THE
NATIONAL
COUNCIL FOR
PALLIATIVE
CARE

#dyingwithdementia

#dementiachallenge

7th Annual Conference on Dementia & End of Life

Rising to the Prime Minister's Dementia Challenge

Tuesday 4th December
15 Hatfields, London

THE NATIONAL COUNCIL FOR PALLIATIVE CARE

#dyingwithdementia
#dementiachallenge

Seminar C: Raising awareness; End of Life Care and Dementia Roadshows Initiative in Merseyside & Cheshire

Caroline Flynn, End of Life Care Lead, Merseyside & Cheshire Palliative & End of Life Care Network &
Dr. Clare Littlewood, Macmillan Consultant in Palliative Medicine, St Helens & Knowsley NHS Trust

Raising awareness of end of life care and dementia in Merseyside & Cheshire

4th December 2012

Dr.Clare Littlewood
Consultant in Palliative Medicine /GP Advisor Knowsley
Caroline Flynn
End of Life Care Service Improvement Lead
Merseyside & Cheshire Palliative & End of Life Care Network

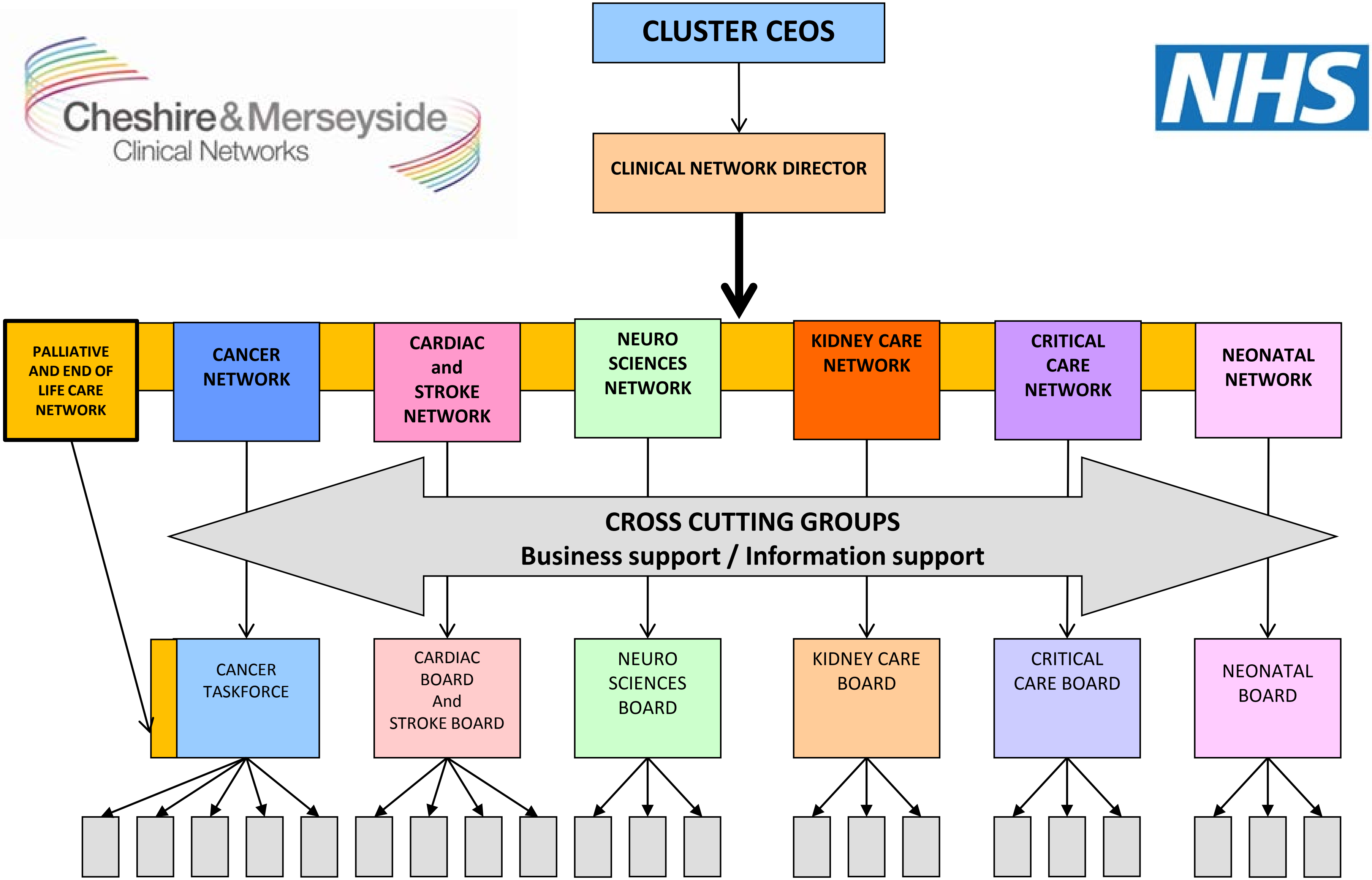
What are Networks?

- *Oxford English Dictionary : a group or system of interconnected people or things which interact with others to exchange information and develop professional or social contacts*

Promote consistency; equal access to equally good services

Cheshire & Merseyside
Clinical Networks

NHS



CLUSTER CEOS

CLINICAL NETWORK DIRECTOR

PALLIATIVE AND END OF LIFE CARE NETWORK

CANCER NETWORK

CARDIAC and STROKE NETWORK

NEURO SCIENCES NETWORK

KIDNEY CARE NETWORK

CRITICAL CARE NETWORK

NEONATAL NETWORK

CROSS CUTTING GROUPS
Business support / Information support

CANCER TASKFORCE

CARDIAC BOARD And STROKE BOARD

NEURO SCIENCES BOARD

KIDNEY CARE BOARD

CRITICAL CARE BOARD

NEONATAL BOARD

WORKING TOGETHER TO IMPROVE OUTCOMES FOR PATIENTS AND THEIR FAMILIES

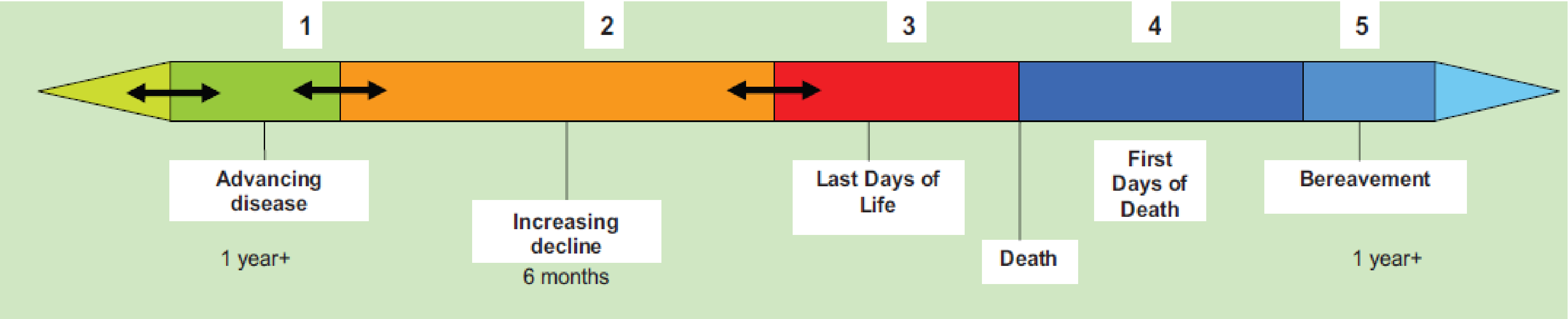
Network End of Life Care Programmes

- Promote the recommendations within the end of life care strategy and NHS North West Healthier Horizons
- End of Life Care understood as the last 12 months of life, not just last weeks/days :**North West End of Life Care Model**
- Promote advance care planning
- Build capacity, capability and confidence within the end of life care workforce
- People to be supported to live and die well in the place of their choice through integrated services

Model content utilised work from Knowsley, Liverpool, Salford, West Lancs, Southport/Ormskirk PCTs

NHS North West

NORTH WEST END OF LIFE CARE MODEL



1 Advancing disease — 1 year+

2 Increasing decline — 6 months

3 Last Days of Life

Death

4 First Days of Death

5 Bereavement — 1 year+

- Single Assessment process completed
- Carer need assessment completed
- GSF/KITE initiated
- Advance Care Planning
- GSF/KITE meetings
- Prognosis communicated
- Key worker team nominated
- Patient-held record issued

- DS1500 completed
- ACP initiated
- OOH, informed of ACP
- Respite care arranged
- DNAR Initiated by GP
- Update NWAS with DNAR & Care Planning Info

- Anticipatory medications initiated
- Anticipatory medications supplied
- Fast track to fully funded Continuing Health Care
- Support arranged for provision of terminal care at home
- ACP reviewed

- Liverpool care of the Dying Pathway initiated
- Out of Hours updated
- Update NWAS

- Verification of death
- Certification of death completed
- Death registration
- Funeral Director
- Significant event analysis reviewed in MDT
- Care after death section of LCP goal 12
- DWP1027
- Notify NWAS

- Psychological support
- Ongoing bereavement support
- Counselling support
- Signposting to providers

Supporting Information

End of Life Care Competencies Training

Communications Skills Training **Psychological Support Training**

Information for Patient & Carer **Mental Capacity Act**

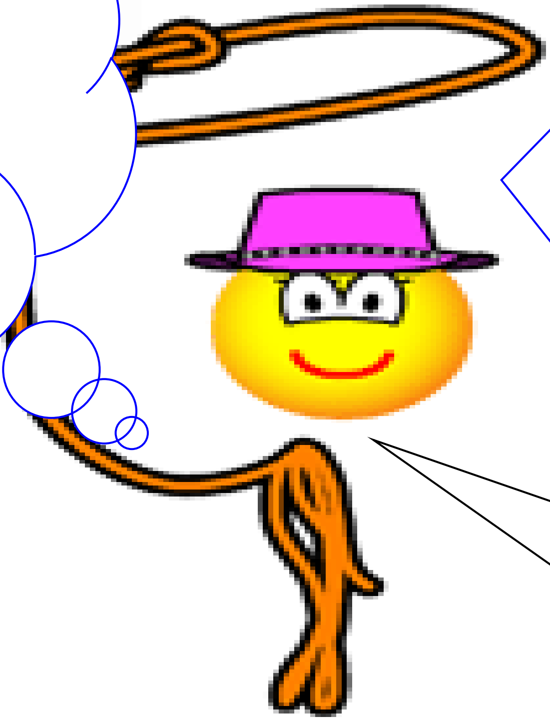
Health and Social Care Processes / Services

- Within the next hour, approximately 8 people will have died in a place not of their choosing, probably a busy hospital ward
- Many will have up to 3 unplanned admissions during the last year of life
- The last of these admissions may have lasted between 8 and 28 days
- On average less than 3 out of 5 people die where they usually live.
- Early identification, honest conversation and a clear plan helps most people remain safely in their own bed with people they know with them
- On average less than half of deaths take place in someone’s usual place of residence (average 41.3%)

(NCPC 2011)

Reduction in unplanned hospital admissions

Patient achieving their wishes and preferences at end of life of where they want to die



Key Levers for improved Care

Equity and access to end of life care

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What wishes and preferences may a patient have?

Is it just about where they want to die?

Conversations for Life Activity

Background

- National Dementia Strategy (2009)
- Number of people with dementia in the Network
- Limited support for dementia patients currently
- Raise awareness of end of life care and dementia

PCT	No of people on a dementia register (QOF)	Estimated no of undiagnosed people	Estimated figures of diagnosed and undiagnosed 2010	Estimated figures diagnosed and undiagnosed 2021	UK Ranking: 1=highest rate of diagnosis 169=lowest rate of diagnosis
1	1463	1672	3135	4223	37
2	858	709	1567	2042	9
3	2233	2149	4382	5209	17
4	1794	2306	4100	5271	55
5	951	1204	2155	3038	52
6	1386	1823	3209	4339	59
7	1838	2590	4428	5603	72

- People with dementia have 4–6 times the mortality than the cognitively intact. Morrison et al (2000)
- Dementia is a terminal condition but people can survive for 7–12 years after diagnosis. Findings from a study completed in 2005 included;

  Women lived an average of 4.6 years after diagnosis, men lived 4.1 years.

  People diagnosed when under age 70 lived 10.7 years compared to 3.8 years for people over 90 when diagnosed.

  Patients who were frail at the time of diagnosis did not live as long, even after adjusting for age.

  Overall, the average survival time for someone in the study diagnosed with Alzheimer's disease or dementia was 4.5 years.

- These analyses give a population based estimated median survival for dementia of 4.5 years. Such estimates can be used for prognosis and planning for patients, carers, service providers, and policy makers. (Brayne et al 2008)

17 Objectives within the Dementia Strategy(2009)

- **Objective 1: Improving public and professional awareness and understanding of dementia.**

- **Objective 3: Good-quality information for those with diagnosed dementia and their carers.**
  Providing people with dementia and their carers with good-quality information on the illness and on the services available, both at diagnosis and throughout the course of their care.

- **Objective 13: An informed and effective workforce for people with dementia.**
  Health and social care staff involved in the care of people who may have dementia to have the necessary skills to provide the best quality of care in the roles and settings where they work. To be achieved by effective basic training and continuous professional and vocational development in dementia.

- **Objective 12: Improved end of life care for people with dementia.** People with dementia and their carers to be involved in planning end of life care which recognises the principles outlined in the Department of Health End of Life Care Strategy. Local work on the End of Life Care Strategy to consider dementia.

There is strong evidence to suggest that people with dementia receive poorer end of life care than those who are cognitively intact in terms of provision of palliative care. Sampson et al (2006)

For example, few people with dementia have access to hospice care.

- People with dementia are core users of health care. At any one time, a quarter of hospital beds are occupied by people with a cognitive impairment aged over 65. Yet widespread evidence suggests there are ongoing problems with the quality of care for people with dementia in hospitals, and with the number of avoidable admissions.

- Only a third (32%) of staff reported feeling that training and development on dementia were sufficient. Half reported they had received insufficient training on how to communicate with people with dementia. And more than half (54%) said they had not received enough training on responding to challenging symptoms of dementia (Royal College of Psychiatrists, 2011).

- Alzheimer's Society (2011) suggested the person with dementia was admitted to hospital unnecessarily because of insufficient care and support in their own home.

- ‘I need to make those decisions while I have enough mental capacity to be able to do that and to understand the implications of it before I get too far down the line. So it has given me the time to think about that. That is important.’ (person with dementia)

National Dementia Strategy 2009

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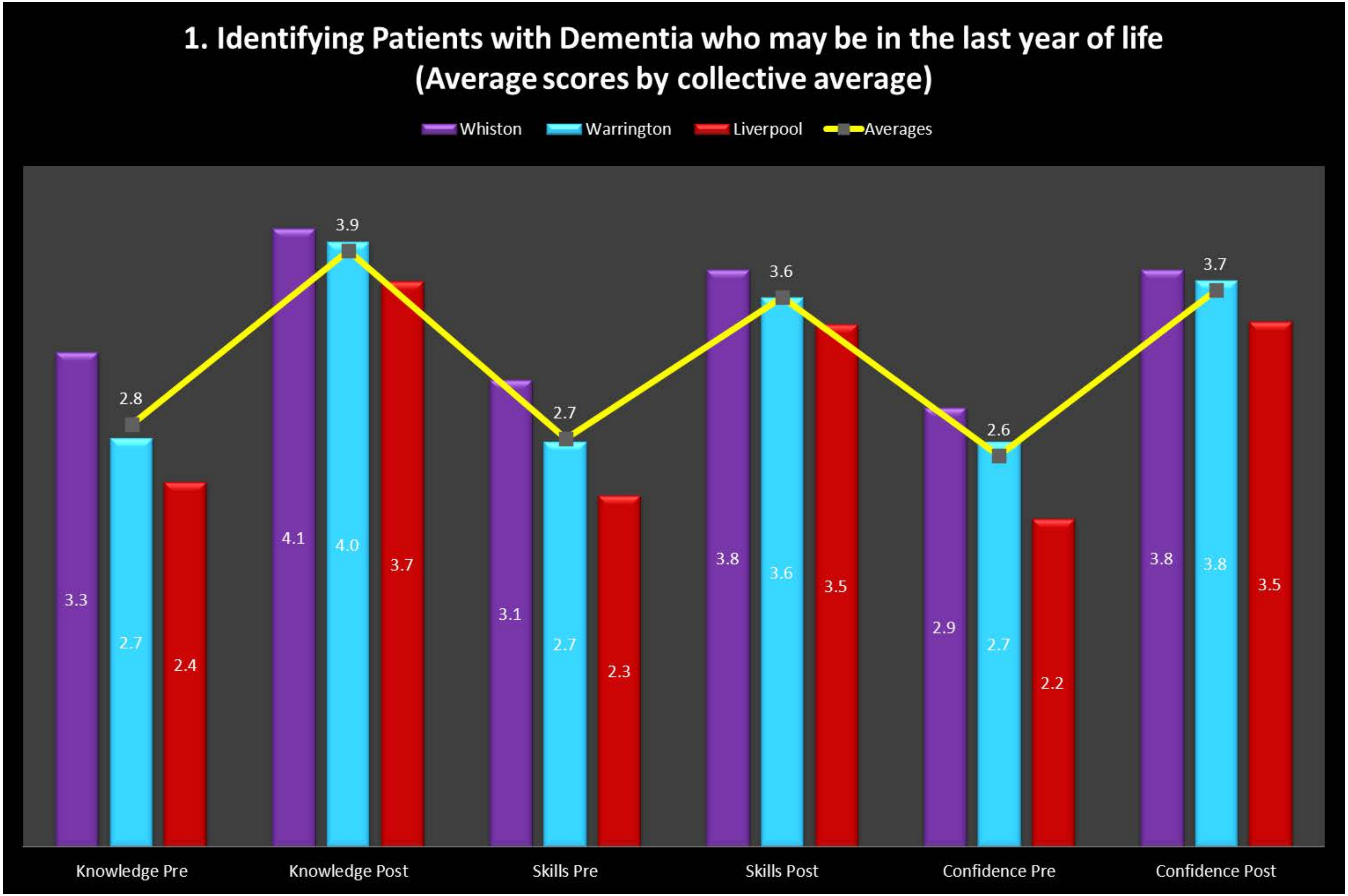
Dementia Roadshows

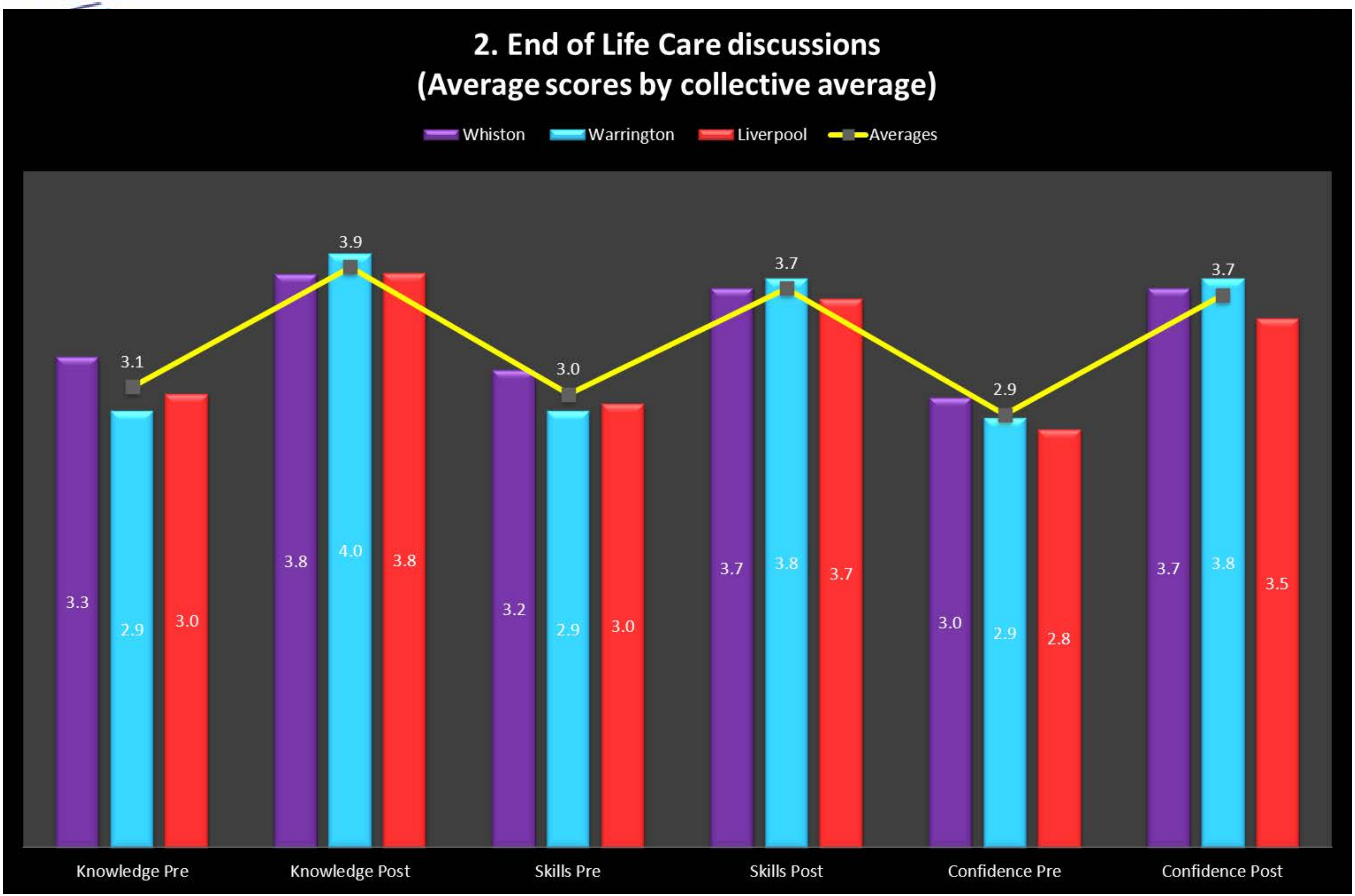
- Pilot in three areas
- Invited neighbouring localities
- Targeted GPs
- Other health professionals
- Lunch
- Great speakers

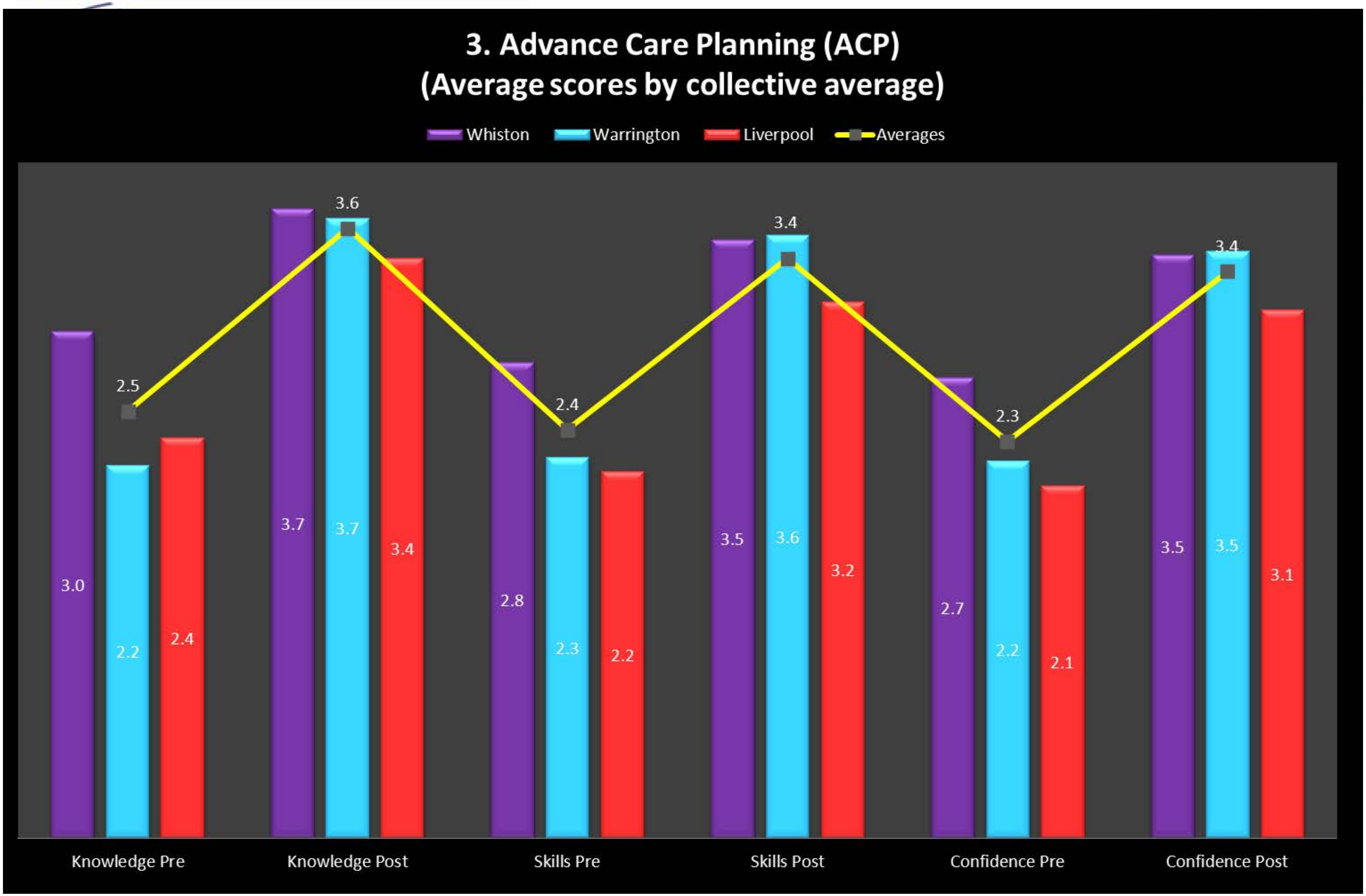
	Subject	Speaker	Organisation
12.15-1pm	**Lunch and Registration**		
1.00pm – 1.15	Welcome and Introduction Overview of end of life care		GP Advisor/ Consultant in Palliative Medicine
1.15- 1.30	The role of the Alzheimers Society		Alzheimers Society
1.30- 1.45	Issues and challenges of caring for a relative with dementia		Carer Representative
1.45- 2.15	Advance Care Planning/End of Life Care Tools		End of Life Care Facilitator
2.15-2..35	**Coffee and networking**		
2.35- 3.10	Identifying advanced dementia		Consultant Geriatrician
3.15-3.40	Advance Care Planning with and for patients with advanced dementia – legal aspects and making capacity assessments		Consultant in Palliative Medicine
3.40-4.15	Reducing burdensome interventions at the end of life		Consultant in Palliative Medicine
4.15-4.30	Questions		
4.30	Close		

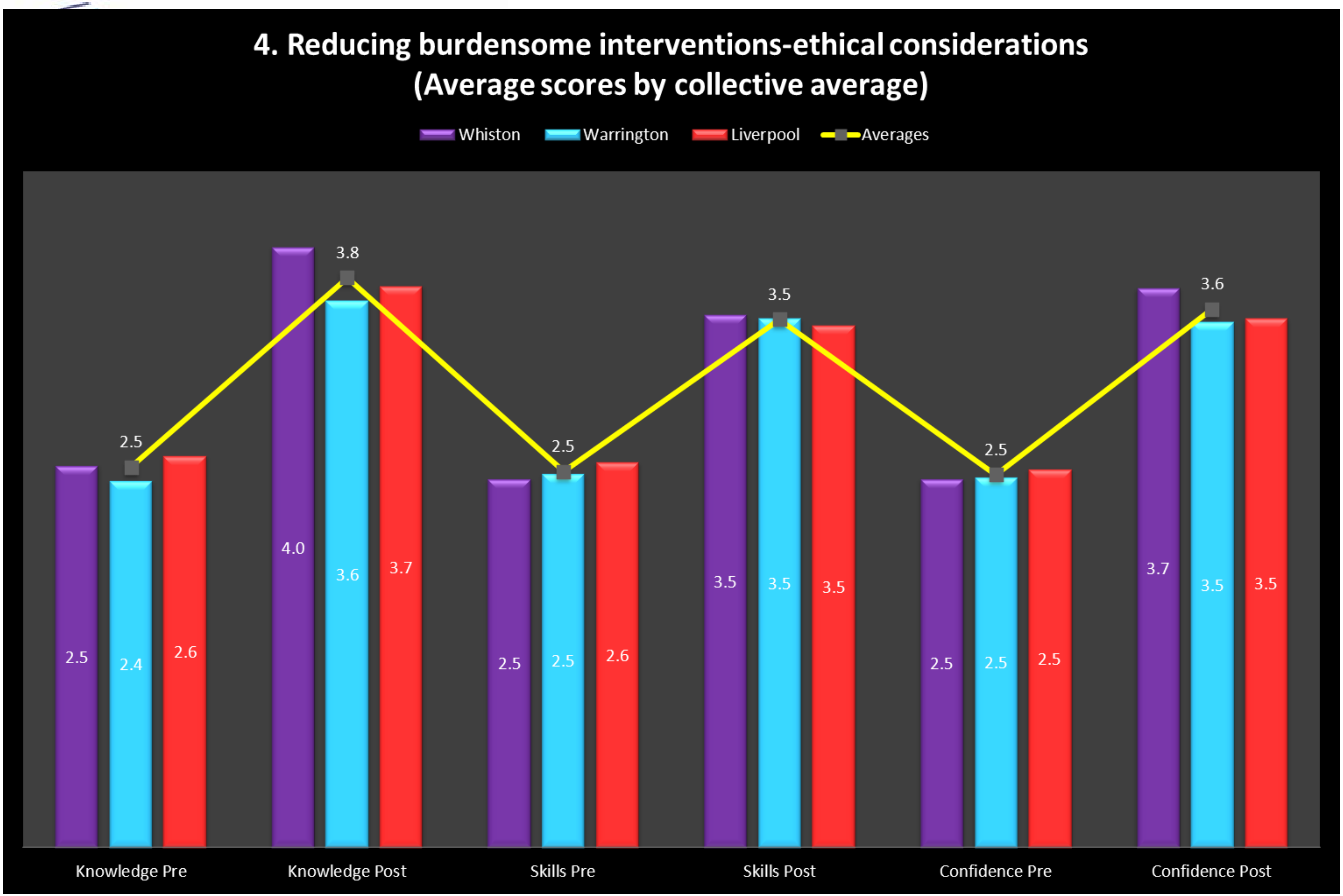
Attendance at each roadshow

	GP	Nurse (any grade)	Consultant	AHP	Commissioner	Care Home	**Total**
Roadshow 1	16	7	0	0	0	0	**23**
Roadshow 2 (PLT)	54	7	1	0	1	0	**63**
Roadshow 3	23	27	2	2	4	6	**64**
Total	93	41	3	2	5	6	**150**


1. Identifying Patients with Dementia who may be in the last year of life
(Average scores by collective average)


2. End of Life Care discussions
(Average scores by collective average)
Whiston
Warrington
Liverpool
Averages
3.1
3.9
3.0
3.7
2.9
3.7
3.3
2.9
3.0
3.8
4.0
3.8
3.2
2.9
3.0
3.7
3.8
3.7
3.0
2.9
2.8
3.7
3.8
3.5
Knowledge Pre
Knowledge Post
Skills Pre
Skills Post
Confidence Pre
Confidence Post


3. Advance Care Planning (ACP)
(Average scores by collective average)
Whiston
Warrington
Liverpool
Averages
2.5
3.0
2.2
2.4
3.6
3.7
3.7
3.4
2.4
2.8
2.3
2.2
3.4
3.5
3.6
3.2
2.3
2.7
2.2
2.1
3.4
3.5
3.5
3.1
Knowledge Pre
Knowledge Post
Skills Pre
Skills Post
Confidence Pre
Confidence Post



4. Reducing burdensome interventions-ethical considerations (Average scores by collective average)

Is there anything you have learnt today you may do differently in practice?

Advance/ Best Interests discussions
Definitely peg feeding and hydration-more confident
Need to get Modern Matron to GSF meetings
ACP & use of Alzheimer’s Society
More likely to initiate ACP in patients with dementia
Intend to start doing ACP/PPC x 6
Feel more confident in tackling the issue
Identification of swallowing issues
Review dementia patients
Be more aware of prognostication in dementia x 8
Discuss at GSF ACP with GPs/1% campaign
As a practice nurse take the opportunity and use skills learnt today to start the process
How to reduce hospital admissions x 2
Take more of a lead in ensuring ACP takes place
Peg-now aware of adverse effect
Use ACP in the early phase of dementia x 2
Less inclined to admit

Better position to advise care homes

Evaluation

Within 1st month – facilitator feedback

3 months evaluation - 5% response rate

6 months evaluation-

"As a direct result of attending it has changed our practice quite a lot

- Now have a Supportive Care Register
- Do our own Advance Care Plans
- Identify patients who may die during the next 12/12
- Identify patients for whom an ACP might be appropriate
- Have discussed all this with geriatrician
- Have arranged for geriatrician to come to our Clinical Meeting in January to give us more help & guidance with this process."

(GP)

Recommendations

- Continue to raise awareness of the need to initiate Advance Care Planning in early stage dementia whilst patient has the capacity to make their own choices.

- Training needs analysis to incorporate end of life care in dementia including Advance Care Planning. Every area to deliver local roadshows using local health professionals to support the delivery of training.

- Those areas that have been part of the pilot project to deliver further road shows to ensure there are an increased number of GPs who have received training within the locality.

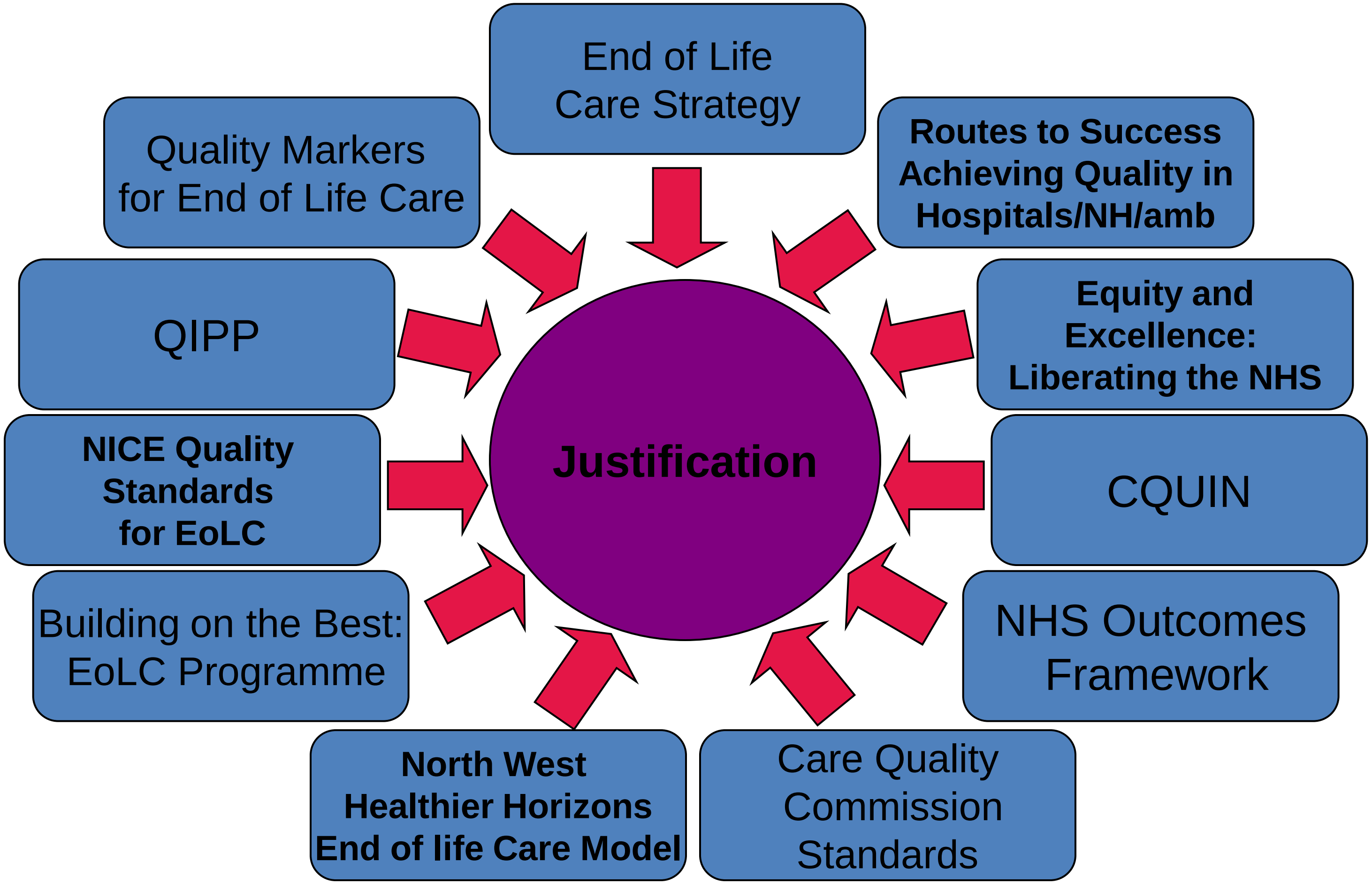
- The roadshows should be made available to a wider audience to include health and social care.

- GP practices to ensure dementia patients who are at the end of life are identified and placed on the practice supportive care register.

- Annual audit of GSF in primary care to include percentage of patients with dementia on the practice supportive care register.

- Local areas to work collaboratively with the Alzheimers Society to promote the sharing of knowledge and expertise

What directs us to think about EoLC?



End of Life Care Strategy

Quality Markers for End of Life Care

Routes to Success Achieving Quality in Hospitals/NH/amb

QIPP

Equity and Excellence: Liberating the NHS

Justification

NICE Quality Standards for EoLC

CQUIN

Building on the Best: EoLC Programme

NHS Outcomes Framework

North West Healthier Horizons End of life Care Model

Care Quality Commission Standards

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What do you think is a ‘good’ or a ‘bad’ death??

Good

- No pain
- Symptoms managed well
- Settled, happy
- Wishes heard
- Good advance planning
- Family and friends nearby
- At home?
- Unnecessary interventions stopped
- Dying with dignity and respect

Bad

- In pain
- Spiritual distress
- Not listened to
- Alone
- Frightened
- Crisis management
- In hospital?
- Painful interventions carry on
- Embarrassed, vulnerable, exposed

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Step 1

Discussions as the end of life approaches

- Open, honest communication
- Identifying triggers for discussion

Step 2

Assessment, care planning and review

- Agreed care plan and regular review of needs and preferences
- Assessing needs of carers

Step 3

Coordination of care

- Strategic coordination
- Coordination of individual patient care
- Rapid response services

Step 4

Delivery of high quality services in different settings

- High quality care provision in all settings
- Acute hospitals, community, care homes, hospices, community hospitals, extra care housing prisons, secure hospitals and hostels
- Ambulance services

Step 5

Care in the last days of life

- Identification of the dying phase
- Review of needs and preferences for place of death
- Support for both patient and carer
- Recognition of wishes regarding resuscitation and organ donation

Step 6

Care after death

- Recognition that end of life care does not stop at the point of death.
- Timely verification and certification of death or referral to coroner
- Care and support of carer and family, including emotional and practical bereavement support

Spiritual care services

Support for carers and families

Information for patients and carers

WORKING TOGETHER TO IMPROVE OUTCOMES FOR PATIENTS AND THEIR FAMILIES

Plan ahead …. Avoid the crisis !!

Early identification

Best time for ACP at diagnosis?

Who should have the conversation?

Documentation

Sharing information

- Planning
- Communication
- Often left until people have lost capacity

Preferred Priorities for Care

Version 2 December 2007 1

Guide to Preferred Priorities for Care

NHS
National End of Life Care Programme
Improving end of life care

Have you thought about what is important to you at the end of your life?

- Do you have a long term illness, or a condition that can't be cured?
- Do you want to discuss your thoughts or concerns and have your wishes and preferences written down?

The Preferred Priorities for Care process can help you with this

For more information please take a copy of the guide to preferred priorities for care leaflet or visit www.endoflifecareforadults.nhs.uk

Preferred Priorities for Care

The care of all dying patients must improve to the level of the best

NHS
National End of Life Care Programme
Improving end of life care

Capacity, care planning and advance care planning in life limiting illness

A Guide for Health and Social Care Staff

www.endoflifecareforadults.nhs.uk

WORKING TOGETHER TO IMPROVE OUTCOMES FOR PATIENTS AND THEIR FAMILIES

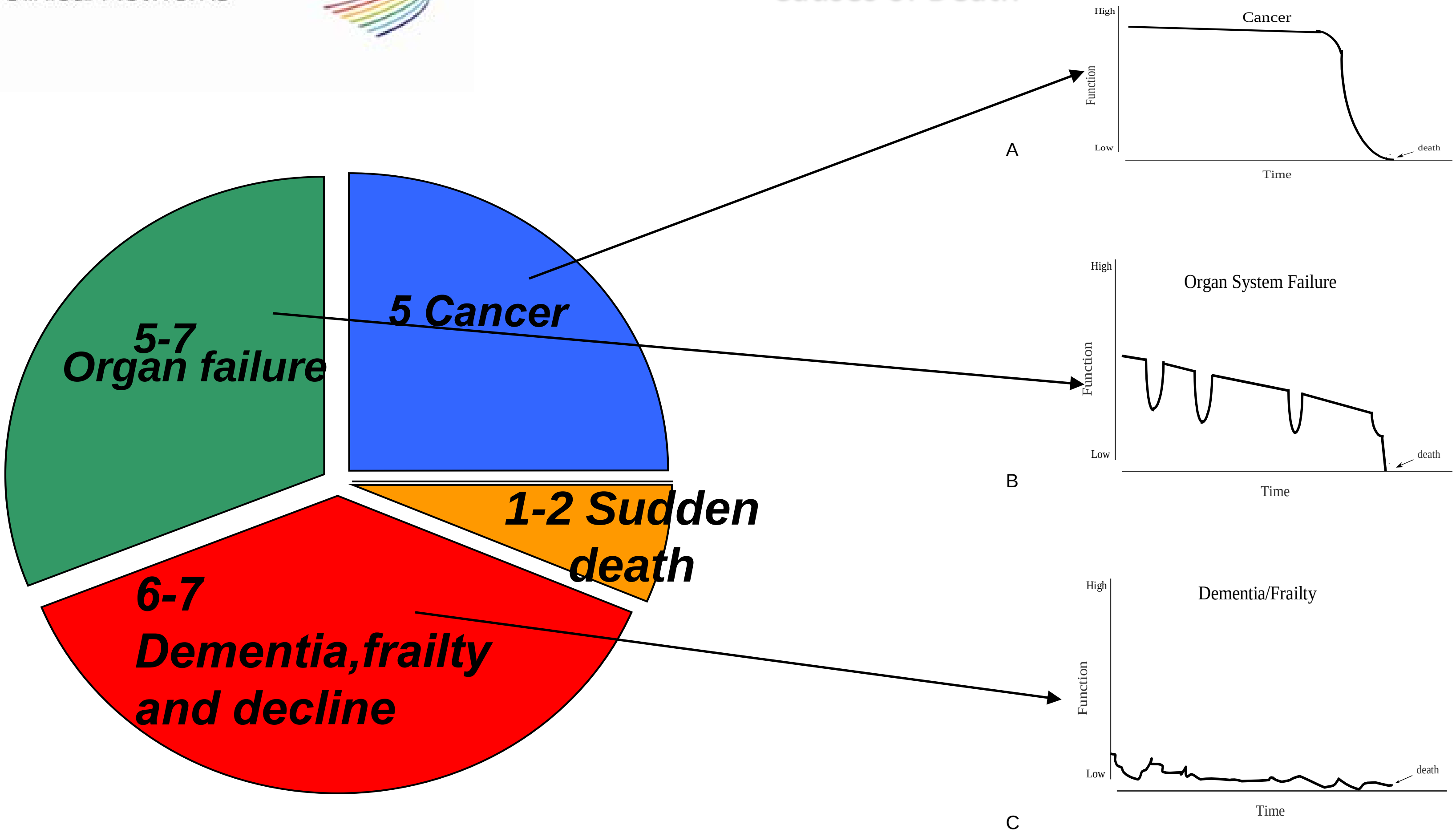
Last days of life

- Has patient with dementia reached last days of life
- Use of EolC Tools can help
- Timely diagnosis dying essential
- Clinical judgement
- Can be difficult- Lack of continuity/ no advance care planning

Diagnosing dying

- Dying dementia patients may be difficult to distinguish from those who are simply **sick**
- Modern medicine treats **dying** patients like they are simply sick
- Fits with medical model of" dying of something"
- Uncertainty… we choose easiest path

GP Practice Population approx 2000
Causes of Death



Goals of care

- Total Cure
- Longevity/ survival
- Comfort/ avoid suffering
- Independence
- Remain in familiar environment

- Goals of care not articulated
- Single goal often assumed – admission to hospital may appear as only option
- Aggressive treatments in dying patients are seen as burdensome and futile
- Futile= totally ineffective

Dying Phase

"Our patients just die in their sleep and don't need anticipatory prescribing" (care home staff)

- Simple analgesics e.g paracetamol suppositories for pain may be all that is needed.
- Attention to detail e.g mouthcare, pressure area care, support for relatives/carers,

Summary

- Identify/assess/plan
- Diagnose dying
- Clarify and prioritise goals
  - start early
  -engage family and carers
  -review/revise/discuss
- Communicate
- Location/location/location

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Useful websites

- www.alzheimers.org.uk
- www.Dyingmatters.org
- **National End of Life Care Programme** www.endoflifecareforadults.nhs.uk
- **National End of Life Intelligence Network** www.endoflifecare-intelligence.org.uk
- **Mental Capacity Act Code of Practice** www.opsi.gov.uk/acts/acts2005/related/ukpgacop_20050009_en.pdf

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