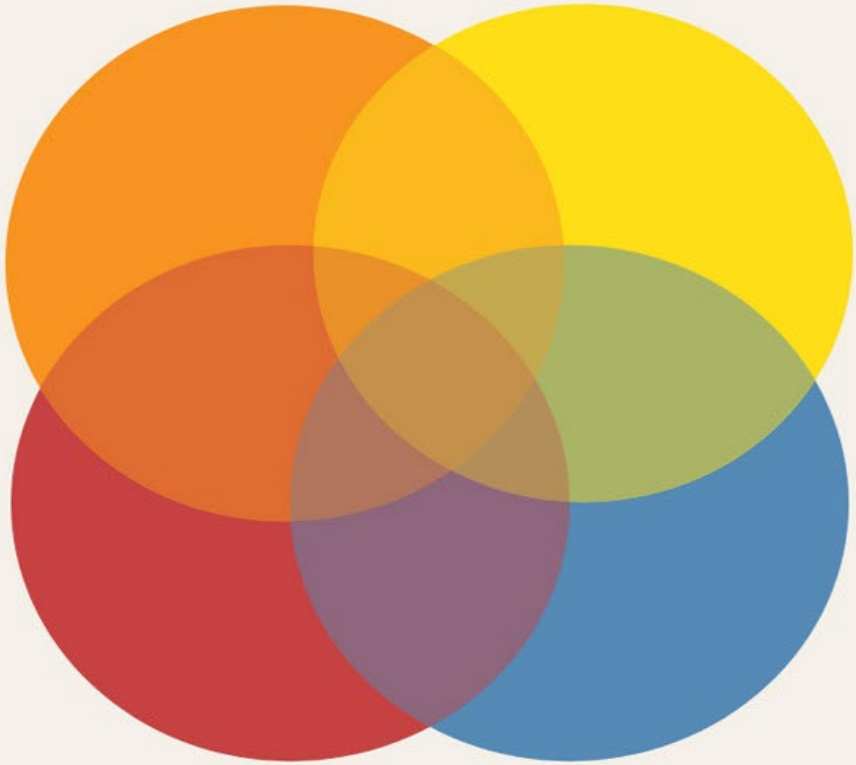
Health inequalities & intersectionality

Socio-economic factors such as:

- Income
- Education

Geography, for example:

- Region



Specific characteristics, for example:

- **Ethnicity**
- **Sexuality**
- **Gender**

Other *socially disadvantaged* groups, for example:

- People experiencing Homelessness

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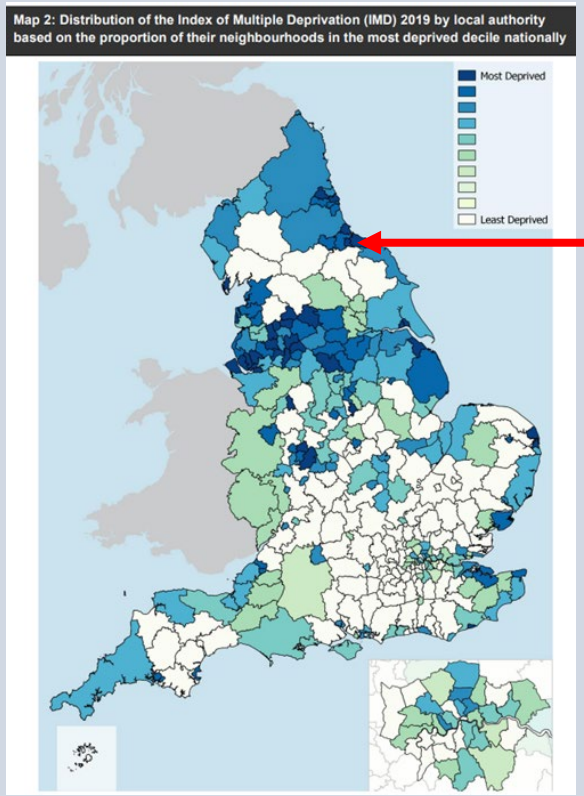
Focus on **socio-economic** & **geographical** inequalities



Tees Valley ICP

- Hartlepool
- Stockton
- Middlesbrough

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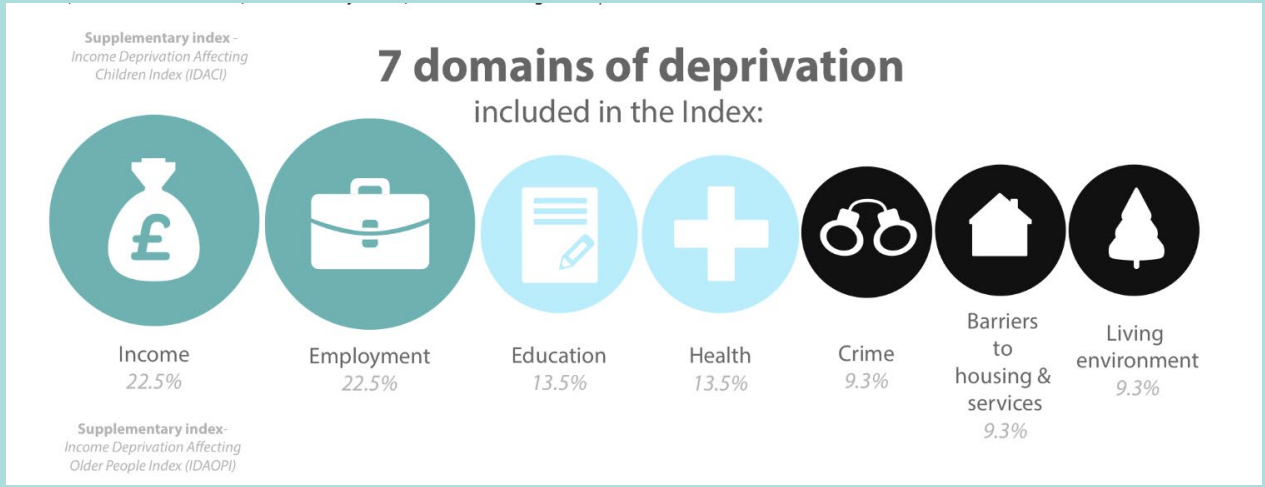
Driven by my own lived-experience

Health Inequalities due to SES

Less wealth= Worse health

Can be complex to measure…..



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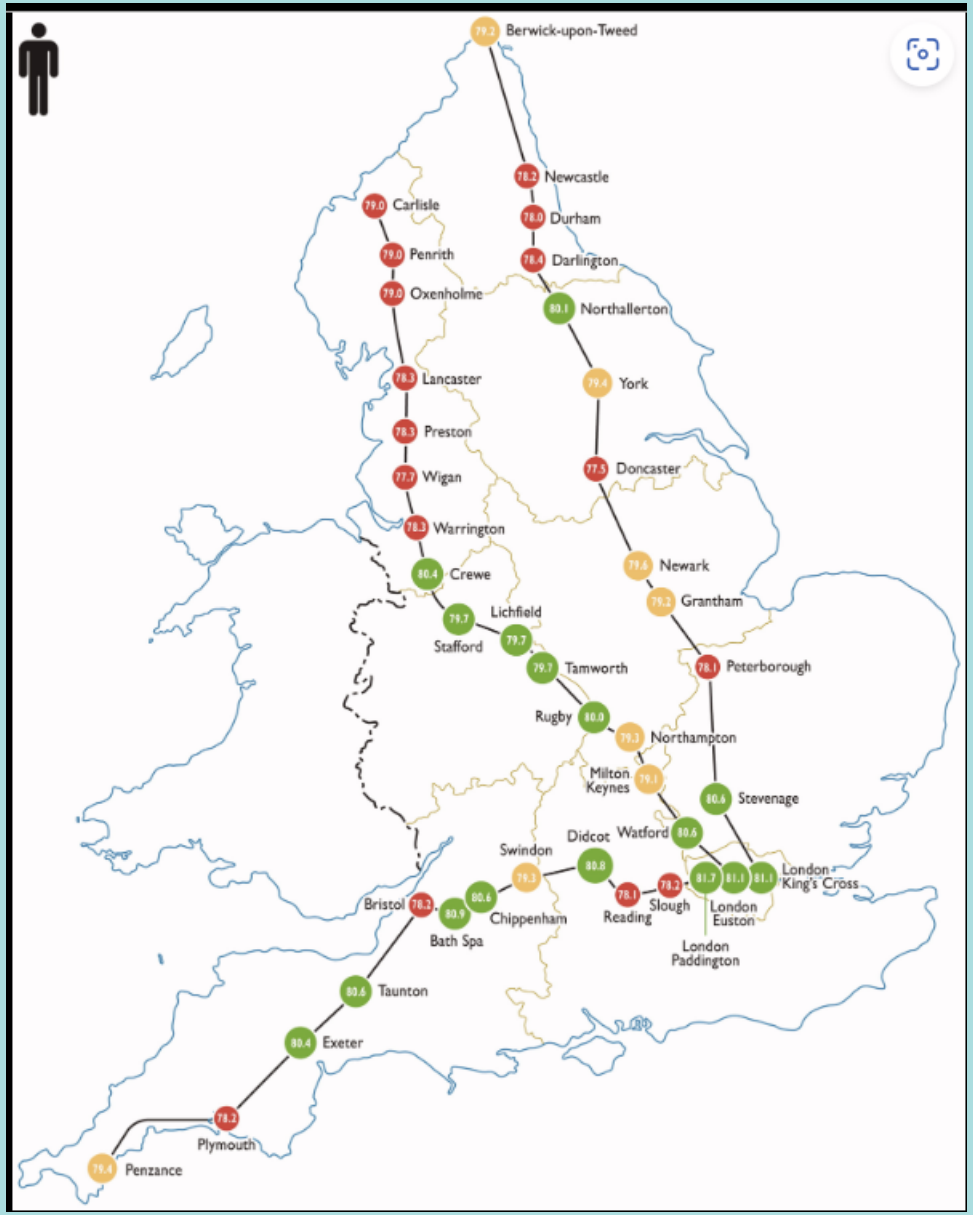
Regional Health Inequalities

- **North/South Divide**

Average life expectancy at birth is lower in the north compared to south, even when comparing areas with similar deprivation levels



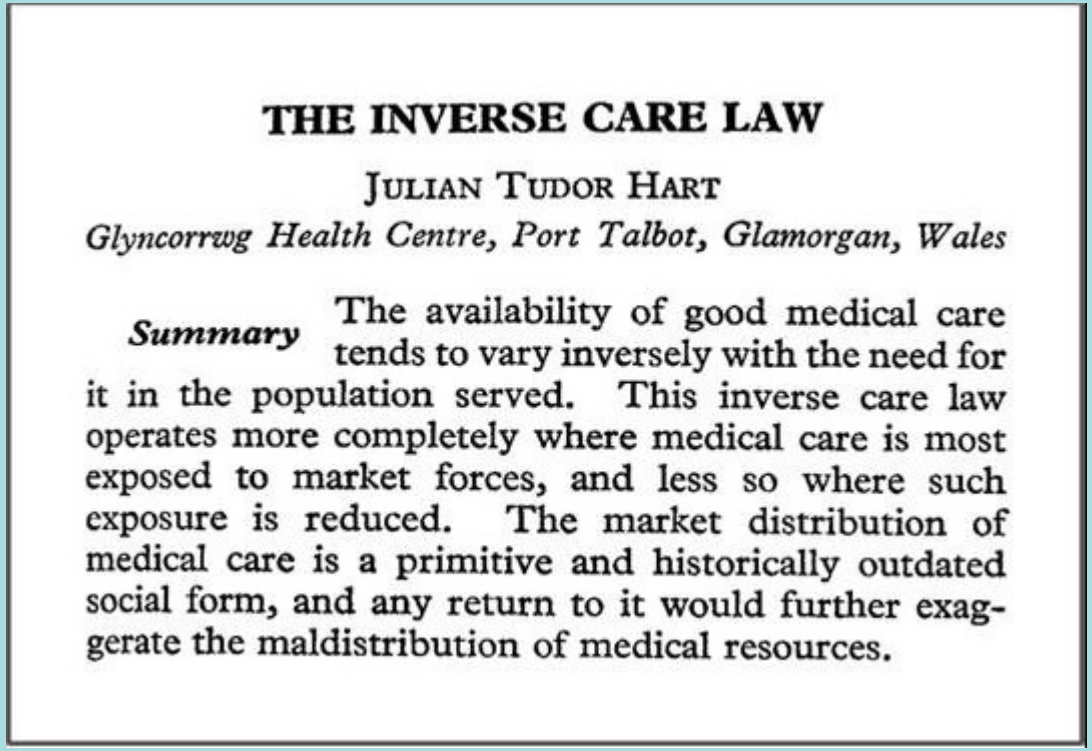
= longer than average

= Meets average

=Lower than average

Bambra, C., & Orton, C. (2016). A train journey through the English health divide: Topological map. Environment and Planning A: Economy and Space, 48(5), 811814. https://doi.org/10.1177/0308518X15621633

Inverse care law



THE INVERSE CARE LAW

JULIAN TUDOR HART
Glyncorrwg Health Centre, Port Talbot, Glamorgan, Wales

Summary The availability of good medical care tends to vary inversely with the need for it in the population served. This inverse care law operates more completely where medical care is most exposed to market forces, and less so where such exposure is reduced. The market distribution of medical care is a primitive and historically outdated social form, and any return to it would further exaggerate the maldistribution of medical resources.

Hart JT. The inverse care law. The Lancet. 1971;297(7696):405-12.

NIHR | Applied Research Collaboration North East and North Cumbria

Literature review- inequalities in lung disease

- Lung disease is more common in socio-economically deprived areas
- However, those in more socio-economically deprived areas are:

Less likely to access lung cancer screening

Less likely to receive:
- Surgery
- Chemotherapy
- Targeted therapy (lung cancer)

Less likely to have specialist MDT discussion

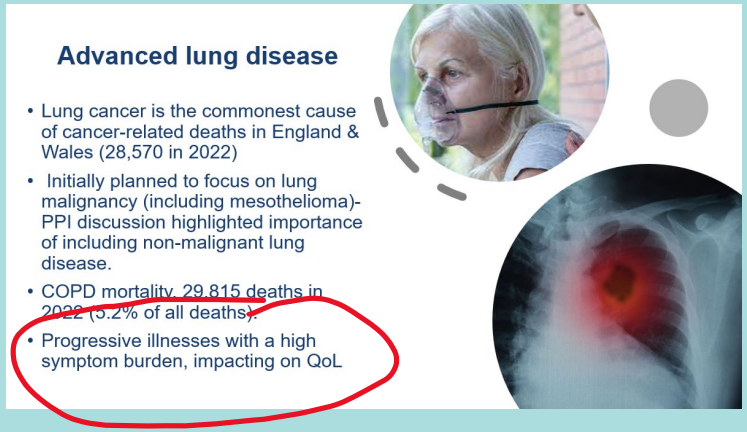
Less likely to be referred to pulmonary rehab (COPD)

Less access to 7-day respiratory services

More likely to be admitted to hospital with an acute exacerbation

1. Hardavella G, Charpidou A, Frille A, Panagiotou E, Catarata MJ, Caruana E, Blum TG. Lung cancer and inequalities in access to multidisciplinary lung cancer services. Inequalities in Respiratory Health. 2023:153.
2. Forrest LF, Adams J, Wareham H, Rubin G, White M. Socioeconomic inequalities in lung cancer treatment: systematic review and meta-analysis. PLoS medicine. 2013;10(2):e1001376.
3. Norris RP, Dew R, Greystoke A, Todd A, Sharp L. Socio-economic Inequalities in Novel NSCLC Treatments During the Era of Tumor Biomarker Guided Therapy: A Population-based Cohort Study in a Publicly Funded Healthcare System. Journal of Thoracic Oncology. 2023.
4. Adamson A AL, Andrews R, Bunning T, Calvert J, Hurst J, Kailla C, Quint J, Smith K, Stone P, Wilkinson T. . National Asthma and COPD Audit Programme: Adult asthma and COPD 2021 organisational audit. Resourcing and organisation of care in hospitals in England and Wales. Summary report. . London: RCP; 2022.
5. Stone PW, Hickman K, Steiner MC, Roberts CM, Quint JK, Singh SJ. Predictors of referral to pulmonary rehabilitation from UK primary care. International Journal of Chronic Obstructive Pulmonary Disease. 2020:2941-52.
6. Williams PJ, Cumella A, Philip KEJ, Laverty AA, Hopkinson NS. Smoking and socioeconomic factors linked to acute exacerbations of COPD: analysis from an Asthma+ Lung UK survey. BMJ open respiratory research. 2022;9(1).
7. Jones RC. Hospital admission rates for COPD: the inverse care law is alive and well. BMJ Publishing Group Ltd; 2011. p. 185-6.
8. Calderón-Larrañaga A, Carney L, Soljak M, Bottle A, Partridge M, Bell D, et al. Association of population and primary healthcare factors with hospital admission rates for chronic obstructive pulmonary disease in England: national cross-sectional study. Thorax. 2010:thx. 2010.147058.

What about palliative care?



- Circling back to slide 1….. these patients have a **high symptom burden** impacting on their **quality of life**
- **Potentially a lot to gain from palliative care support**
- Previous studies have suggested those in deprived areas generally are less likely to access hospice care, and are less likely to access palliative care
  But yet to find solutions…..
- By targeting a specific group, we could be more focused in exploring barriers to palliative care and designing focused solutions

Understanding and addressing **inequalities** in access to **palliative care** for those with **lung disease**; does the inverse care law apply?

21 months → 33 months

April 2021- **Started** Doctoral Fellowship application form

27th January 2023- **Submitted** application form

25th May 2023- Informed short-listed for interview

21st June 2023- **INTERVIEW**

September 2023- **Awarded** Fellowship

1ST January 2024 **Started** Doctoral Fellowship

Whilst finishing Masters in Clinical Research

NIHR | National Institute for Health and Care Research

NIHR Academy
21 Queen Street
Leeds
LS1 2TW

Tel: 0113 532 8410
Email: academy-awards@nihr.ac.uk
www.nihr.ac.uk/academy

October 2023

Dr Donna Wakefield
North Tees and Hartlepool NHS Foundation Trust
Specialist Palliative Care Team,
1st Floor Farndale House
University Hospital of North Tees
Stockton-On-Tees
TS19 8PE

Dear Donna,

NIHR Doctoral Fellowship
Our ref: NIHR303241

I am pleased to inform you that the NIHR Doctoral Fellowship Selection Committee has recommended your application for funding, and the Department of Health and Social Care (DHSC), in their capacity as the National Institute for Health and Care Research (NIHR), has confirmed their intention to award funding. This is based upon acceptance of the terms and conditions set out in the Standard Research Contract (link below), and pending agreement to any conditions set by the Selection Committee (*details of which will have been communicated to you where relevant.)*

NHS North Tees and Hartlepool NHS Foundation Trust

Search...

Menu

Home > News > Research > Doctor secures national research award to study palliative care for people with lung cancer

Friday 22 September 2023

Doctor secures national research award to study palliative care for people with lung cancer

A senior doctor in Teesside who cares for patients at end-of-life has secured a prestigious national research award.

Dr Donna Wakefield, consultant in palliative

NIHR | Applied Research Collaboration North East and North Cumbria

Collaboration is key

Palliative Medicine expertise (Primary supervisory team)

- Professor Fliss Murtagh
- Professor Jonathan Koffman

Hull York Medical School | University of Hull | Wolfson Palliative Care Research Centre

- Dr Joanna Davies

King's College London

Inequalities expertise (& mentorship)

- Professor Clare Bambra

Newcastle University

NIHR | Applied Research Collaboration North East and North Cumbria

Additional advisory group expertise (specific aspects of the work)

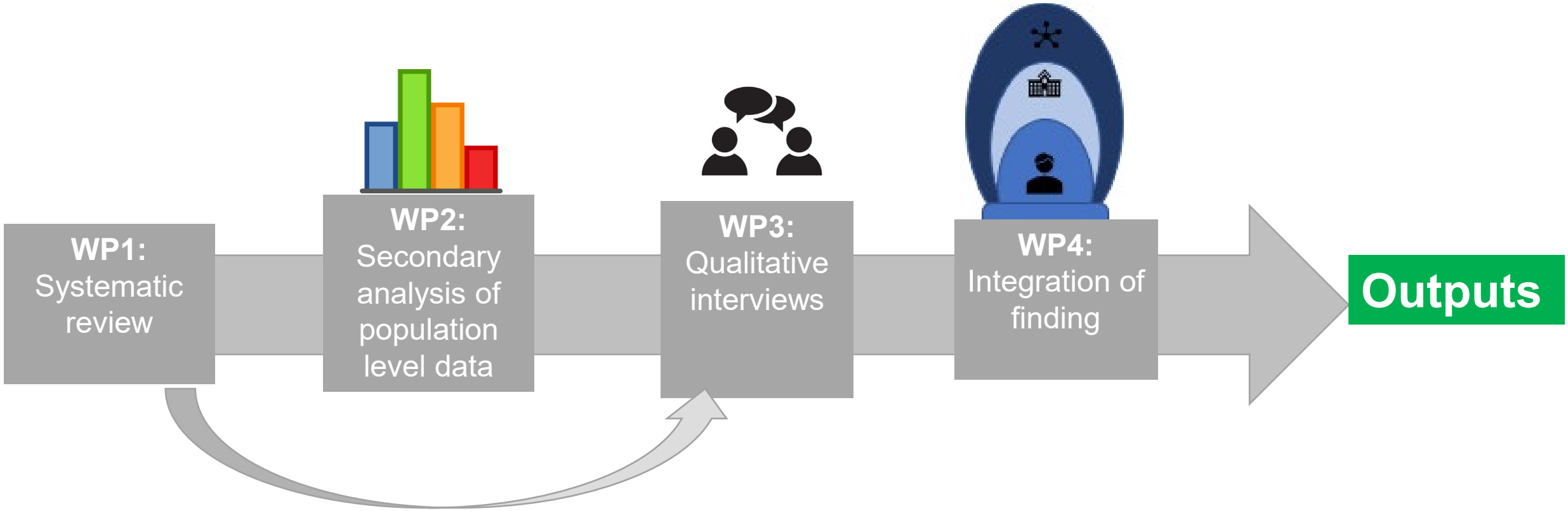
- Dr Niall Cunningham (*Senior Lecturer in Quantitative Human Geography)*

Newcastle University

- Patient & Public Involvement (PPI) members
- + Others

Project Outline:

LUNG PAL EQUITY STUDY



Patient & Public Involvement (PPI)

NIHR | Applied Research Collaboration North East and North Cumbria

WP1- Mixed Methods Systematic Review

LUNG PAL EQUITY STUDY

- Training ✓

Review question:
Do those with advanced lung disease face inequalities in access to, receipt of and/or experience of palliative care?

1: To identify, appraise and synthesise evidence on **inequalities** in **access or receipt** of palliative care for those with advanced lung disease, with specific focus on the effect of **socio-economic status** and other aspects of social inequalities (i.e. race, gender, sexuality).

2: To identify and appraise evidence of inequalities in **experience and preferences** relating to palliative care.

3: To identify and appraise previous **interventions** to address inequalities and any previous recommendations.

WP1- Mixed methods systematic Review

Do those with advanced **lung disease** face **inequalities** in access to, receipt of and/or experience of palliative care?

- Built search strategy in Ovid MEDLINE with support from information specialist. Using and adapting previous search filters such as Rietjens et al (palliative care), Cochrane Register (COPD terms) and Prady et al (inequalities terms)
- Translated the searches into EMBASE, PsycINFO and CINAHL from inception to current date.
- No restrictions on language

MEDLINE 3,480
EMBASE 2,697,
PsycInfo 3,401
CINAHL 587

Total **10,165**

Downloaded into EndNote and duplicates removed= **8,869** title & abstracts for screening

Uploaded to Covidence software

Also, grey literature

WP1- Mixed Methods Systematic Review

Do those with advanced **lung disease face inequalities** in access to, receipt of and/or experience of palliative care?

Timeline:

Early April	April-May	June	July-August	September
Finalise protocol	Screen all titles & abstracts	Pilot qual + quant data extraction forms – 20% check by 2nd reviewer	Quality appraisal by two reviewers using **Mixed Methods Appraisal tool** (MMAT)	Meet with PPI group & supervisory team to discuss results
Register with PROSPERO	Full text screening (in Covidence) -10% check by 2nd reviewer	Then complete data extraction on all relevant papers	Integration of findings (convergent segregation synthesis design) Thematic analysis	Write up paper and create a plan for dissemination .

WP2- Secondary analysis of population level data

To identify if there are inequalities between healthcare utilisation at end of life (including place of death) for those with lung disease according to socio-economic status (based on area-level deprivation) and to quantify this. Does an inverse care law apply?

Data requests (NHS Digital via DARS application) will include:
All patients in England who have died in the past 10 years of lung disease:
o ONS death registration data: Place of death, geographical area and index of Multiple Deprivation
o HES Accident and Emergency: number of unscheduled hospital admissions in the last 3 months of life
o HES Admitted patient care: total number of hospital inpatient days in the last 3 months of life

Courses including
- June-July 2024: Introductory course in Epidemiology & Medical Statistics- London School of Tropical Medicine
- NCRM Introduction to Data Linkage & HES

Training & development with inequalities team at Newcastle University, including GIS training

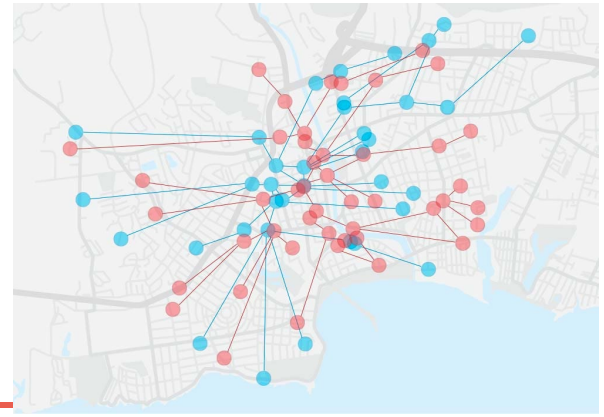
Note:
Not ideal markers
…..but considered the best we currently have available

WP2- Secondary analysis of population level data

Step 1- Descriptive analysis:
Population: Deceased participants who have died over the past 10 years of lung disease (lung cancer, pleural mesothelioma, COPD, interstitial lung disease) in England.

Primary “exposure” variable: Socio-economic deprivation (based on area-level deprivation).

Outcomes: To make comparisons between the following outcomes:
o Place of death (hospital/home/hospice)
o In the final 3 months of life: Number of hospital admissions/admissions to A&E/ inpatient hospital days
Co-variables: Age, Gender & ethnicity, Diagnosis, Geography



Step 2: Multivariate analysis (using STATA) of secondary linked HES-ONS data will include an evaluation of the relationship between the deprivation quintile and outcomes listed above.

Step 3: Data from Step 1, will be **summarised and presented visually using mapping software** (GIS). With discussion with PPI members over which findings would be most important for the public and patients to see in this format

WP3- Qualitative interviews

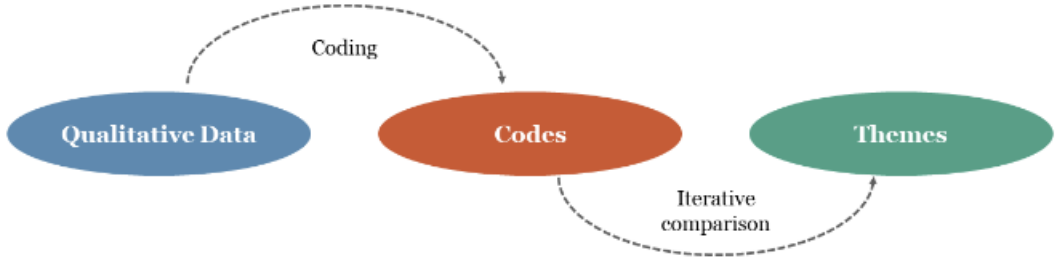
- Qualitative semi-structured interviews
- Thematic analysis

Post—bereavement interviews with **relatives** of those who have died of lung disease

(approx. 30)

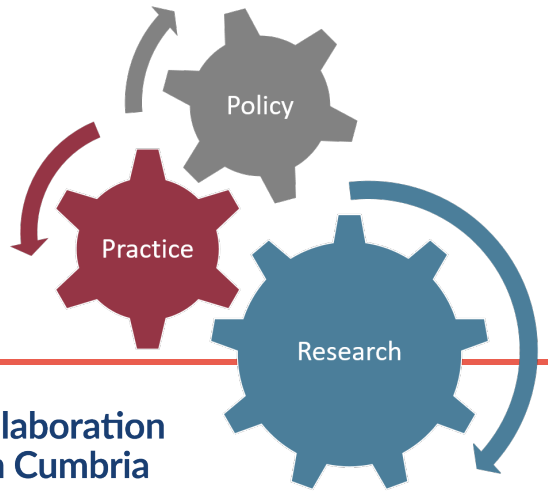
Healthcare professionals - respiratory clinicians and GPs

(approx. 20)



WP4- Integration & implementation

- Triangulation and integration of findings
- Build a framework of key barriers and facilitating and factors
- Identify recommendations & create a toolkit for implementation



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Any questions?

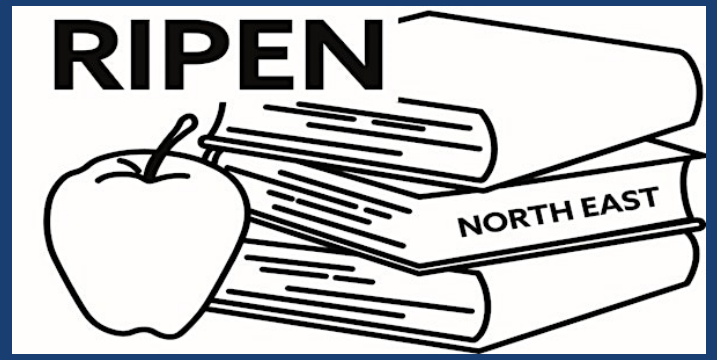
Get in touch:

Donna.wakefield1@nhs.net

Twitter/X: @donnawakefield_

NIHR | Applied Research Collaboration North East and North Cumbria

Research In Palliative and End of life care Network: North East (RIPEN NE)



Tom Sanders

16th April 2024

Addressing inequalities to end of life care in people with liver disease

Tom Sanders

NIHR | Applied Research Collaboration North East and North Cumbria

Morbidity and mortality

In England **70% of deaths for liver disease occur in hospital** (80% for alcohol related liver disease), compared with cancer which stands at 40%

High palliative care needs due to increased symptom burden, poor quality of life, high mortality risk and frequent hospital admission

Disease fluctuation, **prognostic uncertainty**, clinicians' not always able to initiate conversation about palliative care as these imply stopping of active therapy

Early provision of palliative care can lead to improvements in quality of life, physical and psychological symptom burden

Barriers to palliative and end of life care

Reasons for accessing PEoLC are unclear

People with **Alcoholic Liver Disease engage less with palliative** and end of life care services than people with NALD (Non-Alcoholic Liver Disease)

Addiction, **stigma, unaware of diagnosis**

The North-East of England experiences **higher socio-economic deprivation** than other regions (especially the south), with a higher burden of liver disease

Only **30%** of patients with advanced disease **are referred to specialist palliative** or hospice care, often in the last few days of life

Barriers to palliative and end of life care

- **Long lag time between having ALD and experiencing symptoms** – thus evidence for ‘early’ palliative care is unclear
- Focus should be on **‘timely’** palliative care - how can this be defined?
- Specialist **palliative care**, palliative care delivered by primary care hepatology, and supportive care for people **is lacking**, particularly in the last 12 months of life
- Crisis management

Way forward

Integration of palliative care principles into existing hepatology services is potentially more acceptable, deliverable, and accessible

- unclear from current practice **which clinical services need to work together** to provide the care people need
- **which clinicians** should provide which element of palliative care

  (specialist nursing, community nurse liaison, primary care, specialist palliative care, and hepatology/gastroenterology).

Research Plan

- Research Question:

Which combination of services are likely to provide the most effective palliative care, and at which point in the disease course, for people with advanced stage liver disease?

Aims

a) **compare the range of available services**

b) **how people experience palliative and EOL care**

c) **barriers experienced by health and social care providers**

d) **which pathways for accessing timely palliative services are most beneficial (and for who)**

Mapping palliative services

a) Mapping end **stage liver disease services**

b) Palliative care leads (interviews)

c) Health service **utilisation** (CPRD and linked Hospital Episode Statistics (HES)

Clinical Practice Research DataLink (CPRD)

Patient and carer interviews

40 interviews with people and carers

Experiences of end stage liver disease services

Carers' experiences of providing support and their own support needs

Healthcare professional interviews

Barriers and enablers of delivering palliative care services

8 focus groups (n=5 per FG) or up to 40 semi structured qualitative interviews

Range of clinical professionals

Primary, community and secondary care

Outcome

Recommendations for clinical teams, patients/carers

Assess recommendations on achieving change in practice and user engagement with clinical care/self-management

Normalisation Process Theory to assess potential adoption of recommendations

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Dr Felicity Dewhurst

Consultant in Palliative Medicine, St Oswald's Hospice

Senior Clinical Lecturer, Population Health Sciences Institute, Newcastle University

NIHR Advanced Fellow

From PEACE to PROMISE: Developing an interest in palliative care inequity on the road to becoming a clinical academic

What am I going to talk about?

Newcastle University

How did I get in to research?

ncl.ac.uk

Royal College of Physicians/Dunhill Foundation Funded Doctorate:

Newcastle University

Key Learning Points to consider throughout a research career

Newcastle University

ncl.ac.uk

Person – Credibility

Acta Neurologica Scandinavica

Acta Neurol Scand 2013: 127: 198–207 DOI: 10.1111/j.1600-0404.2012.01709.x

The prevalence of neurological in older people in Tanzania

Dewhurst F, Dewhurst MJ, Gray WK, Aris E, Orega G, Howlett W, Warren N, Walker RW. The prevalence of neurological disorders in older people in Tanzania.
Acta Neurol Scand: 2013: 127: 198–207.

Objectives – There are few data on neurological disorders prevalence

F. Dewhurst[1,2], M. J. Dewhurst[1,2], W. K. Gray[1], E. Aris[3], G. Orega[4], W. Howlett[4], N. Warren[5], R. W. Walker[1,2]

[1]Northumbria Healthcare NHS Foundation Trust, North Tyneside General Hospital, North Shields, UK; [2]Institute of Health and Society, Newcastle University,

Rates of diagnosis and treatment of neurological disorders within a prevalent population of community-dwelling elderly people in sub-Saharan Africa

Authors

Felicity Dewhurst[a, b, *, ✉], Matthew J. Dewhurst[a, b], William K. Gray[a], Paul Chaote[c], William Howlett[d], Golda Orega[d], Richard W. Walker[a, b]

a Northumbria Healthcare NHS Foundation Trust, North Tyneside General Hospital, North Shields, UK
b Institute of Health and Society, Newcastle University, Newcastle upon Tyne, UK
c District Medical Office, P.O. Box 27, Hai District Hospital, Boman'gombe, Tanzania
d Kilimanjaro Christian Medical Centre, Moshi, Tanzania
* Corresponding author. Address: Department of Medicine, North Tyneside General Hospital, Rake Lane, North Shields, Tyne and Wear NE29 8NH, UK. Tel./fax: +44 191 293 2709.

Corresponding Author

Felicity Dewhurst ✉

J Neurol (2012) 259:2189–2197
DOI 10.1007/s00415-012-6482-x

ORIGINAL COMMUNICATION

Neurological disorder screening in the elderly in low-income countries

Felicity Dewhurst · Matthew J. Dewhurst · Golda Orega · William K. Gray · William Howlett · Naomi Warren · Eric Aris · Richard W. Walker

Volume 41, Issue 4
July 2012

The prevalence of disability in older people Tanzania FREE

Felicity Dewhurst ✉, Matthew J. Dewhurst, William K. Gray, Golda Orega, William Howlett, Paul Chaote, Catherine Dotchin, Anna R. Longdon, Stella-Richard W. Walker

Age and Ageing, Volume 41, Issue 4, July 2012, Pages 517–523,
https://doi.org/10.1093/ageing/afs054

Published: 19 April 2012 **Article history ▾**

Received: 26 January 2012 / Revised: 12 March 2012 / Accepted: 13 March 2012 / Published online: 12 April 2012

Abstract There are few data on neurological disorder prevalence from developing countries, particularly in the elderly in sub-Saharan Africa (SSA). This is in part due to the lack of a feasible and valid screening instrument. We aimed to develop (and pilot) a brief screening instrument for neurological disorders in an elderly population in SSA. Our study population of 2,232 was selected at random from the entire 70 years and over population of a demographic surveillance site in rural Tanzania. One village, with a population of 277, was randomly selected as a pilot site prior to screening the rest of the study population. We designed a screening questionnaire based on the neurological section of the WHO International Statistical Classification of Diseases and Related Health Problems 10th Revision for use by non-medical interviewers (NMI). Of the 277 participants aged 70 years and over in the pilot village, 82 had neurological disorders, with a further 267 identified as having neurological disorders during the study extension to the remaining study population of 1955. The questionnaire was practical, acceptable to recipients, and easily performed by an NMI. The sensitivity and specificity of the questionnaire were 87.8 and 94.9 %, respectively, in the pilot and 97.0 and 90.4 %, respectively, in the extension. This is the first published screening instrument for measuring the prevalence of neurological disorders in a developing country, which is dedicated to the elderly population. It is feasible to use and has high sensitivity and specificity.

Keywords Neurological disorders · Screening · Africa · Tanzania

Project - My Motivation/Research Interest

- Research is needed to make a case for change
- Care is inequitable
- Complexity is the biggest cause of inequity
  - Ageing (Frailty/MLTC)
  - Deprivation
  - Diversity
- The Multidisciplinary team is our best tool
- Teaching and Education is a close second

Place - A Comprehensive Supervisory Team is Very Important

Newcastle University

ncl.ac.uk

Place - Don't underestimate the value of Teamwork and Collaborations…

Journal of Human Hypertension

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nature › journal of human hyperte

Original Article | Published: 13 Dece

The high prevalence of hypertension in rural-dwelling Tanzanian older adults and the disparity between detection, treatment and control: a rule of sixths?

M J Dewhurst, F Dewhurst, W K Gray, P Chaote, G P Orega & R W Walker

Journal of Human Hypertension **27**, 374–380 (2013) | Cite this article

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JOURNAL OF THE AMERICAN GERIATRICS SOCIETY

Clinical Investigations | Full Access

Frailty Screening in Low- and Middle-Income Countries: A Systematic Review

William K. Gray, Jenny Richardson, Jackie McGuire, Felicity Dewhurst, Vasanthi Elder, Julie Weeks, Richard W. Walker, Catherine L. Dotchin

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ELSEVIER

Medical Engineering & Physics

Volume 34, Issue 10, December 2012, Pages 1441-1447

Accuracy of algorithms for detection of trial fibrillation from short duration beat nterval recordings

angley[a], M. Dewhurst[b], L.Y. Di Marco[c], P. Adams[d], F. D Walker[g], A. Murray[a]

THE JOURNAL OF CLINICAL HYPERTENSION

Original Paper | Free Access

Ambulatory Blood Pressure Monitoring t Coat Effect in an Elderly East African Pop

Ashleigh Ivy MBBS, Jonathan Tam MRes, Matthew J. Dewhurst MD, W Jane Rogathi MSc, Felicity Dewhurst MD, Richard W. Walker MD

First published: 18 February 2015 | https://doi.org/10.1111/jch.12501 | Citations: 17

Annals of Noninvasive Electrocardiology

ORIGINAL ARTICLE | Full Access

Electrocardiographic Reference Values for a Population of Older Adults in Sub-Saharan Africa

Matthew J. Dewhurst M.R.C.P., Luigi Y. Di Marco Ph.D., Felicity Dewhurst M.R.C.P., Philip C. Adams M.A., F.R.C.P., Alan Murray Ph.D., Golda P. Orega B.Sc.N. … See all authors

First published: 09 September 2013 | https://doi.org/10.1111/anec.12078 | Citations: 9

International Journal of Geriatric Psychiatry

Research Article | Full Access

The prevalence of dementia in rural Tanzania: a cross-sectional community-based study

Anna R. Longdon, Stella-Maria Paddick, Aloyce Kisoli, Catherine Dotchin, William K. Gray, Felicity Dewhurst, Paul Chaote, Andrew Teodorczuk, Matthew Dewhurst … See all authors

First published: 20 September 2012 | https://doi.org/10.1002/gps.3880 | Citations: 59

JOURNAL OF THE AMERICAN GERIATRICS SOCIETY

rief Report

trikingly Low Prevalence of Atrial Fibrillation in Elderly anzanians

latthew J. Dewhurst MD, Philip C. Adams MA, William K. Gray PhD, Felicity Dewhurst MD, olda P. Orega BScN, Paul Chaote MD, Richard W. Walker MD

Show author details | rst published: 30 May 2012 | https://doi.org/10.1111/j.1532-5415.2012.03963.x | Citations: 28

Acta Neuropsychiatrica

Dementia prevalence comparison of two di

Levels of functional disability in elderly people in Tanzania with dementia, stroke and Parkinson's disease

Published online by Cambridge University Press: **17 March 2015**

Aloyce Kisoli, William K. Gray, Catherine L. Dotchin, Golda Orega, Felicity Dewhurst, Stella-Maria Paddick, Anna Longdon, Paul Chaote, Matthew Dewhurst and Richard W. Walker

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Stella-Maria Paddick[1], Anna R. Longdon[2], Aloyce Kisoli[3], Catherine Dotchin[4,5]*, William K. Gray[4], Felicity Dewhurst[4,6], Paul Chaote[7], Raj [illegible]

[1]Institute of Neuroscienc Healthcare NHS Foundat Kilimanjaro, Tanzania; [4]N Hospital, North Shields, Tyne, UK; [6]Institute of H [7]District Medical Office, Radiology, Kilimanjaro C

International Psychogeriatrics

A comparison of caregiver burden in older pers persons with Parkinson's disease or dementia i Saharan Africa

Published online by Cambridge University Press: **10 February 2014**

C.L. Dotchin, S.-M. Paddick, A.R. Longdon, A. Kisoli, W.K. Gray, F. Dewhurst, P. Chaote, M. Dewhurst and R.W. Walker

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Journal of Epidemiology and Global Health

< PREVIOUS ARTICLE IN ISSUE NEXT ARTICLE IN ISSUE >

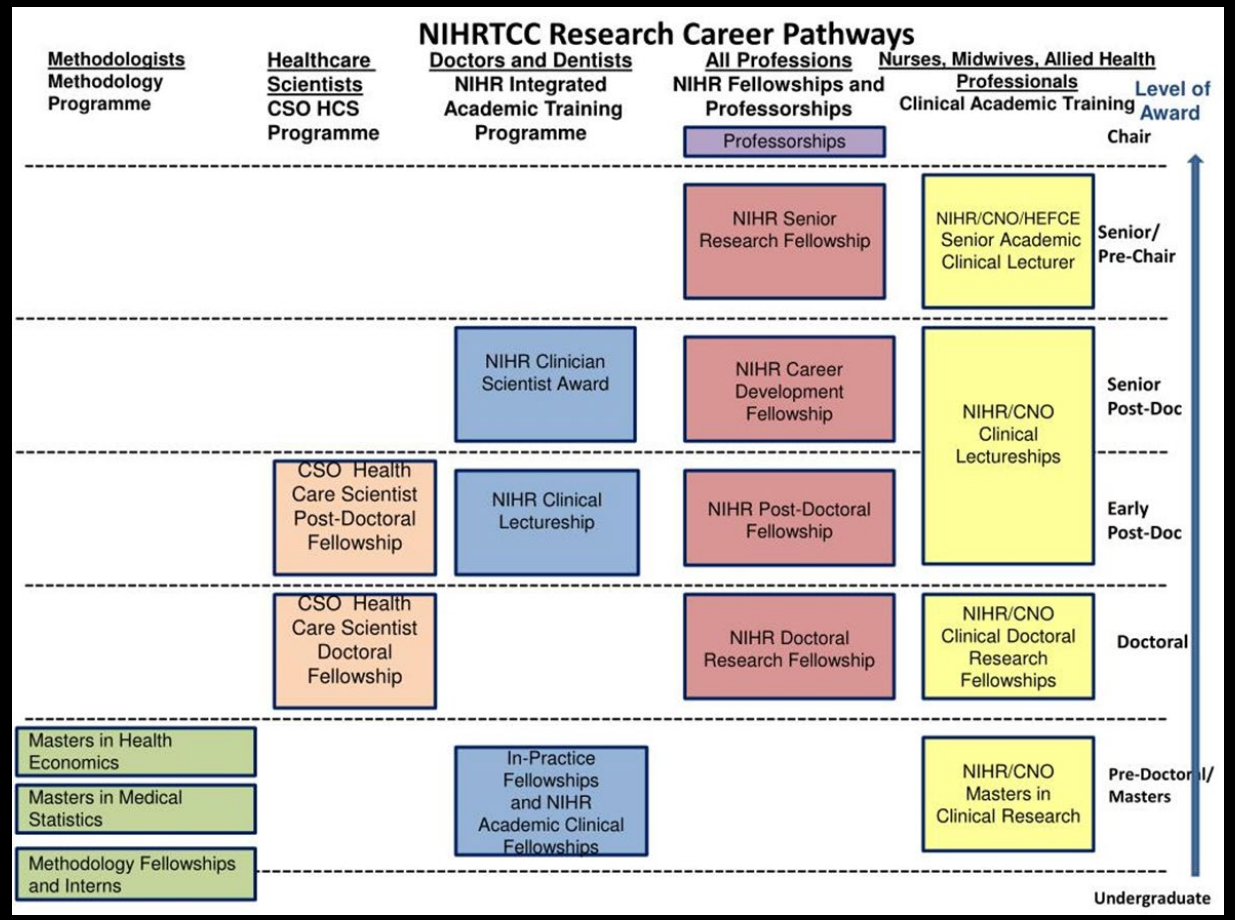
Volume 5, Issue 1, March 2015, Pages 57 - 64

The association between disability and cognitive impairment in an elderly Tanzanian population

Authors

Catherine L. Dotchin[a, b, *], Stella-Maria Paddick[a, c], William K. Gray[a], Aloyce Kisoli[d], Golda Orega[e], Anna R. Longdon[f], Paul Chaote[d], Felicity Dewhurst[a], Matthew Dewhurst[a], Richard W. Walker[a, g]

An Academic Pathway in Palliative Medicine?




Original research

OPEN ACCESS

Qualified and motivated, but limited by specialty-specific barriers: a national survey of UK Palliative Medicine consultants research experience

Donna Wakefield [1,2] Yinting Ta [3] Felicity Dewhurst [2,4] Jamilla Hussain,[5] Charlotte Chamberlain,[6,7] Simon Etkind[8,9]

► Additional supplemental material is published online only. To view, please visit the journal online (http://dx.doi.org/10.1136/spcare-2023-004198).

ABSTRACT

Objectives Providing high-quality safe palliative care requires high-quality clinically driven research. Little is known about how to optimise clinical research capacity in this field.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Expansion of palliative care research is a National Institute for Health and Care Research priority and fundamental to

BMJ Support Palliat Care: first published as 10.1136/spcare-202

ncl.ac.uk

How to get a IAT post badged to Palliative Medicine?

Newcastle University

"It is a long way from Tanzania to Newcastle!" Professor Dave Jones

Person

A credible academic?

- Publications
- Presentations
- Ongoing research activity in clinical training
  - NEPRRA
  - UKPRC

Project

- Care is inequitable
- Complexity is the biggest cause of care inequity
  - Ageing (Frailty/MLTC)
  - Deprivation
  - Diversity
- The Multidisciplinary team is our best tool
- Teaching and Education is a close second

Place

Activity during Palliative Medicine Academic Clinical Lectureship (including extension into a consultant post)

Newcastle University

ncl.ac.uk

Place – aligning interests

Newcastle University

Population Health Sciences Institute strategy -

- Reducing inequalities
- Particularly in ageing societies
- Considering biological, social, behavioural, environmental barriers
- Inter/multidisciplinary approach

St Oswald's Strategy

- Reduce inequity - ensure that everyone has the same chance to access and receive quality palliative and end of life care services.
- Focus on social barriers - build trust/relationships with all local communities
- Talk about death and dying openly

Care is inequitable
Complexity is the biggest cause of inequity
(Ageing (Frailty/MLTC)/Deprivation/Diversity)
The Multidisciplinary team is our best tool
Teaching and Education is a close second

Projects – A few highlights

- **PEACE**
  - Identifying barriers to care and opportunities for change through national collaborations in qualitative research
- **DECIDE**
  - Ensuring Patient and Public Involvement/Co-production
  - Demonstrating the need for education
- **LCOTS/CSCS**
  - Embedding Research in Practice to make a case for Change

PEACE: Palliative and End of life care experiences of people of African and Caribbean dEscent

Identifying barriers to care and opportunities for change through national collaborations in qualitative research

NIHR | Applied Research Collaboration North East and North Cumbria

PEACE: Palliative and End of life care experiences of people of African and Caribbean dEscent

People of African and Caribbean descent:

Experience some of the highest levels of material disadvantage

Less likely to access palliative care services

We sought 39 bereaved relatives and health and social care professionals' views on:

- Experiences
- Barriers
- Suggestions for improvement

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Key Themes

Discrimination, Racism and the Lack of Representation

Relatives:
- Mistrust of the healthcare system/anticipation of inequitable care
- Therefore put off asking for help

Professionals:
- Racism and discrimination entrenched in healthcare
- Services are built around certain people at the cost of others
- Superficial approach to equality and diversity

'So… if you've experienced racism within society, why would you then think in health that you're, you know, that you're going to be treated fairly?'

Lack of Personalisation

- Lack of cultural and religious sensitivity in palliative care services.
- Did not expect service providers to understand their needs/experiences
- Missed out on services because of assumptions

It's just- we don't see ourself there…. because if a White person just comes to talk to you about palliative care and you don't see yourself, I'm like " Well, it's only them. "

Lack of Awareness and Access

- Families left to care for dying relatives without adequate support, equipment or knowledge
- Experiences were overwhelming/significant psychological cost
- Adequate support was more likely if they "knew the system", "fought for their rights"
- Professionals described barriers to equitable care as;
  - Ignorance of how to provide care to diverse communities

'our persistence, insistence, and the nature of us made a difference… 'cause my sister's actually an adult social care manager for the council… so she knows the system'
Relative

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Participants' recommendations for change:

Representation

- Better representation of people of African and Caribbean descent

Personalisation

- Recognition of cultural and religious needs.

Awareness and Access

- Raise awareness amongst diverse communities on the presence and value of palliative care services.
- Build professional confidence and competence to provide culturally sensitive care
    - Training/education
    - Work with community and religious leaders/groups

DECIDE: Diverse Experiences of end-of-life Care for Dementia- Establishing consensus and capacity through collaboration and co-production

- Ensuring Patient and Public Involvement /Co-production
- Demonstration of the need for education

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Methods

Literature review

Demonstrated lack of research at the intersection of dementia, palliative care and inequity

Stakeholder Consultation:
29 Key Stakeholders with self-defined diverse characteristics consulted over 11 workshops

Ethnicity	Asian 11	Black 5	White 13		
Religious Affiliation	Muslim 6	Jewish 3	Christianity 2	No Stated Religious Affiliation 18	
Socio-economic	All Indices of Multiple Deprivation band Represented				
Profession	Doctor 1	Nurse 4	Carer 4	Social Worker 3	VCSO 6
Personal	Family carer -bereaved 7	Family carer– current 4			
Residential	Experienced homelessness 2	Refugee 1	Asylum seeker 1		
Organisation	Palliative care 4	Geriatrics 2	Primary care 2	Care Homes 4	VSCO 6
Gender	Male 10	Female 19			

Explored;

- **The concept of palliative care in the context of dementia**
- **Recommendation for research and improving care**

Key Findings from Stakeholders

- 1. Need for improved Awareness/Education around dementia AND end of life

- 2. Fear and (mis)Trust…

First I don't think we know about dementia in our communities…They don't treat it as a disease. You think it might be spiritual things … So awareness is something really important to be raised in black African communities about dementia.'

P24 – Social worker

Unless you're able to navigate that trust issue which links with the number of people they see like them within the professionals in end of life care you're not going to be able to increase support for them.

P23 - Expert by experience, African Community Organisation

3. Need to improve carer support

the care is merely down to family members (they) will be seen as a bad family member, or (they) don't care… if (they) send them to a care home. It's like something to be looked down on… So …no matter how hard it is, the family members will insist they keep the patient…that will cause problems and pressure within the family

P10, Expert by experience –Charity worker, Chinese community

You don't get end of life care. You don't get any dementia care… It's pretty dire at the best of times.

P12, Expert by experience, experience of homelessness and prison services

4. Need to improve palliative care for people with dementia

- Conclusions

  - People from minoritised and deprived communities miss out on vital support.
  - Families and Carers “wish they’d known”
    - More about dementia and palliative care
    - That help is out there and where to get it
    - That the future can be planned for

Recommendations

- **“Let’s Talk about…”**
  - Dementia AND end-of-life care and enable everyone to “have a voice”
- **“Together” we need to…**
  - Work with carers to provide support and value the contribution they make
  - Talk about individual preferences to get care right for people with dementia when they are dying.

Dementia AND Dying need to be considered, talked about, researched, planned and provided for TOGETHER!

Lung Cancer Outpatient Therapy Service Combined Supportive Care Service

Embedding Research in Practice to make a case for Change

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Lung Cancer Outpatient Therapy Service
Combined Supportive Care Service

Providing care for patients with thoracic malignancy and frailty (CFS 5+)

May 2018
Lung Cancer Specialised Clinical Frailty group founded

April 2021
LCOTS 12m funding
x1 B6 OT
Newcastle Hospitals Charity

May 2022
LCOTS 6m funding
x1 B6 OT
Newcastle Hospitals Charity (inclusive of CSCS)

Feb 2023
LCOTS permanent funding via NuTH cancer growth plan
x1 B7 OT
x1 B7 PT
x1 Associate Practitioner

SOH: Full day clinic x1 Consultant + Access to FOL

Data collection

Jenny Welford
Advanced Occupational Therapist

Publications

Jennifer Skipsey
Advanced Physiotherapist

Robust outpatient therapy model

Emily Rands
Associate Practitioner

Summary of the data from the last 13 Months

Total referrals LCOTS	191 (16 avg monthly)
CSCS	101/191 (59%)
M=F	
Median age	75
Median CFS at referral	5
Referral → Initial assessment	1.8 days
Initial assessment → Date of Death	81 days
Face-to-face contacts	350
Remote contacts	660
Achievement of PPOD	81%
Admission Avoidances	64
Average length of hospital stay reduction	0 (6.5 in pilot)
Index of Multiple Deprivation	1 (Most Deprived) 41% 2 15% 3 14% 4 14% 5 (Least Deprived) 16%

100% of patients…

Rated their experience with the service as *'very good"* and would recommend the service

Overall feedback demonstrates the service is joined up and comprehensive.

"The team were knowledgeable and had different skills and ideas to people we'd met before"

"I can get everything done in one place"

"They were interested in the cancer, but also the other health conditions and how they impact day to day"

"In hospital, I feel like I'm on a conveyor belt and a little rushed. At St Oswald's, I don't think that. I have time to really talk."

"It's not just (for) me, they've met with my partner and my young son and it may be that they support them more in the future, too. That's very reassuring."

We are now trying to use the data to expand → Macmillan/Social finance bid

NIHR

Person – A credible Academic

	Demonstrated Excellent Potential
Research	Royal College of Physicians/The Dunhill Medical Trust Doctorate 1st NIHR Academic Clinical Lecturer Palliative Medicine North East
Leadership	Funding Success: £500K lead, £7M co-applicant Clinical Research Network Specialty co-Lead Invited Expert Hospice UK Frailty Programme
Impact	Academic: Strong publication record Prize winning international presentations Presentations to Policy Audience Hospice UK National Prize for Service Innovation
Capacity	Supervision: Multidisciplinary Healthcare Professionals Education: Masters with Distinction National Collaborations: NIHR Applied Research Collaborations and Policy Research Units

Collaborations

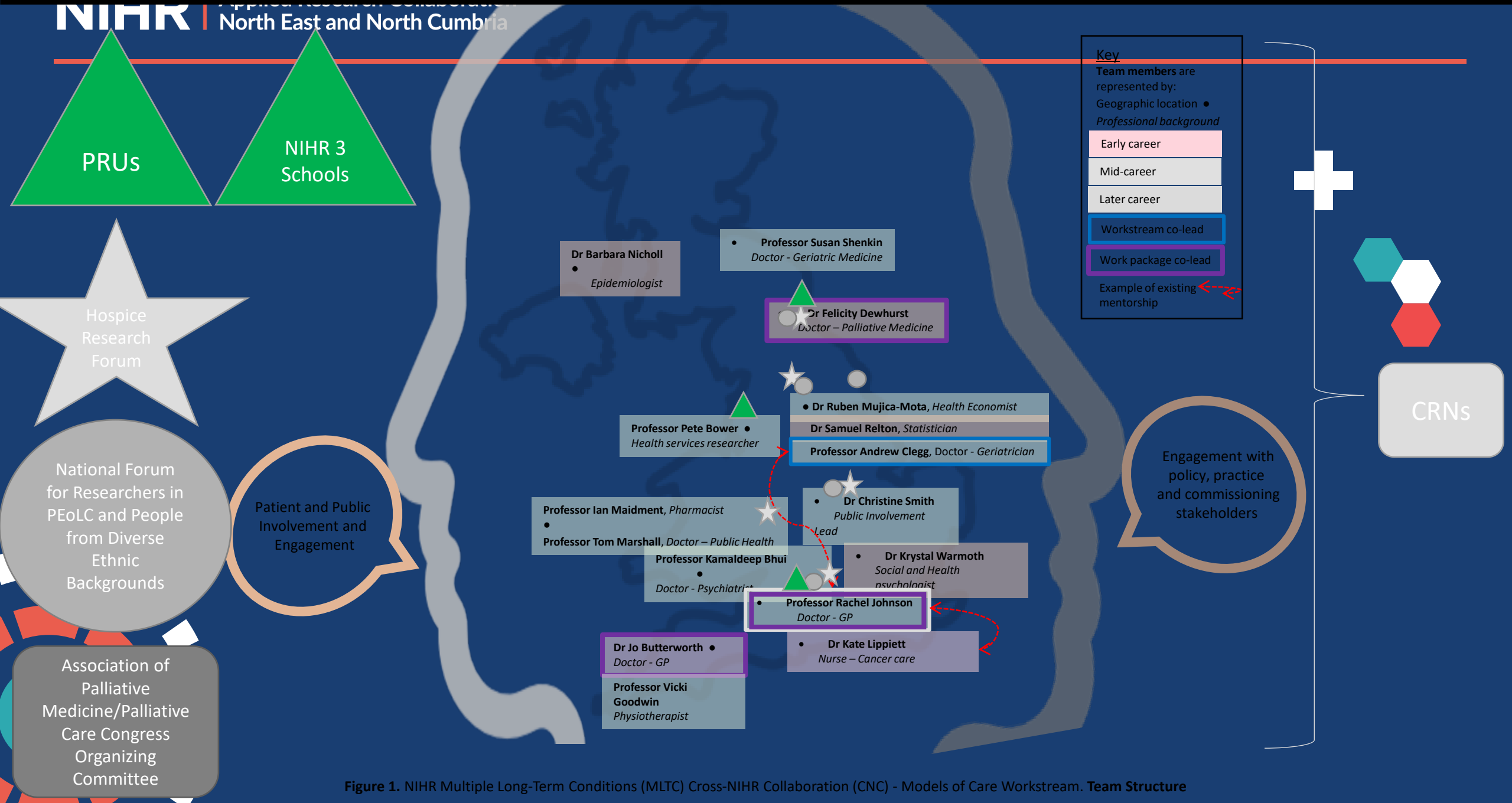


Figure 1. NIHR Multiple Long-Term Conditions (MLTC) Cross-NIHR Collaboration (CNC) - Models of Care Workstream. **Team Structure**

Applying for an Advanced Fellowship

PROMISE: Palliative caRe needs Of people with Multiple long term conditIonS Establishing recommendations for service innovation

Place

Professor Barbara Hanratty

Professor Fliss Murtagh

Professor Caroline Nicholson

Professor Katie Brittain

Newcastle University

HULL YORK MEDICAL SCHOOL

UNIVERSITY OF SURREY

Newcastle University

Project

Most People will Live with and Die from Multiple Long Term Conditions

"As his death approached his medical conditions attracted more problems resulting in more appointments with disparate services. The burden was so big. We just wanted someone to coordinate it all. By the end, everything fell to pieces."

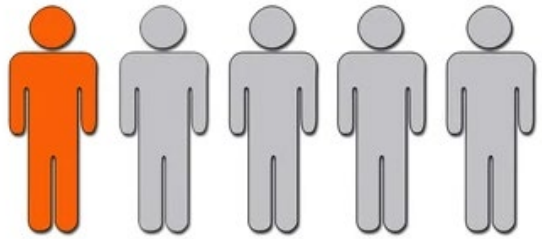
PPI Expert-by-Experience

Needs become increasingly complex and care is fragmented

Appropriate Access to Palliative Care is a Potential Solution

Generalist and Specialist Palliative care providers are supportive teams, providing patient centred co-ordinated care, improving the quality of people's lives

A Universal Human Right



At Least 1/5 Miss Out On Appropriate Support

Project

MLTC and Care Inequity are inextricably linked

People from

deprived areas

have MLTC

10-15 years earlier

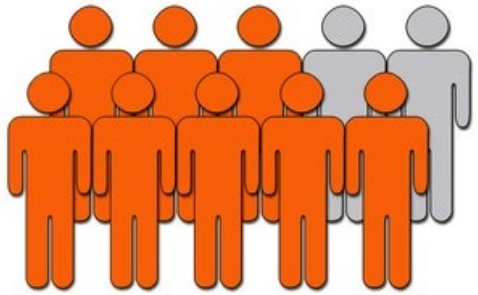
than in affluent areas.

>40%

of people from

ethnic minority

groups die below the poverty line.
MLTC is more common



81%
of the
over 85s
have MLTC

Multiple Long Term Conditions Account for the Majority of Health and Social Care Expenditure

50% of GP appointments

64% of outpatient appointments

70% of inpatient bed days

⅓ of inpatients in hospital are in the **last year of life**

Palliative care has the
highest potential to
lower care costs whilst
improving care quality.

Finding a good way to provide palliative care for people with MLTC could reduce care inequity and healthcare expenditure

Project

IS palliative care the solution?

If so, HOW should it be delivered?

WHO should deliver it?

Project

Newcastle University

AIMS:

1. To determine what people with MLTC need as they approach the end of their lives and how those needs change as they get closer to death.

2. To determine how these needs should be met and by whom.

Project

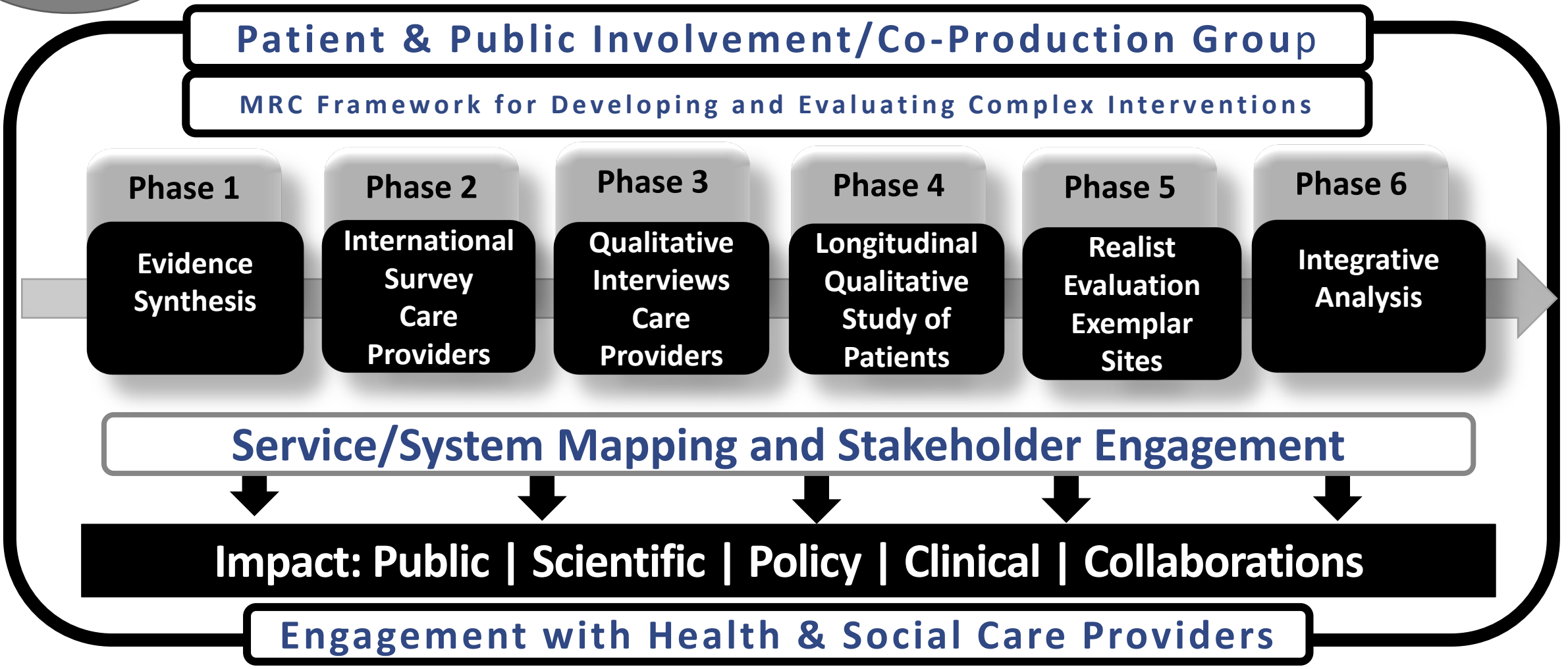
Newcastle University

HYPOTHESIS:

New models of care are needed, that enable access to community multidisciplinary team members, especially allied healthcare professionals and nursing staff, with access to specialist palliative care clinicians as required.

Project

Study Design



Next Steps: NIHR Programme Grant for Applied Research: Feasibility, Pilot, (Inter)national Evaluative Study

Person

Training and Development Plan

	Demonstrated Excellent Potential	Proposed Training for Continued Trajectory
Research	Royal College of Physicians/The Dunhill Medical Trust Doctorate 1st NIHR Academic Clinical Lecturer Palliative Medicine North East	Training in research (mixed) methods and health economics
Leadership	Funding Success: £500K lead, £7M co-applicant Clinical Research Network Specialty co-Lead Invited Expert Hospice UK Frailty Programme	NIHR Future Focussed Leadership Programme
Capacity	Supervision: Multidisciplinary Healthcare Professionals Education: Masters with Distinction National Collaborations: NIHR Applied Research Collaborations and Policy Research Units	Maximise opportunities of Newcastle/NIHR infrastructure e.g. Patient Safety Research Collaboration/Biomedical Research Centre Develop International Collaboration
Impact	Academic: Strong publication record Prize winning international presentations Presentations to Policy Audience Hospice UK National Prize for Service Innovation	Newcastle Policy Academy training Development of policy, practice and academic networks to support dissemination

Future - Clinical Academic with a Chair in Palliative Medicine

Winning Large Grants for Applied Research

Leading **International, Inter-specialty and Inter-disciplinary** Research Teams

Building Capacity in Palliative and MLTC Research

100,000 Die each year without appropriate support. Mostly from MLTC.

By finding out how to provide palliative care for people with MLTC and who should provide it…

My work aims to inform service innovation and influence policy to improve care and reduce inequity.

Newcastle University

In Summary

- Anyone can (and should) do research
- Its never to late to start
- Person, Project and Place are the key to progression and impact

Compassionate COMMUNITIES

THE CONCEPT AND PRACTICE AROUND THE WORLD

Allan Kellehear.
Northumbria University

Compassionate communities
- Becoz you need it too…

- Funnyman Sigmund Freud

A Palliative care re-set

Remember the 95% rule – the limits to service provision

Remember the Social Epidemiology of dying, caregiving, and grief and loss

Remember Health & Wellbeing to balance illness & disease emphasis

Compassionate communities

Becoz Palliative care is everyone's business

- Community development (compassionate communities)
- Social ecology (Compassionate cities)
- Public education (end of life literacy)
- Health Promotion
- Civic policy development (neighborhoods but also schools, workplaces, faith groups, etc)
- Partnerships

Global Developments 1

- Wales, UK (pop. 3 million)
- Ottawa, Canada (pop. 1 mill)
- Plymouth, England (pop. 260,000)
- Birmingham, England (po. 1 mill)
- Inverclyde, Scotland (pop. 82,000)
- Vic (pop.42,000), & Seville, Spain (pop. 750,000) Burlington, Toronto, Canada (pop. 175,000)

Global Developments 2

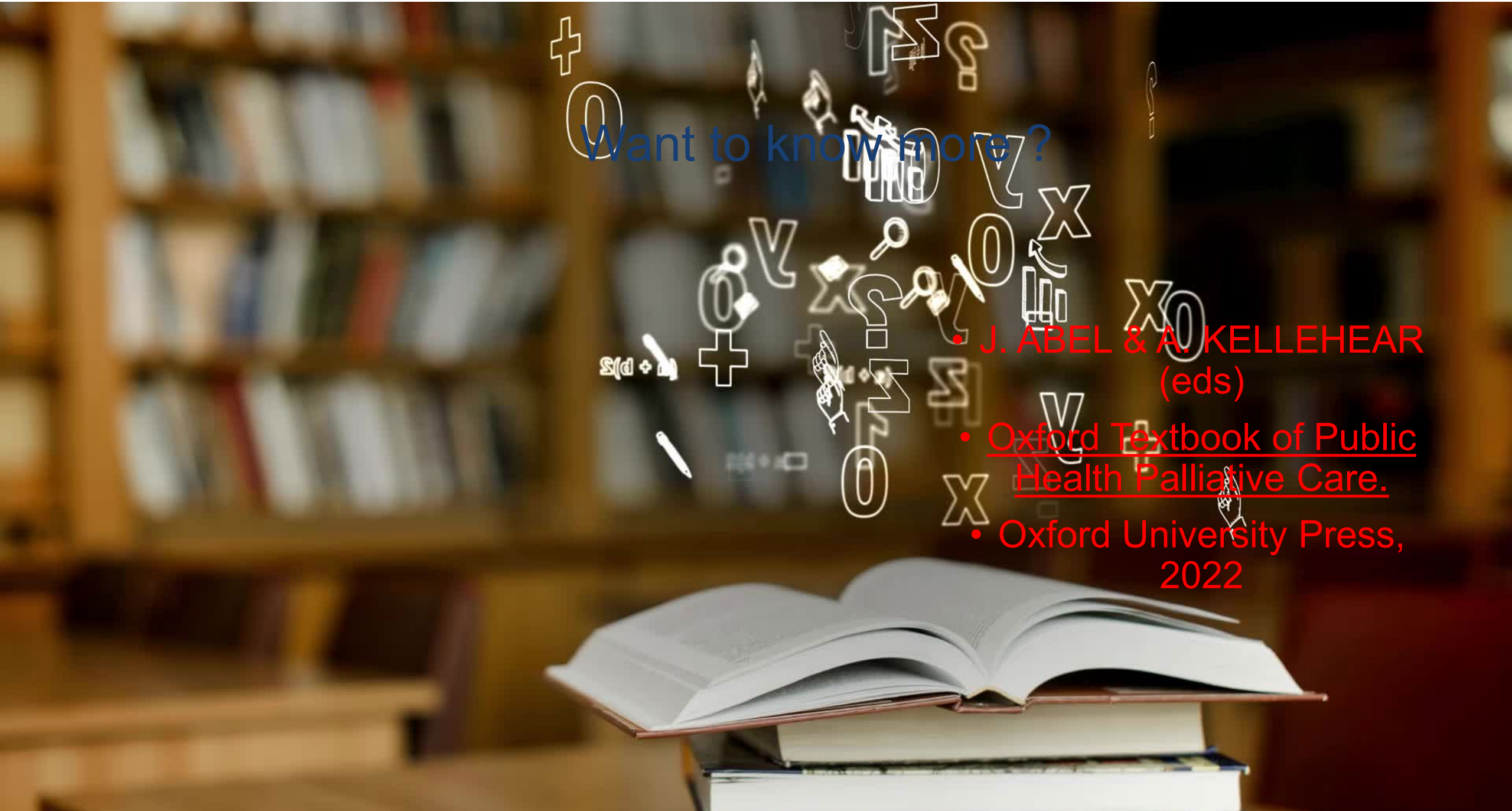
- New Westminster, Vancouver, Canada
- Koshikode aka Calicut, India (pop. 400,000)
- Cologne, Germany
- Mankato, (Minnesota), USA
- Taipei, Taiwan.
- Bern, Switzerland

Professional Developments

- Public Health Palliative Care International (www.phpci.org)
  - Biennial International PHPCI Conference series
- Compassionate Communities UK (https://compassionate-communitiesuk.co.uk)
  - SAGE journal “Palliative Care & Social Practice”
- EAPC (public health) reference group
  - Public Health England and Pallium Canada (Toolkits)
- Scottish Public Health Network/Scottish Partnership for Palliative Care
  - NHS ‘Ambitions’ Policy for Palliative Care 2015-2020.
- First Oxford Textbook in Public Health Palliative Care (2022)

The Limits to public health…

- George Burns on his 99th birthday



Want to know more?

- J. ABEL & A. KELLEHEAR (eds)
- Oxford Textbook of Public Health Palliative Care.
- Oxford University Press, 2022

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Thank you for Joining us!

RIPEN NORTH EAST

Q&A Code