How do we build personalisation into palliative and end of life care services?

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Palliative and End of Life Care

What this should look like for people?

01 Each person is seen as an individual

02 Each person gets fair access to care

03 Maximising comfort and wellbeing

04 Care is coordinated

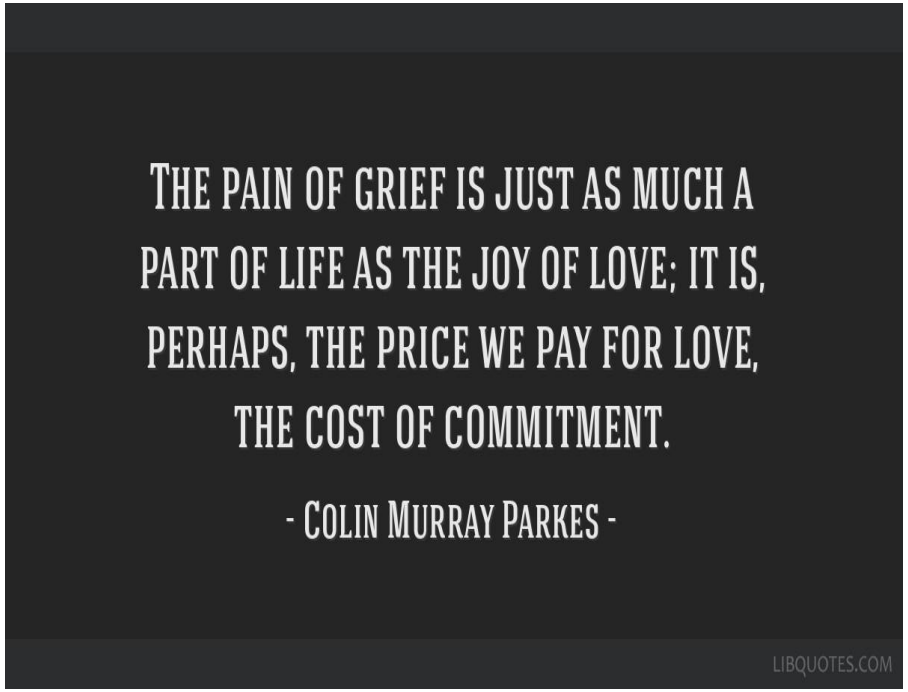
05 All staff are prepared to care

06 Each community is prepared to help

"I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carer(s)."

" You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die."

Dame Cicely Saunders

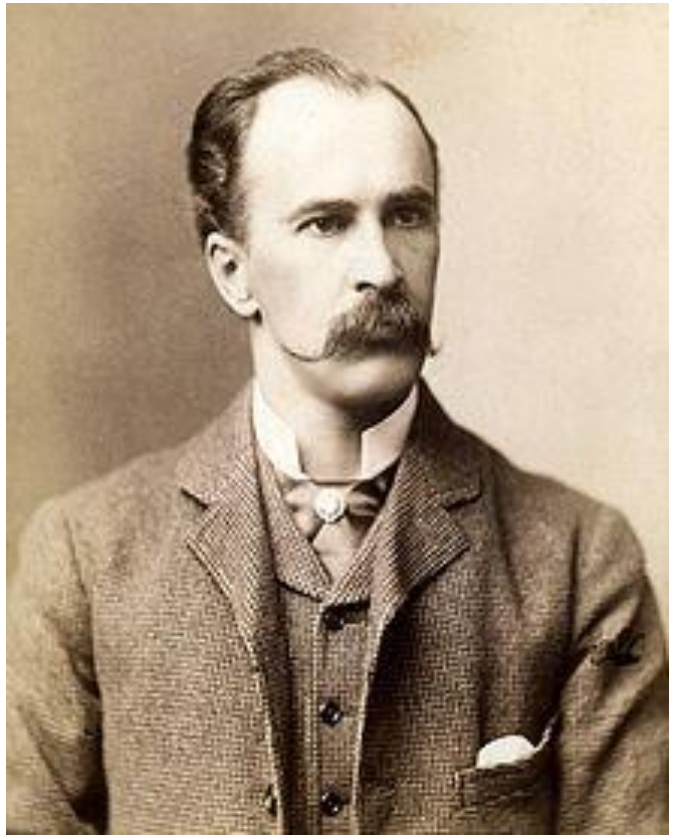

THE PAIN OF GRIEF IS JUST AS MUCH A PART OF LIFE AS THE JOY OF LOVE; IT IS, PERHAPS, THE PRICE WE PAY FOR LOVE, THE COST OF COMMITMENT.
- COLIN MURRAY PARKES -
LIBQUOTES.COM

Patient-centred medicine

“Learn to study patients, not cases— individuals, not diseases”

“The good physician treats the disease but the great physician treats the patient”

Sir William Osler (1849-1919)



NHS Constitution

- The NHS provides a comprehensive service, available to all
- Access to NHS services is based on clinical need, not an individual's ability to pay
- The NHS aspires to the highest standards of excellence and professionalism
- **The patient will be at the heart of everything the NHS does**
- The NHS works across organisational boundaries
- The NHS is committed to providing best value for taxpayers' money
- The NHS is accountable to the public, communities and patients that it serves

Source: https://www.gov.uk/government/publications/the-nhs-constitution-for-england/the-nhs-constitution-for-england

Dimensions of patient-centred care

1. Compassion, empathy and responsiveness to needs, values and expressed preferences
2. Coordination and integration
3. Information, communication and education
4. Physical comfort
5. Emotional support, relieving fear and anxiety
6. Involvement of family and friends

Institute of Medicine, 2001

Person centred care can be conceptualised…..

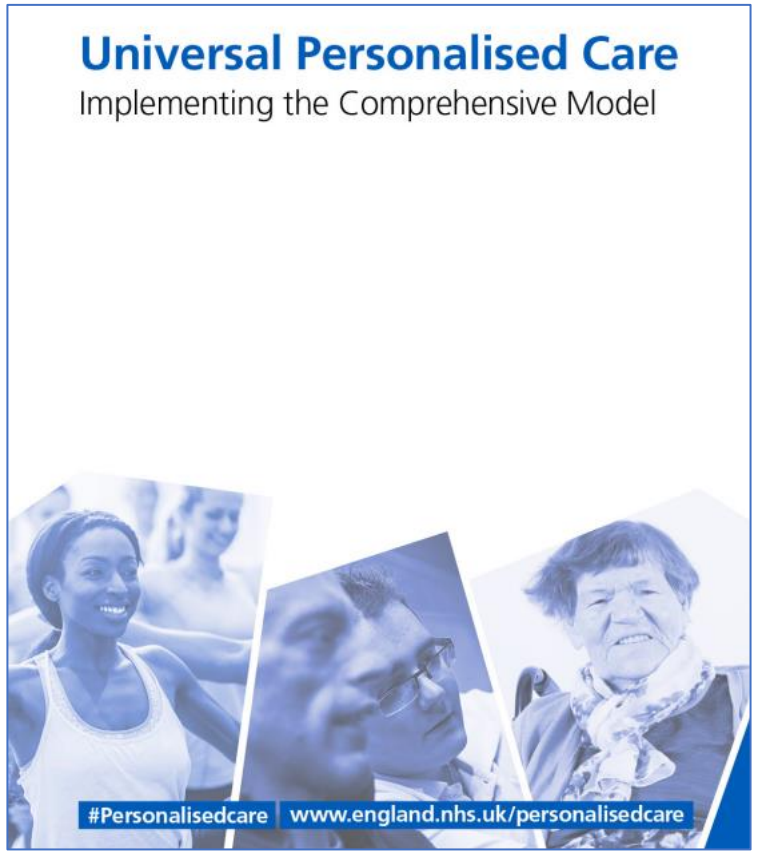
- …as an overarching grouping of concepts
- …emphasising personhood
- …as partnership

Source: Health Policy Partnership, 2015

Comprehensive Model for Personalised Care

Brings together 6 components, each defined by a standard, replicable delivery model:

- Shared decision making
- Personalised care and support planning
- Enabling choice, including legal rights to choice
- Social prescribing and community-based support
- Supported self-management
- Personal health budgets and integrated personal budgets.



https://www.england.nhs.uk/wp-content/uploads/2019/01/universal-personalised-care.pdf

Palliative Care

An approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual

Palliative and End of Life Care

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Universal Palliative and End of Life Care

Interventions

Personalised Approaches

Shared decision making; identification of people likely to be in their last year of life; personalised care and support planning; social prescribing, self management; personal health budgets; compassionate communities, including wellbeing interventions and bereavement support.

Specialist (plus targeted and universal)

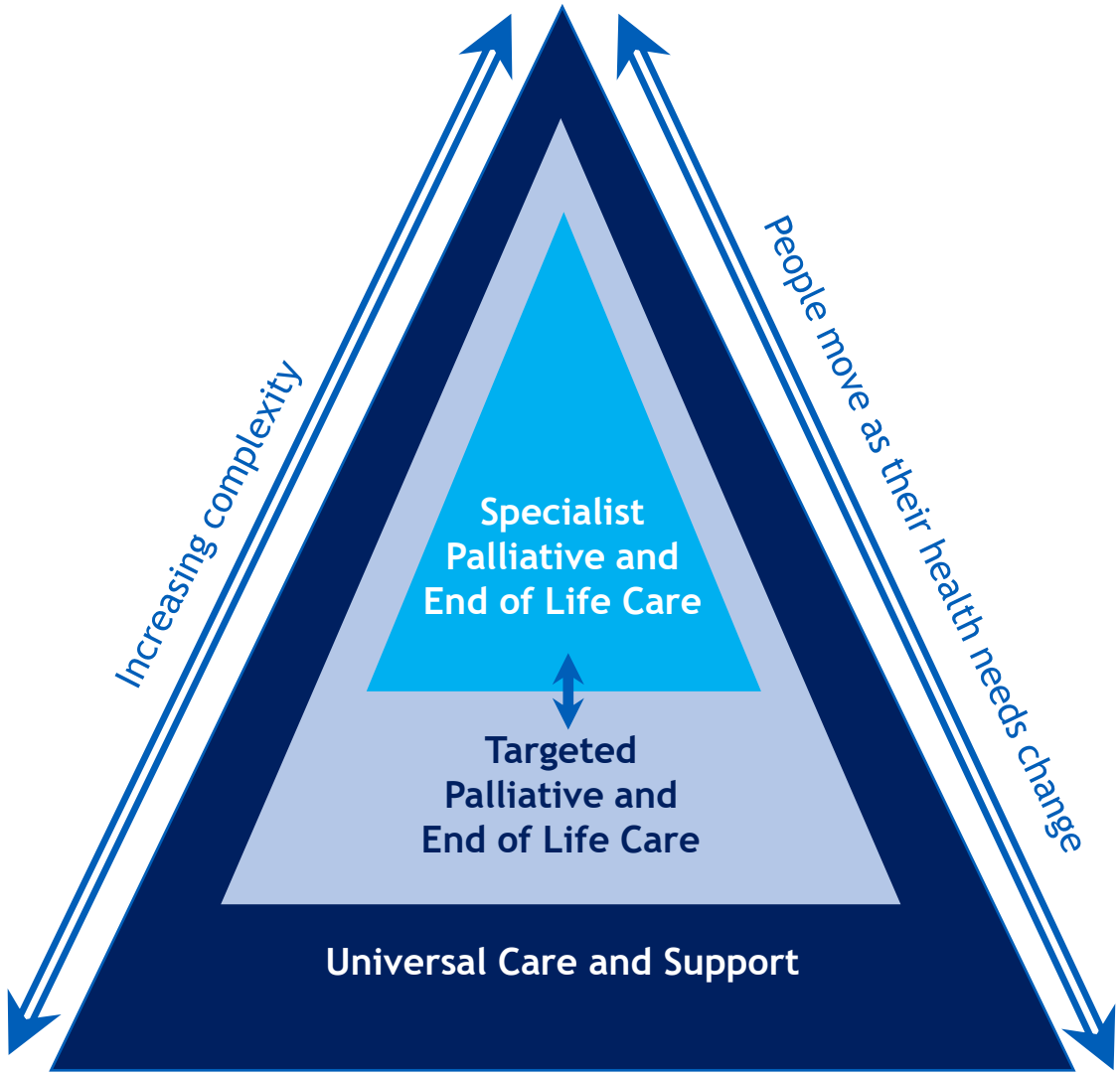
Tertiary or specialist palliative care services in hospices, community and hospital: 24/7 advice or care, complex symptom management and specialist equipment

Targeted (plus universal)

Non-specialist palliative care delivered in hospitals; hospice at home, respite care and hospice day services (may be generalist and/or specialist level)

Universal

Non-specialist palliative care delivered by primary, community, acute and urgent care services



Outcomes

I am treated with dignity and respect

I have a personalised care and support plan that records my preferences, wants and needs

My pain and symptoms are proactively managed

I am seen as an individual

I have fair access to care

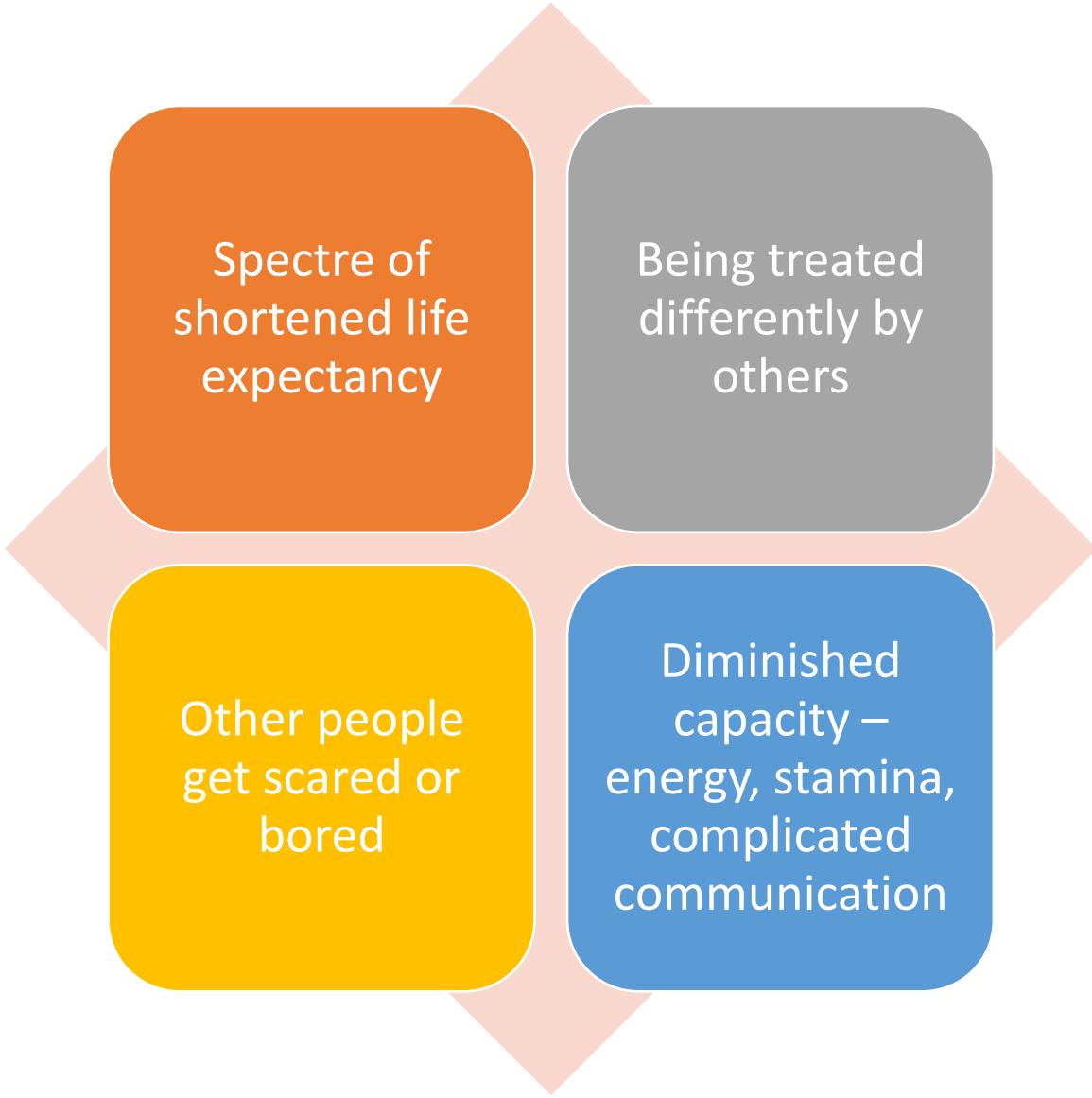
My care is coordinated and seamless

I can expect my carer/family have their needs recognised and are given the support they need

Living and dying well

Pause:
Focus on Health Inequalities

How is this different in context of PEoLC?



Factors that may impact on equity

- Age, gender and sexual identity
- Condition
- Location
  - Geography
  - Place
- Race and belief system
- Socio-economic status and deprivation

- Those who do not have somebody to speak for them
  - Isolation
  - Household vulnerability
  - Literacy and/or digital exclusion

Why isn’t person centred care a given?

“As the system has grown more complex and fragmented, and as providers feel more pressure to see more patients in less time, care has become centered not on the needs of patients, but around the needs of the system itself.”

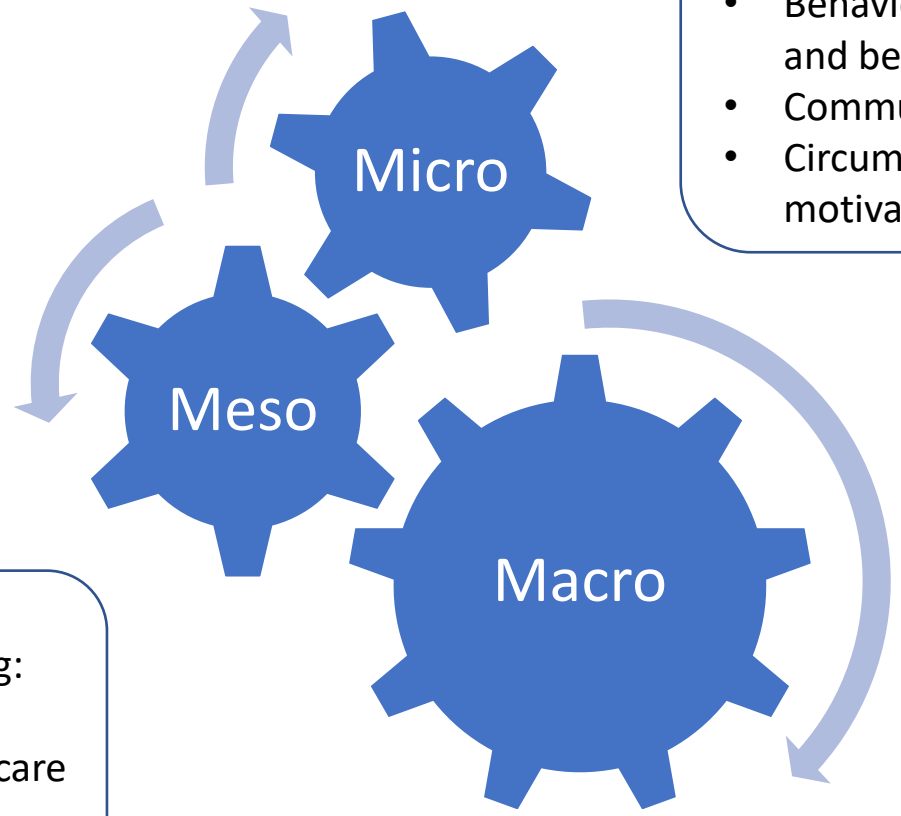
Source: IHI

“Every complex problem has a solution which is simple, direct, plausible…….

and wrong”

H.L.Mencken

System level factors affecting delivery of end of life care



Micro level

Individual variation:

- Behaviours, preferences and beliefs
- Communication
- Circumstances and motivation

Meso level

Commissioning:

- Structures
- Models of care

Education:

- Priorities

Macro level

Policy and strategy

- Existence of policy
- Extent of leverage
- Models of population health

Health system

- Structure of health service
- Economic environment
- Workforce pressures

Population

- Demographics and needs

Source: Barker et al: J of Health Services Research & Policy, 2020
DOI: 10.1177/1355819620914939

Implementing and measuring person centred care: key areas of development

Organisational development

Formal education and training for workforce

Support for professional ethics and values

Communication, shared decision making, co-production and self-management are some of the most operationalised components

Integrated care and health IT can be huge enablers

Measurement is critical test – patient satisfaction, patient experience, and patient reported outcome measures – but limitations

Need to move away from standardised measures - develop and apply more person-led outcomes and measures

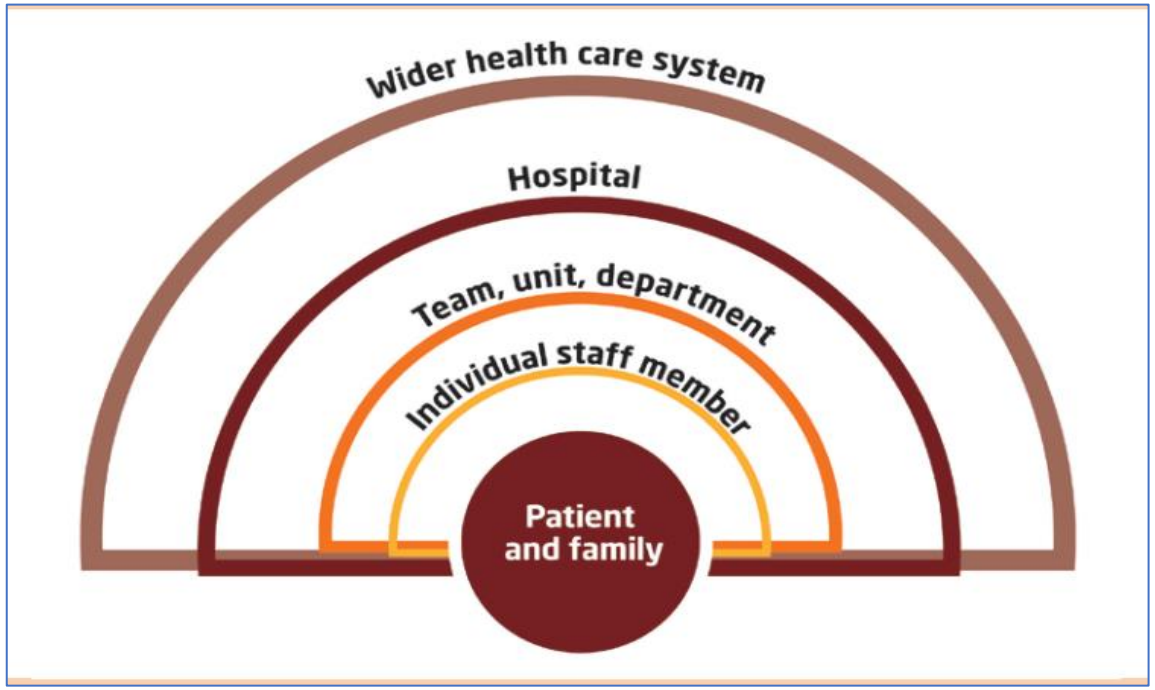
Source: Health Policy Partnership, 2015

SEEING THE PERSON IN THE PATIENT

The Point of Care review paper

Joanna Goodrich and Jocelyn Cornwell

Framework for analysing factors influencing patient experience



The Point of Care Programme, King's Fund 2008

Factors shaping individual patient experience

Staff		Patient
Organisational factors	**Human factors**	
Job description	**Morale**	Age
Education & training, qualification	Experience	Spoken English
Induction, preparation	Health status	Clinical need
Delegated responsibilities & accountability	**Tiredness, stress, wellbeing**	**Mental and physical capacity**
Status – permanent/temporary	**Attitude and values – personal, professional**	Depression, anxiety, fear
Support, supervision, appraisal	Support	**Social status**
	Spoken English	**Able to speak for self**
		Active family or other support

Source: Goodrich & Cornwell, 2008

Factors at team level

Organisational

- Performance management
- Governance and accountability
- Division of labour
- Clarity/conflict over job boundaries
- Access to ICT
- Operating procedures
- Record keeping
- Skill mix and deployment
- Capacity management
- Stability of staffing

Human factors

- **Leadership**
- Morale
- Communication
- Experience in team
- Flexibility
- **Team ethos and values**
- Priorities

Source: Goodrich & Cornwell, 2008

Factors at institutional level

Technical

- Set direction
- Ensure delivery
- Maintain governance
- Adequate info about trends and potential issues at ward and specialist level

Human

- **Create an open culture in which staff feel able to voice concerns**
- **Create a culture of effective teamworking**
- **Model enabling and supportive management styles**
- **Expect and encourage professional staff to speak out on behalf of patients**

Source: Goodrich & Cornwell, 2008

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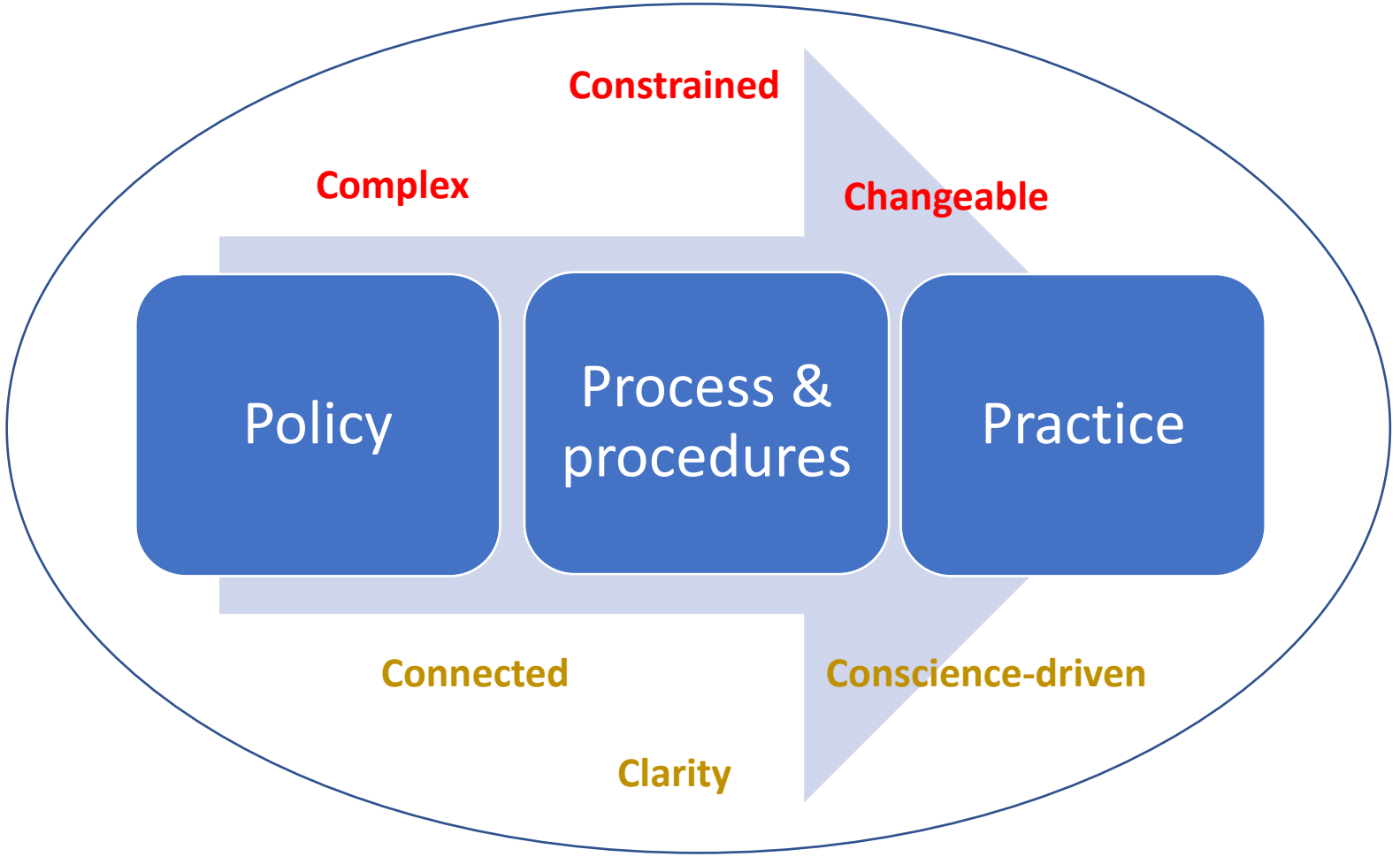
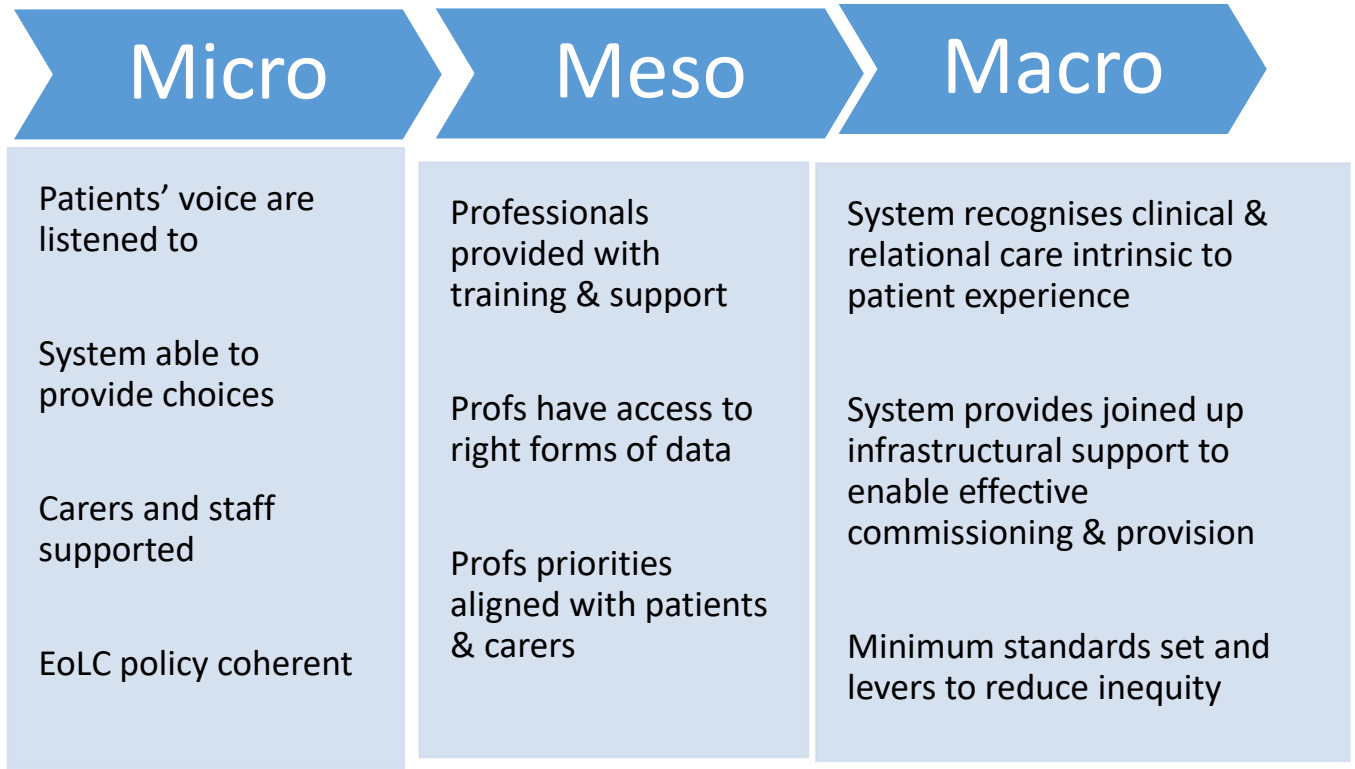


How policy impacts on experience

If:



then

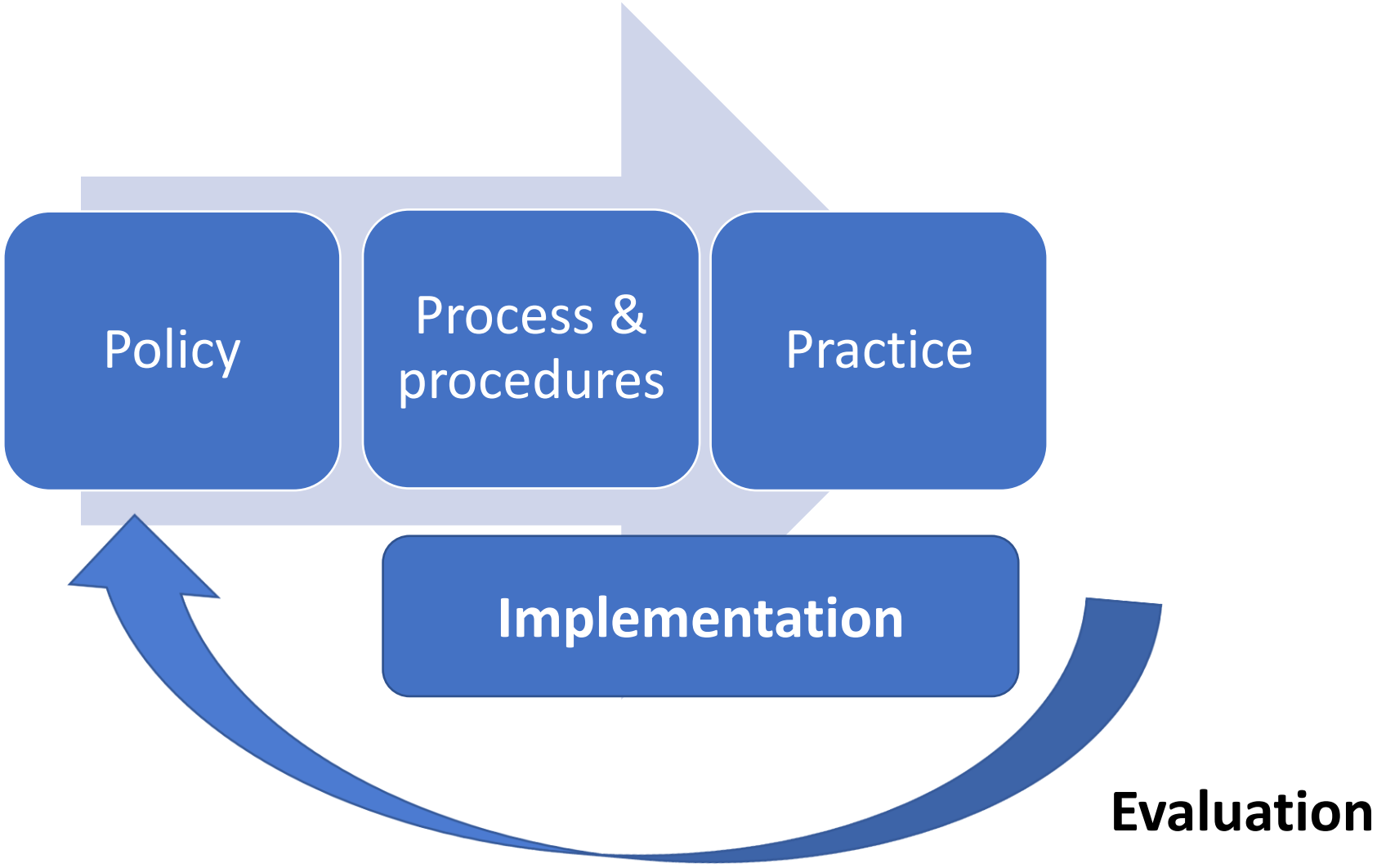
Prof engage - policy
Prof - value to patient
Stakeholders act tog

and

Patients more likely to have their wishes recognised and fulfilled

Source: Barker et al, 2021: DOI: 10.1017/S1463423621000621

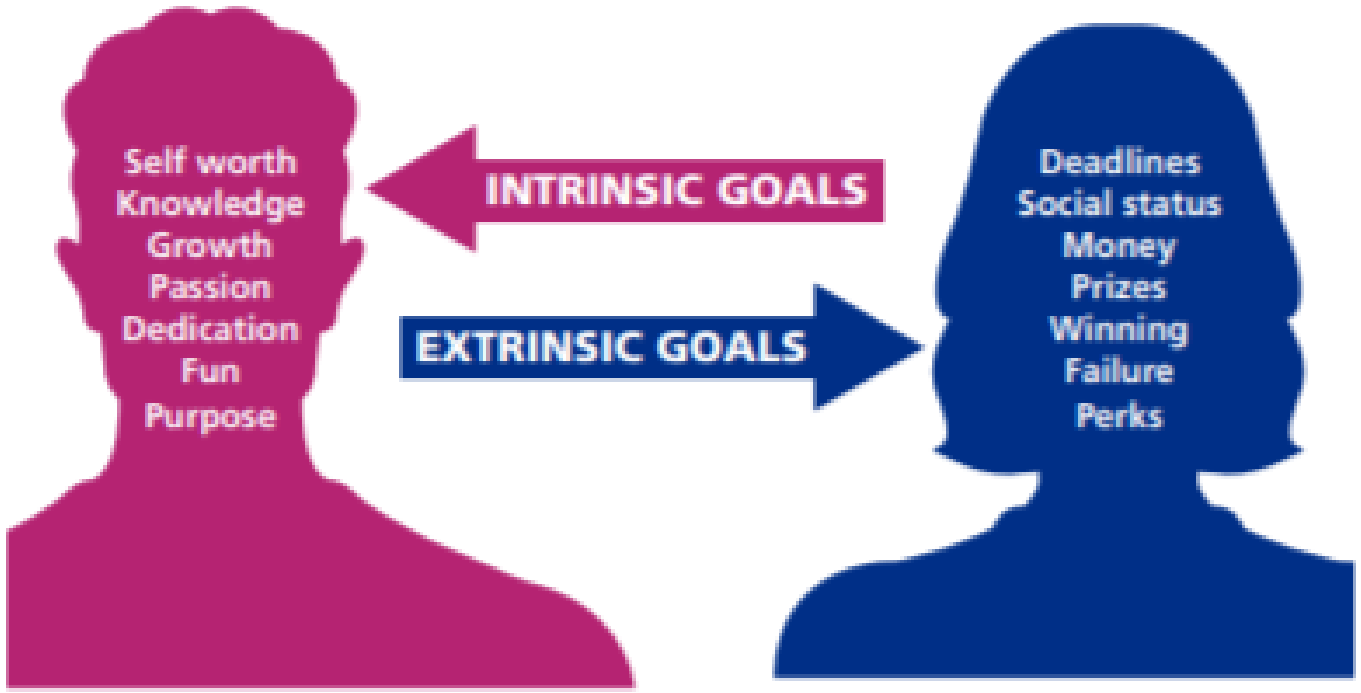
Policy to practice…..



The Change Model

Source: Change Model Guide, NHS England

Motivate and mobilise



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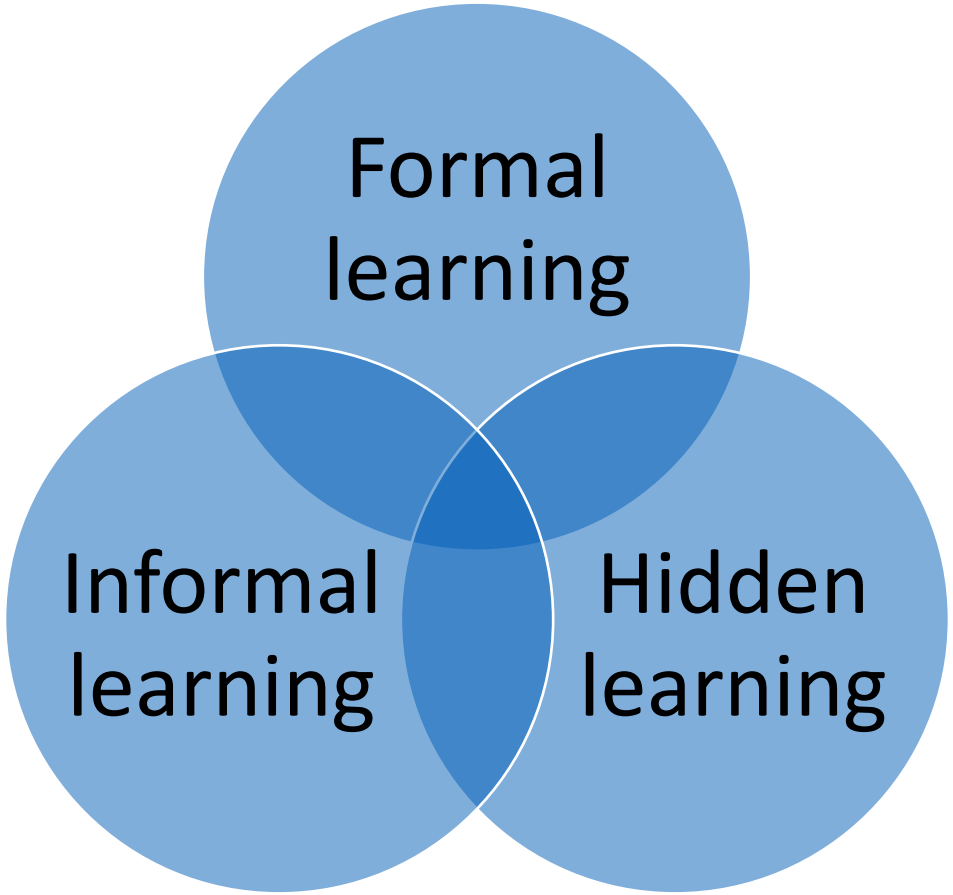
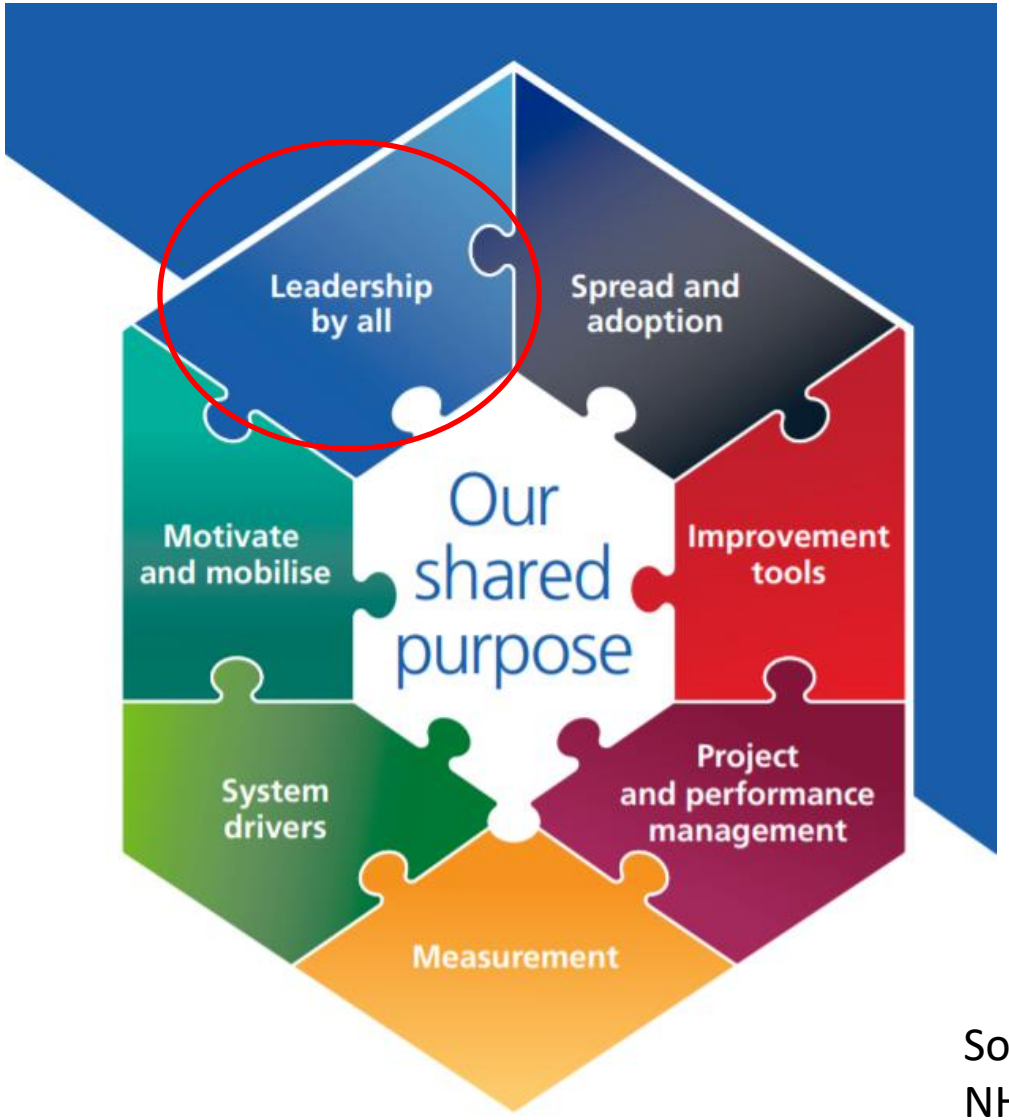

Formal learning
Informal learning
Hidden learning

The Change Model

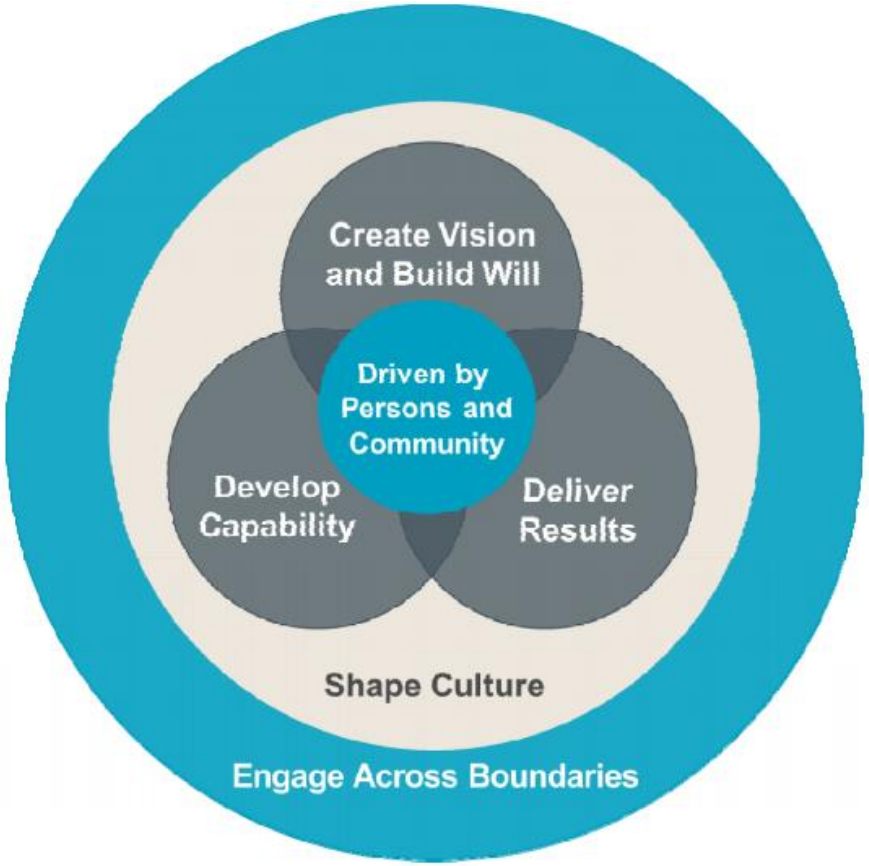


Source: Change Model Guide, NHS England

System leadership

The collaborative leadership of a network of people in different places and at different levels in the system, creating a shared endeavour and cooperating to make a significant change

IHI high impact leadership framework: where leaders focus effort



Swensen S, Pugh M, McMullan C, Kabcenell A. High-Impact Leadership: Improve Care, Improve the Health of Populations, and Reduce Costs. Cambridge, MA: Institute for Healthcare Improvement; 2013. Available on www.ihi.org.

Leadership for ‘policy to practice’: personal take home messages

- Recognise relationship building is ongoing
- Invest in building and maintaining the foundation
- Recognise agendas – legitimate, just different
- Recognise difference in language and culture
- Value different voices – including dissonant ones
- Stay authentic but connect to wider picture as far as possible
- Hang on to sense of curiosity – individual, team, system

Resources

- Ambitions for Palliative and End of Life Care: National framework for local action 2021-26: https://www.england.nhs.uk/eolc/
- Barker et al (2020) Does national policy in England help deliver better and more consistent care for those at the end of life? Journal of Health Services Research and Policy DOI: 10.1177/1355819620914939
- Barker et al (2021) How does English national end-of-life care policy impact on the experience of older people at the end of life? Findings from a realist study. Primary Health Care Research and Development 22(e57): 1-8.
- NHS Constitution (updated Jan 2021): https://www.gov.uk/government/publications/the-nhs-constitution-for-england
- The state of play in person-centred care (2015) – Harding et al, Health Policy Partnership, The Health Foundation
- Seeing the person in the patient (2008) – Goodrich & Cornwell, The King's Fund
- Universal Personalised Care (2019): https://www.england.nhs.uk/personalisedcare/comprehensive-model/
- Universal Principles for Advance Care Planning (2022): https://www.england.nhs.uk/publication/universal-principles-for-advance-care-planning/