

## Feedback on Ambitions for End of Life Care

### Specific responses to questions (three groups each in different colours)

The approach being taken by the Partnership makes sense to me

- Like simple approach, ease of understanding statements (both professional and lay audiences), good clear structure

Please tell us if there is more we could do to make sure that our Ambitions and the Building Blocks that we see as important to delivering them, are sensible and ring true to you

- Greater emphasis on supporting bereaved – needs to be more explicit
- Use of age and stage appropriate language (dementia etc)
- 7<sup>th</sup> ambition specifically for bereaved people? Or clarify title of document 'death, dying and bereavement'
- Need clear statement of intent and audiences – what do we mean by x
- Need to include bereaved children and young people
- Have to be explicit about who this affects and who it is for
- Need definitions of end of life care Also discussion cognitions and include bereaved children both before and after death
- Predominance of reference to physical health withough much attention paid to emotional or mental health needs
- Only reference to distress was associated with physical symptoms and can be exacerbated by emotional distress
- Drug/medication
- Repeated use of the word 'individual' worries that this may not translate cross-culturally – collectivist cultures often don't consider themselves in 'I' terms
- Need to be very clear whether this document is intended to cover those who die after sudden illness or trauma including suicide. If so, it will need some additional insertions/explanations. If not, this will need to be made clear (eg using the same preamble as in the NICE draft guidance on care of the dying adult). However, if it isn't intended to cover sudden death, this will leave us without an overarching document intended to cover care in these circumstances, as it is included in the EOLC strategy – this will be a significant gap
- Need to be slightly clearer for a lay audience in places
- Suggestion of alternatives to 'end of life care' eg
  - 'end of life care: dying, death and bereavement'
  - 'care in dying, death and bereavement'
  - end of life care including bereavement
  - end of life care into bereavement

The Building Blocks described by the Partnership provide a comprehensive vision of what is important if we are to achieve our objectives

- How do we defined 'people important to me' particularly in the cae of family conflict or conflict of interest>
- How to handle complex relationships – need for sensitivities around communication

Lease tell us if you think we have missed out some of the important Building Blocks that will be needed to achieve our Ambitions

- 'compassionate AND resilient communities' must be included
- In the counselling sector 'person-centred care' has a different meaning. Need a clear glossary of terms with clear definitions
- P21 use of 'vicissitudes' overly complex given the simplicity of all other language used. We need a new word
- There needs to be a building block to the building block 'those important to the dying person – more detail needed
- Need to be explicit that it covers all groups, right at the beginning
- Maybe have the last ambition first and be explicit it is for all ages groups
- Statement on 'people important': what does 'must be offered' mean?
- If family is going to be a part of the care-coordination team how will they be supported to do that? Care coordination is often done by a family member and will often be the bereaved person
- Need for more on faith groups
- Preference among this group to weave bereaved people more explicitly into this structure rather than inserting a new ambition, but if this will make the sentence structures too long, might be better to have a separate ambition
- Is there enough on people's own personal resources that they bring to their experiences at the end of life?
- Needs some specific insertions on children in the family
- Hope to see VOICES and 'Life After Death' included in references

Please tell us if there is more that we could do to ensure that our approach has authority and impact

- While it seems to have brought together authorities on the matter to create the document, it remains to be seen whether it will act as an authoritative framework
- Might be helpful to have a separate call for local people to help them hold HWBoards to account and ensure implementation is more likely – eg section on 'what I can do to ensure my needs get met'

## Specific comments/suggested insertions (page numbers refer to full document)

P1 title: ideally needs to be clearer upfront that eolc includes into bereavement

- Suggestion of alternatives eg

- 'end of life care: dying, death and bereavement'
- 'care in dying, death and bereavement'
- end of life care including bereavement
- end of life care into bereavement

P4 Exec summary

- Somehow need to get across that the document covers bereavement care for those bereaved suddenly as well as those whose bereavement was anticipated because the person had palliative care needs – this is a key concern for us

P5 end of first para – consider inserting 'including those bereaved suddenly'

P10 Those important to the dying person – needs elaboration including

- specific reference to children and young people in the family
- again, explanation that this includes those bereaved suddenly and unexpectedly

Maybe could also expand '...care and support before and after the death'

P10 Education and training – suggest inserting 'and bereavement' after 'end of life' to make this explicit

P12 – Ambition 1 – somehow we need to get it across more strongly that 'being seen as an individual' applies to bereaved people themselves in relation to assessment and delivery of organised bereavement support

P12 what we already know – might want to say something about bereavement care being patchy and inconsistent

P12 third line from bottom insert 'and bereaved' after 'dying'

P13 clear expectations – needs to be clearer that this applies to bereaved people too eg end of first sentence insert 'the end of their lives or face bereavement'.  
End of second sentence insert 'or bereavement'.

P14 Giving people control – this applies to bereavement too, maybe insert 'and in bereavement' after 'at the end of their life' in the first sentence

P16 Addressing all forms of distress – maybe need something here on distress related to relationships.

P17 overall ambition – needs more focus on the role that volunteers play – linking in to ambition 5 but needs something on training and support for volunteers which may sit better in ambition 3

P17 what we already know – maybe insert something about patchiness of response from staff to bereaved people (see Life After Death for refs)

P17 support and resilience – consider including something here on the mix of personal and professional experiences that staff face, not only the impact of patients dying

P18 knowledge based judgement – maybe insert ‘or bereaved’ after ‘wherever people are dying’. Also at end of paragraph.

P18 using new technology insert ‘or dealing with bereavement’ after ‘approaching death’.

P19 Care is coordinated – currently very patient focused but again applies to bereavement, and may need insertion in ‘what we already know’ to make it relevant – eg gaps in provision for some groups (Alison can supply refs)

P19 Clear roles: insert ‘for people who are dying or facing bereavement’ at end of first sentence

P20 Everyone matters – needs explicit mention of children and young people facing bereavement. Also maybe replace ‘who will have to live with loss’ with ‘who are living with loss’

P23 Ambition 6 – needs to encompass bereaved people explicitly again – eg insert in ambition ‘I get good end of life and bereavement care...’

P23 what we know – again Alison can supply refs about patchiness of provision of organised bereavement support

P23 Using existing data – insert ‘and bereavement’ at end of paragraph

P23 Community partnerships – reference to children and young people not clear whether this means dying children or bereaved children or both. Needs clarifying.

P24 Population based needs assessment – ‘end of life care and bereavement services’. Really important that bereavement services get a specific mention here.