

End of Life Research Priority Setting

Collaboration for Leadership in Applied Health Research and Care (CLAHRC) Greater Manchester

4th February 2016

Prof. Gunn Grande

Plan for today

Time	Topic
09:00-09:30	Registration and refreshments
09:30-09:45	Speed networking
09:45-09:50	Aims of the day/ What is CLAHRC?
09:50-10:25	National research priorities and how our projects fit with these: The national context and our EOL priority setting work.
10:25-11:10	Group discussion 1
11:10-11:25	Break and refreshments
11:25-12:10	Group discussion 2 (All delegates move to new table with a new topic)
12:10-12:30	Feedback
12:30-12:45	Round up of the session
12:45--13:15	Lunch and networking

Aims

National Research Priorities



Local priorities and research questions

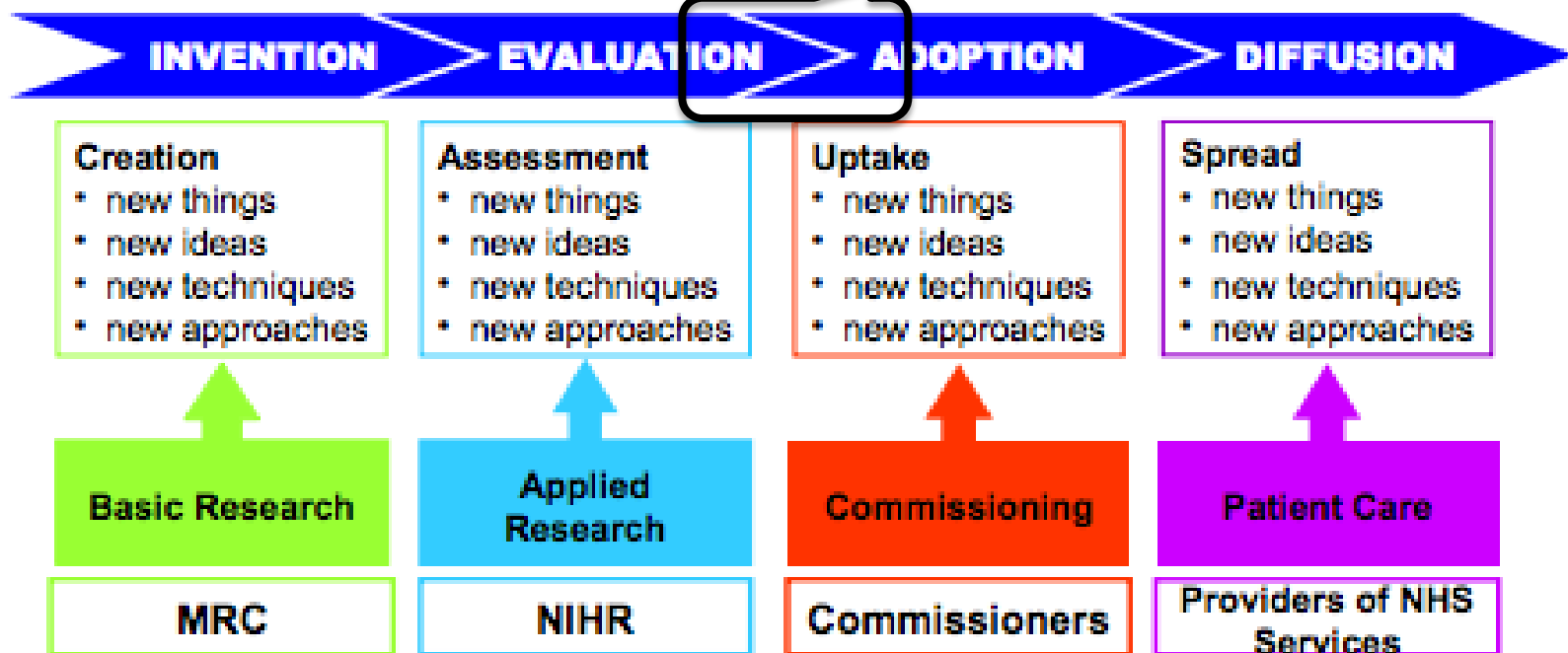


Local research agenda for collaboration

The role of CLAHRC Greater Manchester

The Research Pathway

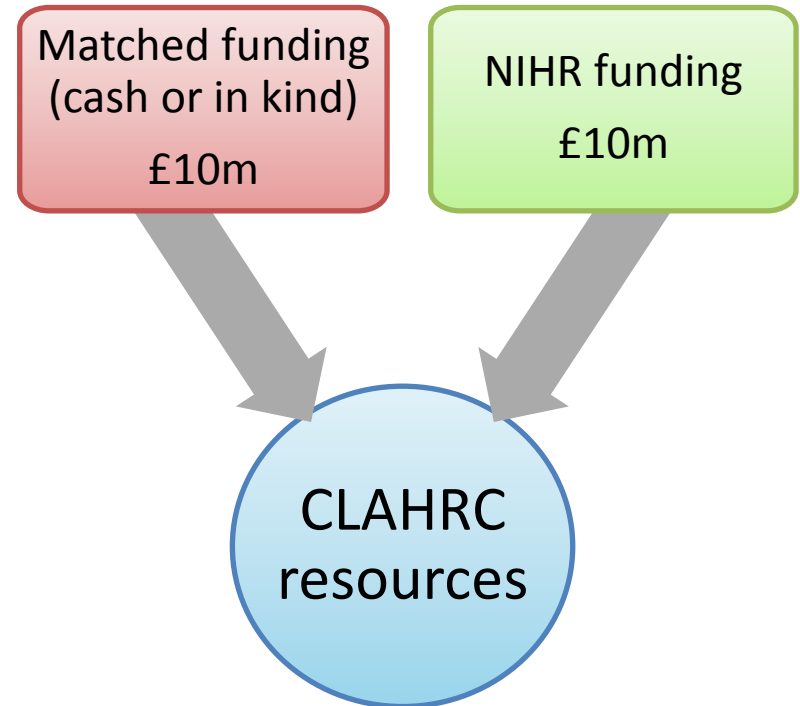
CLAHRCs: bridging a gap in translation



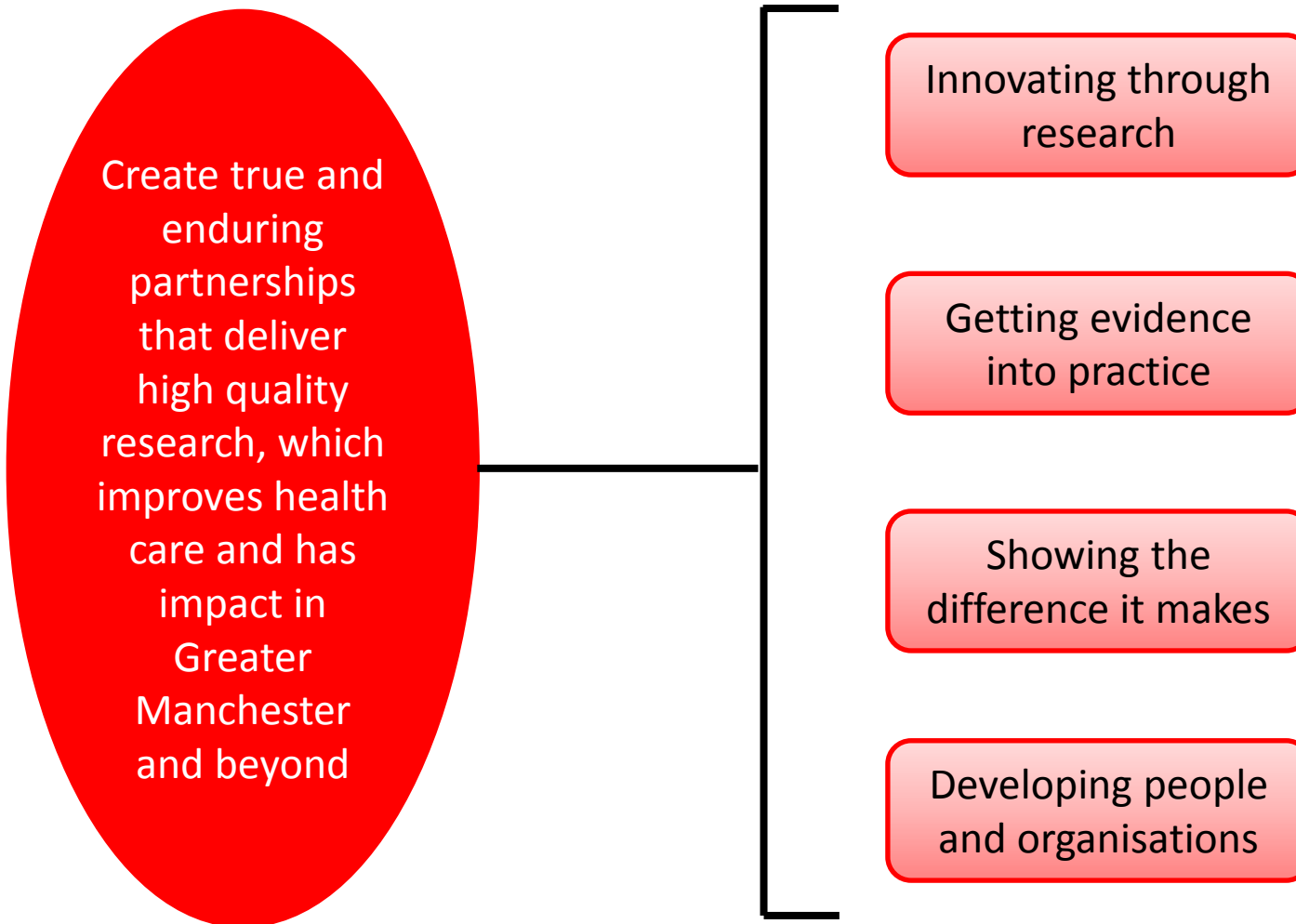
*“NIHR CLAHRCs address the **evaluation** and **identification** of those **new interventions** that are effective and appropriate for everyday use in the NHS and the **process of their implementation** into routine clinical practice”*

Large scale NIHR investment

“£124 million has been allocated to 13 new collaborations that demonstrated a substantial portfolio of world-class applied health research, particularly in research targeted at chronic disease and public health interventions, and held a track record in translating research findings into improved outcomes for patients”



CLAHRC GM vision and objectives



Themes and enabling networks

Primary Care

Assess and improve:

- cardiovascular health
- access to primary care
- patient safety

Community Services

Assess and improve:

- wound care
- end of life care

Patient-centred care

Assess and improve care for people with:

- multiple long-term conditions
- mental health issues
- stroke

Stakeholder engagement

Capacity development

Learning and evaluation

Community Services: partners

- Central Manchester University Hospitals NHS Foundation Trust (CMFT)
- Salford Royal NHS Foundation Trust (SRFT)
- University Hospital of South Manchester Foundation Trust (UHSM)
- Pennine Care NHS Foundation Trust
- East Lancashire Hospitals NHS Trust
- Marie Curie
- Macmillan
- Dimbleby Cancer Care
- Hospice UK

Greater Manchester



End of Life

Vision:

To support high quality end-of-life care in the community, prevent unnecessary hospital admissions and facilitate appropriate hospital discharges.

Stage 1:

- a) Mapping of end-of-life pathways to support care at home
- b) Supporting family carers

Stage 2:

- c) Build networks of professional stakeholders, informed by active service user involvement
- d) Collaborate to undertake new research regarding EoL within the community

Stage 3:

- e) To develop new knowledge about how research findings can be implemented into practice in community services

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End of Life Research Priority Setting

Palliative and end of life care Priority Setting Partnership (PeolcPSP)

Putting patients, carers and clinicians at the heart of palliative and end of life care research

www.palliativecarepsp.org.uk

- Marie Curie and James Lind Alliance
- 30 organisations and groups
- Patients, carers, health and social care professionals



Surveys in two stages



Priority setting workshop

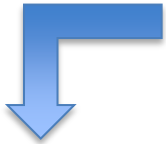
Top 10 unanswered questions

- How can we ensure **staff are adequately trained**?
- What **information and training do carers and families** need?
- What are benefits and best ways of **providing care in patients' homes**?
- What are the best ways of providing care **outside working hours**?
- How can **access to palliative care** be improved?
- What are the benefits of **Advance Care Planning**?
- What are the best ways of ensuring **continuity of care** at end of life?
- What are the best ways of determining and addressing needs of patients with **non-cancer diseases**?
- What are the best ways to **assess and treat pain and discomfort**?
- What are the **core palliative services** that should be provided regardless of diagnosis?

National Priorities



Local EOL stakeholder mapping



Training - staff

Training – families

Providing Care at Home

Out of Hours care (24 hours)

Equal Access

Advance Care Planning

Continuity of care

National Priorities

Local EOL stakeholder mapping

Training - staff

Training – families

Providing Care at Home

Out of Hours care (24 hours)
Equal Access
Advance Care Planning
Continuity of care

Patient and carer views

EOL Priority Setting workshop

EOL Advisory Group

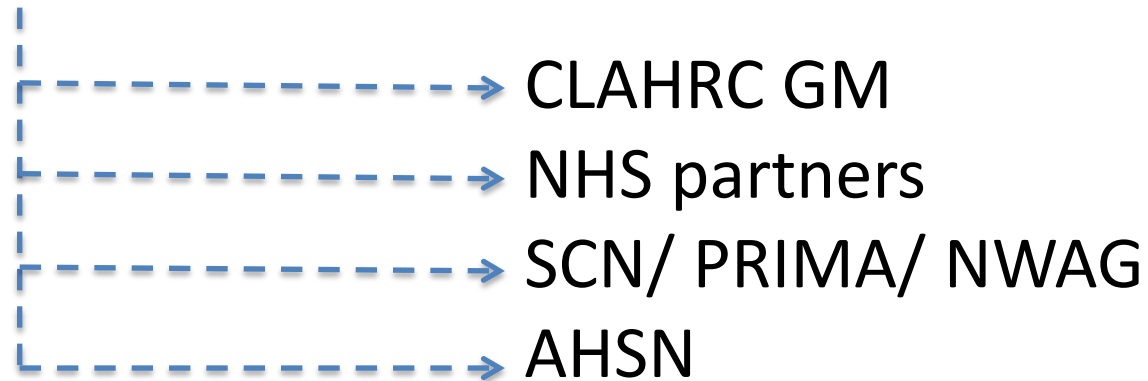
Local priorities

Aims of the day

- Identify research priorities of greatest relevance locally
- Develop researchable questions



Priority document



Developing researchable questions

- **C** Client – at whom is the service aimed?
- **L** Location – where is the service sited?
- **I** Improvement – what improvement are you looking for?
- **P** Professional – who is involved in providing/ improving the service?
- **P** Patient or population
- **I** intervention
- **C** comparator
- **O** Outcomes

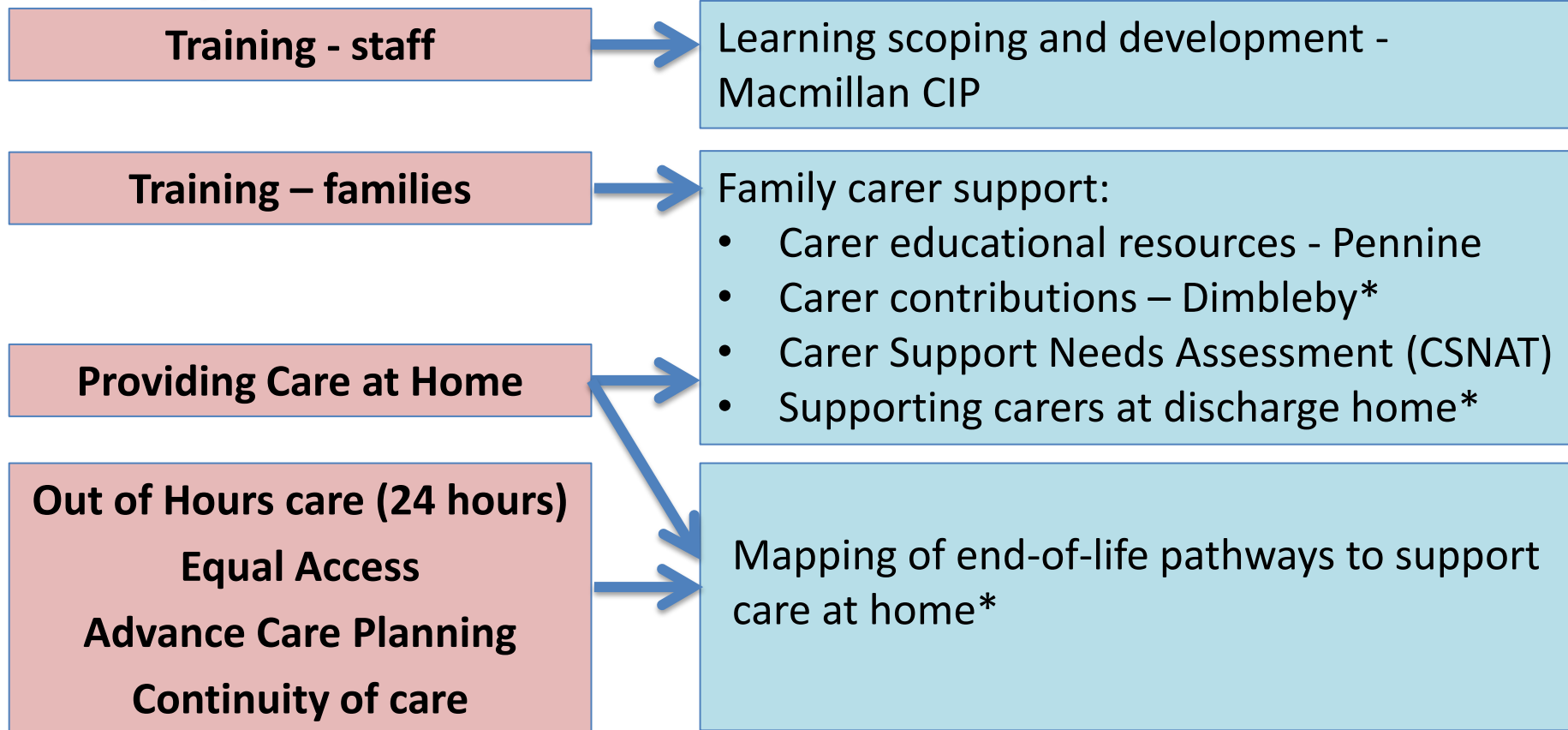
“How can we improve ACP for patients with advanced HF within community HF Specialist Nursing?”

“Does use of intervention X within community HF specialist nursing improve ACP for patients with advanced HF compared to usual care?”

CLAHRC GM projects in the context of national priorities

National Priorities

Local EOL stakeholder mapping



Supporting Carers at discharge home

Background:

Family carers play a central role in supporting successful discharge from acute care to community at end of life, but they have little involvement in discharge planning or preparation

Aim:

To improve support for carers at discharge

To utilise and adapt a Carer Support Needs Assessment Tool



Carer Support Needs
Assessment Tool



Care and support
through terminal illness

Supporting Carers at discharge home

Methods:

- Funded through Marie Curie
- Involving:
 - Qualitative interviews with bereaved and current carers to explore content, timing and format of support they required during discharge
 - Focus groups and interviews with acute and community health and social care professionals
 - Consultative workshops on how to adapt and integrate carer support needs assessment into discharge pathways

Results so far:

- 22 carers interviewed Central Manchester
- 40 practitioners in 8 focus groups across Central, North and South Manchester
- 2 workshops with 5 carers and 14 practitioners
- Preliminary findings
 - Palliative care discharges were complex
 - Although carers were at times involved in discharge discussions, the focus was on patients' needs
 - The simple question format of the CSNAT was valued
 - Permitted anticipatory work with carers who had not yet thought through the extent of the caring role at home; manage expectations
 - Enabled carers to articulate concerns and the issues discussed to come from carer's perspective

Supporting Carers: The cost and contributions of family carers at EoL

Background:

Family care giving is vital in enabling care at home at EoL, but is not quantified and remains 'invisible'

Aim:

To measure the costs, contributions and impact of family care giving at EoL



Supporting Carers: The cost and contributions of family carers at EoL

Methods:

- Funded through Dimbleby Cancer Care
- Focus on carers of cancer patients in first instance, however not exclusively
- Development of content and format of survey with local user groups – 3 stage process utilising
 - Group discussion
 - Individual cognitive testing
 - Pilot survey
- National survey of bereaved carers via the Office of National Statistics

Results:

- 5215 surveys sent: 1479 responses so far (28% response rate)
- This will tell us
 - How many hours spent caring and on what tasks
 - Expenses, impact on work and income
 - Patterns by area of deprivation and age
 - Impact of care giving and who is most likely to be negatively affected

Reducing variations in end of life care in primary care

Simon Bailey, Manchester Business School

Laura Anselmi, Centre for Health Economics

On behalf of the CLAHRC EoL pathways team

Outline

- Overview of the project
 - How it fits EoL priorities
 - Where it fits in CLAHRC
- Current findings
 - Quantitative analysis of death in usual place of residence (DIUPR) at general practice level
- Ongoing analysis
 - Quantitative mapping study
 - In depth qualitative study

Overview of the project

Our overall aim is to reduce variations in the management of end of life care in primary care within demographically diverse populations

What we want to know:

- How to reduce variations in the provision of life care that aligns with patient preferences for place of care and death
- How to reduce variations related to social and ethnic diversity
- How to reduce variations related to different general practices

How we will find out:

- Quantitative analysis at practice level to identify the relative importance of organizational and population demographic factors
- Mapping study to explore importance of different practice characteristics
- In depth qualitative study with staff to develop responses to variation

How does this fit CLAHRC EoL research priorities?

The main goal in delivering good end of life care is to be able to clarify a person's wishes, needs and preferences and deliver care to meet these needs.

1. Education/ Knowledge

What information & support do families and carers need? What training and development do staff need?

2. Access to 24 hr care

What are the best ways of providing care 24 hours a day to avoid crises and help patients to stay in their place of choice?

3. Equal access for all

How can access to end of life care services be improved for everyone regardless of where they live?

4. Planning end of life care in advance

What are the benefits of planning end-of-life care in advance? Who is best placed to help patients and families plan in advance?

5. Care at home

What are the benefits of providing care at home and what are the best ways of doing this?

6. Consistent care

What are the best ways to make sure there is reliable quality of care at the end of life?

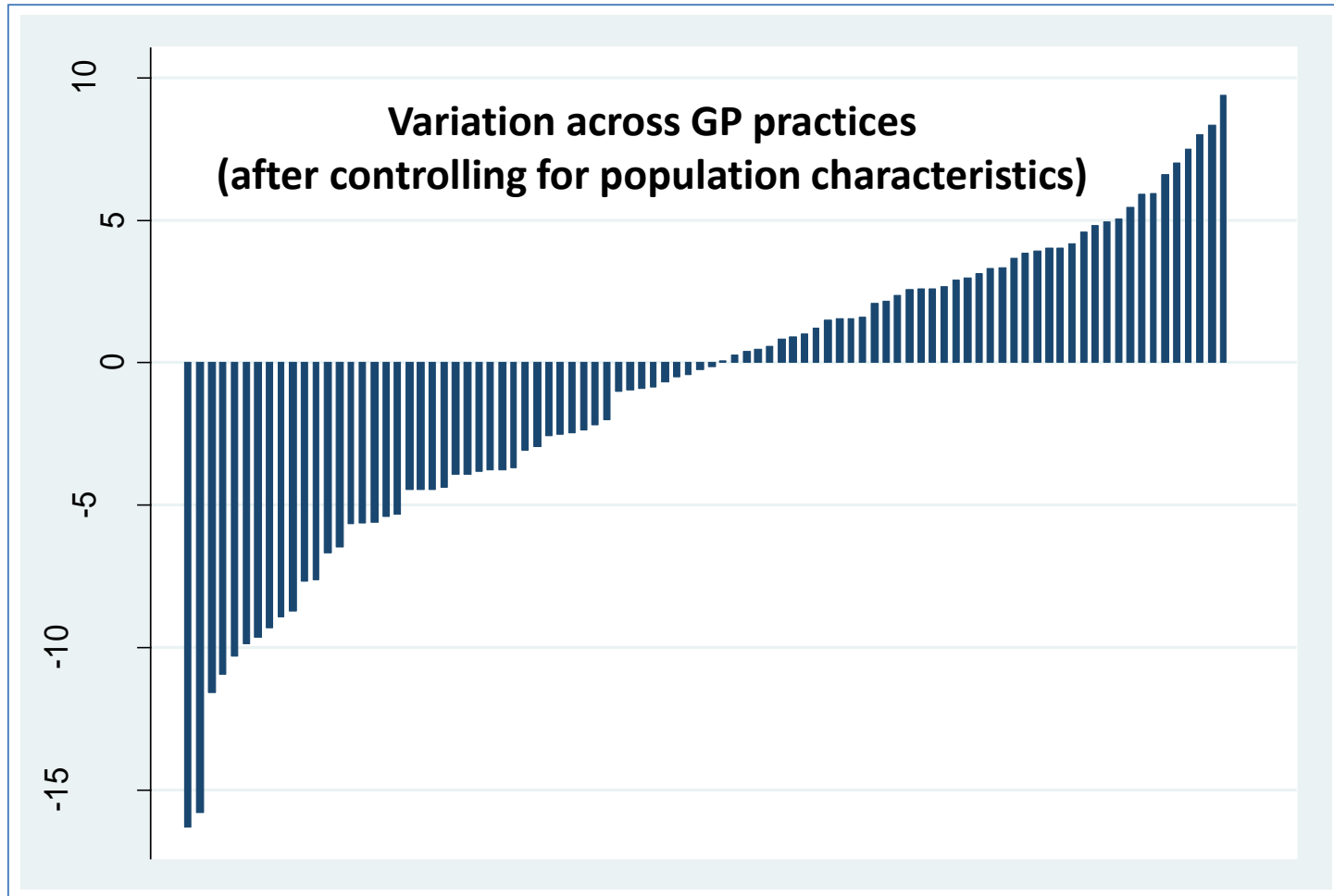
Analysis of expected outcomes in GP practices: Method

- Focus on Deaths in Usual Place of Residence (DIUPR): home or care home
- 93 anonymised GP practices (North, South & Central Manchester) over 17 quarters (Jan 2011–Mar 2015)
- Data from Primary Care Mortality Database:
 - Place of death (Home, Care Home, Hospice, Hospital, Other)
 - Cause of death, gender, age, LSOA of residence, CCG of the GP practice
 - Average characteristics of LSOA population by ethnic group, religion and deprivation (linked from Census 2011)
- Analysis at the GP practice level:
 - Quantify factors associated with proportion of DIUPR
 - Predict proportion of DIUPR in each GP practice for given characteristics
 - Compare predicted and observed proportions of DIUPR

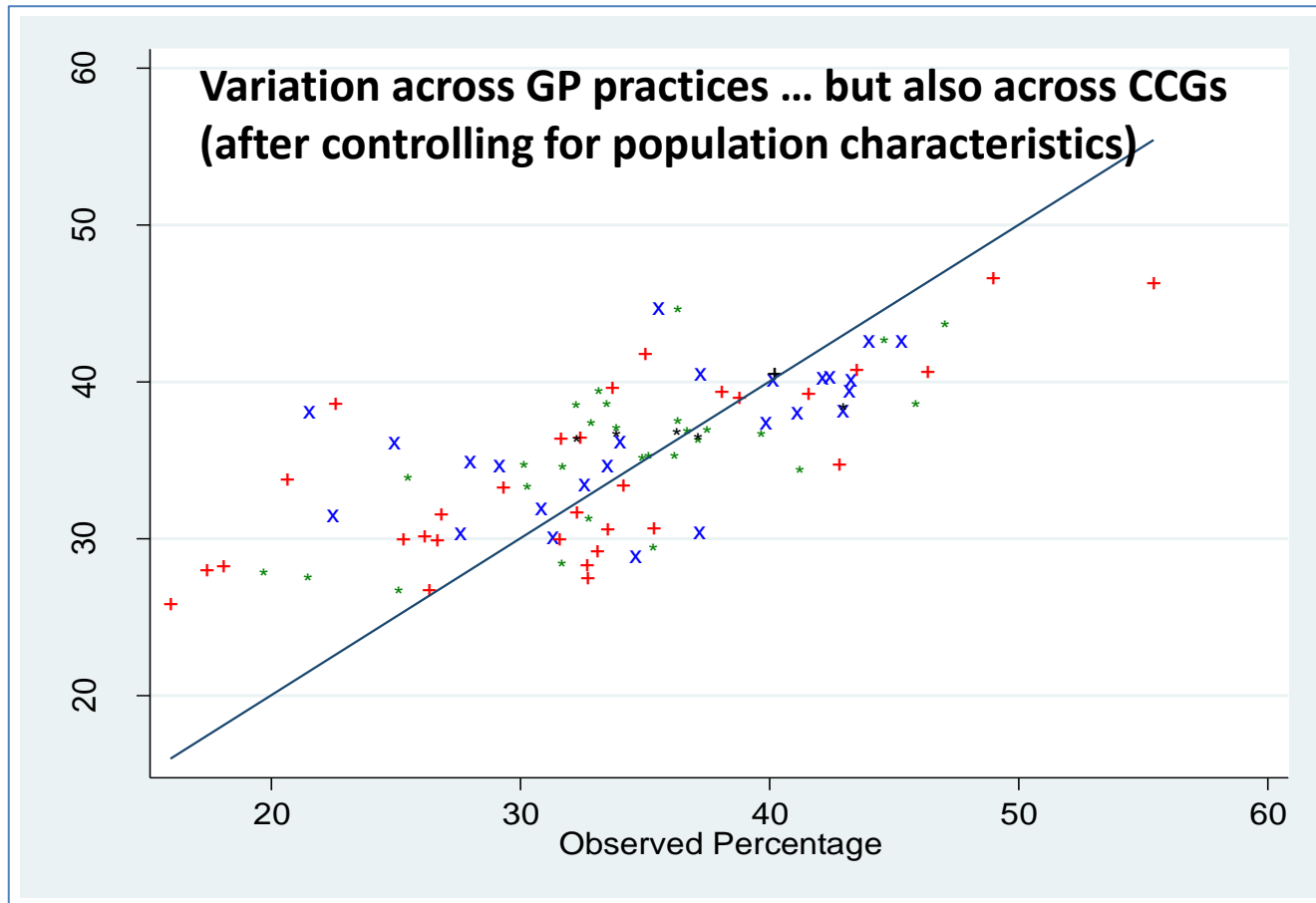
Analysis of expected outcomes in GP practices: Findings

- The proportion of **DIUPR has increased** over time (37.22% to 39.67%)
- The proportion of **deaths in hospital has decreased** (from 67.49% to 57.90%)
- Central Manchester has the lowest percentage of registered DIUPR (35.80%) and South Manchester the highest (38.66%)
- **Higher proportions of DIUPR are associated with:**
 - Higher percentage of deaths due to **cancer, coronary heart diseases and dementia**
 - Average composition of LSOA population including
 - **higher percentage of mixed population** (lower percentage of other ethnic groups)
 - **higher percentage of non-religious population or with no-stated religion**
- The same factors may have opposite effects on death at home or in a care home

Differences between observed and predicted rates of DIUPR:



Differences between observed and predicted rates of DIUPR:



Ongoing analysis

Quantitative mapping study to identify the factors at the GP practice level that may affect DIUPR:

- Link data on GP practice characteristics from different sources (e.g. QOF, GPPS) with GP practice data to explain the variation (depends on our access to data)
- Include information on staffing, patient satisfaction, service provision (e.g. personalised care plans) and accessibility
- Carry-out the analysis at the individual level (depends on our access to data)
- Highlight potential factors that affect differences in the GP practice performance

Proposed qualitative study

- To examine in depth reasons for variation and develop targeted responses
 - Define case studies based on ‘over’ and ‘under’ performers, and range of practice characteristics
 - Conduct interviews and observations with staff in primary & community services
 - Conduct interviews with staff in acute and specialist services
 - Develop recommendations

Next, next steps

- To use the current study as a foundation for larger scale national project
 - National mapping project combining quant analysis of expected outcomes with organisational characteristics in general practice
 - In depth case studies across UK to capture national social and demographic diversity
 - Project will make up part of end of life programme in CLAHRC 3...(we hope!)

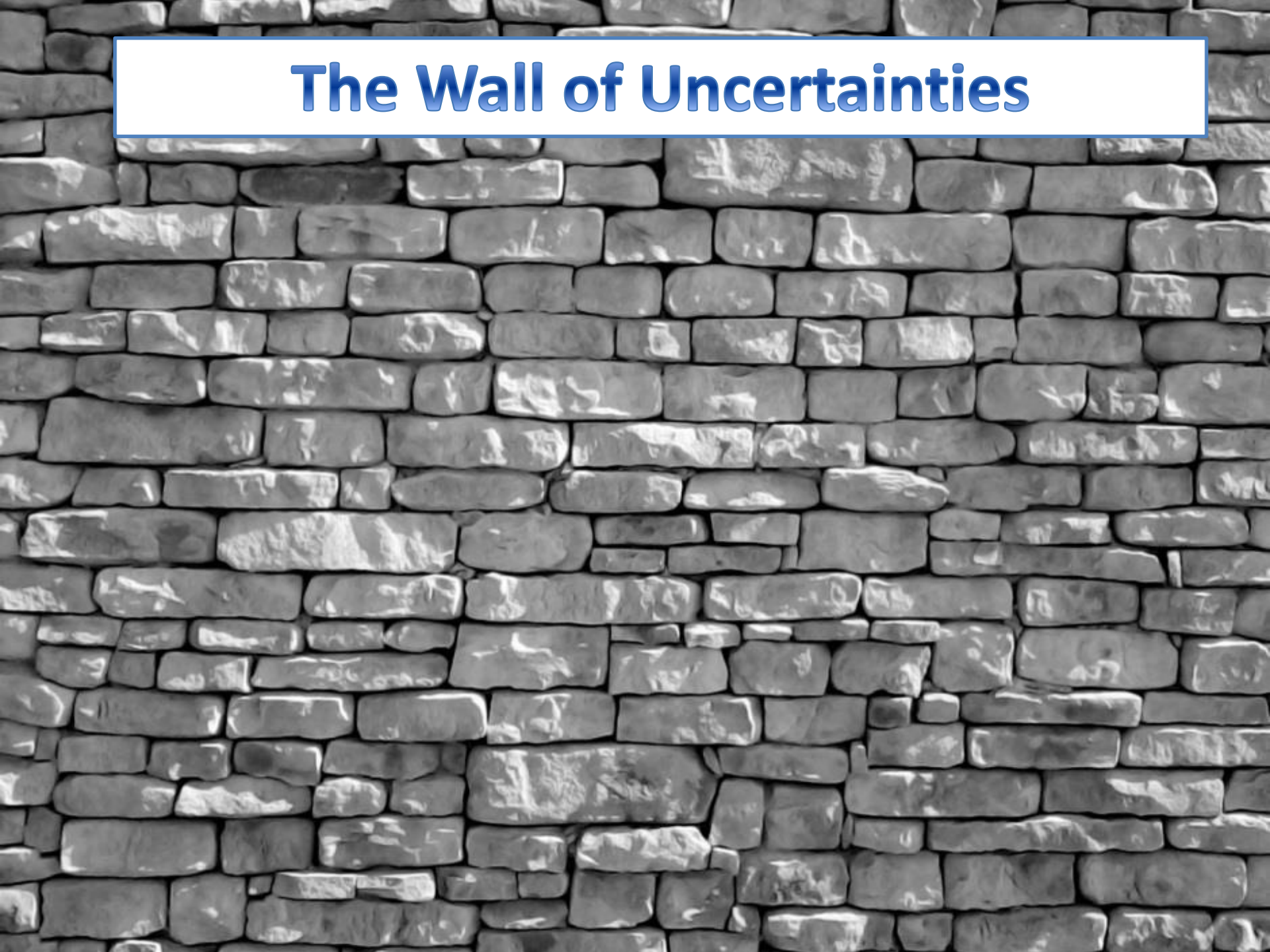
Group Discussion 1

At your tables, consider the following questions with regard to your research topic:

- What is important to you about your research topic? (***10 minutes***)
- What are the research questions you'd like to be answered within this topic? (***25 minutes***)
- What are the top 3 research questions within this topic? (***10 minutes***)

45 minutes

The Wall of Uncertainties



Group Discussion 2

Please move to your second table and consider these questions with regards to your new topic:

- What is important to you about your research topic? (***10 minutes***)
- What are the research questions you'd like to be answered within this topic? (***25 minutes***)
- What are the top 3 research questions within this topic? (***10 minutes***)

45 minutes

Tony Bonser

tbonser@aol.com

Trustee NCPC

Local Champion Dying Matters

Fund Raiser Macmillan Cancer Support

Trustee at St Catherine's Hospice

Panel member, LCP Independent Review





The National Council for Palliative Care (NCPC) is the umbrella charity for all those involved in palliative, end of life and hospice care in England, Wales and Northern Ireland. We believe that everyone approaching the end of life has the right to the highest quality care and support, wherever they live, and whatever their condition. We work with government, health and social care staff and people with personal experience to improve end of life care for all.

Dying Matters is a coalition of 30,000 members across England and Wales which aims to help people talk more openly about dying, death and bereavement, and to make plans for the end of life.



“Many consider death to be the last great taboo in our society and ...most of us find it hard to engage in advance with the way in which we would like to be cared for at the end of life.”

End of Life Care Strategy, Department of Health, 2008

Our greatest fear

How scared are you of the following happening to you?

- Dying in pain 83%
- Dying alone 67%
- Being told you are dying 62%
- Dying in hospital 59%

Compare with:

- Going bankrupt 41%
- Divorce/end of a long-term relationship 39%
- Losing your job 38%

ComRes 2011

HOW SCANDAL HAS GROWN

**DOCTORS TO ACT
ON CARE PATHWAY**

Mail yesterday

**Family revive
father doctors
ruled wasn't
worth saving**

October 13

**Son calls police
over mother's
death on the
'care pathway'**

October 10

**Care? No,
this is a
pathway
to killing**

October 15





“The dying person and those important to them, are involved in decisions about treatment and care to the extent that the dying person wants.” OCTGIR

“Discuss the dying person’s prognosis with them (unless they do not wish to be informed) as soon as it is recognised that they may be entering the last days of life and include those important to them in the discussion if the dying person wishes.” N.I.C.E.

....and what do
YOU want,
Neil?



**“WE AIM TO
DELIVER PERSON-
CENTRED GOAL-
ORIENTATED
CARE”**