

# Palliative and End of Life Care

Sheffield City Council Health subcommittee  
scrutiny panel

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25<sup>th</sup> January 2024



Agenda Item 9

# Part 1.

## South Yorkshire Integrated Care Board

### All Age Palliative and End of Life Strategy

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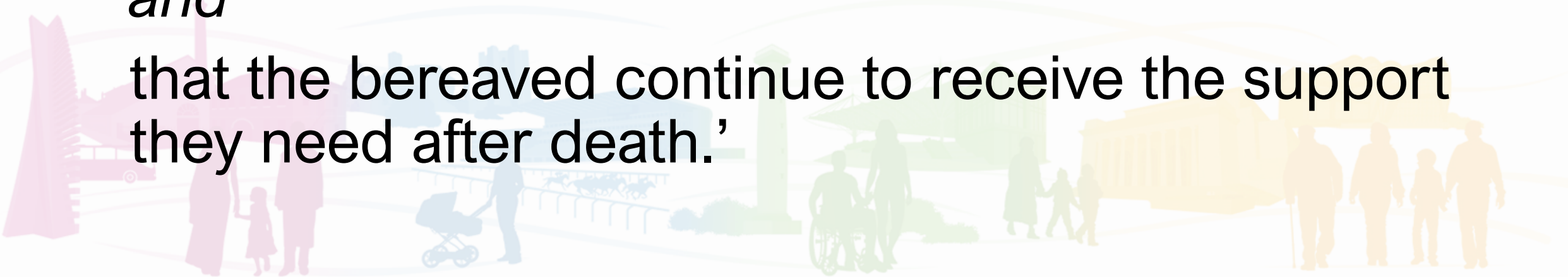


# Our vision

‘To ensure that the people of South Yorkshire living with life limiting illness experience the best possible care in the last years, months, and days of life

*and*

that the bereaved continue to receive the support they need after death.’





# Why do we need a strategy?

- Everyone should be able to access health and social care to support them with illness which can't be cured, and when they are nearing the end of life. This includes people of all ages – from 0 to 100+.
- We are hearing that many people have excellent experiences of care; however, some people have told us –
  - the system is difficult to navigate,
  - people were not identified early enough meaning they didn't have access to palliative care.
  - It's a system which in some areas has limited choice, where carers feel uninformed and are unsure where to turn to for guidance.
- We need a future proof system that can respond to changing patterns of illness, demographics, and financial constraints
- We need a system which addresses health inequalities, particularly around early identification of palliative care need, and equity of access.
- The ICB has a statutory duty to *'arrange for the provision of services or facilities for palliative care as the board considers are appropriate as part of the health service'*. The strategy will govern our work and inform how we decide our priorities.



# What is the role of the ICB?

- The ICB is there as a "system co-ordinator" to help services to communicate and collaborate. We gather information and track progress.
- We work with providers who are part of a person's journey through ill health and towards their eventual death: GPs, hospitals, ambulance service, pharmacies, hospices, care homes, social care, voluntary sector agencies.
- We hold providers to account through contracts, seeking to raise standards and to work through challenges.
- We support innovation (e.g. our recent work with partners to improve palliative care for homeless people).
- We source funding to develop new services.
- We organise education for health and care professionals.
- We uphold professional standards and seek opportunities for improvement.



# Healthwatch findings

People's experiences of palliative and end of life care

January 2024

## 6. Ideas to improve palliative & end of life care

We asked people 'Is there was anything else they would like to tell us about their experience, including what would improve palliative and end of life care?' Below is a summary of the actions people suggested.

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### Information

A guide to navigating health and social care for end of life care

- Knowing what support is available and how to access it – who to contact and when
- Understanding what to expect from the care you receive

### Coordination/joined up working

- Teams and professionals working together to coordinate care
- Being clear about which services are involved and who is doing what

### More community support

- Increase the amount of community care and address the gaps in care (e.g. care at night)

### Family involvement

- Open conversations with families when their relative is reaching end of life
- If someone is at end of life, families should be told with sufficient time for wider family members to travel there

### Follow up after diagnosis

- Ensure people follow up about...

are involved and who is doing what

### Advance Care Planning

- More consistently work with families and individuals on end of life plans
- Support greater knowledge and understanding of Advance Care Planning within community settings – including an emphasis on culturally appropriate conversations

### Communication

- Better communication with individuals and families
- Better communication between services

### Follow up after diagnosis

- Ensure people follow up/check in on people after an end of life diagnosis is given

### More palliative/end of life care knowledge in the wider workforce

- More specialist carers, but also better education for staff working on mainstream wards, or within the community

### More support for carers

- Greater support for family carers, enabling them to spend time for relatives without having to advocate for appropriate care





# Healthwatch findings

## 5. Cross cutting themes

Throughout the survey responses, the interviews and community conversations we have identified a number of cross cutting themes. These themes are ones which are repeated in relation to different services, and different aspects of care. They are shown below.

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<b>Access to services</b> 	Identification of serious health conditions and end of life diagnosis needs to be <b>timely</b> . Delays have negative impact on later care.	<b>Follow up</b> and proactive checking in on people is important but often doesn't happen	<b>Difficult to navigate care</b> – confusion around what is available, and lack of information and support to access it
<b>Information</b> 	<b>Support to understand</b> information is important. People need to understand their condition and the care they are being offered	<b>Information is not always in suitable formats</b> – eg for autistic people or dyslexic people	<b>Lack of information for carers</b> about how to navigate the system; what to expect, how best to care for their friend/relative
<b>Compassion and understanding</b> 	Importance of <b>sensitive communication</b> and appropriate language	<b>Traumatic experiences</b> of death have an ongoing impact on people's health and wellbeing after bereavement	<b>Treating people with compassion</b> is important, for instance by providing time and space for privacy

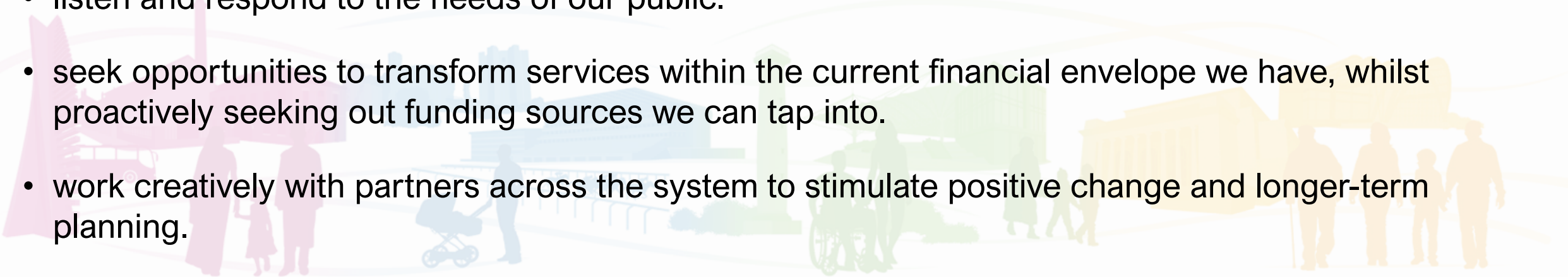
<b>Quality of care</b> 	<b>Praise for staff</b> – across the system we heard about staff who had delivered excellent care	<b>Care in the community</b> was generally preferred, and often described as better quality	<b>Services working together</b> – we heard examples where this did not go well, but also the difference this can make when it happens
<b>Equity</b> 	<b>Culturally appropriate care</b> is important but not always available	Some people, especially those facing other barriers to care, <b>don't know what services are available</b> , or how to access them	<b>Voluntary sector organisations</b> play a vital role in linking people to support and advocating for them
<b>Carers</b> 	Relatives and friends <b>help people access services</b> and equipment that they need	Relatives and friends <b>provide support where there are gaps</b> in services	Families and carers <b>need support themselves</b> – the biggest gaps are after bereavement





# Our principles

- build on the good work already happening across South Yorkshire
- build a palliative and end of life care system which reduces unwarranted variation in access and outcomes. e.g
  - conditions – cancer, dementia, respiratory, heart failure
  - communities – e.g. homeless, ethnic minority communities, learning disabilities
  - age – including for children and young adults
  - Geography – where people live and where they receive their care
- listen and respond to the needs of our public.
- seek opportunities to transform services within the current financial envelope we have, whilst proactively seeking out funding sources we can tap into.
- work creatively with partners across the system to stimulate positive change and longer-term planning.







# How? 6 Ambitions, 33 priorities, 1 action plan

01

## Each person is seen as an individual

*I, and the people important to me, have opportunities to have honest, informed and timely conversations and to know that I might die soon. I am asked what matters most to me. Those who care for me know that and work with me to do what's possible.*

02

## Each person gets fair access to care

*I live in a society where I get good end of life care regardless of who I am, where I live or the circumstances of my life.*

03

## Maximising comfort and wellbeing

*My care is regularly reviewed and every effort is made for me to have the support, care and treatment that might be needed to help me to be as comfortable and as free from distress as possible.*

04

## Care is coordinated

*I get the right help at the right time from the right people. I have a team around me who know my needs and my plans and work together to help me achieve them. I can always reach someone who will listen and respond at any time of the day or night.*

05

## All staff are prepared to care

*Wherever I am, health and care staff bring empathy, skills and expertise and give me competent, confident and compassionate care.*

06

## Each community is prepared to help

*I live in a community where everybody recognises that we all have a role to play in supporting each other in times of crisis and loss. People are ready, willing and confident to have conversations about living and dying well and to support each other in emotional and practical ways.*





# To achieve our vision our priorities include...

- Working with partners, primary care, acute trusts and hospices **to ensure delivery of good quality, personalised integrated community care.**
- **Minimum quality standards** of what people should expect
- Creating information for the public and professionals e.g. a **website** (one stop for useful information)
- Co-design our system
- Introducing new ways of **increasing early identification of palliative care** – moving from a SY average of 0.4% to 0.6%. E.g. SPICT, MDTs, IT solutions.
- Focus on **continued improvement in the quality of ReSPECT Plans** as we move on from roll out.
- **Introduce a clinical and professional reference group and communities of practice**
- **Development of a new model for children and young people**
- **Training and development plan**
- **Focus on projects to address health inequalities**
- *Timing and delivery are all dependent on funding streams becoming available.*



# What we want to achieve

- Improve early identification of palliative care to 0.6% of the practice list size
- Reduce unplanned hospital admissions for those in the last 90 days of life
- Reduce unnecessary hospital admissions and A&E attendances
- Offer training which increases confidence and knowledge
- Continue to hear and respond to improve experiences of PEOLC
- Increase the number of deaths happening in the community
- Increase the number of people with an advanced care plan
- Ensure that people receive good symptom control; physical comfort and emotional, psychological and spiritual support *in whatever setting they receive their care*



# Our plans

What we will do	The desired outcome
We adhere to the statutory duty and the national strategy.	The ICB partnership board is satisfied with the progression of the strategy action plan. Our place based steering groups report that their objectives are progressing / completed. We start to see measurable shifts e.g. in national audit scores, identification of palliative care need
Undertake a review of progress against the National Ambitions Framework.	Progress against the National Ambitions Framework has been made, as measured by each place-based partnership group. Progress achieved in repeat future benchmarking
<p>We will work with our patient and carer representatives to agree patient experience outcomes.</p> <p>Use our Healthwatch survey results from 2023 as a benchmark.</p>	<p>Improvements made in PEOLC satisfaction levels for all services rated '<i>satisfied or very satisfied</i>'.</p> <p>Improvements on our 'I' statements</p>
Look to review how the palliative and end of life care system is funded and work towards recurrent funding.	There is a dedicated PEOLC budget within the ICB.



<p>We will develop PEOLC quantitative outcome measures to monitor progress and introduce a data dashboard – using ONS data and local data.</p>	<p>0.6% of the practice population identified as palliative and added to the GP palliative care register (Baseline 0.4%)</p> <p>Similar to or better than the national average for the number of people admitted to hospital within the last 90 days of life.</p> <p>An increase in the number of people who have palliative care needs who have an advance care plan.</p> <p>Deaths in the community continue to increase towards and above 30%.</p> <p>Develop an intelligence system where we understand where people want to die, compared to where they die. Then increase those dying in the place where they want.</p>
<p>Have a workforce plan which ensures staff have increased knowledge and confidence in working with patients who are palliative and end of life care.</p>	<p>Feedback from training shows increased confidence and increased knowledge in palliative and end of life care.</p> <p>There is an active long-term plan in place to train, attract and retain specialist clinical expertise, including for children and young people.</p> <p>Provide training opportunities across general sectors in care at the End of Life.</p>
<p>Our strategy and services are co-designed with people who have experience of the system.</p>	<p>SY ICB PEOLC public engagement is completed regularly.</p> <p>Peer network is established and engaged.</p> <p>Increased number of peers working with us and being consulted.</p>



# Overview of next steps

January

Professional consultation ends

Action plan starts being populated

February

Strategy updated

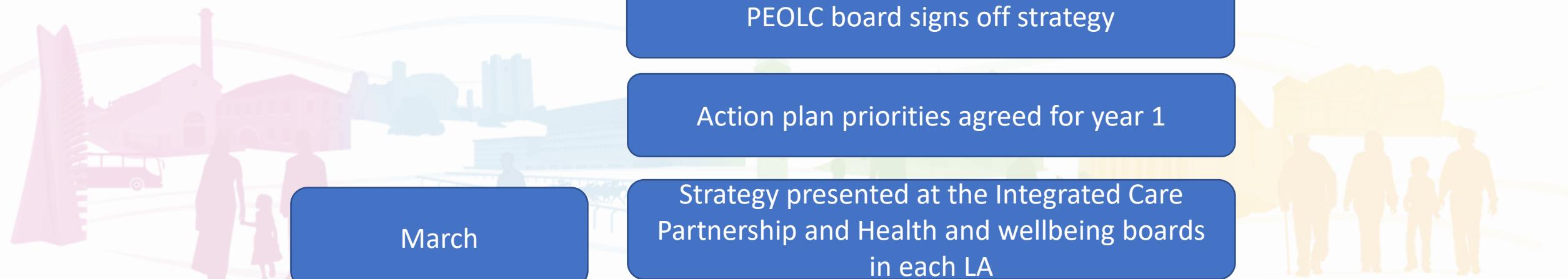
Public / easy read version created and shared

PEOLC board signs off strategy

Action plan priorities agreed for year 1

March

Strategy presented at the Integrated Care Partnership and Health and wellbeing boards in each LA





# Feedback and contact details

- Feedback via this [link](#) with any comments
- Have we got the emphasis right?
- Are our priorities correct?
- Have we missed anything?
- Is there anything we should remove, and why?

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- Final date for comments is 26<sup>th</sup> January 2024.

- [louise.potter7@nhs.net](mailto:louise.potter7@nhs.net) / [sarah.muir6@nhs.net](mailto:sarah.muir6@nhs.net)



# Part 2. ReSPECT

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## Recommended Summary Plan for Emergency Care & Treatment





- ReSPECT is a process that creates personalised recommendations for a person's clinical care in **emergency situations** in which they are not able to decide for themselves or communicate their wishes.
- Developed over 2 years by the Resus Council and service users
- Anyone may have a ReSPECT plan, increasing relevance for people with particular needs (LTC, EOLC, nearing end of life, or any other reason).
- ReSPECT plans include other recommendations as well as CPR. **Some patients may have a ReSPECT plan and be for resuscitation.**
- ReSPECT plans have **replaced** DNACPR forms in Sheffield from 2nd May 23. (not binding)

# Why replace DNACPR forms?



Often poorly discussed and not individualised

DNACPR was misunderstood as people thought **all other care** and attention was going to **be withheld too** - which wasn't true. This led to differences in care.

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CQC highlighted some issues with DNACPR including a blanket roll out in some areas during COVID-19

**Different form designs nationwide - no standardised way that DNACPR is recorded.**

RESPECT	DNACPR
Not legal	Not legal
Includes CPR recommendation (for and against)	Only has CPR recommendation (against)
Includes other medical recommendations	Does not include other medical recommendations
Includes what matters to the patient	No patient wishes/wants included



# ReSPECT aims to....

1

Put each individual at the centre of the conversation.

2

Achieve shared understanding between person and clinician.

3

Focus on treatments to be given, not just one to be withheld.

4

Record agreed clinical recommendations not just CPR recommendations.

5

Be recognised across all boundaries/healthcare organisations.

**ReSPECT** Recommended Summary Plan for Emergency Care and Treatment

**1. This plan belongs to:**

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

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: \_\_\_\_\_

**4. Clinical recommendations for emergency care and treatment**

Prioritise extending life  Balance extending life with comfort and valued outcomes  Prioritise comfort

clinician signature \_\_\_\_\_ clinician signature \_\_\_\_\_ 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: \_\_\_\_\_

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

Patient Details

Preferences for care

Clinical recommendations for care

Cardiopulmonary resuscitation decision

Person and their health

**5. Capacity for involvement in making this plan**

Does the person have capacity to participate in making recommendations on this plan?  Yes  No

If no, in what way does this person lack capacity? \_\_\_\_\_

If the person lacks capacity a ReSPECT conversation must take place with the family and/or legal welfare proxy.

**6. Involvement in making this plan**

The clinician(s) signing this plan is/are confirming that (select A,B or C, OR complete section D below):

A This person has the mental capacity to participate in making these recommendations. They have been fully involved in this plan.

B This person does not have the mental capacity, even with support, to participate in making these recommendations. Their past and present views, where ascertainable, have been taken into account. The plan has been made, where applicable, in consultation with their legal proxy, or where no proxy, with relevant family members/friends.

C This person is less than 18 years old (16 in Scotland) and (please select 1 or 2, and also 3 as applicable or explain in section D below):

1 They have sufficient maturity and understanding to participate in making this plan

2 They do not have sufficient maturity and understanding to participate in this plan. Their views, when known, have been taken into account.

3 Those holding parental responsibility have been fully involved in discussing and making this plan.

D If no other option has been selected, valid reasons must be stated here: (Document full explanation in the clinical record.)

**7. Clinicians' signatures**

Grade/speciality	Clinician name	GMC/NMC/HCPC no.	Signature	Date & time

Senior responsible clinician: \_\_\_\_\_

**8. Emergency contacts and those involved in discussing this plan**

Name (tick if involved in planning)	Role and relationship	Emergency contact no.	Signature
Primary emergency contact: <input type="checkbox"/>			optional
<input type="checkbox"/>			optional
<input type="checkbox"/>			optional
<input type="checkbox"/>			optional
<input type="checkbox"/>			optional

**9. Form reviewed (e.g. for change of care setting) and remains relevant**

Review date	Grade/speciality	Clinician name	GMC/NMC/HCPC No.	Signature

If this page is on a separate sheet from the first page: Name: \_\_\_\_\_ DoB: \_\_\_\_\_ ID number: \_\_\_\_\_

www.respectprocess.org.uk

Mental capacity

Clinician details

Emergency contacts & those involved in completing a plan

Review details

ReSPECT ReSPECT ReSPECT ReSPECT ReSPECT ReSPECT ReSPECT ReSPECT ReSPECT ReSPECT

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# ReSPECT in Sheffield



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Including local areas: South Yorkshire, Derbyshire, Leeds. 80% of UK counties have now adopted ReSPECT

# Training and Engagement



## Pre-Launch

- Patient first panel
- HCP public forum
- Healthwatch & VAS



## Post-Launch

- Mandatory training
- Tailored information packs
- GP information sessions – group & individual practices
- ECHO programme for care home staff
- Regional ECHO for clinicians
- Public & VCSE engagement: Carers Roadshow, Information sessions, Social prescribing link worker sessions

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- Organisational steering/operational groups, presentations across Sheffield

## GP Locality engagement

- Comms toolkits, and count down comms – Raising awareness
- YAS engagement in person session

## Ongoing: Delivery Group & Audit Group

# Where can I find more information?

- [Sheffield Citywide website](#)

with resources (HCP) (FAQs, guides/top tips, example plans, patient leaflets, and the citywide policy)

- [National Resus Council ReSPECT website](#)

## Joe's Journey :

Watch here [Joe's ReSPECT journey – a ReSPECT explainer for people and their families - YouTube](#)



**ReSPECT Training**

**TIER 1: BASIC AWARENESS**  
This is aimed at all health and social care staff, including admin and clerical staff.

Read Training Resource Leaflet 1 and watch 'Joe's ReSPECT Journey' video.

Sheffield HCP  
Health and Care Partnership

**TIER 2: AWARENESS AND HANDLING EMERGENCIES**  
This is aimed at staff who are directly caring for patients and any healthcare professional in regular contact with patients who may benefit from a ReSPECT plan.

Option 1 - Complete 'What is ReSPECT' module provided by the national ReSPECT e-learning tool.

Option 2 - Complete 'ReSPECT awareness' module by the E-LFH training portal.

ReSPECT elfh  
elearning for healthcare

**TIER 3: AUTHORSHIP FOR CONDUCTING ReSPECT CONVERSATIONS**  
This is aimed at staff who will be carrying out the ReSPECT conversation and completing the plan.

Option 1 - Complete all modules on the national ReSPECT e-learning tool.

Option 2 - Complete both 'ReSPECT awareness' and 'ReSPECT authorship' modules provided by the E-LFH training portal.

ReSPECT elfh  
elearning for healthcare



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# Part 3. Specialist bereavement services







# Background

- 2021 bereavement strategy published and signed off by the MH partnership board
- Strategy identified gaps in provision that were addressed by commissioning the following
  - T2 (short-term bereavement interventions)
  - T3 (counselling) specialist bereavement services
  - Brief intervention bereavement training; to address those affected by bereavement following a COVID death.
- Cruse, Mind and Faithstar / Divercity commissioned, Education for professionals provided by St Luke's and Mind.
- Joint commissioning between Sheffield CCG (and then ICB) and SCC. Services end March 2023, May 2023 and September 2024.
- No previous funding from NHS or SCC.
- No budget for 2024/25 in NHS/ ICB or SCC
- New statutory duty in relation to palliative care; with NHSE guidance recommending this includes specialist health interventions for bereavement.





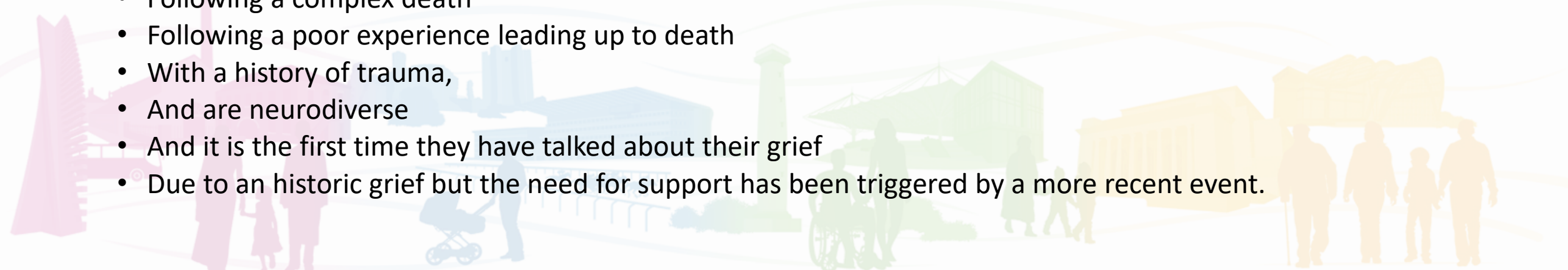
# What we know and what we have learned (1)

- Around 10% of all those affected by bereavement each year (est. 4,900) will have their health affected by bereavement and may benefit from specialist bereavement support.
- Over 2,500 adults, children and young people have benefited from the services commissioned in the two years.
- 90% have good outcomes. Case studies and feedback are overwhelmingly positive. Most negatives are in relation to waiting times and / or limitations about provision available e.g. 6, 9 weeks of support.

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We have identified a continued need for these services.

- Those who need counselling / specialist services often present ...
  - Following multiple deaths
  - Following a complex death
  - Following a poor experience leading up to death
  - With a history of trauma,
  - And are neurodiverse
  - And it is the first time they have talked about their grief
  - Due to an historic grief but the need for support has been triggered by a more recent event.





# What we know and what we have learned (2)

- The funding has helped reduce waiting times at Cruse from 2 years to around 6 months. Through the Clouds (Mind) and Here to hear were new services. Mind's list is growing.
  - The services have developed and responded to the needs of the people e.g. Mind offered 6 sessions originally, this was extended to 9 sessions.
  - Here to hear offer an ethnic minority and faith-based approach. Offered in a range of languages. For some is the first time they have talked about their grief.
- Many costs benefit to funding:
- bereavement support can reduce the use of health care services, e.g Gp appointments c. £36.





# Research shows us...

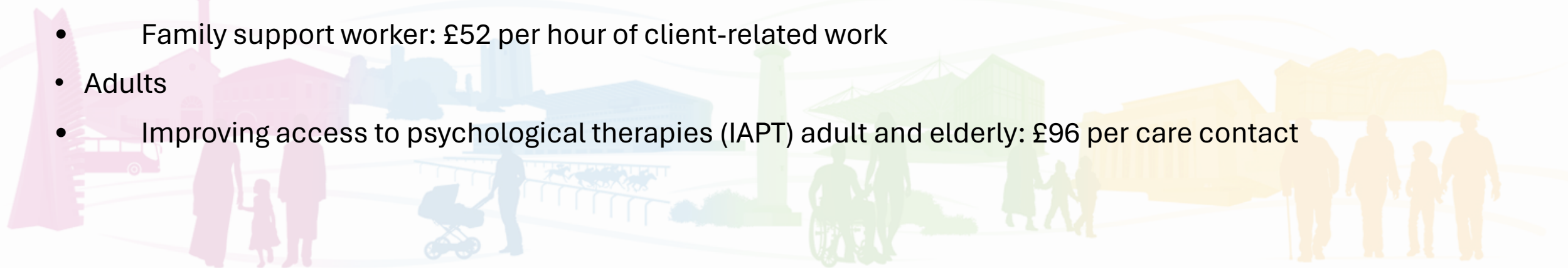
- Bereaved people make greater use of healthcare services (Stroebe et al, 2007) including GP services, mental health services, acute and psychiatric hospitals, and consumption of medicines.
- These increases begin before the death, spike immediately after it, and may last for months or years. Some services are used twice as much in the year following the death (Guldin et al, 2012)
- Organised bereavement support can reduce the use of health care services, including GP consultations (Relf, 2000)

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Unit costs of health and social care, 2016-17 (Curtis and Burns, 2016) e.g

All ages

- GP consultation of 9.22 minutes: £36
- Social worker (adult or children's services): £79 per hour of client-related work
- Family support worker: £52 per hour of client-related work
- Adults
- Improving access to psychological therapies (IAPT) adult and elderly: £96 per care contact





# Challenge and next steps

- Challenges...to secure funding to continue with specialist bereavement support.
- Paper to the ICB Sheffield Place executive team in March
- Paper to the Health Care Partnership in April
- Charitable funding opportunities are also being explored.



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