2024

East Suffolk and North Essex NHS Foundation Trust

# End of life care

Presentation to Board

# Key components of end of life care

East Suffolk and North Essex NHS Foundation Trust


Threads

- Communication (involve and inform)
- Empathy and compassion
- Time
- Education and attitude
- Practical support & environment

Care after death

# Demographic changes

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- The need for palliative is expected to increase between 25 and 47% by 2040.
- End of life care needs are expected to increase by more
- This is due to increasingly aging population and increasing comorbidities with resulting complexity.
- These projections do not include increases required to meet currently unmet palliative care need at current service provision levels[9].

Etkind et al. How many people will need palliative care in 2040? Past trends, future projections and implications for services. BMC Medicine (2017) 15:102

# Who provides end of life care?

East Suffolk and North Essex NHS Foundation Trust

Generalist teams

Chaplaincy

Butterfly team and volunteers

Specialist palliative care

Non clinical (e.g. porters, ward clerks, house keeping)

Others

Not just who: Time garden and facilities

# How we monitor and assess care?

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**Last days**

- Individualised Care plans for last days of life

**Last weeks and days**

- Watchpoint (end of life module)

**Last year**

- Electronic Palliative Care Coordination System (EPACCS)

Alongside complaints, incidents, end of life meetings/feedback regionally. Discharge to preferred place of death

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## Individualised end of life care plans

| | 22/23 | 23/24 | Target |
|---|---|---|---|
| Colchester | 59% | 70% | 60% |
| Ipswich | 63% | 61% | |

Note: Monitoring and assessment more important that arbitrary target

## Watchpoint (End of life module)

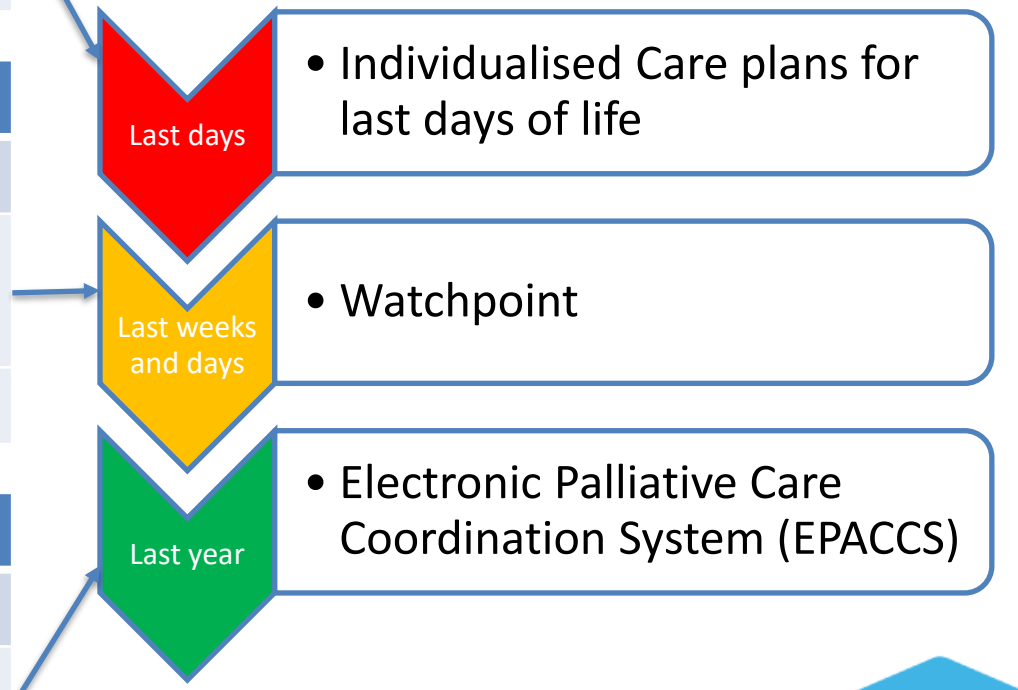
| | 22/23 | 23/24 | Target |
|---|---|---|---|
| Colchester | 49% | 50% | 60% (red if below 40) |
| Ipswich | 42% | 45% | |

Note:

## EPACCS review

| | 22/23 | 23/24 (so far to jan) | Target |
|---|---|---|---|
| Colchester | 78% | 77 | 75% |
| Ipswich | Yellow folder system but no EPACCS | | |

Note:% of patients with an EPACCS register entry where it was seen



# Complaints and incidents

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| Complaints | | | |
|---|---|---|---|
| | Number of complaints | Number of deaths | % of deaths with complaints |
| 2021/2022 | 23 | 2886 | 0.7% |
| 2022/2023 | 47 | 3254 | 1.4% |
| 2023/2024 | 40 | 3046 | 1.3% |

| Key themes of complaints | Notes |
|---|---|
| Communication | Themes monitored 6-12 monthly<br>Most common themes consistent and match with local report from National audit findings |
| Poor care | |
| Symptom management | |
| Recognition of dying | |
| Poor attitude | |
| Visiting issues | |

**Incidents:** monitored continuously by end of life team and local end of life board

# National audit- as reported by families

East Suffolk and North Essex NHS Foundation Trust

## Hospital right place to die in circumstances

| | 2023 (agree/strongly agree) | 2023 (disagree/strongly disagree) | 2022 (agree/strongly agree) | 2022 (disagree/strongly disagree) |
|---|---|---|---|---|
| Colchester | 71.3%(UK73.1) | 19.2 (UK 15.4) | 77% | 11% |
| Ipswich | 72.7%(UK73.1) | 14.6%(UK 15.4) | 90% | 6.6% |

## Care to patient

| | 2023 (good/outstanding) | 2023 (poor) | 2022 (good/outstanding) | 2022 poor |
|---|---|---|---|---|
| Colchester | 63.9%(UK71.1) | 16.7% (UK 16.1) | 73% | 9% |
| Ipswich | 69.1%(UK71.1) | 16.4%(UK 16.1) | 80% | 13% |

## Care to family

| | 2023 (good/outstanding) | 2023 (poor) | 2022 (good/outstanding) | 2022 (poor) |
|---|---|---|---|---|
| Colchester | 58.9%(UK65.6) | 26 (UK 18.9) | 63% | 14% |
| Ipswich | 65.4%(UK65.6) | 20%(UK 18.9) | 70% | 17% |

# National audit- Key points

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Evidence of good care but polarised

Need better communication:
assessment of needs, support and involvement
ent

Need better recognition of RISK of dying

Better elements of documentation

Community hospitals- Qualitative data from relatives supports high quality compassionate care

# Monitoring and assessment-other

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- Regular local and regional coordination and issue sharing
  - ESNEFT group
  - Local: Ipswich and East Suffolk and North East Essex
  - Regional: Integrated care system end of life group
- Ad hoc direct clinical input at the time of issues

# Improving quality

# Monitoring and assessment

- As previously described
- Included here again to emphasise that the monitoring and assessment has been an important part of driving quality improvement

# Education and training

East Suffolk and North Essex NHS Foundation Trust

Mandatory training → Most staff

Higher level clinical training → Freely available to those interested: Most grades of doctors, nurses and AHPs

EOL specific communication skills → Colchester: available

Ipswich: In development

Ad hoc clinical training at time of need

## Challenges

- Training capacity
- Release of staff for training
- Access to staff most in need of coming to self initiated training

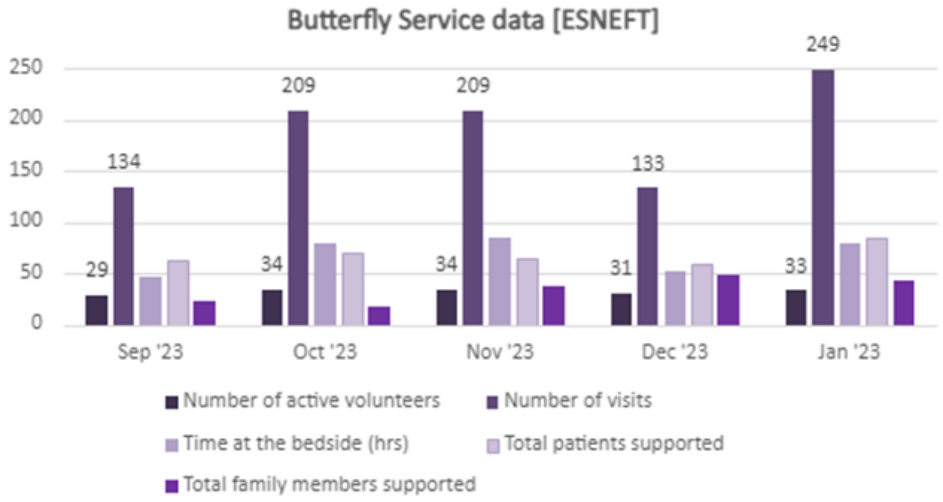
# Working together and Compassionate communities

East Suffolk and North Essex NHS Foundation Trust

- Regional coordination as discussed
- Contribution towards developing compassionate communities
- Suffolk-
    - Continued development of compassionate companions led by a local GP
- Essex-
    - Working closely with system partners and community organisations in developing a Compassionate City Charter for Colchester
    - Hope of becoming accredited as an official ‘Compassionate City’ in July 2024.
    - Steering groups are held monthly to drive this project forward. There are plans to expand this to Ipswich the following year, once established in Colchester.

# Butterfly service

*"Patient C was unconscious and her husband was constantly with her refusing to take a break unless a Butterfly could sit with her, we visited over 14 times, this allowed him to go home and shower, collect medication and have meals. He was very grateful for all the support he received."*




For illustration of the type of data and trend: data not meant to be easily visible for this presentation

- Sitting service
- Centres offering advice and support
- Volunteers supported by coordinators
- Funded to March 2025
- Fundraising appeal is planned to launch in Dying Matters week (6-12th May 2024) for more sustainable funding

# Data: Equality, diversity and inclusion

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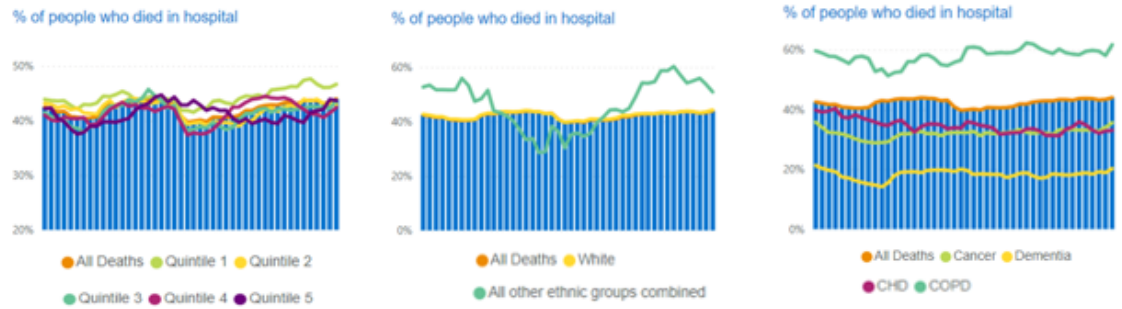
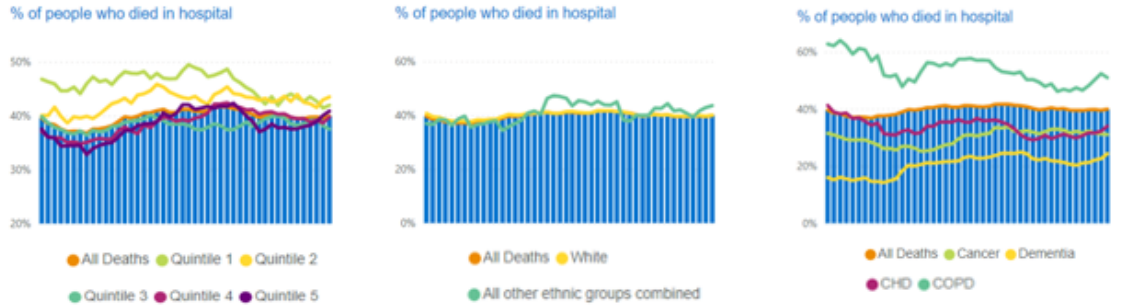
- Data is now captured on the Suffolk & North East Essex EOL dashboard including: Ipswich and East Suffolk, North East Essex and West Suffolk populations
- You are more likely to die in hospital if you live in Quintile 1 and Quintile 2 of deprivation, non white ethnic background or have COPD
- In development due to data quality and interpretation

For illustration of the type of data: data not meant to be visible for this presentation

**In North East Essex:**

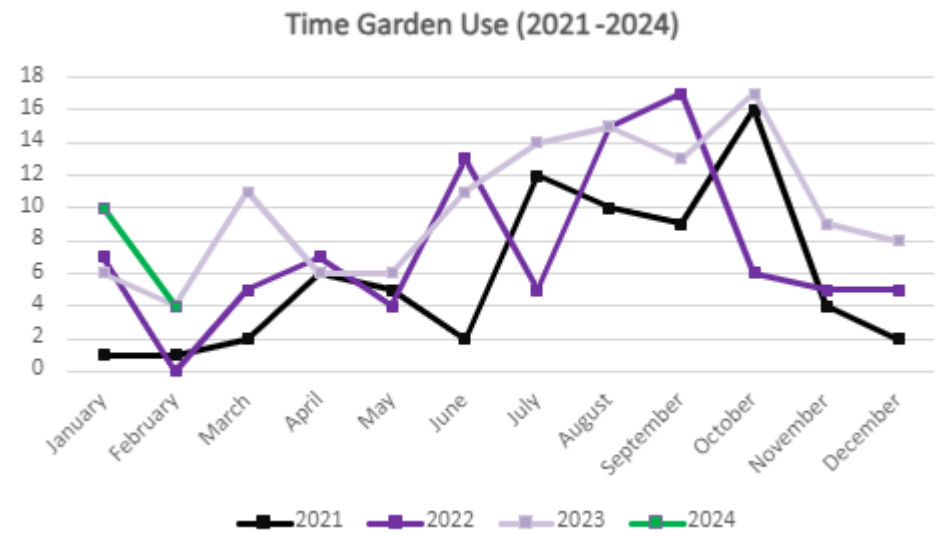



**In Ipswich and East Suffolk:**



# Environment

- Colchester Time garden



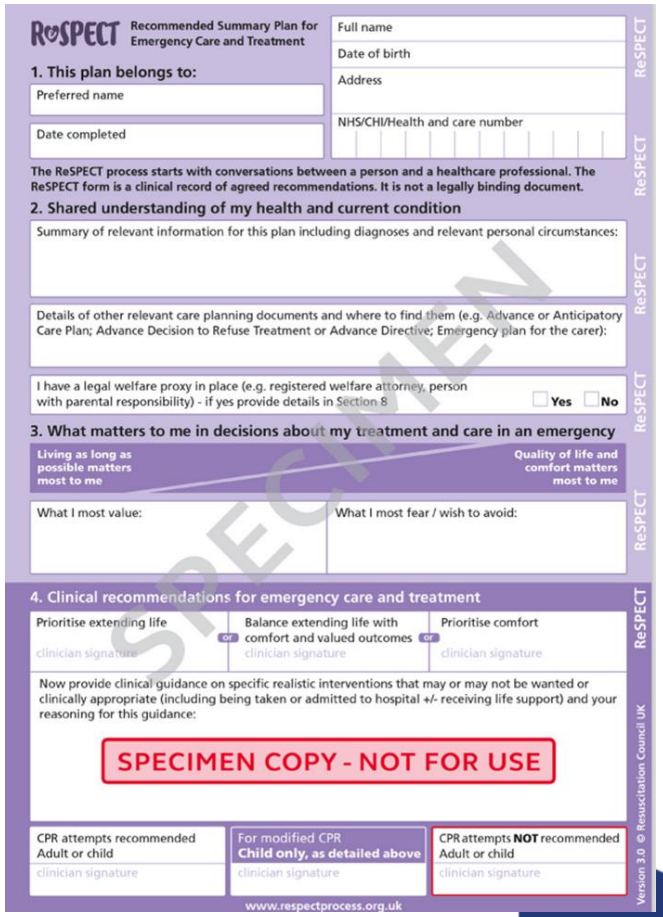

- Ipswich Time garden
  - Project group in progress
  - Initial potential site identified and project group investigating options and planning fundraising appeal

*"Had a wonderful day with my Dad. A pint and pizza. Thank you for this wonderful space to have this special time with him."*

# RESPECT

East Suffolk and North Essex NHS Foundation Trust

- REcommended Summary Plan for Emergency Care and Treatment
- Alternative to stand alone Do Not Attempt Resuscitation form
  - Aims to frame conversation if better context
  - More emphasis on patient priorities
  - Covers more aspects of patient treatment
- Now introduced across region



ReSPECT Recommended Summary Plan for Emergency Care and Treatment

Full name
Date of birth
Address
NHS/CHI/Health and care number

1. This plan belongs to:

Preferred name
Date completed

The ReSPECT process starts with conversations between a person and a healthcare professional. The ReSPECT form is a clinical record of agreed recommendations. It is not a legally binding document.

2. Shared understanding of my health and current condition

Summary of relevant information for this plan including diagnoses and relevant personal circumstances:

Details of other relevant care planning documents and where to find them (e.g. Advance or Anticipatory Care Plan; Advance Decision to Refuse Treatment or Advance Directive; Emergency plan for the carer):

I have a legal welfare proxy in place (e.g. registered welfare attorney, person with parental responsibility) - if yes provide details in Section 8 ☐ Yes ☐ No

3. What matters to me in decisions about my treatment and care in an emergency

Living as long as possible matters most to me — Quality of life and comfort matters most to me

What I most value:

What I most fear / wish to avoid:

SPECIMEN

4. Clinical recommendations for emergency care and treatment

Prioritise extending life (clinician signature) OR Balance extending life with comfort and valued outcomes (clinician signature) OR Prioritise comfort (clinician signature)

Now provide clinical guidance on specific realistic interventions that may or may not be wanted or clinically appropriate (including being taken or admitted to hospital +/- receiving life support) and your reasoning for this guidance:

SPECIMEN COPY - NOT FOR USE

| CPR attempts recommended Adult or child | For modified CPR **Child only, as detailed above** | CPR attempts **NOT** recommended Adult or child |
|---|---|---|
| clinician signature | clinician signature | clinician signature |

www.respectprocess.org.uk

Version 3.0 © Resuscitation Council UK

# Action

# Already in progress

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- Continued commitment to
  - Education & training
  - National audit
  - Direct clinical support
  - RESPECT
  - Regional integration and coordination
  - In house monitoring systems (accountability framework, Watchpoint, EPACCS etc)
  - Investigating equipment to improve physical environment for relatives staying overnight

# Next steps

East Suffolk and North Essex NHS Foundation Trust

- Electronic Palliative Care Coordination system (EPACCS) for Suffolk
- Optimising opportunities for advance care planning
- Opportunities via EPIC
- Sustainable funding for butterfly service coordinators via fundraising
- Time garden Ipswich
- New communication skills training for Ipswich
- My Care Choices Register QI project June - December 2024
- Working on ‘sick enough to die’

# Challenges

East Suffolk and North Essex NHS Foundation Trust

- General clinical workload for wards
- Specialist palliative care clinical staffing and capacity
- Capacity to deliver training on end of life care
- Ability of staff to be released for training
- Short term challenge from introducing EPIC but likely longer term benefit

# Questions?

# NACEL 2023:Colchester Hospital

50 Case note reviews (CNR), 73 quality surveys (QS), 20 staff reported measures. Boxes indicate local results. Red is >10% below national average or %score below 60%. Orange is above 60% but below national average or 70%. Hexagons represents composite scores from multiple parameters.

Communication with the dying person: 9.2 (UK 8.0)

Communication with families: 6.2 (UK 7.1)

Involvement in decision making: 9.4 (UK 9.2)

Individualised plan of care: 7.1 (UK 7.6)

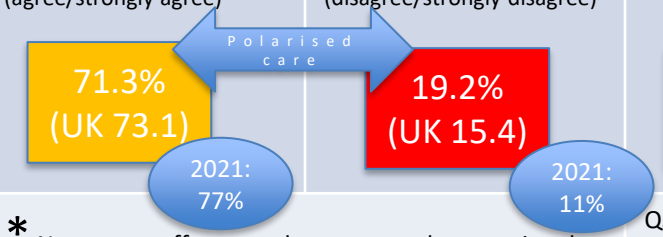
Needs of families and others: 4.9 (UK 5.5)

Families experience of care: 5.7 (UK 6.3)

Staff reported measures: *

Workforce/Specialist Pall care: 10 (UK 8.1)

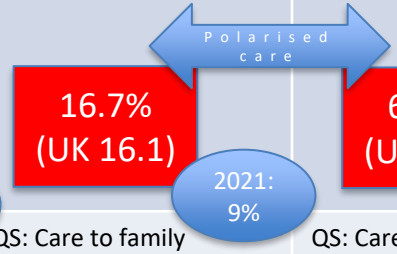
QS: % hospital right place to die in circumstances (agree/strongly agree)




QS: % hospital right place to die in circumstances (disagree/strongly disagree)



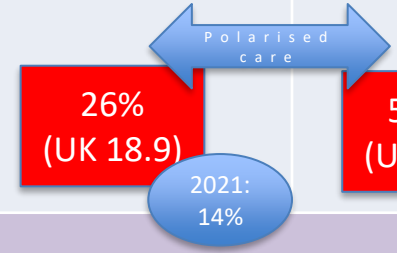

QS: Care to patient poor




QS: Care to patient Good to outstanding


* Notes on staff reported measures: above national average for staff confidence 7.6(NA7.5), staff support 8 (7.1) and care & Culture 7.6 (7.6) but difficult to interpret relevance given a very small number of respondents and significantly different proportions of different staff types from the national average

QS: Care to family poor

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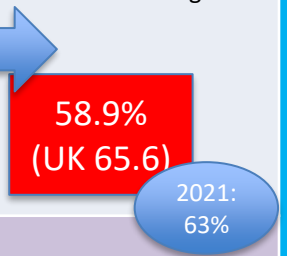


Data review:
The top 4 hexagons reflect documentation in notes and represent some quantitative deficits in care which is reflected in family perceptions of care.
The second row of hexagons indicate that many elements of care and support as perceived by family have not improved and are too low. The three key parameters of 'was the hospital the right place to die', and 'perceived care to patient and family' have got worse.

## Key learning:

1. Evidence of good care but polarised i.e. Mostly very good care but a significant minority rated care and communication as poor. Any result below 100 represents a patient or family under supported.
2. Recognition of the RISK of dying needs to be earlier. This can help allow preparation and increase the chances of patient involvement if they wish.
3. Communication, needs assessment and support (particularly for families): Promotion of involving patients and families in care and effective, proactive communication can be improved at both sites
4. Proactive patient involvement: Overall good care but Improvement needed in giving patients an opportunity for involvement in decisions earlier
5. Documentation and detail: Key areas for improvement include mental capacity assessment, nutrition/hydration discussions, potential for drowsiness from medication. Balance needed between burden of documentation and need to spend time with patient/family. of care plans at key sites noted
6. Overall good use of medication with improvement needed in discussion with relatives, writing indication on prescription and discussion of risks and benefits

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# NACEL 2023: Ipswich Hospital

50 Case note reviews (CNR), 54 quality surveys (QS), 23 staff reported measures. Boxes indicate local results. Red is >10% below national average or %score below 60%. Orange is above 60% but below national average or 70%. Hexagons represents composite scores from multiple parameters.

Communication with the dying person


Communication with families


Involvement in decision making


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Families experience of care


Staff reported measures


Workforce/Specialist Pall care


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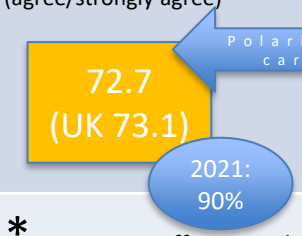


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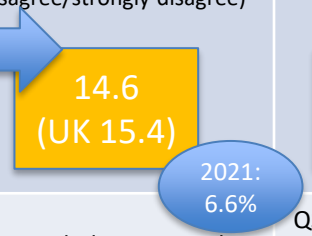


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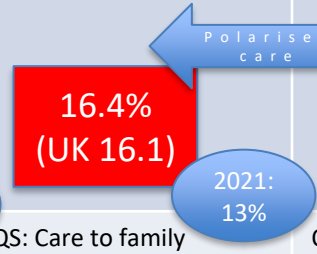


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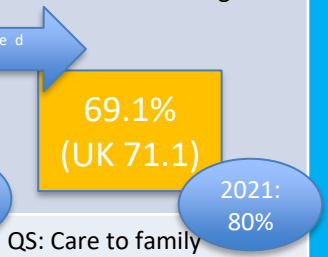


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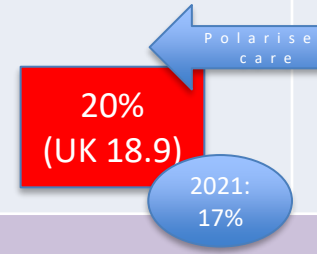


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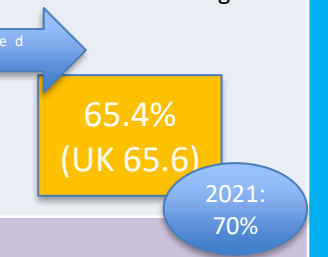


Data review:
The top 4 hexagons reflect documentation in notes and represent quantitative improvements in care with a tentative correlation between improved documentation and family perceptions of care but with further qualitative improvements needed.
The second row of hexagons indicate that many elements of care and support as perceived by family have improved but not enough. Despite these improvements the three key parameters of 'was the hospital the right place to die', and 'perceived care to patient and family' have got worse.
Ipswich Hospital Specialist Palliative Care Team now has substantive staff changes and 7 day a week working which will return the workforce score to its maximum of 10

## Key learning:

1. Evidence of good care but polarised i.e. Mostly very good care but a significant minority rated care and communication as poor. Any result below 100 represents a patient or family under supported.
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