# Palliative and EOLC Strategy

## Workforce and Citizen Insights

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# Background and context

- Dying well is a priority for the Health and Wellbeing Board (Surrey Health and Wellbeing Strategy 2020)
- In preparation for a Palliative and End of Life Care Strategy to be developed, the Research and Engagement team have conducted a programme of primary research with workforce and citizens.
- This followed a desk research phase which helped inform the development of themes and focus for the primary phase.
- This presentation reports the findings from 9 interviews with citizens / citizen representatives and 16 members of the workforce.

# Methodology

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| Approach | 25 qualitative interviews were conducted remotely with citizens, citizen representatives and workforce |
| Design | The workforce topic guide was developed based on findings from desk research and tested with HCPs |
| Design | The citizen guide was co-designed with HCPs and an unstructured approach was adopted to allow the citizen (or representative) to tell their story in their own words |

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| Populations in focus | It was considered essential to include the perspective of workforce who specifically work with people from BAME populations, who have learning disabilities, who have diagnosed dementia, and who are currently in a transition phase from child to adult care services. |
| Representative | A spread of geography, sectors (primary, secondary, community, acute, third sector), and providers were involved |

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| | Primary care | Secondary care | Community Care | Acute care |
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| Workforce | X1 GP | X1 Lead nurse for supportive, palliative and EOLC | X1 Nurse consultant | X1 Paramedic |
| | X1 Out of hours GP | X1 Palliative care clinical nurse specialist | X1 Clinical nurse specialist | |
| | | X1 Consultant Psychiatrist | X1 Lead for inpatient services | |
| | | | X1 Social Worker | |
| | | | X1 Specialist in Children's Community Nursing Services | |
| | | | X1 Fast track Domiciliary Care Worker | |
| | | | X2 District Nurse Team Leader | |
| | | | X1 Consultant in Palliative Medicine | |
| | | | X1 Pharmacy Representative | |

| | Citizen | Third Sector (Citizen representative) |
|---|---|---|
| Citizens | Patient receiving palliative care | Age representative (Age UK) |
| | Carer | Bereavement representative (Cruse) |
| | Bereaved representative (Surrey Minority Ethnic Forum) | Bereaved representative (Surrey Minority Ethnic Forum) |
| | | Disability and frontline volunteer representative (Parkinson's UK) |
| | | Faith representative (Diocese of Guildford) |
| | | Palliative charity representative (The Brigitte trust) |

# Interviews with citizens and professionals outlined four key factors which contribute towards a good death:

## Planning ahead

- Allowing enough time to meet all needs
- Anticipating and mitigating risks

## Pain relief and symptom control

- Relieving pain as much as possible while maintaining decision-making ability

## Involving families and carers

- Ensuring that family and carers are involved in the journey

## Having flexibility and choices

- EOLC planning can start up to 1 year before death
- Preferences will change

# Barriers to delivering palliative and EOLC (1)

**Late Referrals-** due to HCP not recognising patient is at EOL, patient in denial of needing EOLC or cultural preferences preventing patients and families seeking help earlier.

As a consequence:

Patients cannot make EOLC plan, families not knowing patient's wishes, unable to build trusting relationship with HCPs who can provide support to patient and family.

**Overstretched resources -** organising care in the community is known to be challenging and, at times, inconsistent. Gap in provision in out-of-hours care.

Limited resources mean patients can be left without care for large periods of time, and sourcing medication is a challenge. A patient who may wish to die at home can find it impossible due to gaps between visits and difficulty in sourcing medication, thus their EOL wishes are not met.

*"They can't die at home and be comfortable if you can't get the drugs there" - Clinical Nurse Specialist*

# Barriers to delivering palliative and EOLC (2)

As a consequence:

**Lack of coordinated care - o**ften patients nearing the end of life need a multi-disciplinary approach, however each organisation tends to have their own IT system and computer records. Additionally, confusion over roles can arise.

Without easy access to patient records, providing the right care can be tricky. Confusion over roles can lead to care not be provided or efforts being duplicated.

**Unpredictable or emergency situations -** While the staff do their best to uphold a patient's wishes, if there is an acute change in condition, HCPs may not have access to EOLC plans.

Despite the advance care planning, cases of emergency may end up with the patient's EOLC needs not being met.

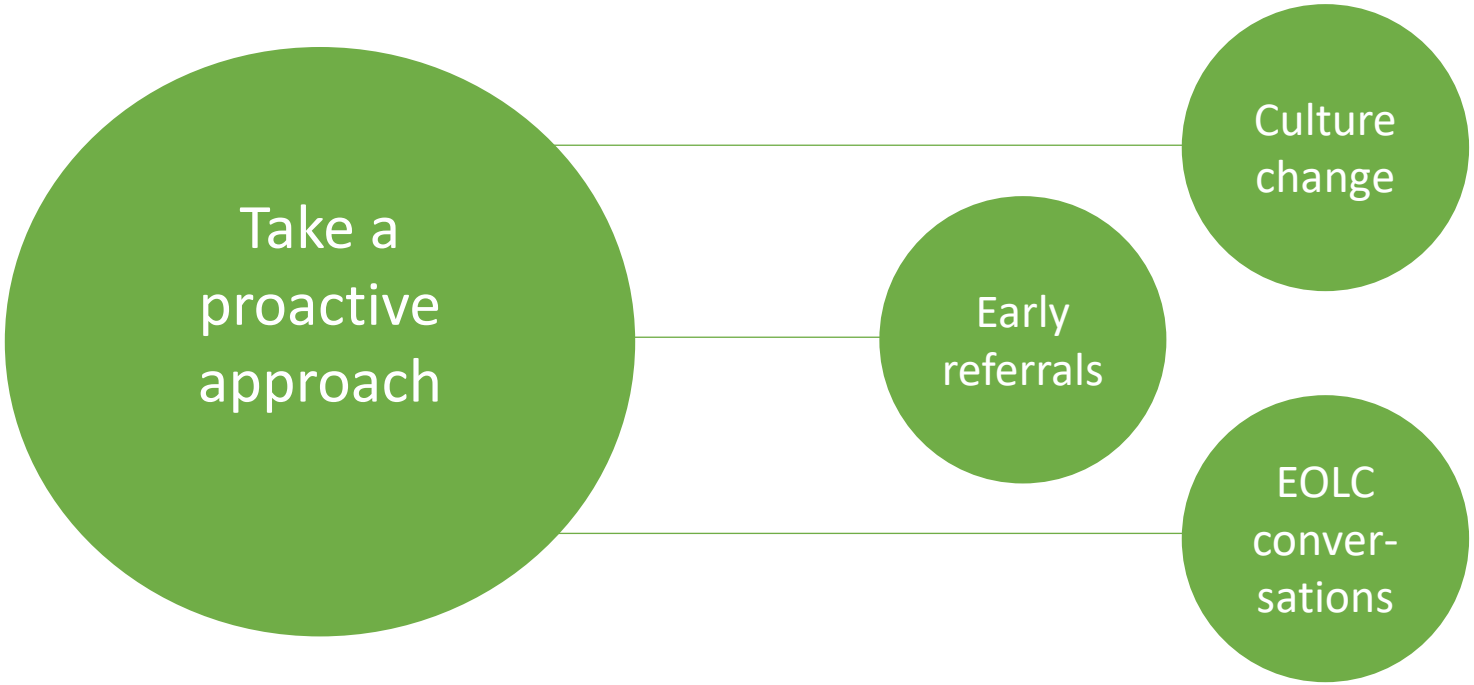
**HCPs may not have the training or confidence-** some frontline staff lack the skills / knowledge to communicate and deliver palliative care effectively.

Missed opportunities to have EOL conversations results in reduced chances for the patient/family/carer to think about EOL preferences.

# Strategies to overcome barriers (1)

Multiple participants emphasised the importance of **proactive preparation** rather than a reactive approach.

When all arrangements are made earlier on, there is a smoother transition which allows more time to talk to the patient and the family about what might happen.




*"You'd think those conversations will have been had by the time they get to a hospice but often they haven't." – (Nurse Consultant)*

# End of Life conversations

EOLC conversations

EOL conversations should be **patient led:**

- Timing
- Who is present
- Content
- Language

Iterative:

EOL conversations are ongoing and EOLC plans are likely to change as the patient's health deteriorates

Recognise barriers:

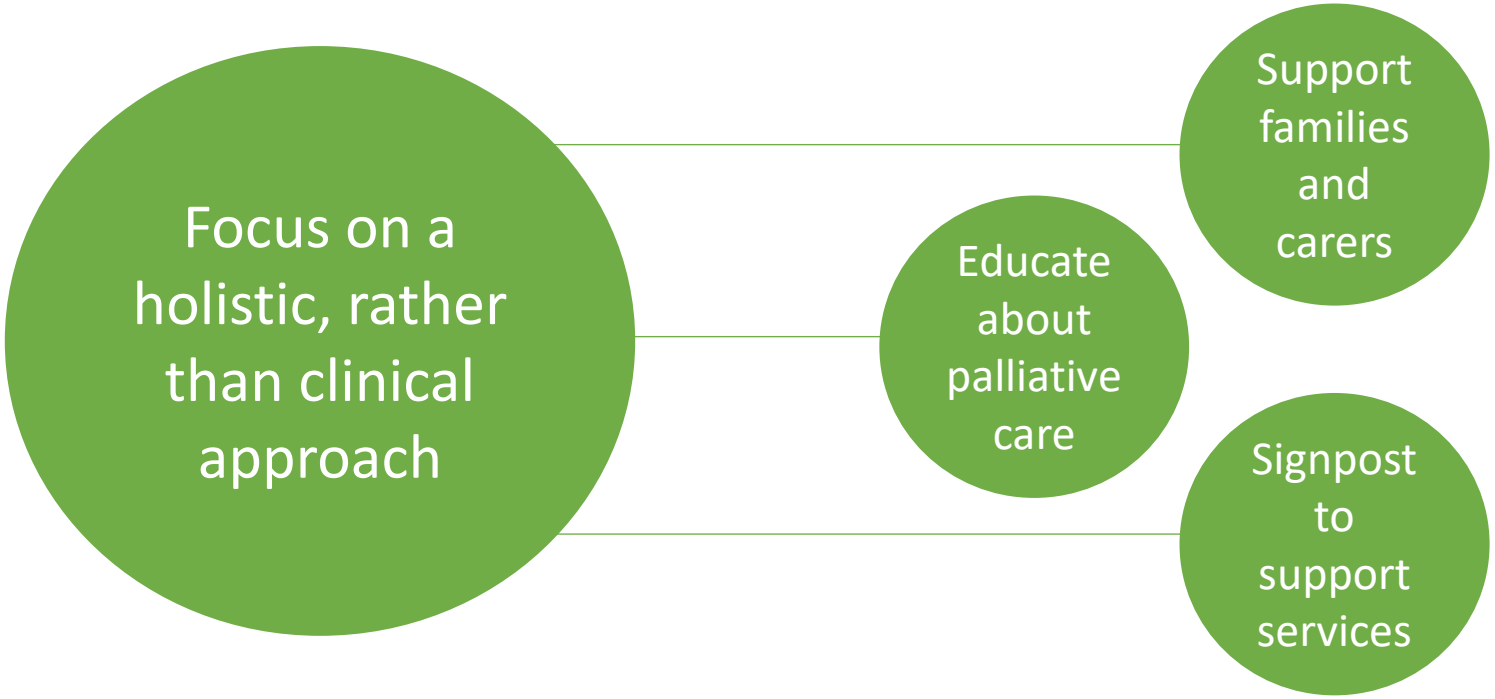
Relies on an acceptance that curative treatment is no longer an option

*"Lack of treatment doesn't mean there's a lack of alternative. Lack of curative treatment means there's treatment which is more palliative." – Consultant Psychiatrist*

# Strategies to overcome barriers (2)

Palliative and EOLC encompasses more than managing the symptoms associated with an illness.

There is also an aspect to acknowledge the patient's spiritual needs, their emotional needs and their concerns for their loved ones

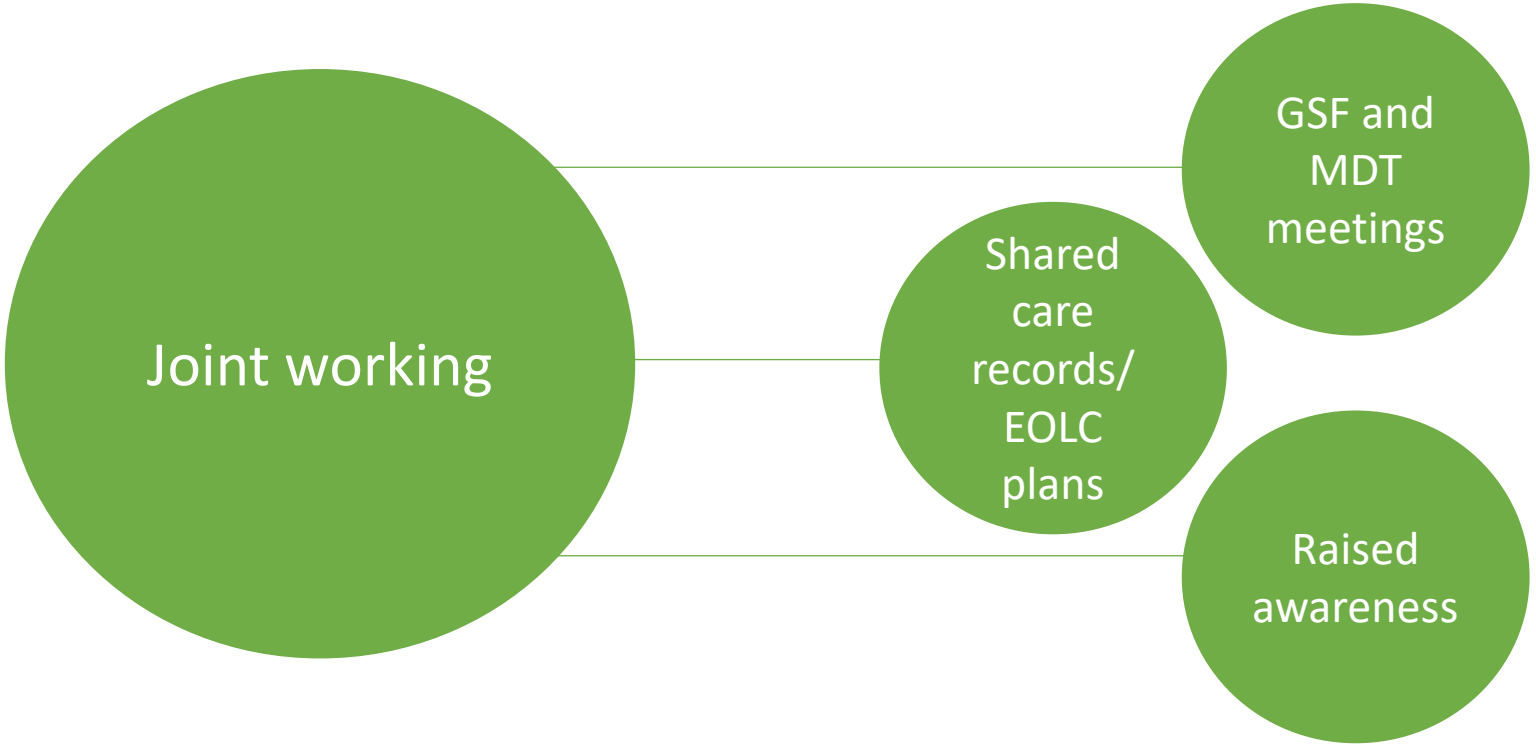



*"So there's that broad spectrum of support that is available, but it's facilitating those conversations to happen between family and the HCP who is involved at a very early stage, so people do get the right care at the right time." – Consultant Psychiatrist*

# Strategies to overcome barriers (3)

Almost all HCPs interviewed explained that coordination of care could work better across all organisations.

The degree of coordination is variable across the geography and depends on whether the HCPs involved already have a good working relationship, how efficiently information can be shared and how much resource is available.

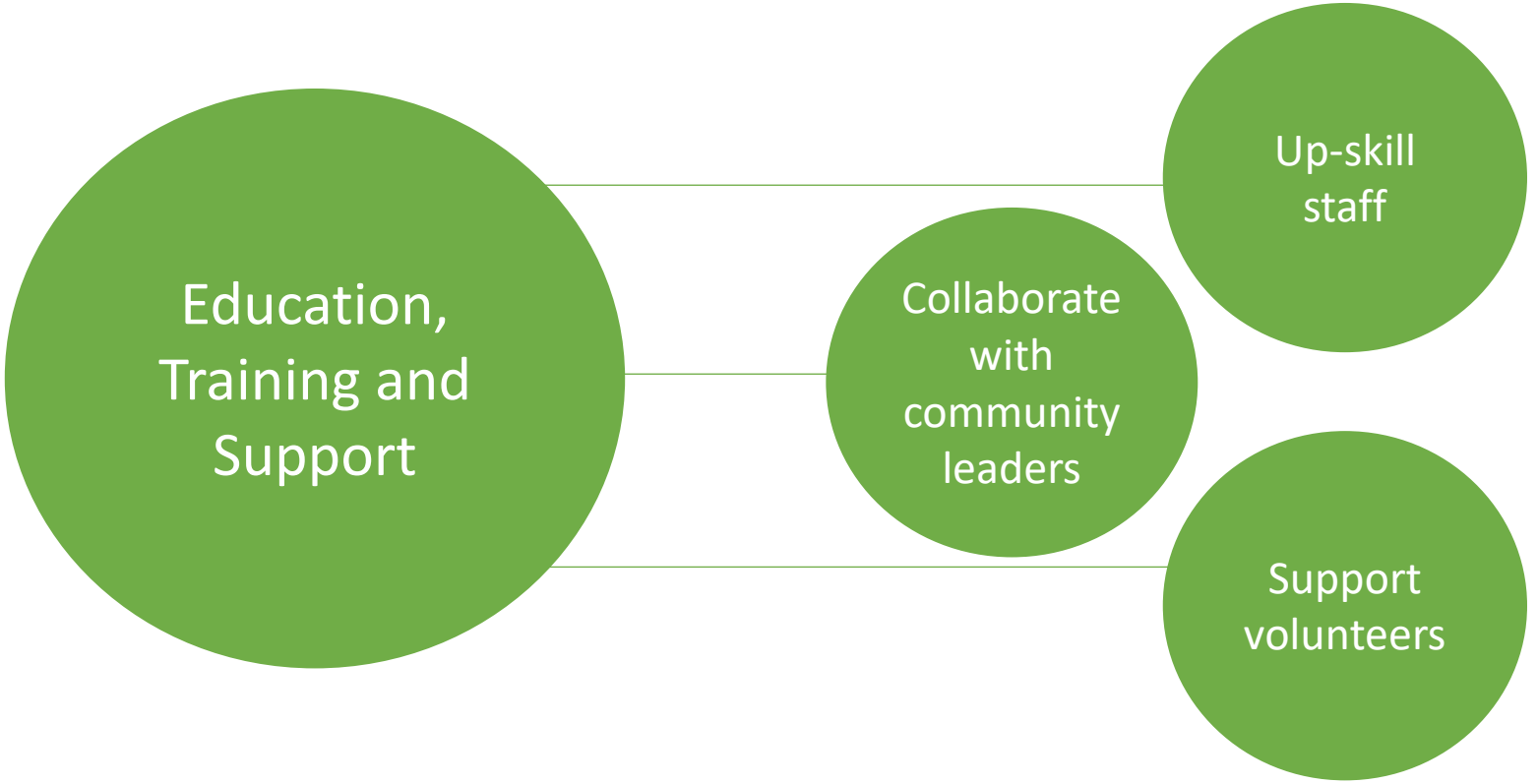



*"…working with the GPs and the community nurses – and liaising with the hospitals and secondary care. I've got to talk to a patient's oncologist, what would be the treatment options if she's deteriorating. It's a bit of a link up sometimes, trying to get everyone to work together." – Consultant in Palliative Medicine*

# Strategies to overcome barriers (4)

Providing communication and EOLC training for new and less experienced staff could help to address some barriers relating to HCPs.

There are gaps in knowledge about what is important to the BAME population when it comes to EOLC, and similarly there could be a lack of awareness in this population about what palliative and EOLC services are




*"Our spiritual care lead, from working with other faith leaders, has realised that a lot of BAME people want to care for their own at home or in a certain way and they think we can't accommodate that. So she'll go and talk about what we can do and how we can adapt and meet the needs. I think that's certainly an area that needs to develop." – Nurse for inpatient Services*

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Planning ahead

Pain relief and symptom control

Involving families and carers

Having flexibility and choices

Late Referrals

Overstretched resources

Unpredictable or emergency situations

Lack of coordinated care

HCPs may not have the training or confidence

Take a proactive approach

Focus on a holistic, rather than clinical approach

Joint working

Education, Training and Support