

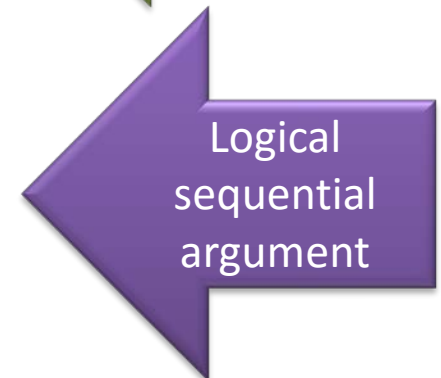
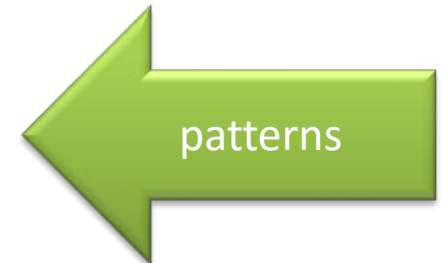
St Christopher's

A real world perspective on
research


Heather Richardson



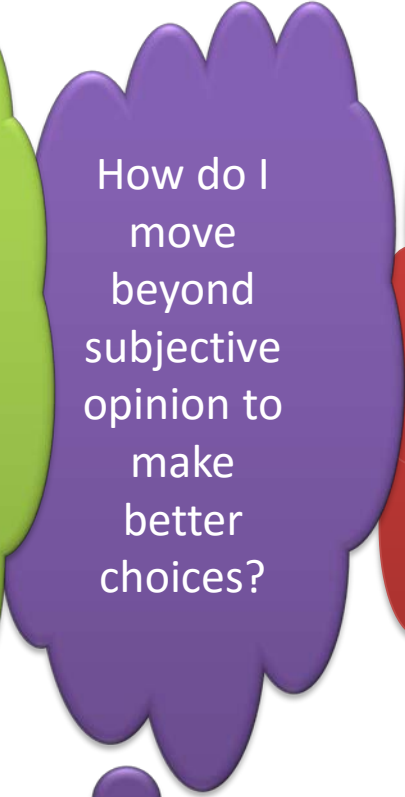
Introduction to me....



Becoming research active...



Who should I listen to ?



How do I move beyond subjective opinion to make better choices?



How can I think more critically about the relative value of services?



What does good research look like?



How do research findings get translated into practice

Aims of the research

- To learn about Palliative Day Care (PDC) from the perspective of those using the service
 - how they experienced the service
 - what value they placed on it
 - how it related to their lives and their experience of living with a progressive and life threatening condition
- To explore whether patient experiences varied between services
 - if so, for what reason(s)
 - in the event of a common experience, to examine it, describe it and consider it in relation to other stakeholders experience of PDC
 - to consider these experiences in relation to the various models of PDC

The Chosen Approach

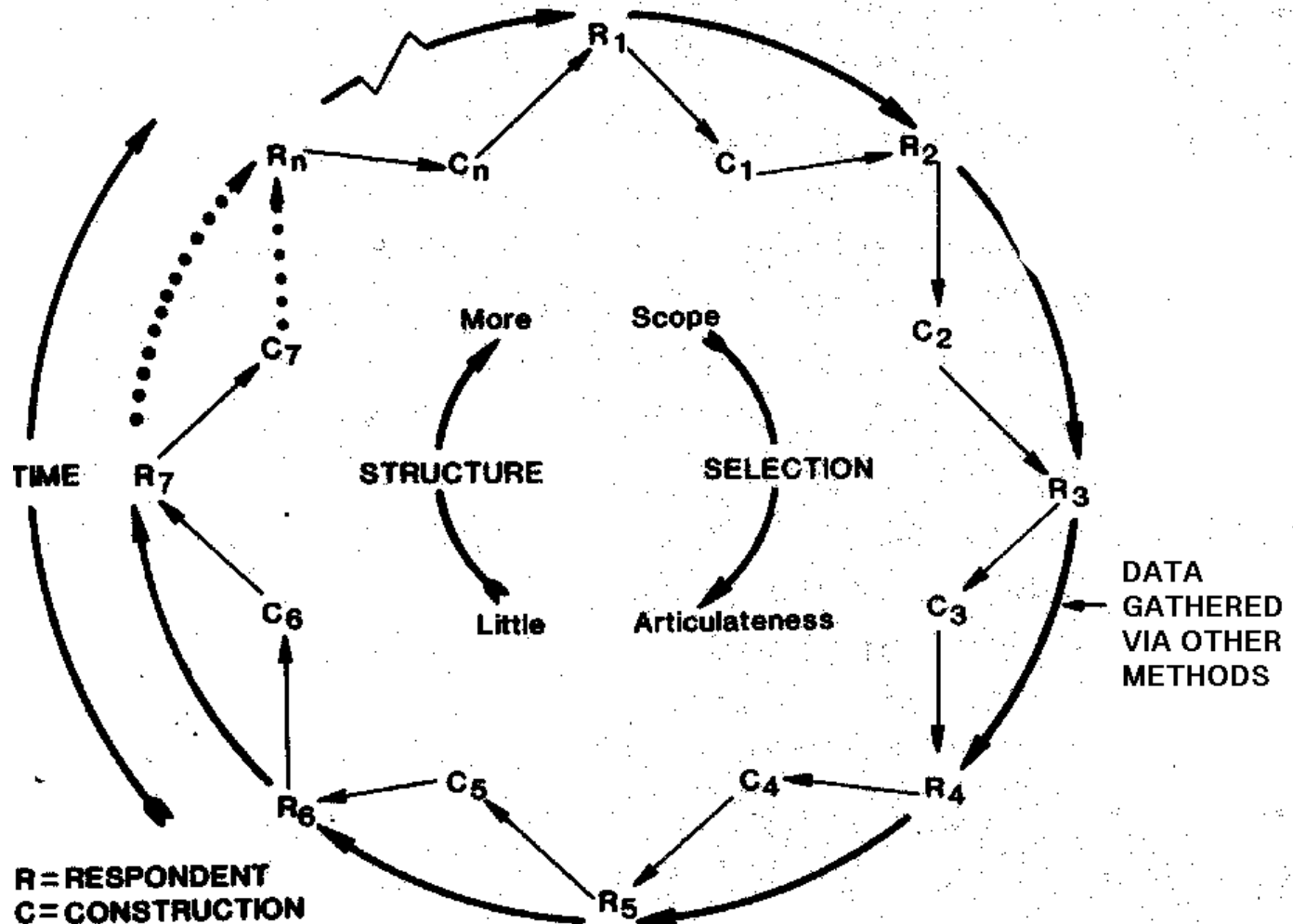
- A study of 2 day care services over 11 months in total (plus a pilot):
 - Using case studies
 - Using qualitative methods of data collection: observation, interviews, examination of documents and a focus group
 - Interviews undertaken with a variety of stakeholders of the service, starting with patients
 - Data collection and data analysis undertaken concurrently to build a picture of the services studied

Gathering the data within each case



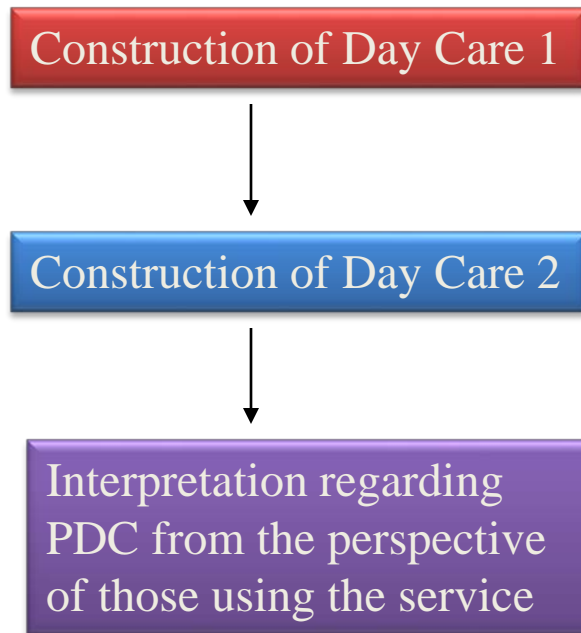
Learning through iteration

THE HERMENEUTIC DIALECTIC CIRCLE



Adapted from Guba and Lincoln 1989

Building the findings



Outcome of my research

- Great learning about the value of case study as an approach
- Interesting findings about PDC in general
- Alternative perspectives on some long term conundrums about PDC
- Some valuable insights into the more complex aspects of that service eg why discharge is so difficult
- But... little impact on practice.



Finding answers from other projects..

- Description of four research projects that have really shaped practice in hospice care
- My reflections on what made them so valuable
- Thinking further about the shape of new research projects that could have similar impact
- How researchers, managers and practitioners need to work together to achieve this

Four projects:

1. Compassionate neighbours programme in East London
2. Heart failure project in Bromley
3. Support for care homes in SE London
4. OACC and C Change across the UK

Project 1: Evaluation of compassionate neighbours in East London



Libby Sallnow

Doctor in training in palliative
medicine

PhD student registered at
University of Edinburgh

Previous experience of working in
Kerala

Research question

What are the impacts that arise from a public health (health promoting) approach to end-of-life care and what processes support or impede each of these?



Research approach

- Exploratory mixed methods study
 - Congruent with the principles of the project
 - Flexible – open to unanticipated outcomes
 - Engaging a wide range of stakeholders
- Ethical approval through University of Edinburgh
- Participant researcher perspective
- Analysis: modified grounded theory (Charmaz 2014)



Methods

- 17 in depth interviews
 - 7 staff members, 7 compassionate neighbours, 3 community members
- Participant observation
 - 12 events
- Documentary analysis
 - Policy documents, marketing, meeting minutes, service use data



Results

1. Impact

2. Facilitators

3. Barriers



1. Impact



2. Facilitators



3. Barriers

Not a standardised intervention

Personality dependent

Clinical individualised approach

Population approach

Charitable approach



Conclusions

- Significant impacts for communities involved
- Impacts seen beyond EoLC and traditional beneficiaries
- Beyond befriending – different model yields different results
- Issues of social isolation, connectedness, ageing beyond palliative care
- Questions of whose responsibility
- But can only be tackled by whole community approaches
- Value in adapting projects from other contexts



Project 2: Feasibility study of a case management approach delivering palliative care for people with heart failure



Mary Brice

Consultant nurse in heart failure

Working at St Christopher's
Hospice

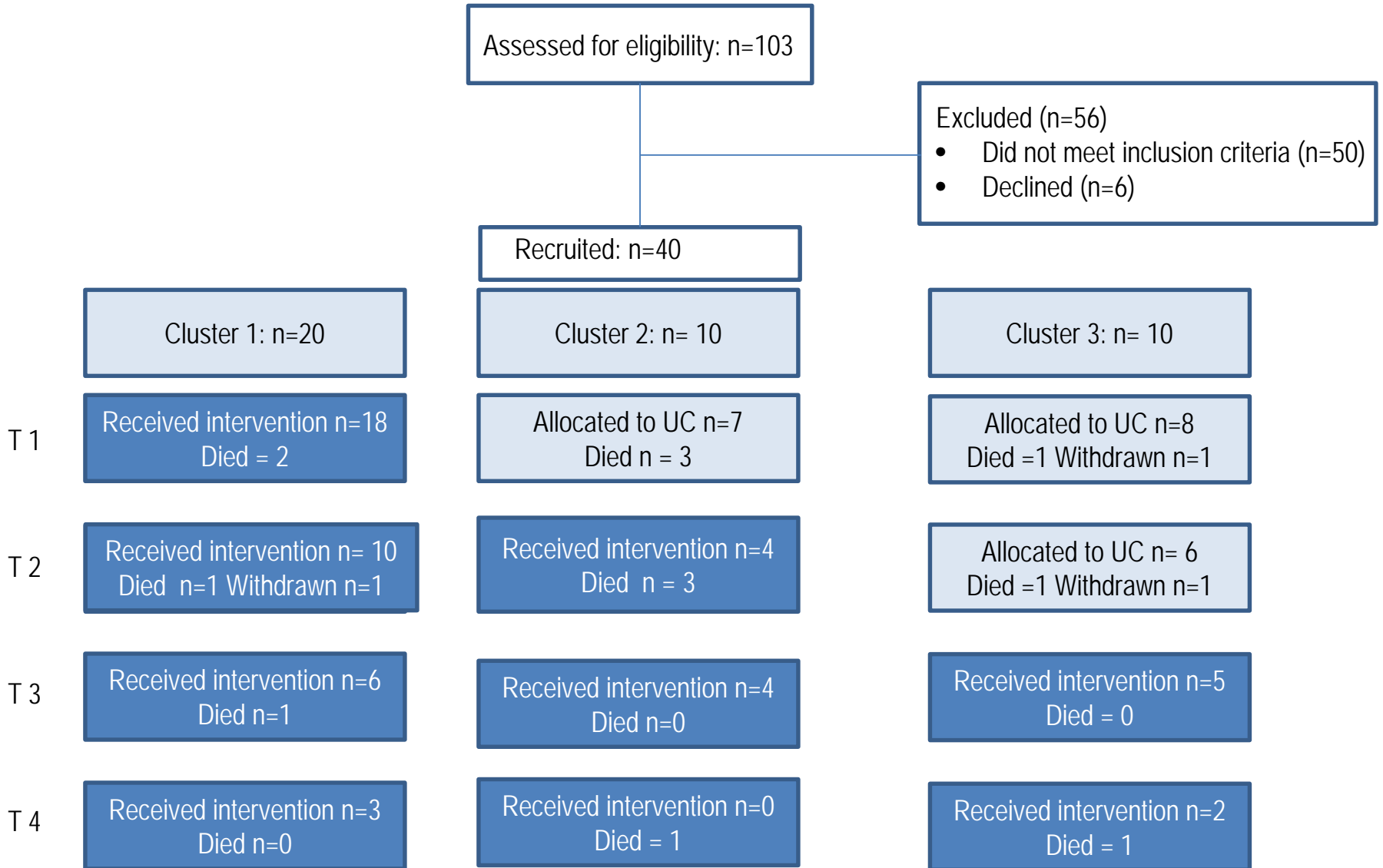
Previous experience of working in
a local CCG and community
nursing services

Aims and Objectives

- Testing the research methods (recruitment & data collection) to evaluate a heart failure palliative care case management intervention
- Defining, testing and modifying the intervention
- Assessing potential impact of intervention
- Economic assessment of intervention
- Impact on professional cultures

Method

- Stepped wedge randomised trial: phased intervention at 3 month intervals.
- Intervention: case management by heart failure palliative care nurse (HFPCN) or usual care by Bromley Care co-ordination center or GP
- Entry criteria: Advanced heart failure, high symptom burden
- Recruitment period: June 2014 – April 2015
- Research Follow-up – 12 months –maximum 378 days, minimum 22 days, mean 183 days



Intervention: Heart failure palliative care case management

- Home or clinic (hospice) visit
- Individual needs assessment and care planning
- Holistic case management in partnership with GP
- Co-ordinated care: cardiologist & palliative care/hospice team
- MDT meetings
- Full menu of hospice services

Results

- 27 male and 13 female patients (mean age 84 years, range 60-99) were recruited.
- Integrated Palliative care Outcome Scale scores, compared with an age-gender- matched specialist palliative care population, demonstrated significantly higher levels of:
 - fatigue (mean score 2.6 v 1.9, $p= 0.01$),
 - poor mobility (2.75 v 1.6, $p= 0.00$),
 - drowsiness (2.03 v 0.6, $p=0.00$),
 - breathlessness (2.2 v 0.9 , $p= 0.00$),
 - sore/dry mouth (1.4 v 0.6, $p=0.004$),
 - depression (1.4 v 0.5, $p=0.002$)
 - not feeling at peace (1.6 v 0.9, $p=0.02$).
- 67% (95% CI 49-79%) were severely/overwhelmingly affected by poor mobility and 50% (95% CI 34-65%) were affected by weakness/fatigue in the previous week.
- In qualitative interviews (8 patients, 6 carers and 2 joint), patients sought heart failure care critical for optimal symptom control, and whilst realistic about the limitations of therapies, wanted parallel support to prepare for and manage future deterioration.

Conclusions and implications for practice

- People with advanced heart failure have considerably greater needs than an age-matched palliative care population.
- They have realistic expectations about interventions available but identify practical support and appropriately skilled healthcare teams as important to their care.
- Professionals skilled in both heart failure and palliative care interventions in an integrated service model are needed.

Project 3:



Julie Kinley

Consultant nurse

Worked closely with Jo Hockley
who had initiated this work

Passionate about care homes

Continues to work with care
homes post research

Overview of research

- Cluster Randomised Controlled Trial (CRCT) examining the effect of different models of facilitation when implementing GSF in Care Homes
- Commenced in 2009, building on the previous work of Hockley (2006),(2010) which identified the importance of both 'high facilitation' and 'action learning' when implementing change in nursing care homes.
- Twenty-four nursing care homes formed two intervention groups. Both groups received high facilitation as they implemented the GSFCH programme within their nursing care home whilst the managers of one group additionally received nine months of action learning.
- Fourteen nursing care homes acted as a third observational group and received the usual GSFCH facilitation available locally in their area
- Complemented by a mixed methods study considering process of change within 38 care homes

Results:

Demographic details – from 2,444 residents

- **Mean age:** 85 years (range 33-107 years)
- **Gender:** 61% were female
- **The mean length of stay:** 20 months with a median of 8 months (range 1-6,393 days)
- **Length of stay:**
 - Nineteen per-cent of residents died within their first month of admission
 - Thirty-four per-cent of residents within the first three months of admission
 - Fifty six per-cent died within a year

Comparison of data on DNaCPR; ACP & ICP – 2009 to 2012

Care Home Project Team, St Christopher's, London

	PCT 1	PCT 2 & 3	PCT 4	PCT 5	Total
DNaCPR:					
2009/10	43% (n=155)	41% (n=265)	68% (n= 384)	54% (n=271)	52%
2010/11	45% (n=218)	74% (n=329)	75% (n= 435)	71% (n=397)	66%
2011/12	75% (n=214)	84% (n=284)	86% (n= 492)	76% (n=361)	80%
ACP:					
2009/10	48% (n=155)	44% (n=265)	60% (n= 384)	51% (n=271)	51%
2010/11	62% (n=218)	61% (n=329)	74% (n= 435)	63% (n=397)	65%
2011/12	76% (n=214)	60% (n=284)	83% (n=492)	79% (n=361)	75%
ICP for last days:					
2009/10	33% (n=155)	5.5%(n=265)	44% (n=384)	17% (n=271)	25%
2010/11	59% (n=218)	30% (n=329)	60% (n= 435)	37% (n=397)	47%
2011/12	70% (n=214)	51% (n=284)	72% (n= 492)	59% (n=361)	63%

Comparison of place of death across nursing care homes

2007-08

2008-09

2009-10

2010-11

2011-12

2012-13

2013-14

Percentage of deaths occurring in nursing care homes

57%

[n=324
deaths
across
19 NHs]

67%

[n=989
deaths
across
52 NHs]

72%

[n=1071
deaths
across
53 NHs]

76%

[n=1375
deaths
across
71 NHs]

78%

[n=1351
deaths
across
71 NHs]

77%

[n = 1375
deaths
across
72NHs]

76%

[n = 1232
deaths
across
72NHs]

Conclusions

- Proportionally better outcomes with high facilitation and action learning but not significant
- Completion of eolc programme significant with high facilitation.
- Care homes need to learn at individual, organisational and cross organisational levels. Completion of eolc programme enabled with this process.

So, what made the difference to some of the researchers?

- Being part of a research community
- Having access to people who have done the journey before
- Having opportunities to talk regularly about progress and challenges
- Making regular presentations
- Being forced to think about the implications
- Being able to write with others who have expertise/experience of doing so

Project 4: OACC



A team of researchers led by Fliss Murtagh, working at the Cicely Saunders Institute

Linked to the C-Change programme

Building on historical work related to measuring outcomes

Reasons for St Christopher's to engage in OACC

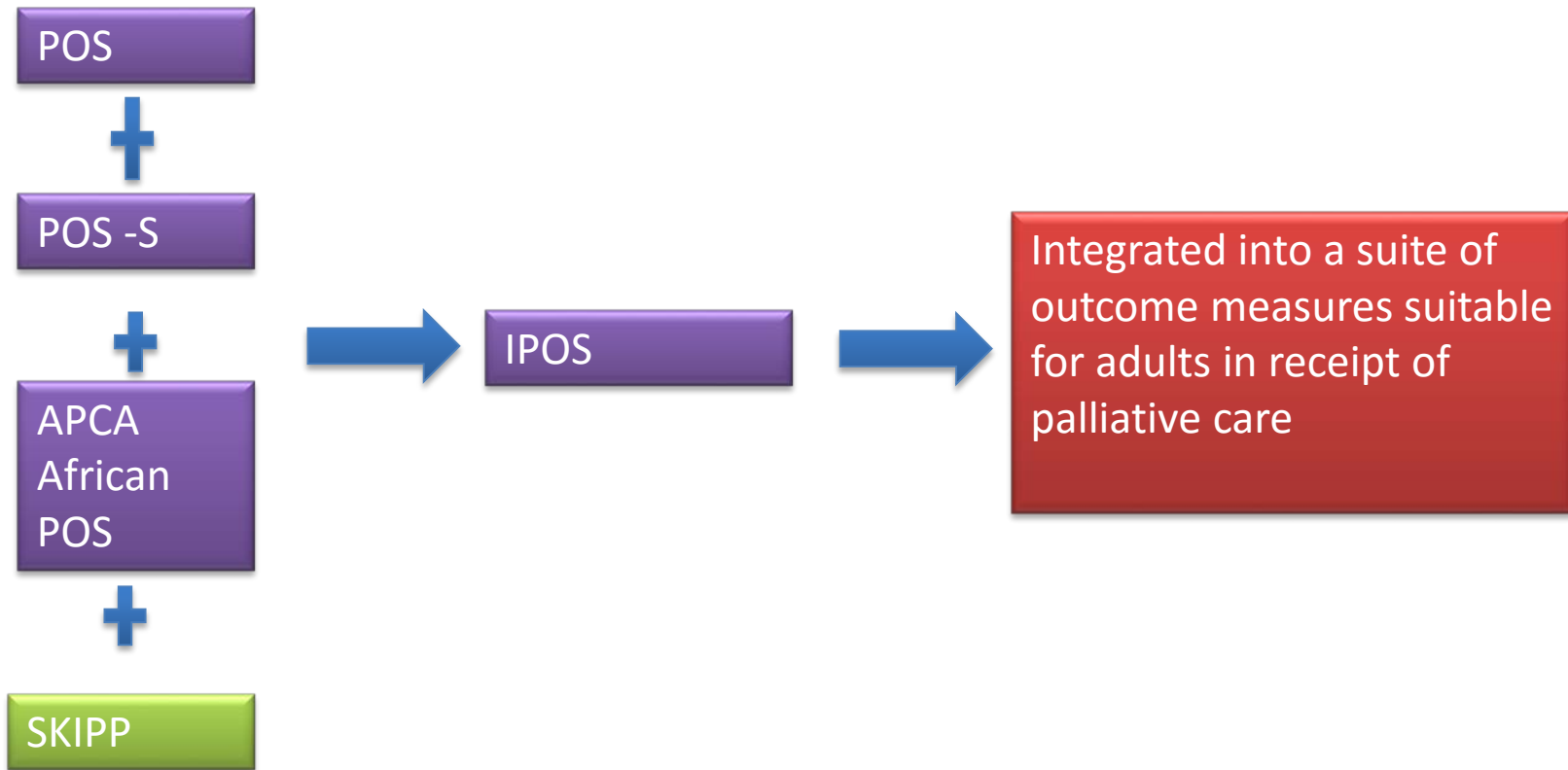
How do we move beyond thank you cards to confirm our value to government, commissioners and others

Are our patients really becoming more complex in nature or are there other reasons for the increasing burden staff feel in their work?

If experience of EOLC is similar in institutions other than hospices how do we justify our costs?

How do we explore the relative value of the different services we provide?

OACC – the history



And more planned eg IPOS DEM....

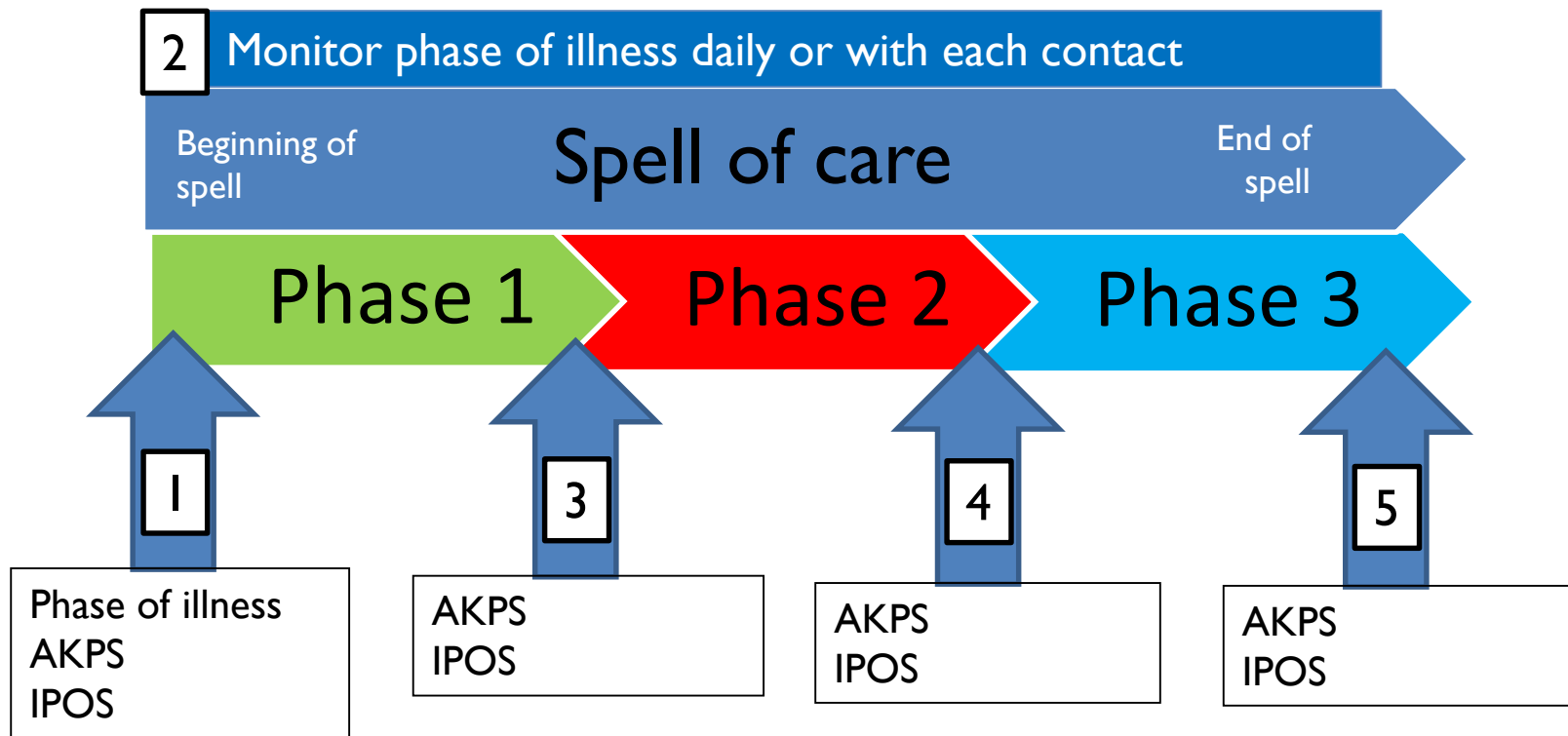
OACC in practice

- Data being collected in community, inpatient and care home settings on:
 - Phase of illness
 - Australian Karnofsky performance Score
 - IPOS – measuring symptoms and problems
 - Views on care
 - Barthel – ADL
 - Zarit carer interviews

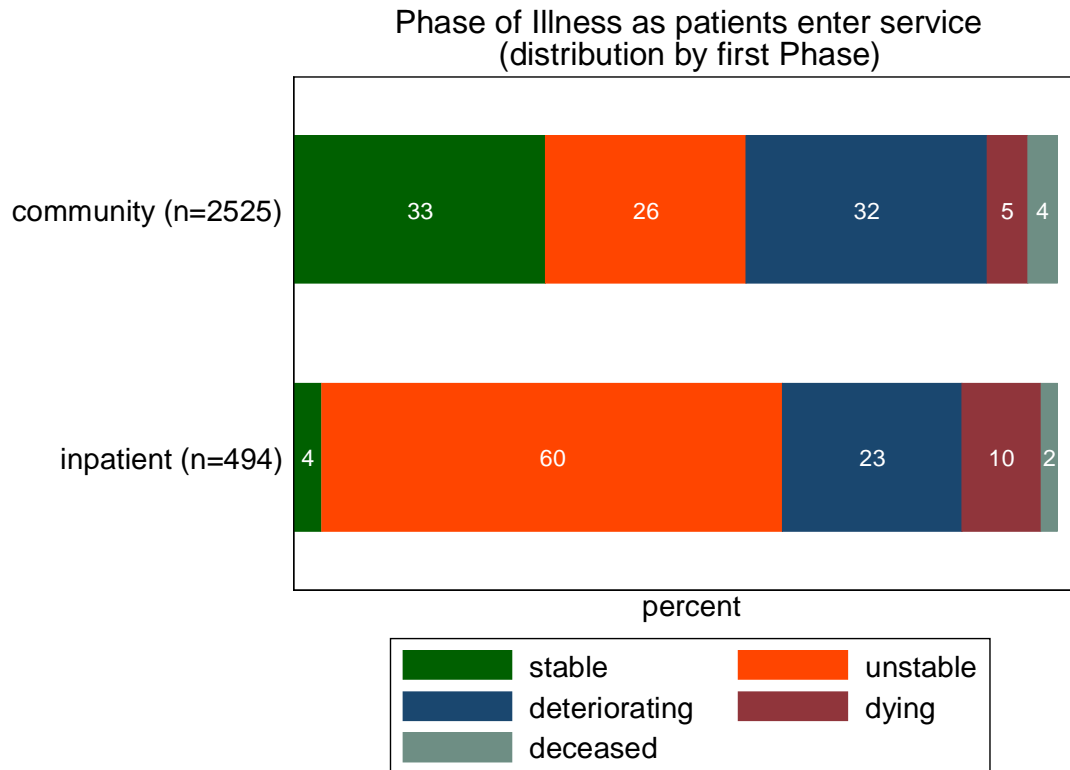
Data collected between Jan and July 2016:

- 2,465 patients
- 3,023 spells of care
- 4,915 Phases of illness

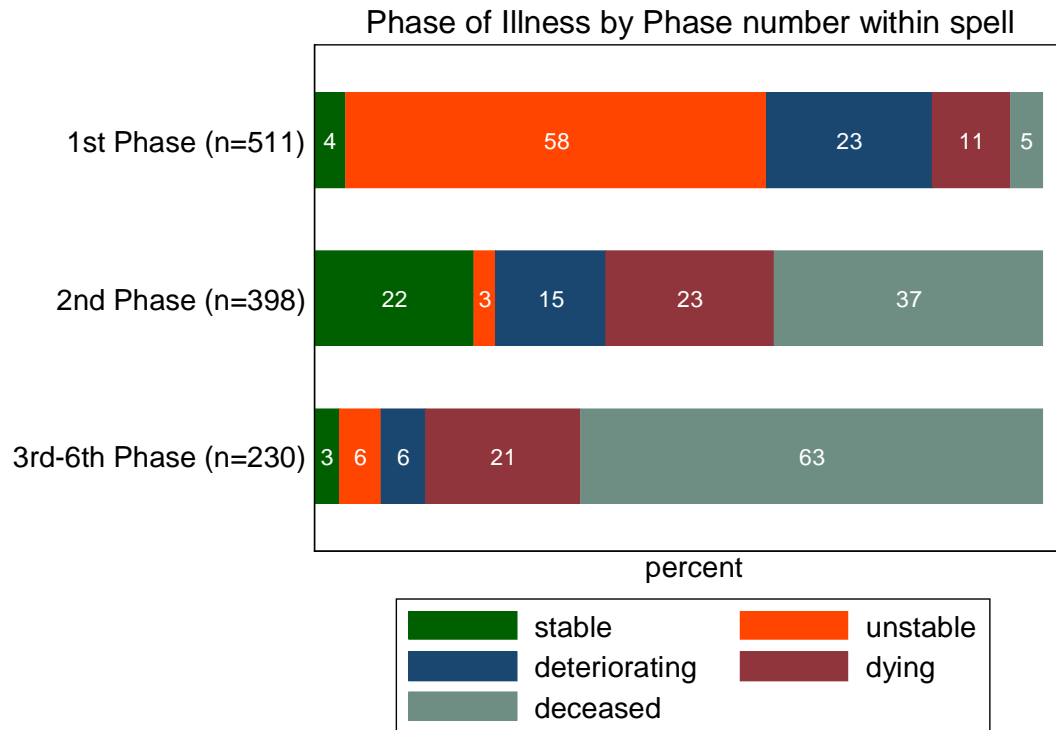
What do we collect and when?



Phase of Illness in St Christopher's patients



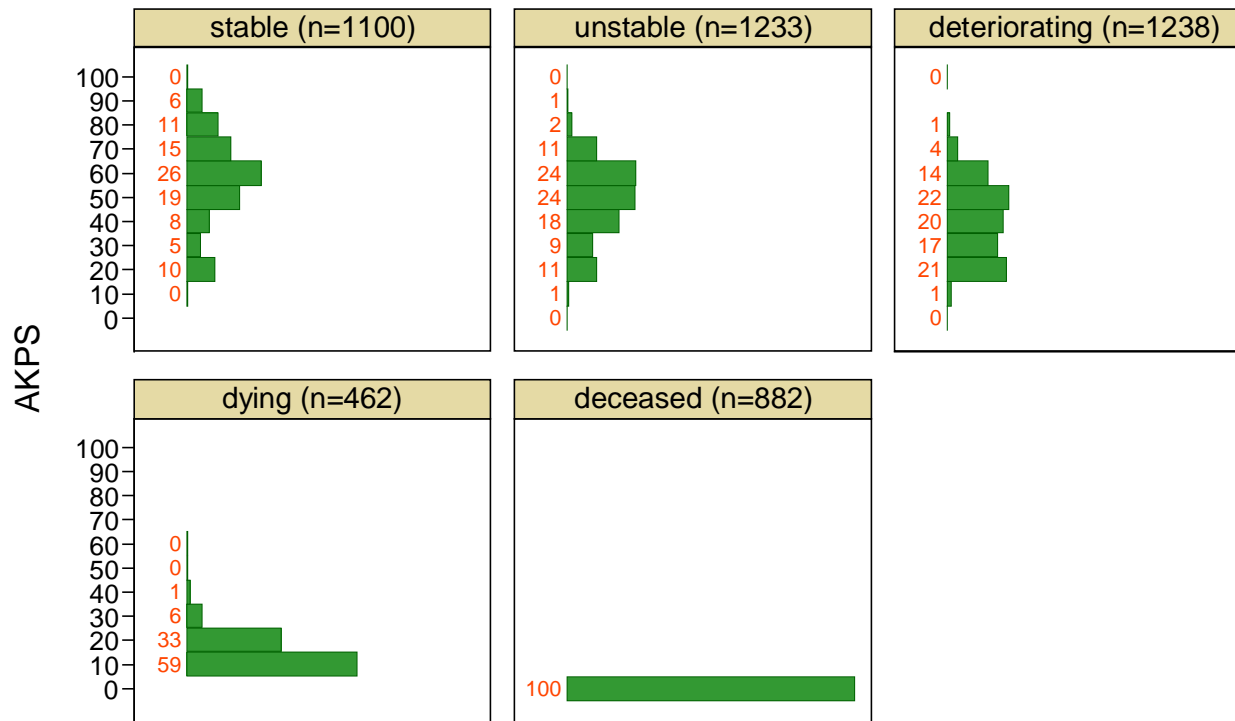
Phase of illness by Phase number within spell - inpatients



inpatients

Phase and AKPS

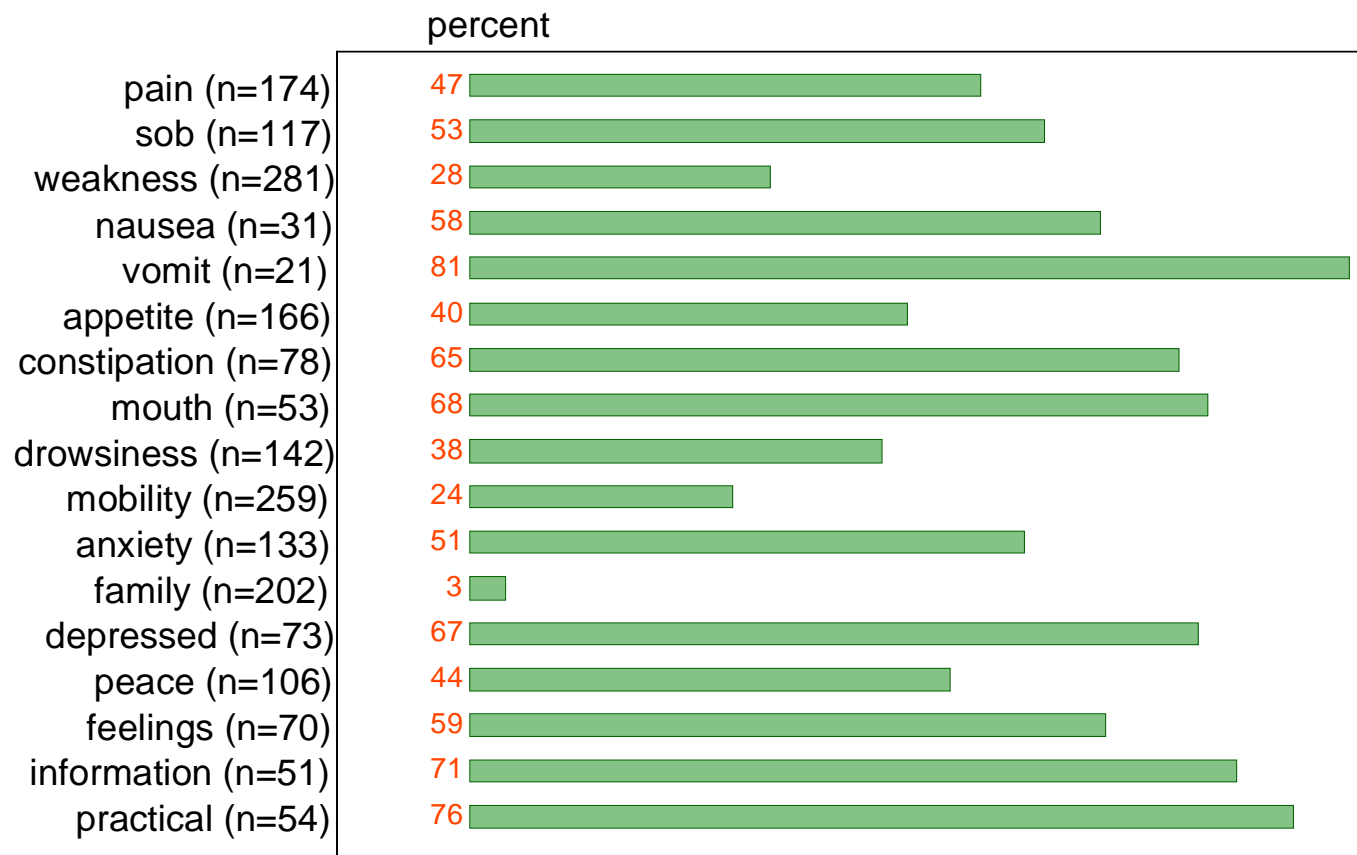
Distribution of AKPS by Phase; community and inpatients combined (all Phases)



red numbers indicate percentage
0= deceased; 100=perfect function

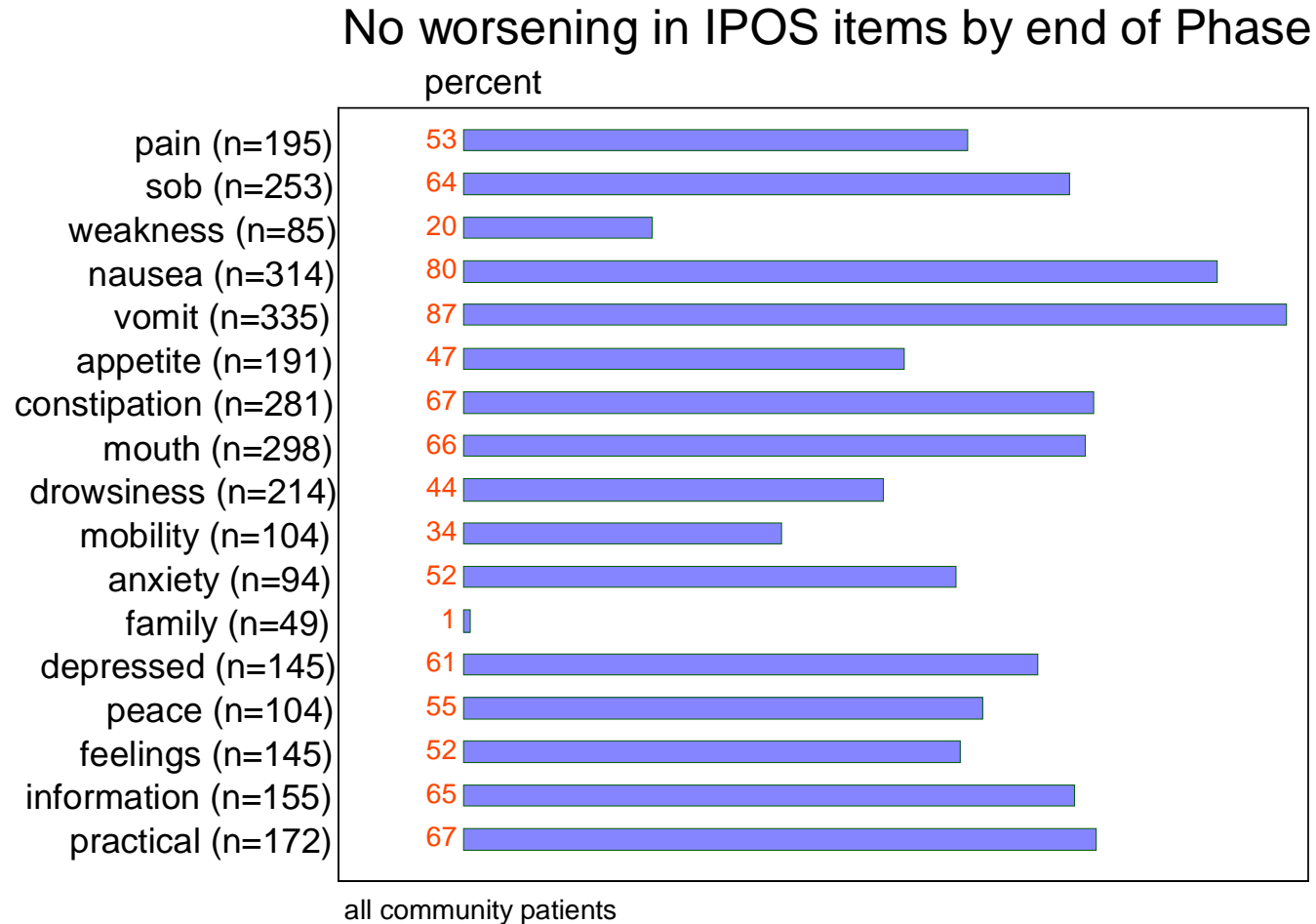
% of patients who had moderate/severe/overwhelming problems at the start of Phase and had improved by the end of Phase:
Community

Improvement in IPOS items - by end of Phase

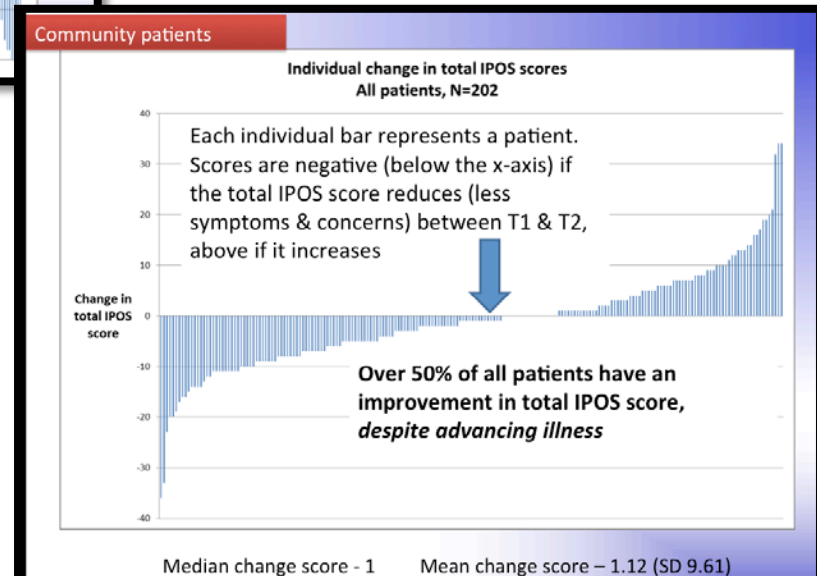
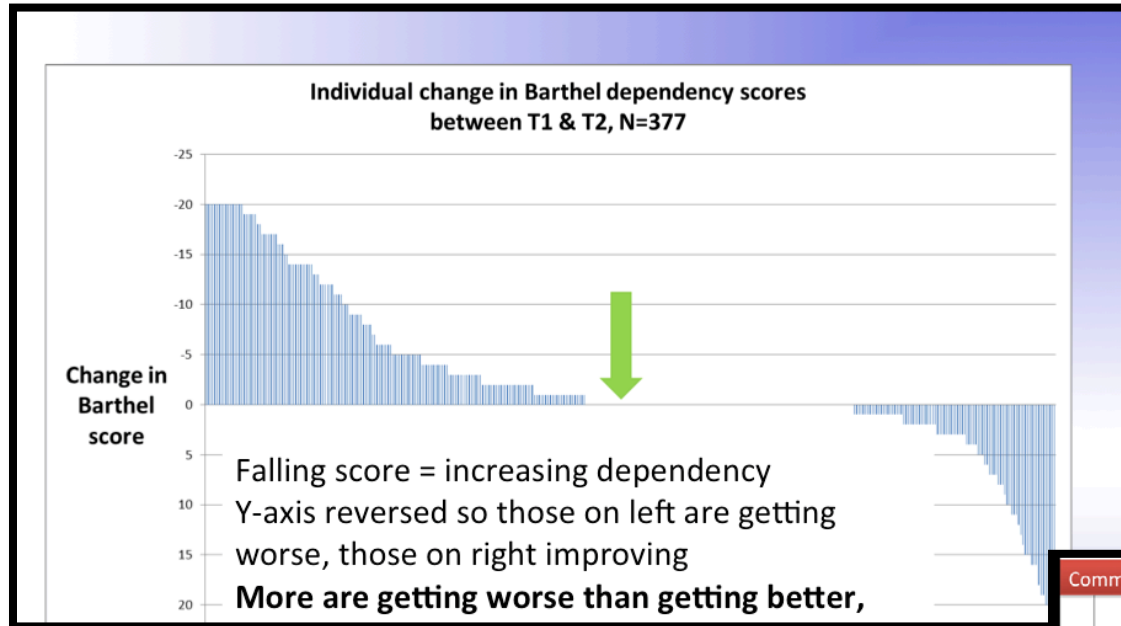


all community patients

% of patients who had absent or mild problems at the start of Phase who did not deteriorate by the end of Phase: Community



Symptom reduction and functionality



Using the data in practice

- Identifying which of our services is best for people seeking help from the hospice, according to phase of illness and symptom burden
- Identifying links between models of care within the hospice and different outcomes
- Engaging with our commissioners to establish an outcomes based contract in the future

Further work anticipated

- Improving the quality and completeness of our data
- Considering benchmarking with other hospices about levels of improvement and prevention of distressing symptoms
- Using tools as part of the assessment and development of care plans of individuals
- Using scores to communicate effectively between professionals and professionals and patients/families
- Integrating learning from OACC and C change in practice

Reflecting on what made these studies so valuable

- All have answered troubling and significant questions facing practitioners. They arose following reflections in/on practice
- Those doing the research are passionate about its subject
- Those leading the research all have an investment in integrating findings back into practice

What about the most successful?

- There is evidence of incremental learning – the studies build on previous research and take the learning one step further
- There is a strong working interface between researchers and individuals interested to test the findings in practice
- The links between research, education and practice are established and each contribute to the other

Examples

HELP THE HOSPICES COMMISSION
Into the future of hospice care

Cicely Saunders International
Better care at the end of life

KING'S College LONDON

Current and future needs for hospice care: an evidence-based report

Natalia Calanzani, Irene J Higginson, Barbara Gomes

hospiceUK

Help the Hospices has changed its name to Hospice UK

This resource was published prior to the change and so still refers to the old name

January 2013

Hospice UK. Company limited by guarantee. Registered in England & Wales no. 2701046. Charitable Incorporated Organisation & Company. No. 1014887 & 04069470. 02047112

hospiceUK

Hospice enabled dementia care


The first steps

to help hospices establish people with dementia, their families and carers

hope for home
SUPPORTING PEOPLE AT HOME

Resilience

A framework supporting hospice staff to flourish in stressful times

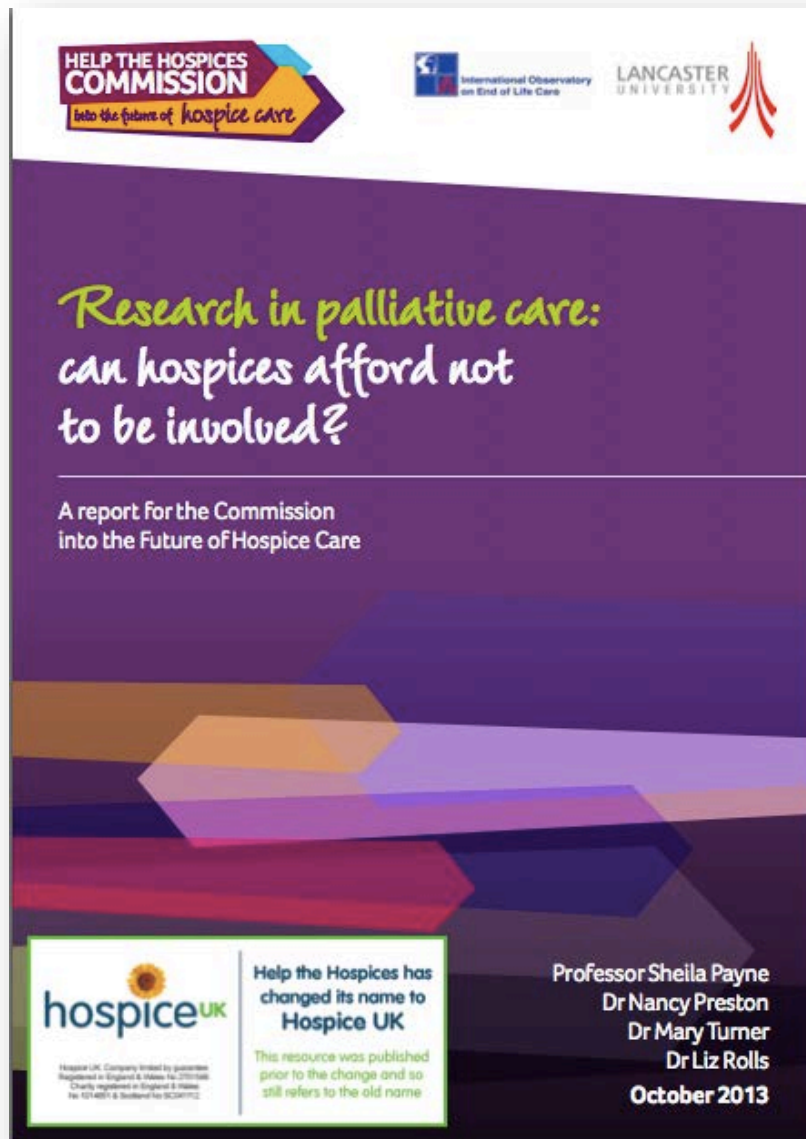


The Point of Care Foundation

Final thoughts

- Evidence guiding our work and important decisions in the future remains poor
- The contribution of research by individuals who have worked in hospice and palliative care can be particularly helpful as they know what we don't know!
- Where people can work together to strengthen and broaden knowledge significantly, this is most valuable
- Even if you don't go on to become an academic, the learning from being a researcher is a fantastic skill...

Final words



“Research is something of an investment for the future; without research we cannot sustain high quality hospice care into the future. If we are to understand how to deliver best care in the context of an ageing population, changing patterns of disease, an increasing range of treatment options, and limited resources, we absolutely need research to tell us which hospice based interventions are effective and how they work and which models of care are best, and whether they are both effective and cost-effective.”

Fliiss Murtagh. Foreword

Thank you

H.Richardson@stchristophers.org.uk