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North Thames
NHS Genomic Medicine Service Alliance

Lung Cancer Clinical Nurse Specialist's (LCCNS) view on optimising patient engagement

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Lead Lung Cancer Clinical Nurse Specialist (CNS) - UCLH

Hosted by NHS Great Ormond Street Hospital for Children NHS Foundation Trust

What is a Darzi Clinical fellowship?

Systems leadership

Quality Improvement

Innovation to improve

Waiting for results versus, managing patient expectations, controlling symptoms of advanced stage / complex patients …. ?

Why do our patients need to wait so long for their pathology results?

Do our patients need to have consent for CtDNA?

https://www.scie.org.uk/integrated-care/research-practice/enablers/system-leadership#:~:text=Systems%20leadership%20facilitates%20the%20adoption%20of%20more%20integrated,the%20lives%20of%20individuals%2C%20families%2C%20and%20local%20communities

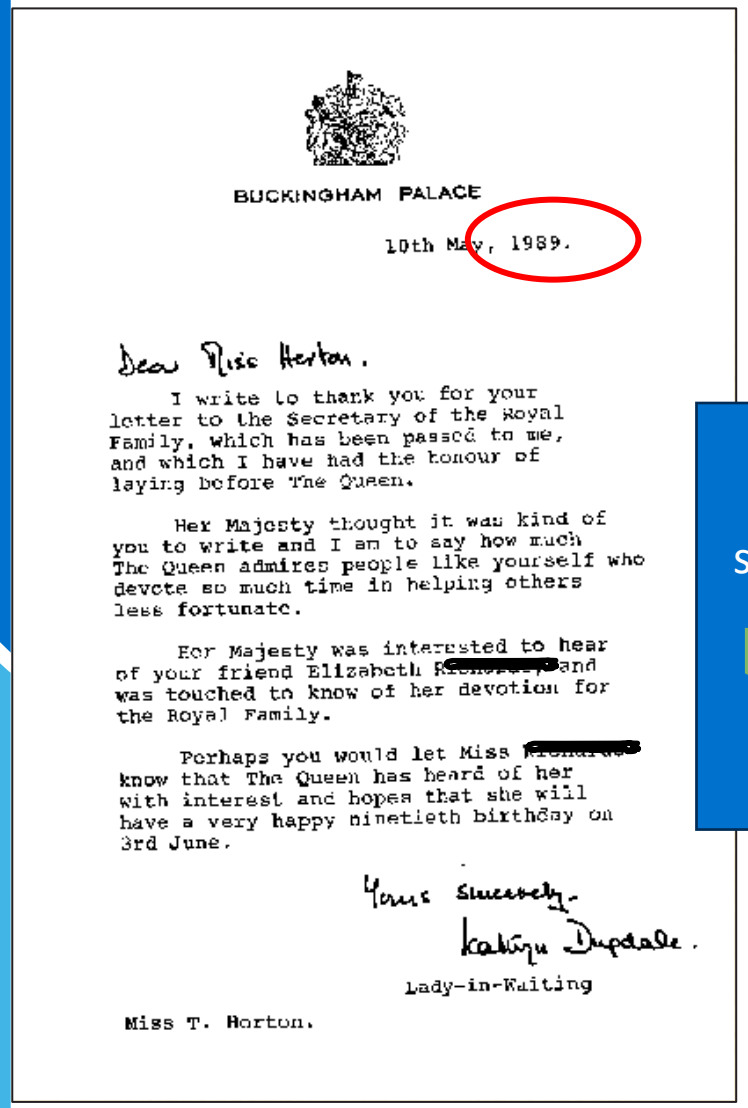
Systems Leadership

(Ghate et. al 2013)

Figure 1

Public service context, systems leadership and systems leaders - an integrated model

The power of a story…



BUCKINGHAM PALACE

10th May, 1989.

Dear Miss Horton.

I write to thank you for your letter to the Secretary of the Royal Family, which has been passed to me, and which I have had the honour of laying before The Queen.

Her Majesty thought it was kind of you to write and I am to say how much The Queen admires people like yourself who devote so much time in helping others less fortunate.

Her Majesty was interested to hear of your friend Elizabeth [redacted] and was touched to know of her devotion for the Royal Family.

Perhaps you would let Miss [redacted] know that The Queen has heard of her with interest and hopes that she will have a very happy ninetieth birthday on 3rd June.

Yours sincerely,
Katherine Dupdale.
Lady-in-Waiting

Miss T. Horton.

"The use of patient and staff narratives should be embedded across the NHS and social care system to humanise and improve the quality of healthcare" (BMJ 2022)

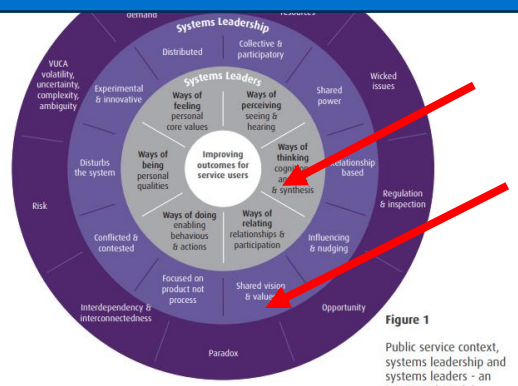


Figure 1

Public service context, systems leadership and systems leaders - an integrated model

Section 3

USING STORYTELLING IN HEALTH CARE IMPROVEMENT: a guide

The Health Foundation

Briefing summary

- **Who:** For people involved in health care improvement projects who want to use stories to communicate and share important learning from their work.
- **Why:** Telling stories about the experiences of patients and health care professionals is well-established as an effective means of engaging others in improvement work.
- **What:** This briefing includes practical tips on how to identify and tell a good story.

Why is storytelling important in improvement work?

Never overlook the power of a good story. This is what people will remember about your work."
ane Maher, Chief Medical Officer, Macmillan Cancer Support

tories have been used to hand down learning and knowledge for thousands of years. A good story engages our uriosity, emotions and imagination. It can help us make sense of the world.

n many safety-critical industries, stories of real events are actively used to capture and share lessons with staff n the workplace because they are more memorable than data or lengthy manuals. In the NHS, stories involving atients have become an established way for board members to focus discussions on quality and patient experience. Patient stories also speak strongly to frontline staff, who are often motivated most of all by their individual interactions with patients.

By using real stories as you communicate your improvement work, you can:

- demonstrate there is a need for the work and challenge complacency
- make the potential benefits or outcomes feel tangible to the people you need to influence
- ensure the patient's voice and/or the experience of individual staff members is heard
- get a message across – good stories are remembered and can be passed on.[1]

Using-storytelling-in-health-care-improvement.pdf

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A brief glimpse into ‘my story’…

Currently seconded to … NHS North Thames

NHS Genomic Medicine Service Alliance

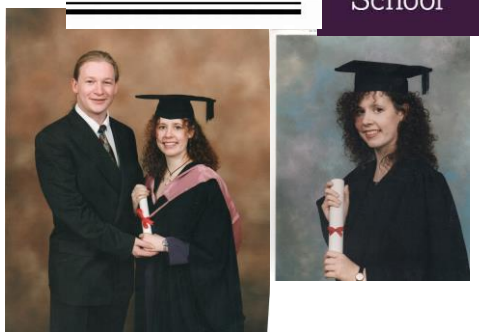
Studied at…

NHS Barts Health NHS Trust

CITY UNIVERSITY OF LONDON EST 1894

KING’S College LONDON

The ROYAL MARSDEN School



Worked in our NHS continually

from 1991 > current time

Including working ‘across the system’ @ 2006-2012

St Christopher’s Hospice

Figure 1

Public service context, systems leadership and systems leaders - an integrated model

Lead Lung Cancer CNS @ 2017-2022

ucl NHS

Our vision and values continue to underpin everything we do

ucl We are committed to delivering top-quality patient care, excellent education and world class research

Safety Kindness Teamwork Improving

Main carer for (& lost through cancer) Mum & MIL (2021), Dad (2003)

… added ‘purpose’

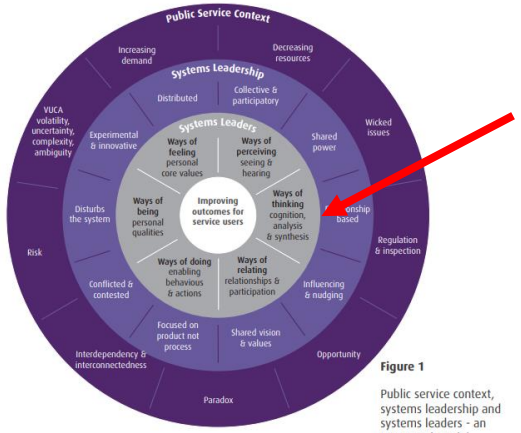
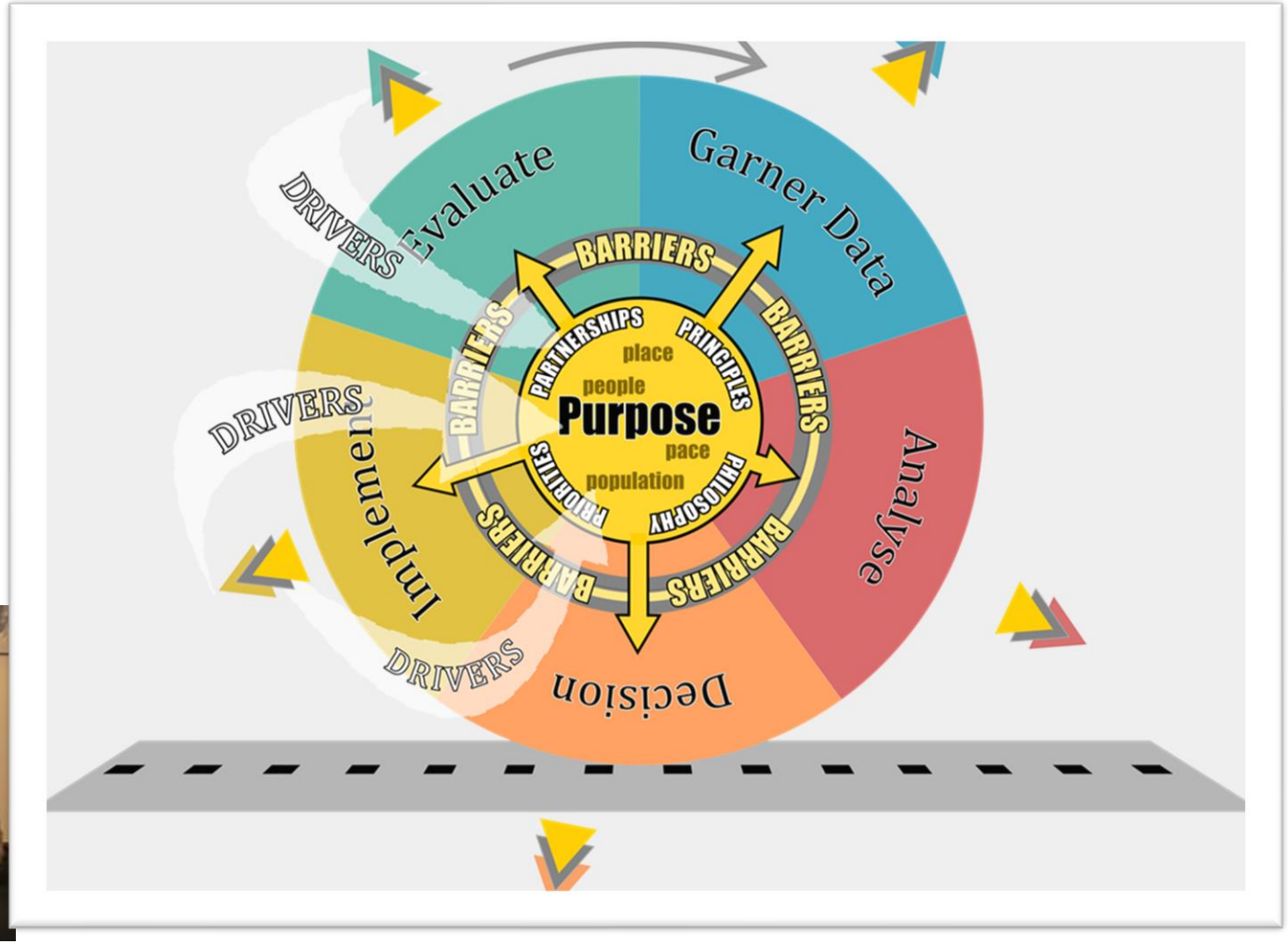


Figure 1

Public service context, systems leadership and systems leaders - an integrated model



The ‘P’ Wheel of Integrated System Change
Quality Improvement, Leadership and Learning Health Systems

What's getting in the way ? Barriers to improvement in the NHS

The Health Foundation 2015
(Author: Dr Debra de Silva)

Prevalence of barriers to the implementation of improvement

	Design	Delivery	Dissemination
Initiative-related barriers			
Insufficient evidence base	X		X
Usability of interventions		X	
Fit with processes		X	
Individual barriers			
Staff resistance	X	X	
Staff skills and knowledge		X	
Role demarcation		X	
Organisational barriers			
Culture and stability	X	X	
Lack of leadership	X	X	
Management	X	X	X
Insufficient use of data	X	X	X
Lack of time allocated	X	X	X
Lack of funding	X	X	X
System-wide barriers			
NHS culture	X	X	X
Lack of stability	X	X	
Partnerships		X	X
Incentives and funding	X	X	
Note: crosses indicate where barrier have been found to exist most prominently			

Collaborative and Compassionate Leadership

Compassionate Leadership: 4 key elements needed for innovation			
Inspiring vision and strategy	Positive inclusion and participation	Enthusiastic team and cross-boundary working	Support and autonomy
- Unwavering focus on high-quality, continually improving compassionate care - Inspiring and meaningful vision - Shared understanding - Clear, aligned, manageable challenges and tasks - Alignment between workload and resources	Ensure all voices heard Create psychological safety & encouraging teams to be compassionate to one another Valuing diversity including patient groups, positive attitude to differences Fair resolution of conflict	- Working compassionately with other teams (inter-team compassion) - Being supportive and collaborative - Having a 'how can we help' attitude	- Creation of a positive climate - high levels of engagement, positivity and creativity - Freedom to be autonomous, but with support - Treating staff with compassion

4 behaviours of compassionate leadership

Attending

Understanding

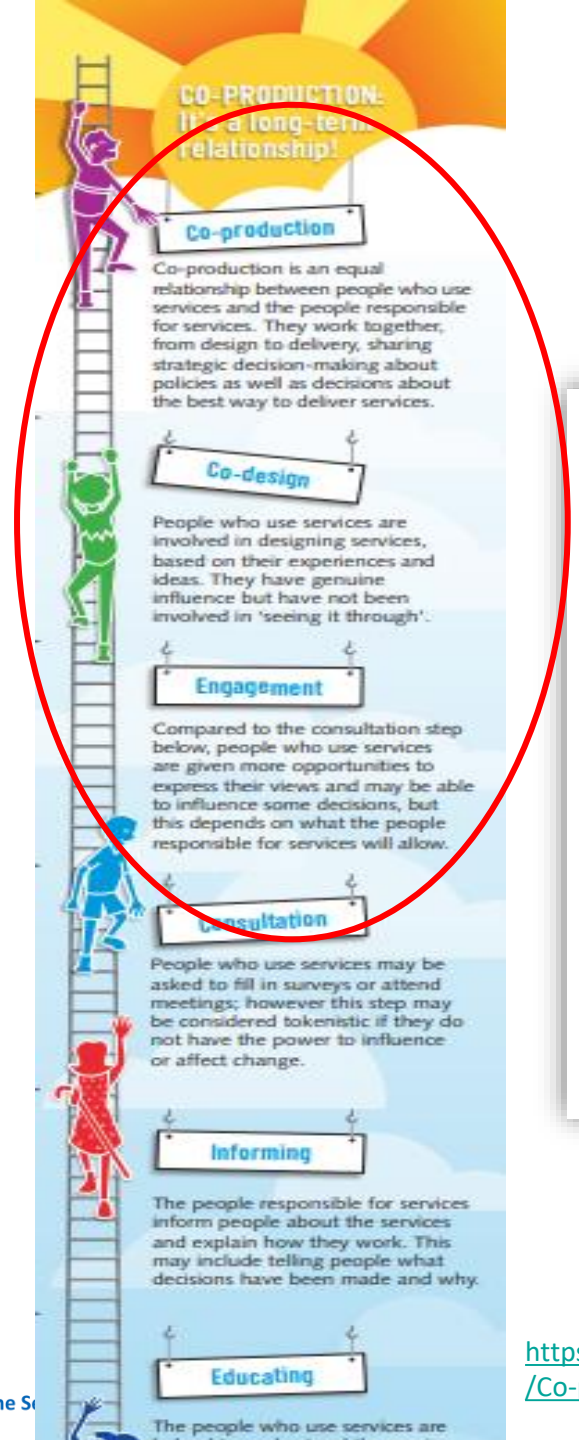
Empathising

Helping

https://www.kingsfund.org.uk/audio-video/michael-west-collaborative-compassionate-leadership

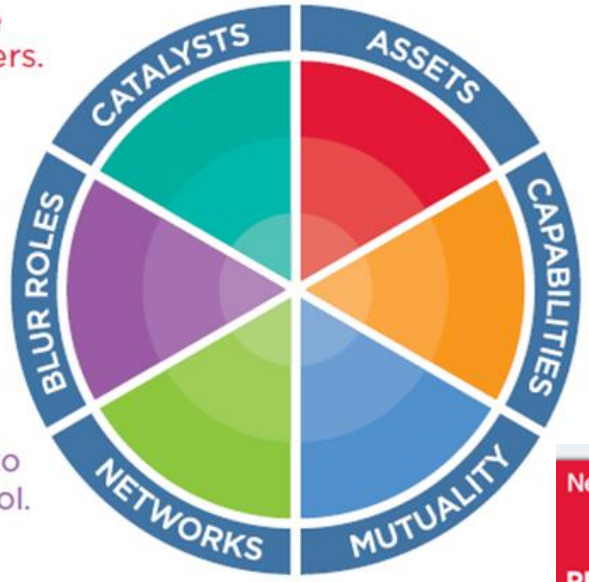
https://www.kingsfund.org.uk/publications/what-is-compassionate-leadership#the-four-behaviours-of-compassionate-leadership

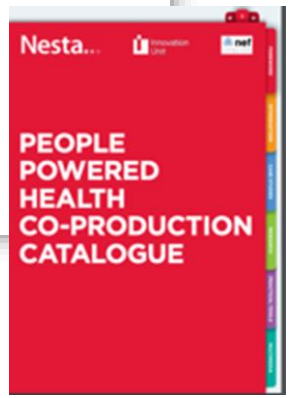
Patient engagement, co-design or co-production...



https://www.thinklocalactpersonal.org.uk/Latest/Co-production-The-ladder-of-co-production

Assets:	Transforming the perception of people from passive recipients to equal partners.
Capabilities:	Building on what people can do and supporting them to put this to work.
Mutuality:	Reciprocal relationships with mutual responsibilities and expectations.
Networks:	Engaging a range of networks, inside and outside 'services' including peer support, to transfer knowledge.
Blur roles:	Removing tightly defined boundaries between professionals and recipients to enable shared responsibility and control.
Catalysts:	Shifting from 'delivering' services to supporting things to happen and catalysing other action.





https://media.nesta.org.uk/documents/co-production_catalogue.pdf

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FPN 1166P

SOCIAL DETERMINANTS OF LUNG CANCER IN EAST LONDON

C. Alves Soares*, [a], F. Chamberlain*[a, b], U. Mukherjee[a], W. Ricketts[a], J. Conibear[a], J. Steele[a], P. Szlosarek[a, b], F. Lim[a] and A. Januszewski[a]
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Correspondence: catarina.alvessoares@nhs.net

NHS Barts Health NHS Trust

Background

- In England, patients from more deprived backgrounds are more likely to acquire lung cancer and have a higher associated mortality[1]
- More deprived populations have greater exposure to lung cancer risk factors[2]
- The English Indices of Deprivation measure deprivation according to several domains* by post code – scored out of 10 (1 most deprived, 10 least deprived)[3]
- *EGFR* and *KRAS* are the most frequently observed lung cancer oncogenic mutations

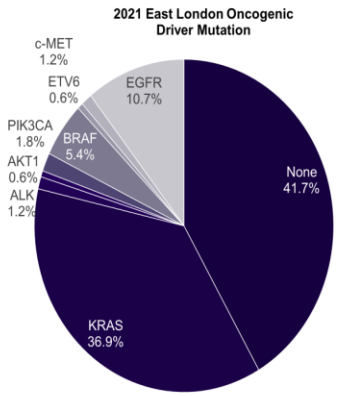
Hypothesis

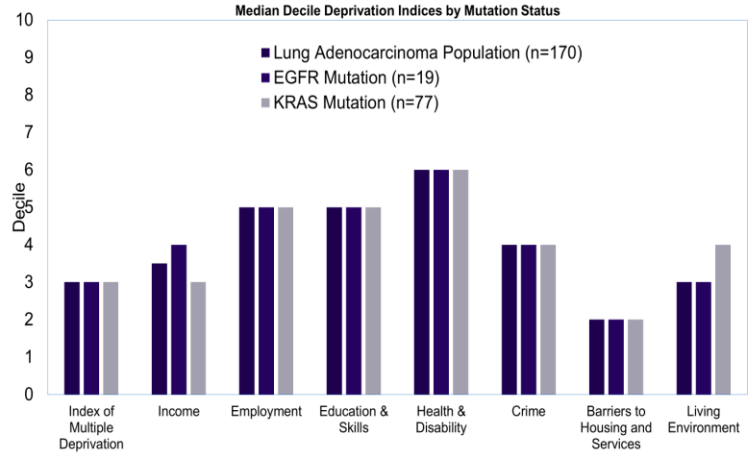
- There is an association between oncogenic mutations and socioeconomic deprivation.

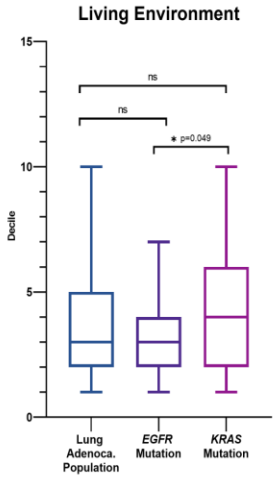
Inclusion Criteria

- Barts MDT adult patients lung adenocarcinoma pts diagnosed in 2021 with reported tumour mutational status

	Lung Adenocarcinoma Population n=170	Oncogenic Mutation Population n=99	No identified oncogenic mutations n=71
Median Age (years)	69	69	69
Gender			
Male (%)	93 (55)	51 (52)	42 (59)
Female (%)	77 (45)	49 (49)	29 (41)
Ethnicity			
White (%)	125 (74)	73 (74)	53 (75)
Black (%)	14 (8)	12 (12)	2 (3)
Asian (%)	17 (10)	9 (9)	8 (11)
Other (%)	8 (5)	2 (2)	5 (7)
Not Stated (%)	6 (4)	4 (4)	3 (4)
PDL1 Status			
<1% (%)	92 (54)	50 (51)	42 (59)
1-49.9% (%)	52 (31)	33 (33)	20 (28)
<50% (%)	26 (15)	17 (17)	9 (13)







Results

- *EGFR* mutations associated with higher deprivation in the living environment domain compared to those with a mutation associated with a smoking history (p=0.0491) (corrected for multiple comparisons)
- No other significant relationship between deprivation and mutational status identified

Discussion

- Lung cancer patients at St Bartholomew's Hospital are distributed along a deprivation gradient
- More deprived populations are exposed to a multitude of risk factors for oncogenesis, beyond smoking tobacco

Conclusion

- Further work required to expand cohort
- Our data suggest a drive to reduce cancer burden in more deprived groups must not be limited to interventions tackling smoking but include methods to tackle pollution

References:
1. Berglund A et al. Social differences in lung cancer management and survival in South East England: a cohort study. BMJ Open. 2012;2(3).
2. NCRAS. Cancer by Deprivation in England 1996 - 2011 [Internet]. 2014.
3. National Statistics English Indices of Deprivation [Internet]. 2019

No conflict of interest to declare

European Society for Medical Oncology (ESMO) 2022
https://doi.org/10.1016/j.annonc.2022.07.1289

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SERVICE EVALUATION OF DIVERSITY RECRUITMENT IN THORACIC CANCER CLINICAL TRIALS AT A TERTIARY CANCER CENTRE

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[1]Barts Thorax Centre, St Bartholomew's Hospital, London, EC1A 7BE

[2]Barts Cancer Institute, Queen Mary University of London, London, EC1M 6BQ

Barts Cancer Institute, Queen Mary University of London

NHS Barts Health NHS Trust

Background

- Barts Thoracic MDT diagnoses the most thoracic cancers in London/year
- Patients in studies often do not represent "real-life" patients[1]
- Women, elderly, lower socio-economic & ethnic minorities often under-served by trials[1,2]

Questions Asked

- Does the clinical trial patient cohort reflect the diagnosis patient cohort at Barts?
- What are the barriers for diversity recruitment and monitoring to thoracic trials?

Inclusion Criteria

- Barts MDT adult patients diagnosed or enrolled in a trial in 2019 (pre-COVID recruitment disruption)
- Path confirmed NSCLC, SCLC, mesothelioma, carcinoid or thymoma

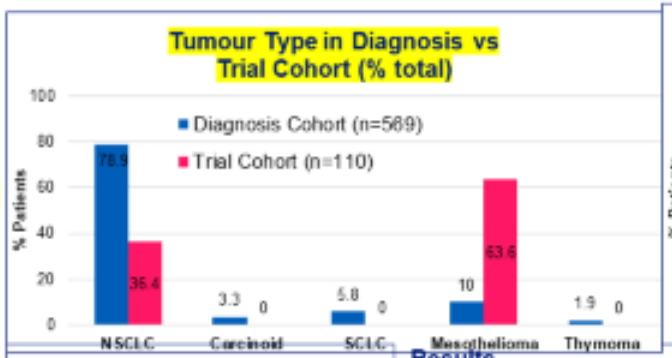
Exclusion Criteria

- Screening trials
- Other or benign path

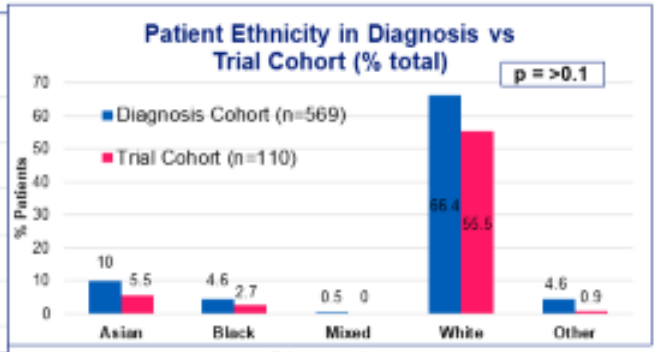
References:

1. M. Witham et al. 2020
2.NIHR INCLUDE Roadmap 2020

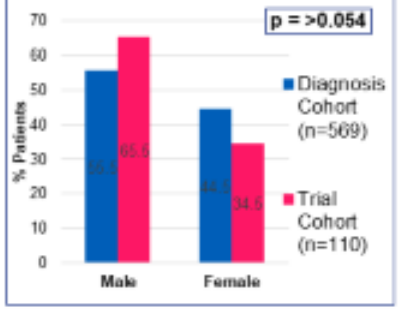
Tumour Type in Diagnosis vs Trial Cohort (% total)



Patient Ethnicity in Diagnosis vs Trial Cohort (% total)



Patient Gender Diagnosis vs Trial Cohort (% total)



Results

- Seven trials open in 2019 (4 lung ca, 3 mesothelioma)
- Greater proportion of trial patients were mesothelioma vs NSCLC
- Median ages of the cohorts were similar (72 years vs 71 years, p>0.1)
- Trend to significance in % females in the trial vs diagnosis cohort (p=0.054)
- No difference in the ethnicity makeup in the cohorts (p>0.1) but more ethnicity data unavailable in trial cohort (35.5% vs 13.9%)
- No socio-economic data recorded

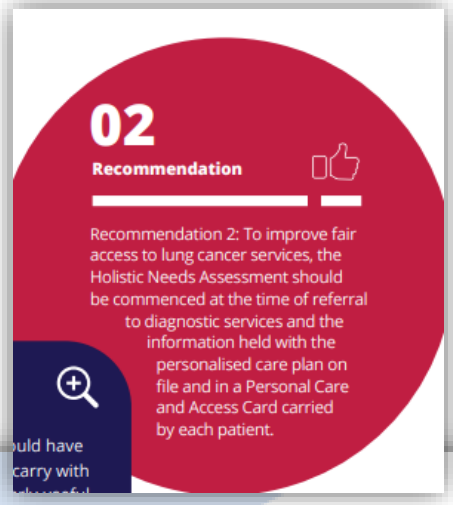
Discussion

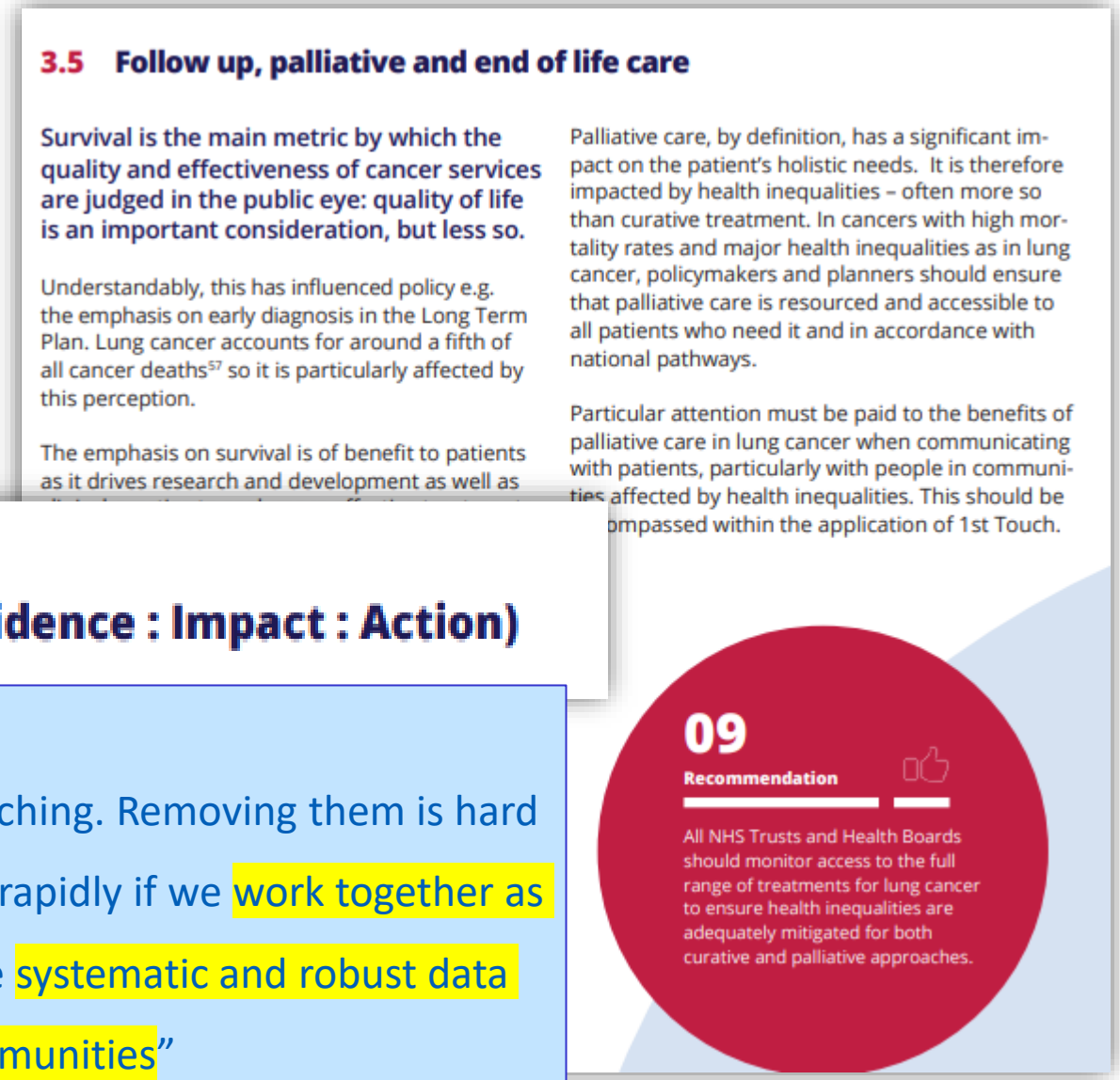
- Improvement needed in recording diversity data to understand true picture
- Gender differences ?related to meso trial recruitment (male predominant disease)
- Trial portfolio expansion – currently 19 studies open at Barts (vs 7 in 2019)

Strategies

- Follow INCLUDE 2020 roadmap
- Patient & Public Involvement
- Trial PIS in local languages
- Explain My Procedure video animations for clinical trials
- Diversity data collection at study enrolment
- Re-evaluate the service after implementation

Chamberlain, Florence et al. "Service evaluation of diversity recruitment in thoracic cancer clinical trials at a tertiary cancer centre." Lung Cancer (2022) https://doi.org/10.1016/S0169-5002(22)00136-2





3.5 Follow up, palliative and end of life care

Survival is the main metric by which the quality and effectiveness of cancer services are judged in the public eye: quality of life is an important consideration, but less so.

Understandably, this has influenced policy e.g. the emphasis on early diagnosis in the Long Term Plan. Lung cancer accounts for around a fifth of all cancer deaths[57] so it is particularly affected by this perception.

The emphasis on survival is of benefit to patients as it drives research and development as well as

Palliative care, by definition, has a significant impact on the patient's holistic needs. It is therefore impacted by health inequalities – often more so than curative treatment. In cancers with high mortality rates and major health inequalities as in lung cancer, policymakers and planners should ensure that palliative care is resourced and accessible to all patients who need it and in accordance with national pathways.

Particular attention must be paid to the benefits of palliative care in lung cancer when communicating with patients, particularly with people in communities affected by health inequalities. This should be ompassed within the application of 1st Touch.

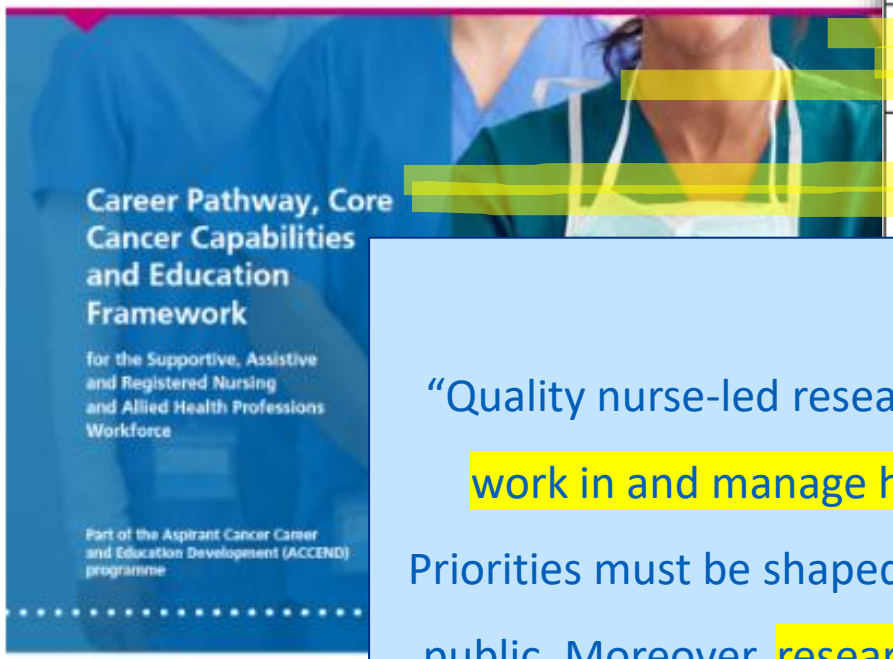
4.0 Addressing health inequalities (Evidence : Impact : Action)

"Health inequalities are complex and far reaching. Removing them is hard and takes time. They will be mitigated more rapidly if we work together as a lung cancer community and ensure more systematic and robust data collection across all communities"

(UKLCC 2022 p4)

ACCEND Framework

https://www.hee.nhs.uk/our-work/cancer-diagnostics/aspirant-cancer-career-education-development-programme/accend-framework

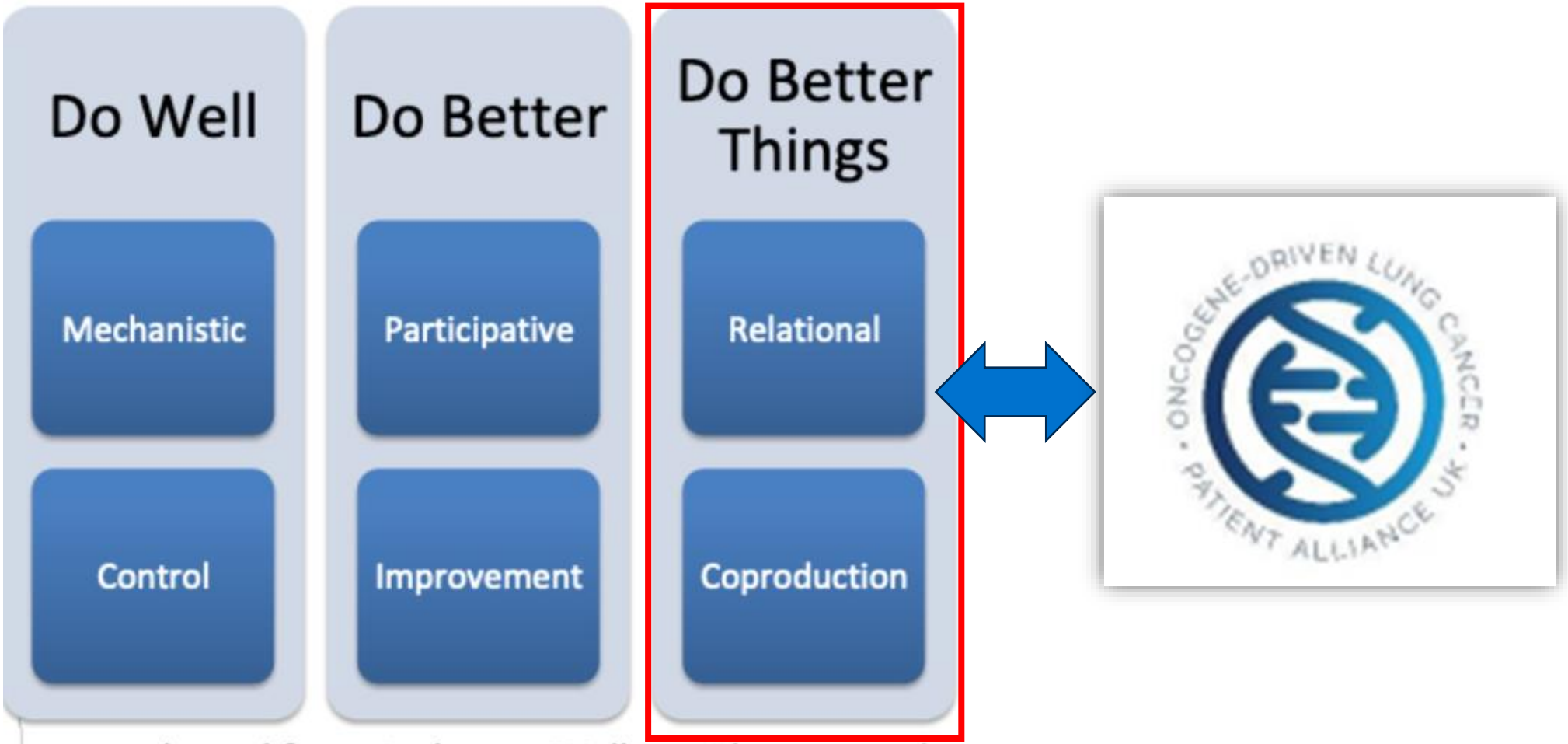


Domain E: Developing evidence-based practice and improving quality 22.0 Capabilities: Research and evidence-based practice The practitioner is able to:
22.14 Proactively network to develop and facilitate collaborative links with specialist cancer services and active researchers in academic and clinical settings to identify potential for further research in cancer care and opportunities to apply for funding, disseminate research and quality improvement through relevant media and fora
22.15 Formulate and implement strategies to act on learning from a range of sources (audit, service user feedback, research, policy) and knowledge of the funding of cancer care services in the NHS and third sector to make improvements, influence and lead new practice and service/system redesign solutions to reduce variation, promote access to underserved communities and enhance quality in response to feedback, evaluation and need

"Quality nurse-led research focuses on the issues most important to those who use, work in and manage health and care services, and succeeds in realising impact. Priorities must be shaped in collaboration with patients, service users, carers, and the public. Moreover, research led by nurses has a role in reducing inequalities in health outcomes across different populations through focusing on social determinants of health."

(NHSE and NHS improvement 2021 p14)

Summary …



adapted from Anderson-Wallace, Blantern and Boydell, 2000-2007

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Thank you!

For more information please contact:

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