Welcome to together for short lives

UCL GREAT ORMOND STREET INSTITUTE OF CHILD HEALTH
Great Ormond Street Hospital for Children NHS Foundation Trust
LDC Louis Dundas Centre for Children's Palliative Care

Great Ormond Street Hospital for Children NHS
NHS Foundation Trust

Being present when a child is dying :

Teaching the unteachable?

Tara Kerr-Elliott
RN, NIHR Clinical Fellow

Why are we here?

“CPC has come of age…2022 will mark 40 years since the birth of our specialty. But in many ways we are still in our adolescence, with much to learn and a mountain to climb…

The CPC sector is home to many talented , dedicated and specialist professionals…but these professionals face a number of challenges…”

- Increasing demand
- Increasing complexity
- Changing political landscape and funding challenges – stretched services
- Opportunities to share and learn from each other are often limited

TfSL (2022)

Disclaimers….

Not very academic!

Largely based on experiences and reflections

Likely to lead to more questions than answers….

Recognition of expertise in the room…

All staff are prepared to care…

…and care includes

communication, symptom management, complex medical needs, supporting and facilitating decision making, understanding ethics, social and psychological care, conflict resolution, memory making, support for the whole family, end of life care, bereavement support

“WHAT IS PALLIATIVE CARE?”

Is there a tension here?

“It’s not all about death and dying”

But it includes death and dying…

Presence

“Spending time together without any rush”
(Farkas, 2017)

Being with rather than doing to/for

Using the senses

Being attentive to verbal & nonverbal cues

Showing compassion by **“sitting with the pain”** (Walker & Waterworth 2017)

"I've learned that people will forget what you said, people will forget what you did, but people will never forget how you made them feel."
Dr Maya Angelou

Barriers

- It costs us
- Time and space
- Lacking in confidence / feeling unprepared – fear of getting it wrong or offending
- Not knowing how to react or respond to the answers of questions we might ask
- Hoping someone else will do it!
- Lack of understanding of what it is or it’s importance
- Higher priority tasks
- Just too difficult……

But how might these feelings be expressed?

HOW DID YOU LEARN END OF LIFE CARE?

But how do we prepare and teach…

- That we can’t fix everything.
- Communication skills – to talk about dying
- To facilitate difficult decision making
- How to be brave enough to ask “what’s important to you?” and **to really listen**.
- About spiritual pain and spiritual care?
- About managing feelings associated with death? With distress? With discomfort?
- About hope?
- Resilience and recovery?
- Self-awareness – own beliefs about death and dying

Historical perspective

- Children have always died
- Unseen work
- Rarely documented
- Reducing death rates and changes in society
- Less exposure

A bit of theory

Learning in the affective domain – the way individuals respond emotionally or the way in which they act (Bloom's taxonomy)

Impact of our own attitudes to death and dying on the work we do …. And vice versa so need for increased self-awareness

Transformative Learning – experiential - disorienting dilemma – use of critical reflection

Use of simulation – good evidence base

Sharing experiences

Challenges

- Linguistic barriers?

“well-being”, “psychological support”, “looking after yourself” , “reflective practice”….often poor engagement

- Space / online?
- Time
- Changing team cultures

Successes

- BACK TO BASICS
- SIMULATION
- **Study** days (“these should be mandatory twice a year to improve morale”)
- Interdisciplinary faculty
- Use of videos/ documentary clips
- Schwartz rounds
- Webinars – role modelling
- Virtual works!

EDUCATION OR SUPPORT?

- Knowledge, information, understanding
- Validation
- Peer support
- Time to talk
- Setting expectations
- Self-care
- Schwartz rounds
- Supervision
- Realising value – taking pride
- Self-awareness
- Role modelling and leadership
- Like minded people
- Spotting red flags

Suggestions for future planning:

1. Include Transformative learning – use of simulation
2. Encourage greater self-awareness
3. Promote psychological safety
4. Consider affective domain of learning
5. Include interdisciplinary approaches
6. Plan for sustainable, flexible and dynamic training.
7. Back to basics

I cannot teach anyone anything.
I can only make them think.

(Socrates)

Thank you for listening.

@KerrElliott

Great Ormond Street NHS
Hospital for Children
NHS Foundation Trust

Coventry University

UNIVERSITY OF BIRMINGHAM

IMPROVING COMMUNICATION WITH PARENTS OR CARERS WHO HAVE LOST A CHILD

Prof. Jeannette Littlemore and Dr Sarah Turner

on behalf of the research team

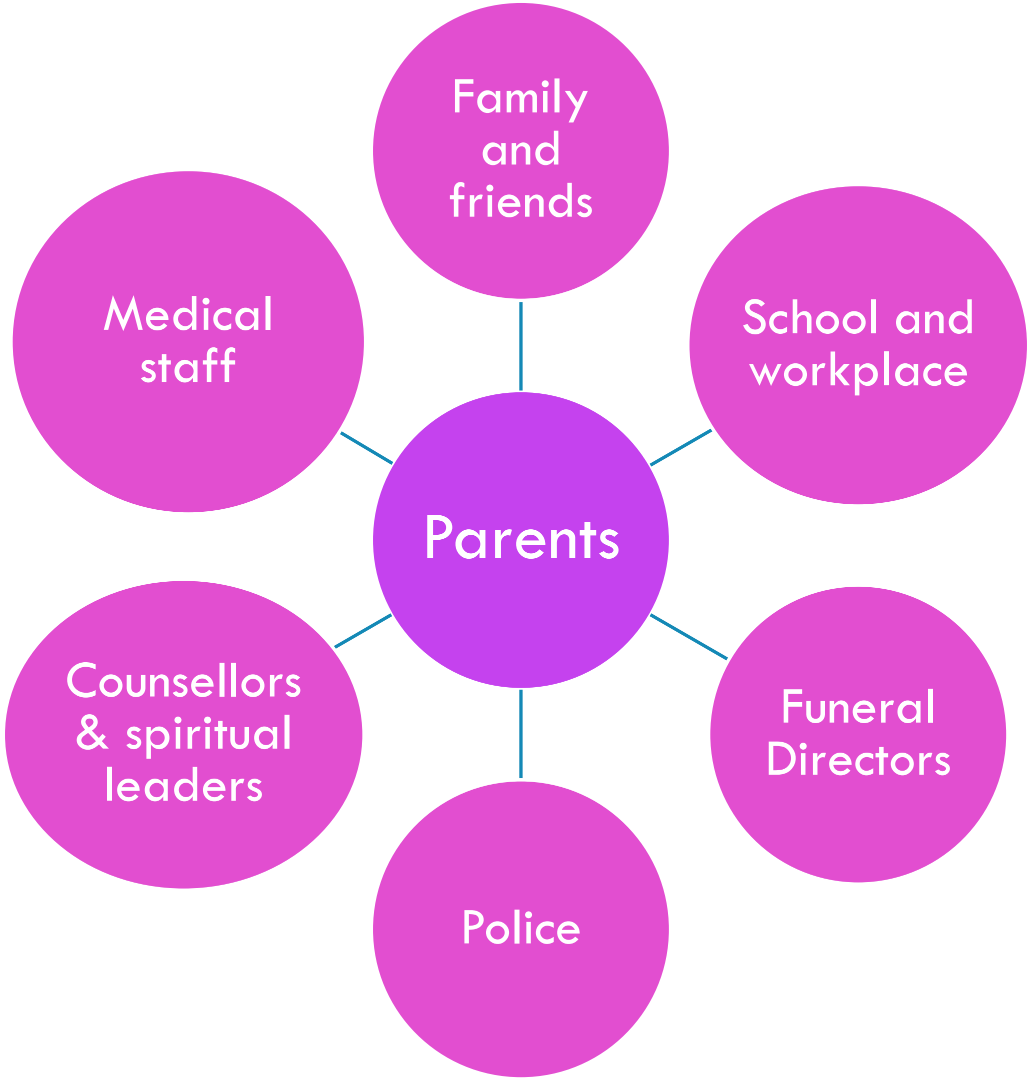
Jeannette Littlemore, Sarah Turner, Eloise Parr
Julie Taylor and Annie Topping

The True Colours Trust

INTRODUCTION – THE POWER OF COMMUNICATION

"Years later, **I can remember every word.** I can even remember his tone of voice as he said it. Absolutely **etched with acid into my brain**"

WHO IS INVOLVED?



Parents

Family and friends

School and workplace

Funeral Directors

Police

Counsellors & spiritual leaders

Medical staff

RESEARCH QUESTIONS

1. How is the loss of a child experienced?
2. What do parents/carers recollect of their communication with healthcare professionals, registrars and funeral professionals?
3. What aspects of this communication do parents perceive to be effective and ineffective?

>>>> How is language used?

PARTICIPANTS AND METHODOLOGY

- 21 interviews with 24 parents who had lost a child
- Children aged 17 days – 28 years
- Deaths occurred between 1980 and 2019

OUR PRESENTATION

We hope our presentation will give you:

1. A clearer understanding of how the death of a child is experienced by parents;
2. An insight into the important role played by healthcare and healthcare-related professionals in helping parents to manage their grief;
3. Ideas for how to provide empathetic and supportive care and communication, which reflect the unique challenges presented by the death of a child.

OUR FINDINGS

Two themes:

1. How is the death of a child experienced?
   - Altered relationship to time, space and the outside world;
   - Continued parental identity and relationship with child;
2. Empathy and small acts of kindness

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HOW IS THE DEATH OF A CHILD EXPERIENCED?

- Altered relationship to time, space and the outside world
- Continued parental identity and relationship with child

“It's the empathy. It's trying to get into our shoes to try and understand the situation, and then work around that”

ALTERED RELATIONSHIP TO SPACE, TIME AND THE OUTSIDE WORLD

- Many parents we spoke to reported feeling disoriented and 'out-of-sync' following the death of their child.
- A sense of extreme and sudden loss can leave people feeling detached and fragmented, as through the world is continuing without them.

> "We felt like we were thrown from this one universe of wonderful normality… just forcibly thrown out into this awful universe of just misery and pointlessness"

> "When you lose a child, it's like part of you has gone. You can't find it again but you just keep pouring stuff in trying to fill it up… but nothing ever fills it up really"

> "We just wanted to hide. Literally had this sense of I wanna get a cave, I don't wanna see the world, I don't wanna engage with anybody or anything"

THE IMPORTANCE OF TIME

- Many parents do not feel that they are in a sound state of mind from which to make decisions following the death of a child
- By giving parents clear guidance as to the options available and lots of time to reflect, professionals can support parents with these decisions.

“Timing seems to be really important, like giving you time and space … And not hitting you with a whole load of stuff at once. … And realising we might change our minds at times. … We can’t always be ‘logical’. Your mind is just messed up”

“We were allocated a bereavement worker from the hospital. I remember he was very kind, I remember he was very directive, which is kind of what we needed… took kind of charge I think in terms of getting mementoes because we’d never have thought of those things, and then we’d have probably really regretted not having them, so I think we did need that bit of direction in those few days.”

CONTINUED PARENTAL IDENTITY AND RELATIONSHIP WITH THE CHILD

- Parents also expressed a desire to continue enacting their identities as parents after their child's passing
- Parents are often left feeling a strong and sustained bond with their deceased child.
- Many appreciate opportunities to express this bond by talking about their children and celebrating their unique identity.
- It is important that professionals are sensitive to the enduring relationship between parent and child following a child's passing.
- Many parents are concerned that, following their child's death, their identity and personhood is respected and that the body is treated with care.

"Even though you know by then it's just your child's body, you still don't want your child to be alone"

"I just wanted to show her the house, even though we weren't showing her the house because she'd died, but yeah, that felt important to me"

RESPECTING THE CONTINUING IDENTITY OF THE CHILD

“[The nurses] would tell us what they were doing [...] ‘We’re just gonna do this, gonna clean NAME’s mouth so she feels nice and comfortable’ and they would tell us what they were doing. And ‘We’re just gonna give her a little wash and freshen up’ or whatever.”

OUR FINDINGS

Two themes:

1. How is the death of a child experienced?
    - Altered relationship to time, space and the outside world;
    - Continued parental identity and relationship with child;
2. Empathy and small acts of kindness

EMPATHY AND SMALL ACTS OF KINDNESS

"[The consultant] came along to tell us what was going on. And I can actually remember his words, exactly word for word all these years later and what he said is, 'NAME won't survive without a liver transplant, NAME won't survive an operation, so NAME probably won't survive' and he cleared off. He didn't say to us, 'What do you understand? What do you think is going on?', any of that. And he just went."

EMPATHY AND SMALL ACTS OF KINDNESS

"[The counsellor] was textbook and it's so frustrating dealing with people who have not gone through what you have gone through. They've learnt lots of stuff from books and think they know how you should feel. [...] You felt like he was almost lecturing to you and it was utterly pointless… We've had more benefit by talking to other parents who've lost children."

"One of the sessions [the counsellor] went, 'You know, we're concerned about you cos you're raising very high on the suicidal thing' and I was like, 'I'm not suicidal, okay? The last thing I wanna do is leave my wife and ... new baby'. So I just said, 'Look, you haven't listened to a word I've said. All you've taken down is these stupid scores on your piece of paper and you've not put any context into what I've said'."

EMPATHY AND SMALL ACTS OF KINDNESS

"[The funeral director] was a parent of a 17 year old at that point and so he absolutely, he found it hard and the second visit we had with them, he said 'I went home and I cried and I held on to my daughter and I cried for you and for NAME' and knowing that the funeral director absolutely was human and cried for us and for NAME, that was really comforting."

EMPATHY AND SMALL ACTS OF KINDNESS

One parent strongly appreciated the fact that the funeral director had asked about the personality of her two-month-old baby:

> “What he was like, his little things that he did. You know, which is hard when they’re only two months old, but it was still nice that somebody recognised him as a person, as his own person”

EMPATHY AND SMALL ACTS OF KINDNESS

“I was in such a fragile hurt state, that any small act of kindness would have made a massive difference”

- Many of the parents we spoke to still remember small moments of empathy and kindness demonstrated by professionals.
- Often these involved small recognitions of the child’s enduring identity and personhood:
- These moments of recognition let parents know that they are cared for and supported and help to relieve feelings of isolation.

“It was still nice that somebody recognised him as a person, as his own person”

CONCLUSION

> “We used to say to professionals, ‘It’s really worth your while … you are doing good by shining a light in the dark for people”

- The quality of the care and communication received following the death of a child has a significant impact on parents’ experiences.
- Effective communication is that which takes into account the unique nature of the loss, and honours the individual identities of the child and parents.
- Effective communication encompasses both words and actions.

REFERENCES

Open access Original research

BMJ Open

Metaphors that shape parents' perceptions of effective communication with healthcare practitioners following child death: a qualitative UK study

Sarah Turner [1] Jeannette Littlemore [2] Julie Taylor [3,4] Eloise Parr,[5]
A E Topping[3,6]

MORTALITY
https://doi.org/10.1080/13576275.2022.2081495

Routledge
Taylor & Francis Group

OPEN ACCESS Check for updates

'Lights in the darkness', part 1: characterising effective communication with healthcare practitioners following the death of a child

Sarah Turner[a], Jeannette Littlemore[b], Eloise Parr[b], Julie Taylor[c]
and Annie Topping[c]

[a]School of Humanities, Faculty of Arts and Humanities, Coventry University, Coventry, UK; [b]Department of English Language and Linguistics, University of Birmingham, Birmingham, UK; [c]School of Nursing, University of Birmingham, Birmingham, UK

MORTALITY
https://doi.org/10.1080/13576275.2022.2081496

Routledge
Taylor & Francis Group

OPEN ACCESS Check for updates

'Lights in the darkness', part 2: characterising effective communication with professional groups following the death of a child

Sarah Turner[a], Jeannette Littlemore[b], Eloise Parr[b], Julie Taylor[c]
and Annie Topping[c]

[a]School of Humanities, Faculty of Arts and Humanities, Coventry University, Coventry, UK; [b]Department of English Language and Linguistics, University of Birmingham, Birmingham, UK; [c]School of Nursing, University of Birmingham, Birmingham, UK

Family support Hub

Our Support Hub is there for anybody caring for a child with a serious illness. The support we offer includes:

Helpline and live chat

We offer confidential emotional support and information on a range of issues, so that families can spend less time searching for help and more precious time together as a family. Open Monday - Friday, 9am-4pm.

☎ **0808 8088 100**

✉ **helpline@togetherforshortlives.org.uk**

togetherforshortlives.org.uk

Voices for Families: expert legal advice when it matters

Somebody caring for a child with a serious illness could benefit from free expert legal advice, they can reach out to our helpline: 0808 8088 100

Online support group

Our Facebook group is a supportive community that allows families caring for a seriously ill child to connect, share and support one another.

They can join the group here:
togetherforshortlives.org.uk/familyfacebook

Or scan the QR code:

/togetherforshortlives @togetherforshortlives @Tog4ShortLives #TFSLConference

Welcome to together for short lives

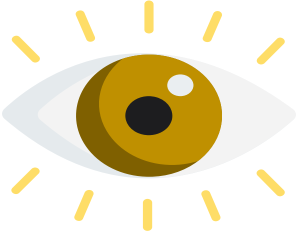
PLENARY SESSION

WHO WE ARE

On Road Media is a charity using communications to change the world. We work with people and

HOW WE WORK

We condense and apply learnings from **research** on how to **shift public perceptions**.



We look at how these narratives play out in **media and public discourse**.

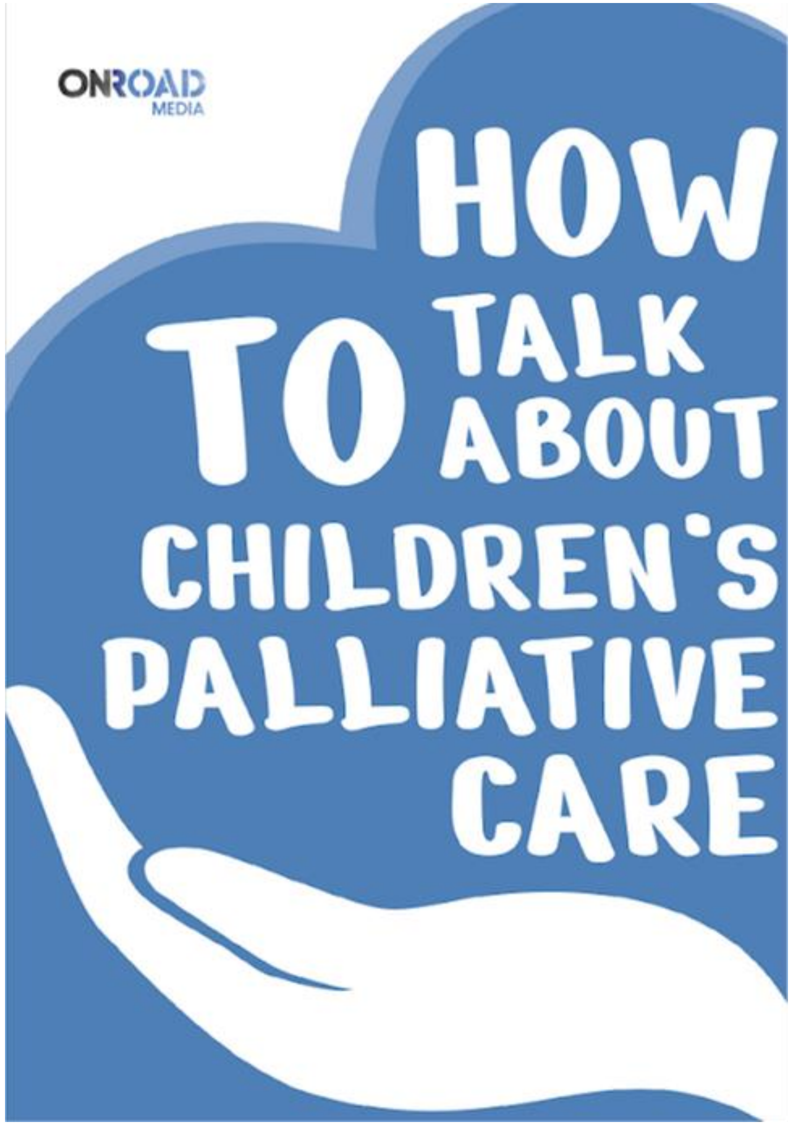
We support **people with direct experience** and connect them with the media.

We can help you move the conversation around children’s palliative care forward to deepen public understanding and improve support.

OUR RESOURCE

With the support of the True Colours Trust
we’ve produced a friendly
Communications Toolkit
with actionable recommendations.

It helps communicators from the sector talk about children’s palliative care in a way that opens up conversations.



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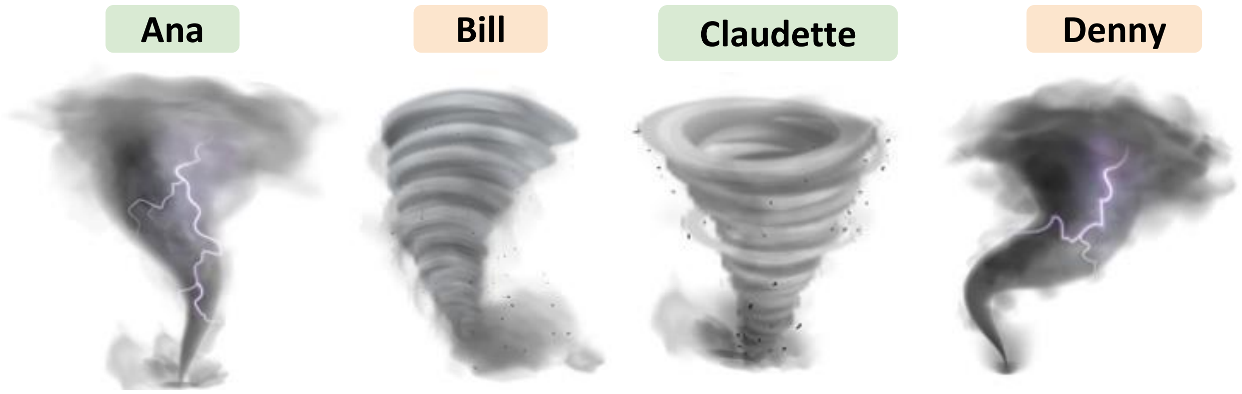
HOW TO TALK ABOUT CHILDREN'S PALLIATIVE CARE

WORDS WE USE HAVE AN IMPACT



What is the impact of naming hurricanes this way?

Researchers found that **female named hurricanes were 3x deadlier than male named hurricanes**

WHY?

~~The higher speeds?~~

~~The warning times?~~

~~Something else?~~

The subconscious reaction to female names meant people didn't take it seriously.

They didn't evacuate.

We think in story…

«Humans cannot spend a moment of their waking life without making inferences. They can spend hours or even days without ever engaging in reasoning.»

Hugo Mercier and Dan Sperber, The Enigma of Reason

OUR RESEARCH QUESTION

What are the stories people think in when they hear the term Children’s Palliative Care?

PEOPLE'S GUT REACTIONS

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THE ISSUE: INACCURATE PERCEPTIONS

1. **Tragedy and finality**

   e.g. *'easing of suffering', sad last medical resort*

1. **Conflict**

   e.g. *families and doctors pitted against each other, moral/legal battle, heroes vs. villains*

1. **The Bubble**

   e.g. *family's isolated, 'far away'*

1. **Money**

   e.g. *quality of care depends on money, cutting costs*

These assumptions are activated by what we hear, read and see in the news.

Alfie Evans has been in a coma for eight months with a mystery illness (Image: Evans family / SWNS.com)

Charlie Gard's mum helping devastated family of terminally ill boy who doctors say should be "allowed to die"

Alfie Evans has been in a coma for eight months with a mystery illness experts suspect is a mitochondrial condition - the same as Charlie

By **SARAH LUMLEY**
17:51, 24 Aug 2017 | **UPDATED 19:43, 24 Aug 2017**

EXPLORING A NEW STORY

After being exposed to new perspectives and case studies, the research participants' perception of Children's Palliative Care tangibly shifted.

The most affecting themes that helped **broaden their thinking:**

CENTRING THE CHILD

TEAMWOR
K

ALL- ENCOMPASSING
CARE

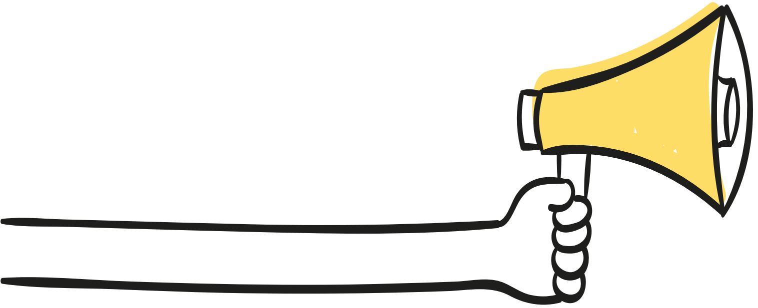
PEOPLE'S PERCEPTIONS AFTER EXPLORING CPC

…so we need to frame carefully.

Framing:

Making intentional choices about how we present information and ideas:

- ➔ What we lead with
- ➔ What we emphasise
- ➔ What we leave unsaid

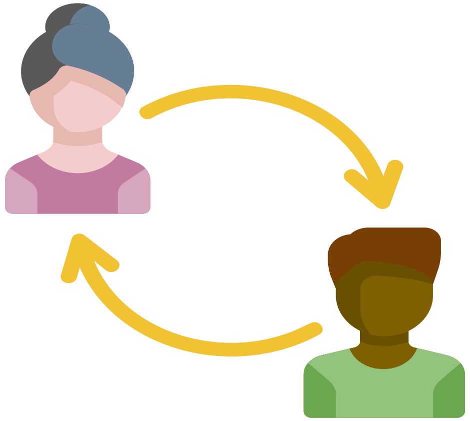


HOW DO WE SHIFT THE CONVERSATION?

We all have a **psychological immune system**:

We put up barriers to **protect ourselves** from things we're scared to face.

We do this **automatically**.



We need to overcome these barriers by inviting people in with our communication and help them relate to the topic.

EFFECTIVELY ADDRESSING MISPERCEPTIONS

Communications scientists have developed a formula for ‘making the truth stick and the lies fade’

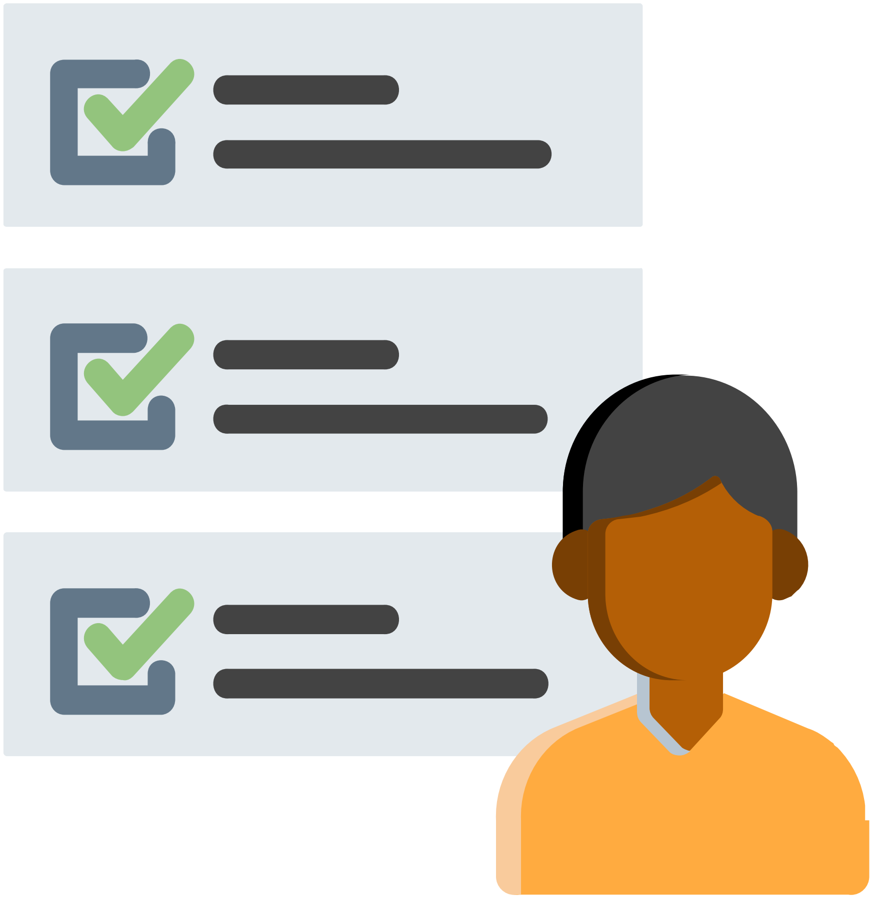
- Lead with **correct information**, not falsehoods
- Be **vivid** and **memorable** when telling the truth
- Make truthful messages **easy to process**: crystal clear and jargon free
- Recognise that people process information by looking for what they **already ‘know’**

By reminding people of their inaccurate assumptions **we risk strengthening existing beliefs,** even if we’re trying to challenge them.

Making The Truth Stick and The Lies Fade: Lessons from Cognitive Psychology

So we need to lead with a new story…

…and we need to keep repeating it.



OUR 3 FRAMING RECOMMENDATIONS

1. Show how children's palliative care is at its best

2. Show how children get to be children

3. Focus on the quality and range of relationships that make for great care

1. Show how children's palliative care is at its best

This means leading with positive, real accounts of how children's palliative care **can and should be**.

EXAMPLE:

"It's comprehensive, ongoing care that promotes the best possible quality of life and support for children and their whole family."

3 REASONS WHY IT'S IMPORTANT

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1 **To** shine a light on the aspects of children's palliative care that people don't see

2 **To** help people feel the value of the services without activating feelings of fatalism

3 **To establish** with positive, real accounts how children's palliative care can and should be

- ➔ Lucy Watts' TedTalk: [One sentence that transformed my life] (particularly 7:56 - 8:55)

2. Show how children get to be children

Show the **everyday moments and experiences** that children's palliative care affords children and families.

EXAMPLE:

"Children who are very unwell need the same things all children need. Things like friendship, fun, laughter, downtime, fun treats and activities that help them discover the world through all five senses."

3 REASONS WHY IT'S IMPORTANT

1 To show the everyday experiences children's palliative care affords

2 **To** show that this is not about 'other' children who are fundamentally different

3 **To help** people connect with universal human experiences


Remove Pin
Claire Matson

3. Focus on the quality and range of relationships that make for great care

We need to show how children, families and a range of professionals - often from different medical teams - **work together to get the care right**.

EXAMPLE:

“Strong, consistent relationships are key to providing the best care. Dedicated people work in partnership not only to make sure children are comfortable, but to give vital support to families facing very tough circumstances.”

3 REASONS WHY IT'S IMPORTANT

1 To counter with high-profile media stories often centre conflict or individual heroism

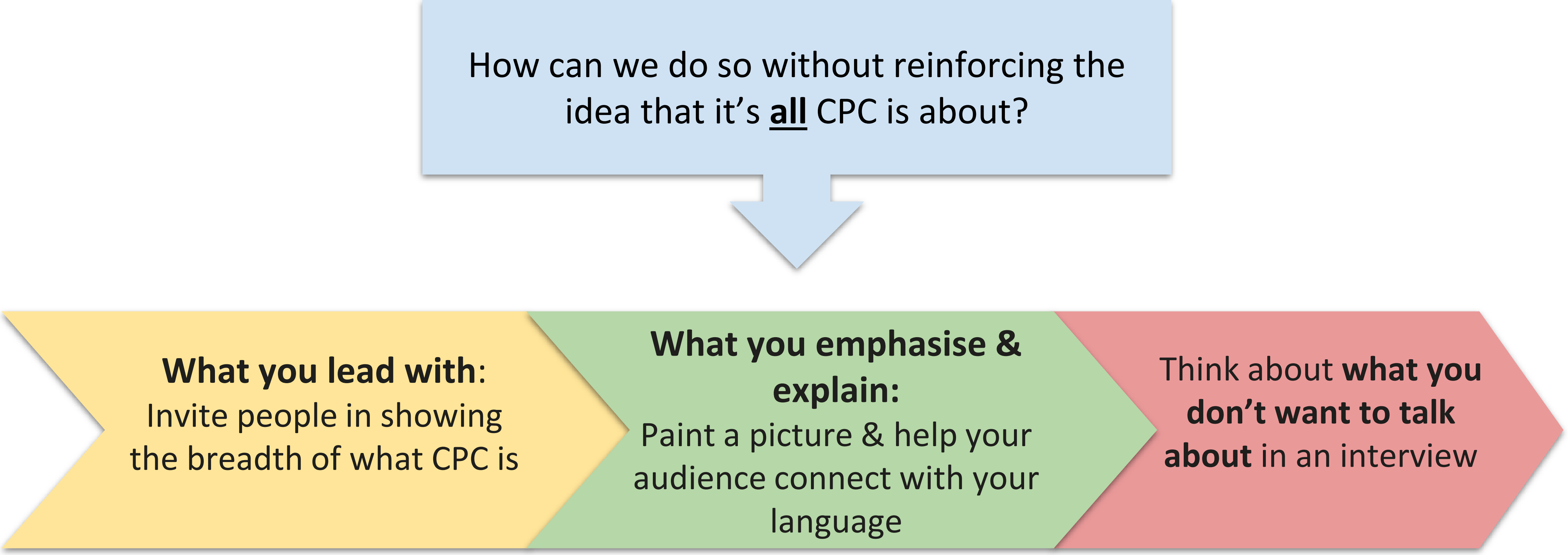
2 **To** highlight the rich professional partnerships that make for the best care experiences

3 **To** build a sense of involvement through depictions of shared experiences


ShowMore
Julie Kembrey she her

TALKING ABOUT DEATH

End-of-life care is a key part of children’s palliative care - and it’s necessary to talk about this aspect of the support

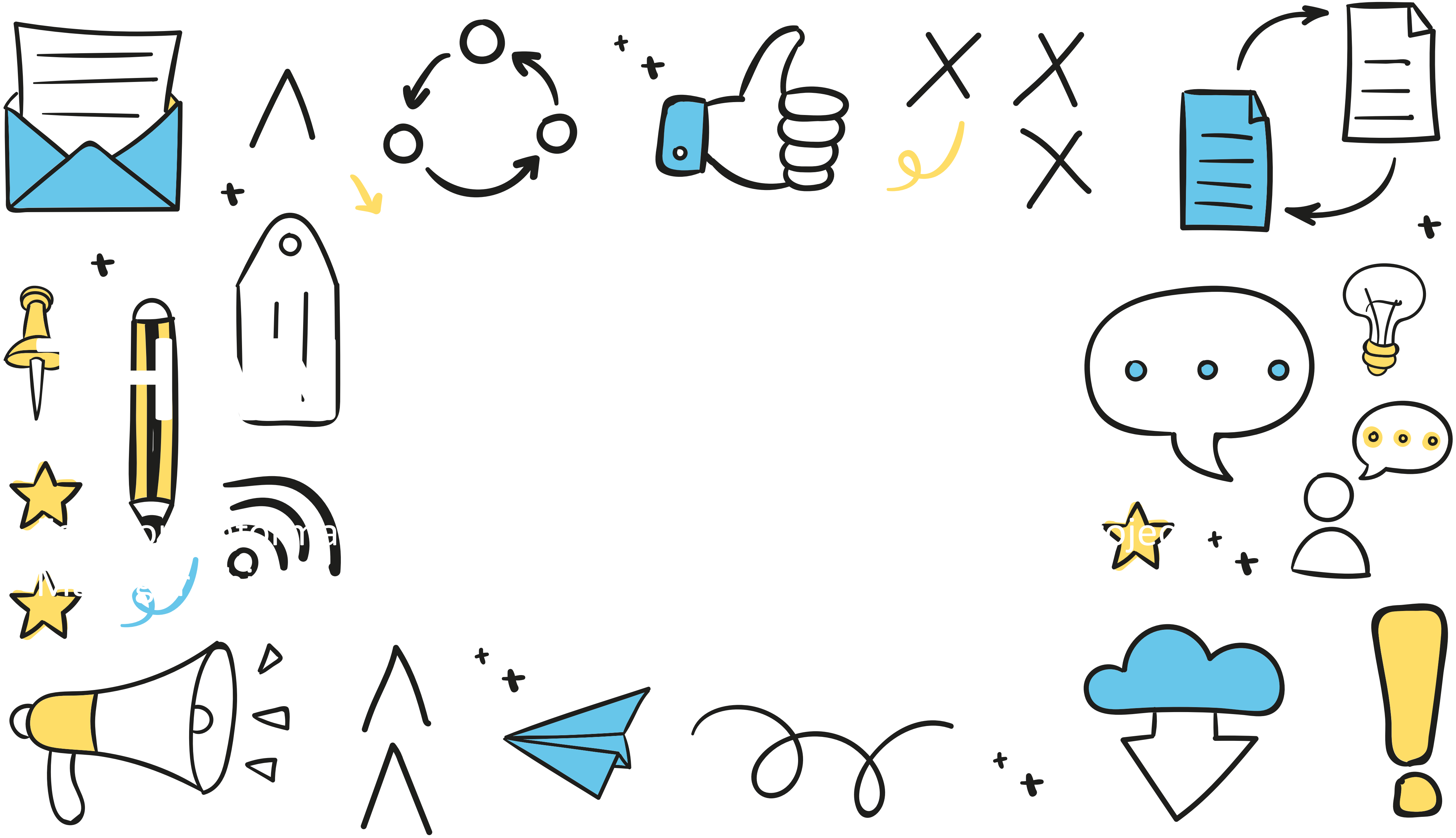


How can we do so without reinforcing the idea that it’s **all** CPC is about?

What you lead with: Invite people in showing the breadth of what CPC is

What you emphasise & explain: Paint a picture & help your audience connect with your language

Think about **what you don’t want to talk about** in an interview



02

Tools and tips to engage with the media safely and with agency

Better Stories:

How to support people with first-hand experience to do great media interviews

ONROAD
MEDIA

ROADMAP

11 - 11.10am	**Introduction and check-in**
11.10 - 11.30am	**Tools and tips to do media work safely**
11.30 - 12pm	**Panel discussion with guest journalists**
12 - 12.15pm	**Q&A with journalists**

AIMS OF THE SESSION

➔ To gain practical tools and tips on how to do media work in a safe and boundaried way

➔ To gain more confidence in engaging with media professionals on your own terms

➔ To have a better understanding of how the media works

➔ To meet and connect with experienced journalists

OUR GUEST JOURNALISTS

K Biswas (Biz)

Freelance journalist and critic.
Founder of The Race Beat. Director of Resonance.

Aasma Day

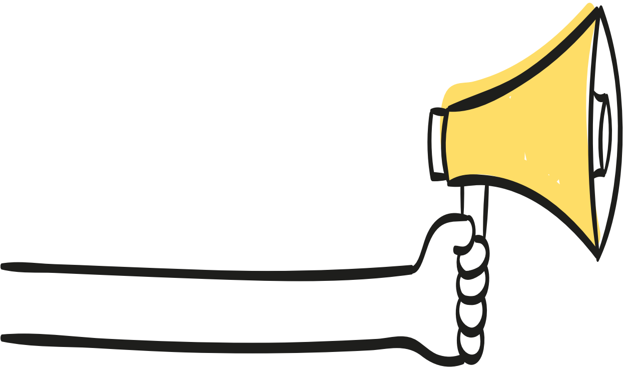
Northern Reporter,
The i Paper

Jo Healey

Former senior broadcast journalist.
Founder of Trauma Reporting

CHECK IN

Which of the images in the next slide reflect how you’re feeling about engaging with the media?




THE ENJOYME
6
BUS

DEVELOPING YOUR STRATEGY

1 Identify the symptoms

Identify what your natural response to media work is.

→

2 Accept that the reaction is natural

Be realistic with your media journey. This takes practice and time.

→

3 Preparation is key

You need to address and practice strategies ahead of media work, not during.

→

4 In the moment

Take a pause, a breath and then carry on.

PRESENCE

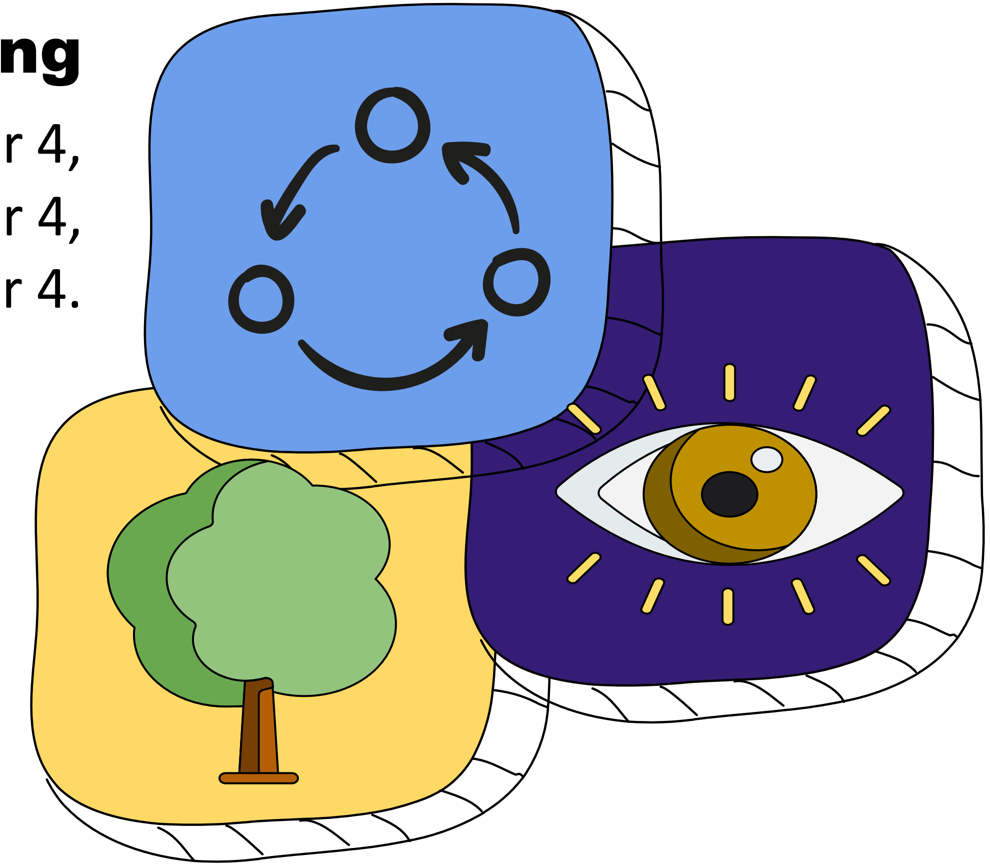
connected to
my body and
emotions

What do I need to stay present when doing media work or in stressful situations?

Take a couple of minutes to have a think about this and **write it down** on a piece of paper.

If you're comfortable, share it with the group.

SOME TECHNIQUES



Breathing

In for 4,
hold for 4,
out for 4.

Grounding

Put your feet flat on the ground and curl your toes. Push your palms into your legs.

What's around you?

Take note of your surroundings. What can you see, hear, smell, feel.

TOOLS FOR PREPARATION

Create a deck of cards

- ➔ **You're in control** over which details are put on the table. This tool helps you work out **what** to say, and **who to**.
- ➔ Work out **which stories will be in your deck**, and discard the ones you want/need to keep to yourself in that context.
- ➔ **Sharing details** can be emotionally draining, leave audiences in an unhelpful place or reinforce unhelpful narratives.

TOOLS FOR PREPARATION

→ Who is your audience?

→ What do you want people to remember?

→ What do you want people to think, feel and do after hearing your message?

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Things I don’t want to/can’t share	Top message		
	Show how CPC is at its best	**Show how children get to be children**	**Focus on the quality and range of relationships**

SHAPING FRAMED MESSAGES

Metaphors

Experiences

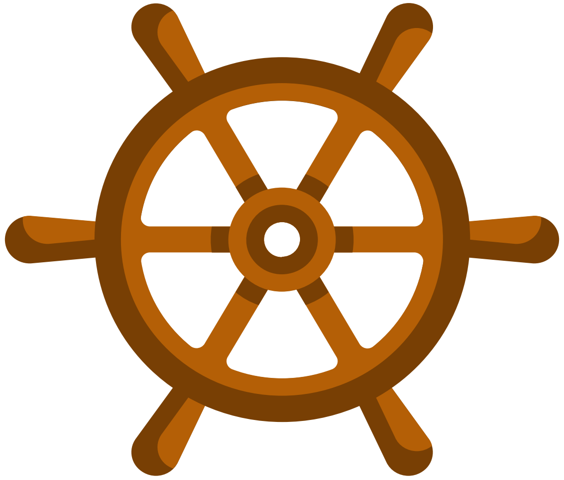
Data

Anecdotes

Examples

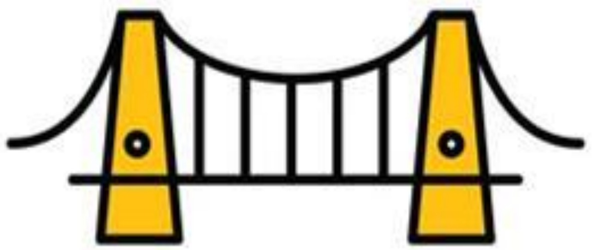
PIVOTING TRICKY QUESTIONS

- **A** Acknowledge the question
- **B** BUT
- **C** Carry on with what you want to say



PIVOTING TOOLS

Bridging



- ‘I wouldn’t want to guess, but what I can tell you is…’
- ‘The short answer is yes, but it’s also interesting that…’
- ‘I disagree, and think you need to look at the broader context…’

Signalling

- ‘The most important thing is…’
- ‘The bottom line is…’
- ‘If you remember one thing it should be. . .’


ShowMore
Tracy (Reenie) EACH (she/her)

USEFUL TIPS FOR INTERVIEWS

BEFORE

- Do I feel **ready** for this right now?
- What do I want to **get out** of the interview?
- Ask for as much **practical information** as possible and get **agreements in writing**
- Think about what **your boundaries are**
- Hold a **briefing** with a colleague or On Road
- Practise **tricky questions**

DURING

- Don't be afraid to ask for the interviewer to **repeat** a question or for a **break** if you need to
- Invite a **friend or family** member to support and cheer you on
- Ask the journalist if they'll run the **final edit and quotes** by you

AFTER

- How are you **feeling**?
- Is there something you shared during the interview that you're **worried about**?
- Think of one thing you're going to do to **relax**

Better Stories: How to support people to do great media interviews https://www.onroadmedia.org.uk/2020/04/21/supporting-people-to-work-with-the-media-heres-how-you-can/

TIPS FROM OUR ACTIVIST NETWORK

- Remind yourself that **journalists need access to you** in order to do their job. You are the **expert**.
- It's ok to have an **agenda**!
- **Take the pressure off** - we will not fix our society in one interview.
- **Walking away** is always an option!

TIPS: APPROACHING DIFFERENT MEDIUMS

Podcast

- 45 - 60 mins, likely to feature other guests
- More chance to convey narrative and story to **more invested audience**
- **Research tone of podcast** and the audience - these are more specific than other mediums
- **Repeat key points** throughout in different ways - reduces likelihood being editing out

Broadcast

- Either live or pre-record, TV or radio - you'll have a **couple of minutes** and a few questions
- Consider **soundbites** - what they're likely to edit down or that can stay in audiences' minds
- Use **short answers** that keep audiences attention
- Keep things **down to earth**

Quote

- **Two or three sentences.** Anything longer will likely be cut
- Adapt it for **relevant audiences**
- Focus on **well-framed and clear messages**, work up set phrases you might like to tweak when working to short deadlines

ROLE OF THE MDT IN COMPLEX SYMPTOM MANAGEMENT

Dr Satbir Singh Jassal MBE

Structure of talk

- The Hains /Jassal paradox
- What is a team
- What is symptom management
- 3 Case studies
- Case studies for discussion
- Finish with Douglas Adams

Statement 1

- Symptom control in paediatric palliative care is in 95% of cases easy and straight forward and can be done by any good doctor

Statement 2

- Paediatric palliative care is very complex and requires a multidisciplinary team with specialist knowledge and a variety of specialised skills

Types of team working

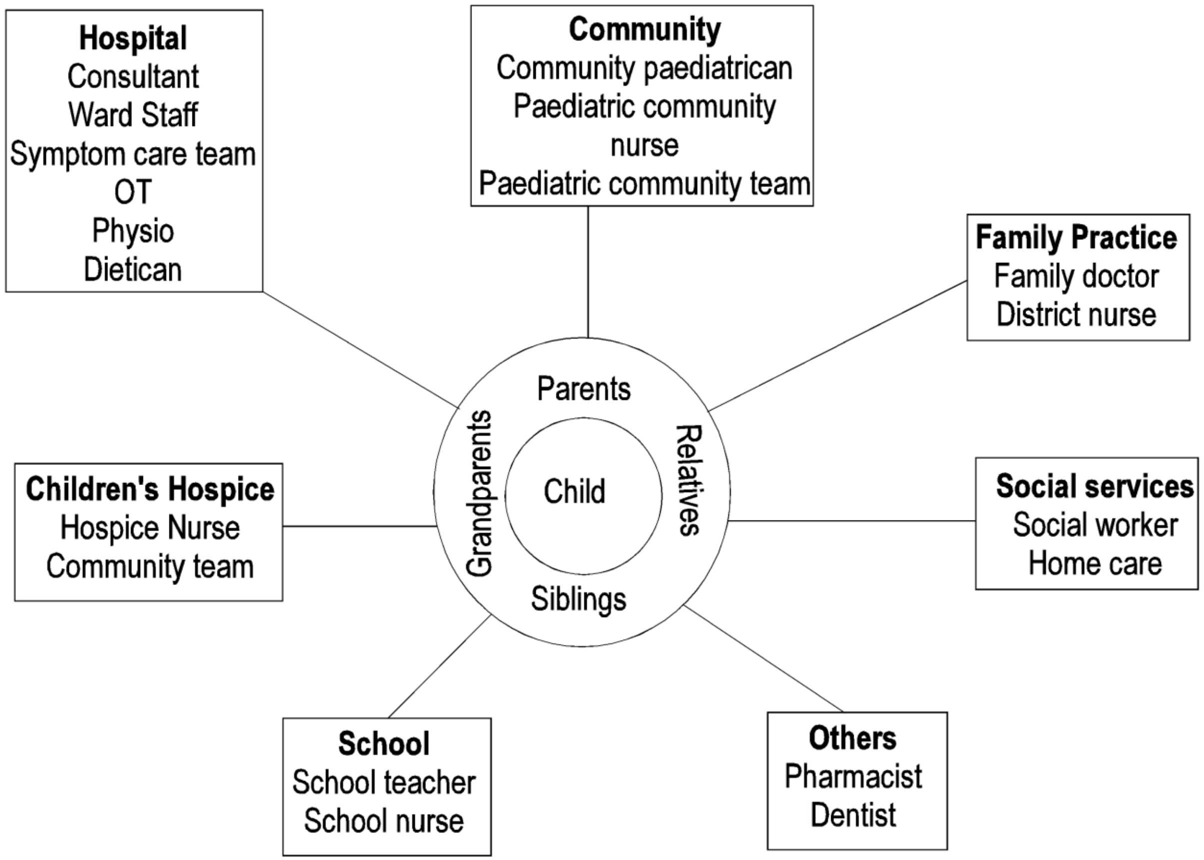
	Definition	Professional	Disciplinary	Agency
Definition		Specifically, functions and activities relating to professional groups	Knowledge and skills of professional roles	**Responsibility and roles of different agencies.**
Multi	Professionals working in collaboration and co-operation, but within set roles	Various professional groups meet together	Those with varying knowledge and skill bases meet together within a single agency	**Different agencies meet together**
Inter	Adaptation of roles, responsibilities, to adjust to those of others in the team. Allows for integration of theoretical models and techniques	Professionals adapt their identified roles to interact with and take account of others in the group	Adjustments to knowledge and skill bases	**Various agency responsibilities**
Trans			**Reformation of roles, knowledge and skills, to create family centred cohesive services, with only one assessment**	

Models for development of teams

Lowe	Roelofsen	Handy
Becoming acquainted	Process-oriented	Forming
Trial and error	Result-oriented	Storming
Collective indecision	Problem-oriented	Norming
Crisis	Interdisciplinary team	Performing
Resolution		

Who is involved

Diagram 1: Professional involvement in the care of a child



Hospital
Consultant
Ward Staff
Symptom care team
OT
Physio
Dietican

Community
Community paediatrican
Paediatric community nurse
Paediatric community team

Family Practice
Family doctor
District nurse

Children's Hospice
Hospice Nurse
Community team

Parents
Grandparents
Child
Relatives
Siblings

Social services
Social worker
Home care

School
School teacher
School nurse

Others
Pharmacist
Dentist

Team Players Hospice / Community

Let's list who is in the team

Who is new to the party?

- Reflexology
- Massage
- Music therapy
- Art therapy
- Counselling

Who gets forgotten

- Cleaners
- Chef
- Fundraisers
- People behind the scenes. List examples.

Two Keys to Symptom Management

- **Communication**
- **Truth**

How is this implemented?

- Multi-disciplinary team approach
- Home/Hospice
- Pharmacological intervention
- Non-pharmacological intervention
- Complementary therapies
- Family at the centre of everything (empowerment)

Case Study 1

- 16yr old wheelchair bound, DMD, no speech used electronic keyboard.
- Sent by paediatrician for initiation of morphine for EOL as had stopped eating, in pain and weight loss.
- GP had tried Ibuprofen for the pain to begin with but then patient had deteriorated.

Empirical medicine

- Had indigestion from ibuprofen.
- Had pain from wheelchair that he had grown out of.
- He thought he was dying.

Case study 2

- Baby boy transferred age 9 days.
- Abdominal cyst diagnosed ante-natally
- Born with grossly distended abdomen.
- Laparotomy x 2. No viable bowel
- Palliative care
- Mother history of mental ill health

- Swapped from IV to SC infusion. Diamorphine initially & midazolam added in
- Breakthrough buccal doses of midazolam & diamorphine
- Abdominal wound care
- NGT on free drainage
- No feeding but dummy dipped in EBM

- Memory making
- Walks in the garden
- Baby massage
- Emotional support for parents
- Hospice doctors ensured mother recovering from her surgery

- Baby died peacefully age 16 days
- Baby cared for in Bereavement Suite
- Parents supported to plan funeral
- Ongoing bereavement support

Case Study 3

Ante-natal referral

- Parents self referred following diagnosis of Trisomy 18 following 20 week scan
- Parents in early twenties. Sibling aged 3
- Hospice Neonatal link nurse visited family at home 25 weeks into the pregnancy
- Tour of hospice at 27 weeks. Family very pleasantly surprised at what they saw and planned to come to the hospice if baby born alive
- Link nurse visited family at home regularly for the remainder of the pregnancy. Close contact with the hospital midwife leading their care

- The family had recorded the baby’s heartbeat and Hospice Music Therapist had visited them at home and created a piece of music to the beat of the baby’s heart incorporating the sibling singing to the baby
- Baby born and transferred to Hospice
- Family welcomed their visitors and used all the hospice facilities during their stay. Quote from them ‘at Hospice we felt we were being cared for by our own family.’
- Baby died at 5 days old in mothers arms. All family present
- Stayed at Hospice using cuddle cot to keep his body cool
- More memory making
- Supported to plan funeral
- Played their cherished piece of music at the funeral
- Ongoing bereavement support

Music therapy

Discussion case 1

- *22yr old with brain tumour, came to hospice to die!!, only wish to go to music concert.*
- *Left on high dose dexamethasone*
- *+++appetite, grossly obese, swollen legs, unable to walk unaided, incontinent of urine, skin breakdown perineum.*

Steroid

- *Diagnosed as diabetic admitted to hospital but discharged without rx.*
- *Hospice nurses questioning if we could put on diabetic diet / autonomy*
- *(ETHICS)*
- *S/B paediatric diabetologist at hospice started on insulin.*
- *Dexamethasone reduced, symptoms reduced without loss of pain control.*
- *Went to concert one week before death*

Discussion case 2

- *8yrs old neuro disabled, unknown genetic diagnosis, unknown cause for pain,transferred from GOS for symptoms management. 'They had tried everything'.*

Pain Syndromes :Central pain

- *Pain appeared to be gut related.*
- *Treated with high dose gabapentin*

Central Pain

- How to manage?
- Drugs
- Feeds
- Fluids
- Eventual gut failure

Discussion case 3

- *Child from Derby, referred by Evelina, poor pain control, mother not happy to give morphine or other opiates.*
- *Noted altered bowel habits, abdominal bloating and urinary problems.*
- *Flare up of severe dystonia*

Pain Syndromes: Visceral hyperalgesia Dystonia

- *On 4 types of anticholinergics.*
- *Child having gut dysmotility due to medication and nerve damage to bowel.*
- *Stopped numerous medication and given prn buccal ketamine.*

Discussion case 4

- *Neonate sent home to die.*
- *Started on small dose morphine, GP keen to help, advised to increase dose by BTP or 30-50%.*
- *Called several weeks later as baby in uncontrolled pain.*

Pain Syndromes: Medication toxicity

- *O/E had myoclonic movements; parent thought was pain.*
- *Morphine toxicity cause*
- *Treated pain by decreasing morphine.*

Discussion case 5

- 3 year old child unknown diagnosis neurodegenerative disease.
- Mother says he is distressed.
- Has neurodisability, respiratory and neurology consultants who all say he is not in pain.
- Has tried paracetamol, codeine and morphine only help a bit.

Symptoms

- Goes sweaty,
- Clammy,
- Heart rate goes up,
- Makes odd noises ,
- Arches back

Dysautonomia

- Clonidine

Discussion case 6

- 4yr old girl with neurological/metabolic disorder.
- Asked to review at HDU for EOL.
- Having intractable epilepsy and HDU unable to stop seizures.
- Increase seizures linked to feeding with head rotation.
- Observed seizure child goes rigid and hyperextends back and arms.

Sandifer’s Syndrome

- Gastro-oesophageal reflux

Principles

Keep it simple

Don’t try to be too clever

The 5 rules

1. Don’t Panic
2. Communication
3. Don’t get burnt
4. You don’t need to be an expert in everything
5. Never be too proud to ask for advise

Cheeky Plug

Basic Symptom Control in Paediatric Palliative Care

https://www.togetherforshortlives.org.uk/resource/basic-symptom-control-paediatric-palliative-care/

SO LONG

AND

THANKS

FOR ALL

THE FISH

The Medical Examiner and the Coroner: Roles and Referrals

Dr Luke Smith RCPathME

Lead Medical Examiner, Guy's and St Thomas' Hospitals

Dr Ruth Williams RCPathME

Medical Examiner, Guy's and St Thomas' Hospitals

History of recording of death….

- Office of the Coroner dates from 11th Century in England
- Established soon after 1066, then formally enshrined in law in 1194.
- Role in lieu of the Crown was established in 1215 in the magna carta
- Coroner was exported to Wales in 1282 by military conquest then enshrined in law in 1284.
- Coroner’s Act 1844 outlined the role of the Coroner similarly to that which exists today.
- Since then, only minor amendments to the Act and other additions
- In 2009 – Coroners and Justice Act received Royal Assent but still not fully enacted

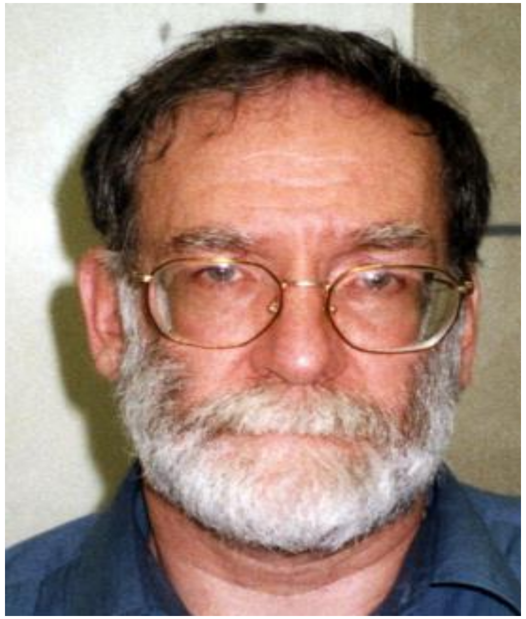
Role of the Coroner and unmet needs

- Amongst others, the role of the Coroner is to investigate the cause and manner of a death if a doctor cannot do so (either due to legal stipulation or inability). The coroner will also investigate when a death is deemed violent or unnatural, where the cause is unknown, where a death is the result of poisoning or industrial injury, or if it occurred in police custody or prison.

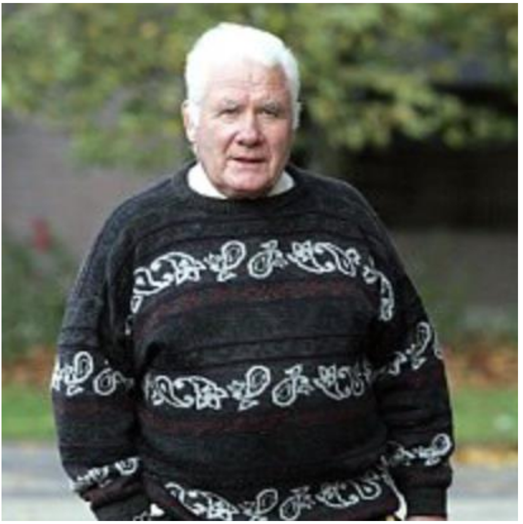
- Thus, the Coroner does not investigate all deaths – majority are not even flagged to the Coroner (approx. 85% of hospital deaths)
- These deaths then go unchecked except by the medical personnel who cared for them in life

- There exists a need for independent verification of deaths not examined by the Coroner

Why do we need to scrutinise non-Coronial deaths?



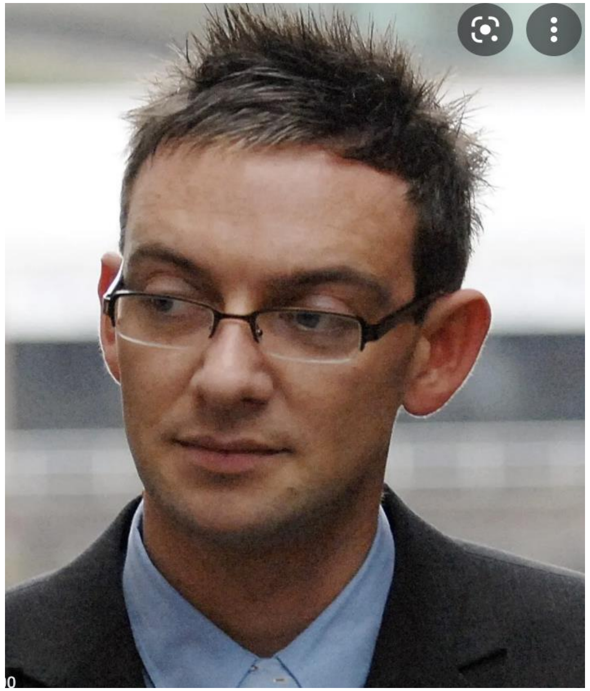
Dr Harold Shipman
Convicted: 218 (480)



Dr Howard
Martin
Acquitted: 3 (?)

Victorino Chua
Convicted: 2

Colin Norris
Convicted: 4 deaths



Dr Thomas Neill
Cream
Convicted:
5 (many more
suspected)

Dr John Bodkin
Adams
Acquitted:
163 deaths (?)

Dr John Henry Arthur
Acquitted: murder 1 (?)

Beverley Allitt
Convicted: 4 deaths

Healthcare Killers Worldwide

Michael Swango US (approx. 60)

Charles Cullen US (40-400)

Donald Harvey US (37-87)

Henry H Holmes US (up to 200)

Jane Toppan US (31)

Niels Hogel DE (85-300)

Jayant Patel AU (3)

Miyuki Ishikawa JP (up to 84)

Stephan Letter DE (29)

Arnfinn Nesset NO (138)

Maxim Petrov RU (11)

The Shipman Inquiry

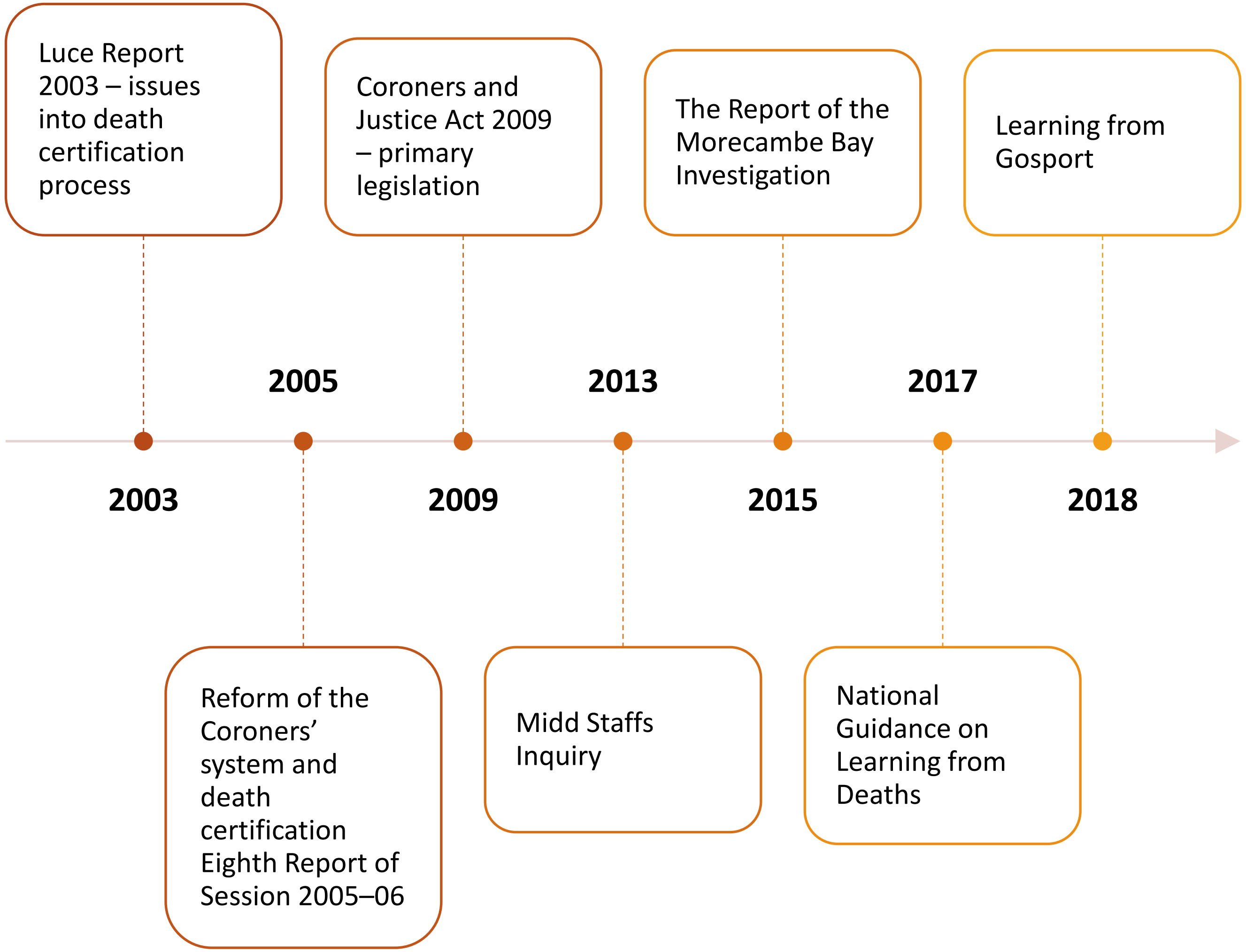
Among the many findings and proposals was the principle that deaths which were not flagged to the Coroner were not independently verified or scrutinised – this was how Shipman was able to evade detection for so long

Reviewed Process in other jurisdictions

Considered options for a more robust future system

Any changes contemplated for the future must seek to ensure that families are kept informed about, and are consulted and involved at all stages of, the post-death procedures. However, their involvement must be handled sensitively and not intrusively. The needs of those minority ethnic or religious groups whose members wish to arrange disposal of the body as soon as possible after the death must also be borne in mind in any proposals for change.

After Shipman, other Inquiries and legislation followed …



2003
Luce Report 2003 – issues into death certification process

2005
Reform of the Coroners' system and death certification Eighth Report of Session 2005–06

2009
Coroners and Justice Act 2009 – primary legislation

2013
Midd Staffs Inquiry

2015
The Report of the Morecambe Bay Investigation

2017
National Guidance on Learning from Deaths

2018
Learning from Gosport

Medical Examiners

- All this legislation and public consultation proposed the role of Medical Examiner as a solution
- Independent doctors to each case – consultant level
- Role is to scrutinise verifiable data and discuss cases with attending staff to determine an independent cause of death to make sure this matches with what the attending team is proposing
- Also discusses with NOK to determine families' points of view and concerns
- Collect data to examine trends and guide future services and anthropological data (feeds into ONS)
- Provide support and advice to clinicians, and act as conduit to HMC
- Central aim is to reduce the likelihood of future healthcare killers

Medical Examiner Officers

- The Medical Examiner is assisted by Medical Examiner Officers (MEOs)
- Similar to bereavement officers, they have responsibility to complete some administrative legal documentation, but can also assist in the scrutiny process and may even be delegated cases of their own
- They undergo formal training and are registered and regulated by the Royal College of Pathologists, as are MEs

Coroner and the ME

The Coroner still maintains authority over all bodies lying in their jurisdiction

The ME is not a deputy for the Coroner – two sides of the same coin; the Coroner maintains the legal aspect while the ME provides medical oversight

The role of Medical Examiner is still not statutory in law – anticipated April 2023

At this point, all deaths in England and Wales will require independent scrutiny either by the Coroner or an ME for Registration to occur

Cases to Refer to the Coroner

"A death under the circumstances set out as follows should always be notified, regardless of how much time has passed since the death … and whenever the injury was caused – in other words there is no automatic cut-off point at which an injury is no longer associated with a death"

- Deaths due to poisoning, incl. medicines and drugs, either accidental or deliberate
- Deaths due to violence, trauma or injury
- Deaths due to neglect, self-neglect or self-harm
- Deaths directly caused by medical treatment, procedures or their adverse effects
- Deaths related to employment
- Deaths in custody or state detention
- Cause of death is not known
- Identity of Deceased is unknown
- No medical practitioner available with timely knowledge of Deceased

Examples - 1

A 15 year old boy was diagnosed with Duchenne muscular dystrophy at aged 4 years

Despite optimal physiotherapy and supportive management he develops severe scoliosis

By age 12 he is unable to mobilise and by age 13 he has respiratory failure requiring continual use of BiPAP

He has recurrent episodes of aspiration and bronchopneumonia requiring hospital admissions

Palliative services are involved early as condition accelerates

He dies at home with full palliative support due to type 2 respiratory failure

Examples - 1

Here, the cause of death is clearly known – respiratory failure due to DMD

There is nothing unnatural or concerning about the death so Coronial referral is not required

In cases where a death is expected, the Medical Examiner can be contacted in advance to pre-scrutinise to reduce delays

This is particularly important in some faith groups, organ donation cases or where children are going into the community to pass away

An on-call Medical Examiner service can also help in expedited child cases or those deaths which occur out-of-hours

Examples - 2

A child of 2 months is deliberately choked by her father

Sustains catastrophic hypoxic brain injuries impeding normal development and she is fully dependent and immobile. Has regular tonic-clonic seizures

Father is arrested and imprisoned for GBH

At 11 years of age, she is admitted to hospital in status epilepticus and aspirates, dying a day later in ITU

Examples - 2

- Here, the cause of death can be suggested:

  1a) Aspiration pneumonia 1b) Status epilepticus 1c) HIE
- However, she would not have developed HIE leading to the sequence causing death if not for the external influence of the father – even if 11 years previous
- In this example, the suggestion that the ultimate death may be as a consequence of previous assault may have future criminal implications, as the original crime may have now altered
- This case should be referred as *to the best of knowledge and belief* the primary event was unnatural

Legal Roles and Burden of Proof

You do not have to be sure of something to refer to the Coroner

(Just as you do not need to be sure on the MCCD)

The burden of proof is “to the best of your knowledge and belief”

Compare to civil cases – “on the balance of probabilities” or criminal cases – “beyond reasonable doubt”

If there is a **credible** suspicion “to the best of your knowledge” of a reason to refer, or a death may be related to (not necessarily caused by) an unnatural act, you have a legal obligation to refer

Examples - 3

- A 15 year old boy dies of glioblastoma which was diagnosed 18 months prior
- Previously fit and healthy and no family history
- The next of kin are keen for referral to the Coroner as they “lived next to a mobile phone mast for 15 years”

- Here the cause of death is known – glioblastoma
- There is no credible link, to date, between glioblastoma and living near mobile phone masts
- *To the best of knowledge*, there is no credible reason to refer this death as it is natural

Legal Roles and Burden of Proof

Your role is to refer cases to the Coroner to investigate

You do not have to be right, you do not have to be sure – just be sufficiently suspicious

The Coroner's role is to determine:

- Who the Deceased is
- When they died
- Where they died
- How they came about their death

Their role is "Inquisitorial" not "Adversarial"

They do not apportion blame or hand down punishments

Can refer a case for criminal proceedings if this is needed

Deaths directly caused by medical treatment, procedures or their adverse effects

- This is difficult to determine and the ME can help a lot here
- There is no requirement per se to refer a patient just because they have had a procedure etc, irrespective of how recent it was
- You should refer if the procedure, to the best of your knowledge, has the suspicion of being directly related to the death only
  - A child develops necrotising enterocolitis and has a laparotomy. Nothing can be done intraoperatively and the patient dies. No referral needed
  - A child has urgent corrective surgery for gastroschisis. The bowel perforates intraoperatively and the patient dies. This does need to be referred (as bowel perforation would not have happened without the procedure necessarily)
  - A child undergoes surgical repair of a tetralogy of Fallot. After initial good surgical recovery, the child suddenly decompensates with a low output state. Echo shows free-flow pulmonary regurgitation and the child arrests and dies before she could return to theatre. Since the actual cause of death here was a complication of the procedure and death was not expected to happen at this time otherwise, should be referred.

Deaths directly caused by medical treatment, procedures or their adverse effects

- Procedures like endoscopy or invasive angiography only need referral if a death has occurred from a known complication, e.g. perforation or haemorrhage, respectively
- All elective procedures leading to death (directly or side effect) should be referred
- Refer unexpected deaths post procedure
- Refer when a procedure goes wrong

Deaths in custody or state detention

- Hospitals, where the Deceased was detained under mental health legislation
- Prisons (including privately run prisons)
- Young Offender Institutions
- Secure accommodation for young offenders
- Secure accommodation under section 25 of the Children Act 1989
- Any form of police custody e.g. the deceased was under arrest (anywhere) or detained in police cells
- Immigration detention centres
- Court cells or cells at a tribunal hearing centre
- Military detention
- Bail hostel
- When the deceased was a detainee who was being transported between two institutions or any death in which the person would ordinarily have been in state detention but had been temporarily released (for example for medical treatment) or had absconded from detention.
- DOES NOT include those held under Deprivation of Liberty (DOLS) order
- Be aware of children or vulnerable people under Ward of Court or known to Social Services – discuss with ME and if in doubt, refer to Coroner and they will arbitrate

CDOP and the ME

The Medical Examiner scrutiny can form part of the CDOP process as the scrutiny is fully independent

Part of the role of the ME scrutiny is discussion with the NOK; this can be offered to parents if they would like

In child deaths, the ME will not regularly contact the parents to discuss the case unless the parents want this

Existing CDOP processes continue as usual; the ME's role is purely in ensuring appropriate recording and registration of the death

Lessons learnt will still be determined by CDOP although ME scrutiny may add to this process if new aspects are identified

In conclusion: benefits of the ME system

Allow	Provide	Reduce	Reduce	Provide	Collect	Provide
Allow greater scrutiny of cause of death to ensure accuracy, transparency, uniformity and a robust system to reduce the likelihood of another Shipman.	Provide support and guidance to the physicians on the teams completing documentation after death.	Reduce unnecessary referrals to the Coroner.	Reduce delays by ensuring that deaths are scrutinised promptly and the necessary paperwork is completed in an accurate and timely manner.	Provide support to the next of kin by explaining the cause of death and acting as an independent person for them to address any questions, feedback or concerns.	Collect data and identify patterns in mortality to assist the learning from deaths/CDOP process and help shape and improve future service delivery.	Provide data to the National Medical Examiner office on mortality trends and statistics to inform public health delivery at a national level.

Questions?

Welcome to together for short lives


a
story

Talk about the conference on your **socials**

Tag us in and use the hashtag **#TSFLConference**

Child and
Young Person's
Advance Care Plan
Collaborative

The development of a national Advance Care Plan

08.09.22

Ross Smith – Consultant in Paediatric Palliative Medicine

Co-Lead of CYPACP

(with Helen Bennett – Director of Care Alexander Devine Children's Hospice)

Aims

- Recognise importance and wide use of Advance Care Planning
- Be aware of work currently going on to produce a ‘National’ Advance Care Plan and why
- Be aware of future work planned with regards to Advance Care Planning

What is an Advance Care Plan (ACP)

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Collaborative

- Discussion (and documentation) between :
  - An individual (where possible)
  - Their care givers
  - Those close to them

....about future care

- Provides information about child's condition and management
  - Specific to the child's individual circumstances
  - Clearly explained and understandable
  - Up to date

Core element of palliative care

NICE - End of life care for infants, children and young people

Child and Young Person's Advance Care Plan Collaborative

- NICE guideline [NG61]
  - Develop and record an Advance Care Plan
  - for each child or young person with a life-limiting condition

Although, clarify should be 'offered'

- NICE Quality Standard (QS160) - **Quality statement 1: Advance care plan**
  - Infants, children and young people with a life-limiting condition and their parents or carers are involved in developing an advance care plan.

Background to Child and Young Person’s Advance Care Plan (CYPACP)

Child and Young Person’s Advance Care Plan Collaborative

- Inspired by a child (Bea)
  - Responsibility for family
    - remember every detail
    - repeat story over and over
  - Watch professionals
    - work out every time if this was end of life
    - skirt around issues resulting in no real decisions

- Aim to create a document that was
  - child centred
  - easy to use in an emergency
  - covered all holistic aspects
  - wherever they happened to be

- **“Document is like having the clinician who knew Bea best at the side of the bed in a strange emergency department or in a new intensive care unit”.**

CYPACP

Child and Young Person's Advance Care Plan Collaborative

- Widely used many areas in the UK
- Endorsed by NICE
- Central website (www.cypacp.uk)
- collaboration/links with ReSPECT, CPCET, EPaCCS

- Helen and I took over leadership
    - New version
    - Revisit idea of truly National document

Value and purpose of National Document

Child and Young Person's Advance Care Plan Collaborative

- Collaborate ideas
  - Wide variable expertise
  - Research
- Central resources
  - Guidance
  - Education
- Easier recognition
  - Wide usage
    - Diff specialties overlap regions
  - APLS
  - Families – Transition between areas e.g. Peri-natal / child / adult
- Influence
  - Funding
  - Policies
    - ReSPECT / CPCET
    - EPaCCS
    - 'Advance Care Principles'
  - Future Research

Care Planning Background

Child and
Young Person's
Advance Care Plan
Collaborative

- Needs to be flexible
- Variety of needs
  - Patients / diagnosis
  - Ages
  - Desires
    - Resus
    - 'passport'
    - detailed planning
- Variety of expertise of professionals
  - Some very happy adapting documents e.g 'additional info'
  - Others need more guidance / prompts
  - Time available

- Largely educational
  - Not all sections need to be completed
  - Understanding principles of care planning
    - E.g. Does not mean limitations in treatment

Balance

Child and Young Person's Advance Care Plan Collaborative

- How important is the national document and benefits of this
  - Vs
- Not necessarily everything you agree with **and** difficulties of change

- With flexibility hopefully we can achieve a good balance

How?

Child and
Young Person's
Advance Care Plan
Collaborative

- CYPACP as starting point
    - Wide use
    - Recognised
    - External Links
    - Central website
- Recognise need to improve
- Used good practice from other care plans in existence
- Involve, utilise and recognise wide expertise
    - Neonatal / Transition / Oncology / PICU / Neuro-dis / Psychology
    - Nursing / Medical / Managerial
    - Hospice / Community / Hospital / Emergency Services
    - Research / APPM / TfSL / PPI

Actual Document

Child and
Young Person's
Advance Care Plan
Collaborative

- 2 Versions
  - 1. Core Product
    - Including emergency management
    - NICE recommendations
    - Less repetition
    - More detail / More flexible
    - Clearer where to put information – prompts
      - (+ Guidance and example documents)
  - 2. Antenatal Product
    - Core + a few added pages
    - Can delete if baby survives
  - Both Versions with and without ReSPECT

Current position

- Draft document
    - Sent for comments
- With PPI group
    - Ensure patients / families are happy with wording

- Awaiting response
    - ReSPECT

Next steps

- Formatting
- Guidance / Policy
- Example documents (particularly for personalised / specialty specific)

- Roll Out
- Push for National acceptance

Further Plans

Child and Young Person's Advance Care Plan Collaborative

- Funding
- Other resources
  - Family
  - Professionals
    - E-learning for Health
    - Mental Capacity guidance
- Website improvement / administration
- Continued collaboration with others (next slide)

Other work

Child and Young Person's Advance Care Plan Collaborative

- Universal Principles for Advance Care Planning – March 2022
  - Definition implied must have capacity
  - Statement – Confirming
    - 'Advance Care Planning is appropriate in children and those without capacity'
- CPCET (Children's Palliative Care eduCation and Training)
  - UK & Ireland
  - Standard Framework for Advance Care Planning
  - Competency framework
- ReSPECT
  - Red Box
  - 'Young Person'
- EPaCCS
  - Distribution / version control

Thank you
Any questions ?

Child and
Young Person's
Advance Care Plan
Collaborative

Appendices

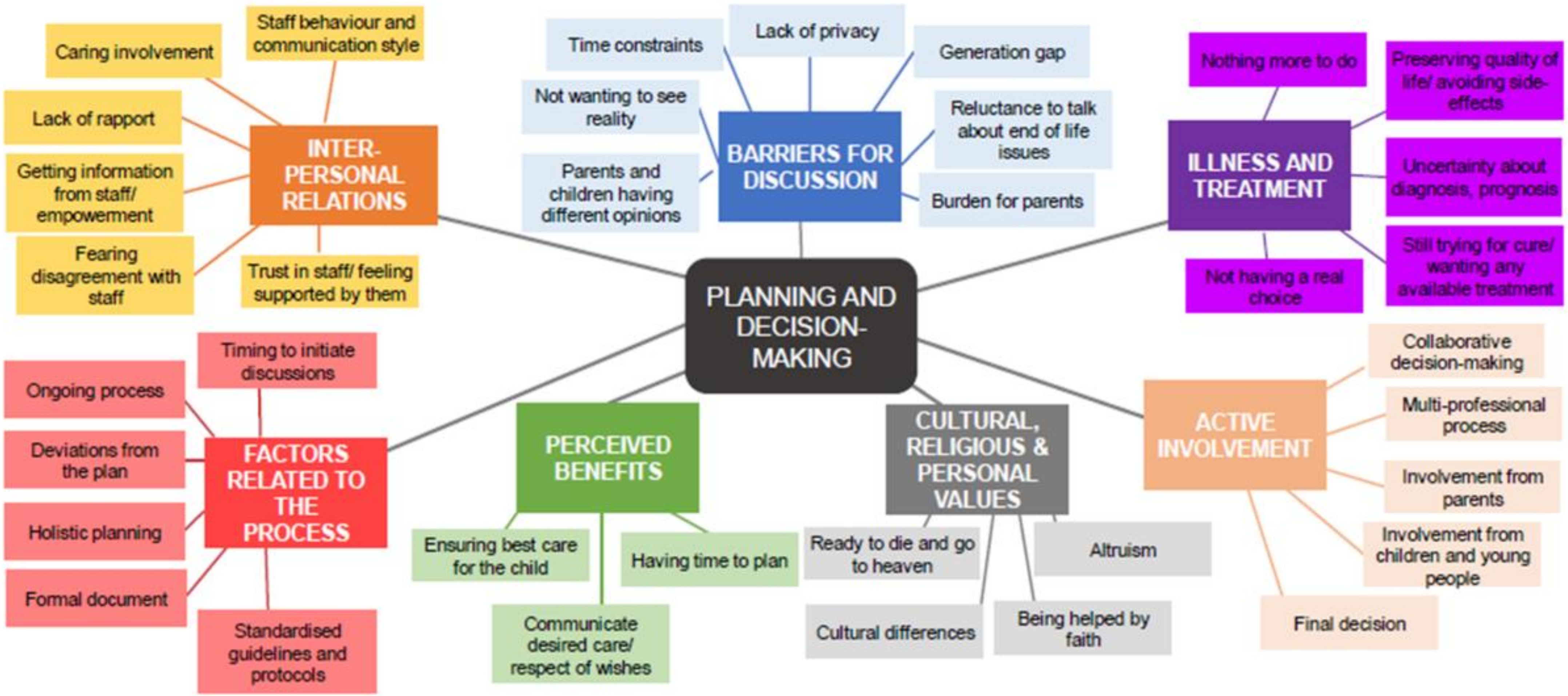
NICE Guidance

Child and Young Person's Advance Care Plan Collaborative

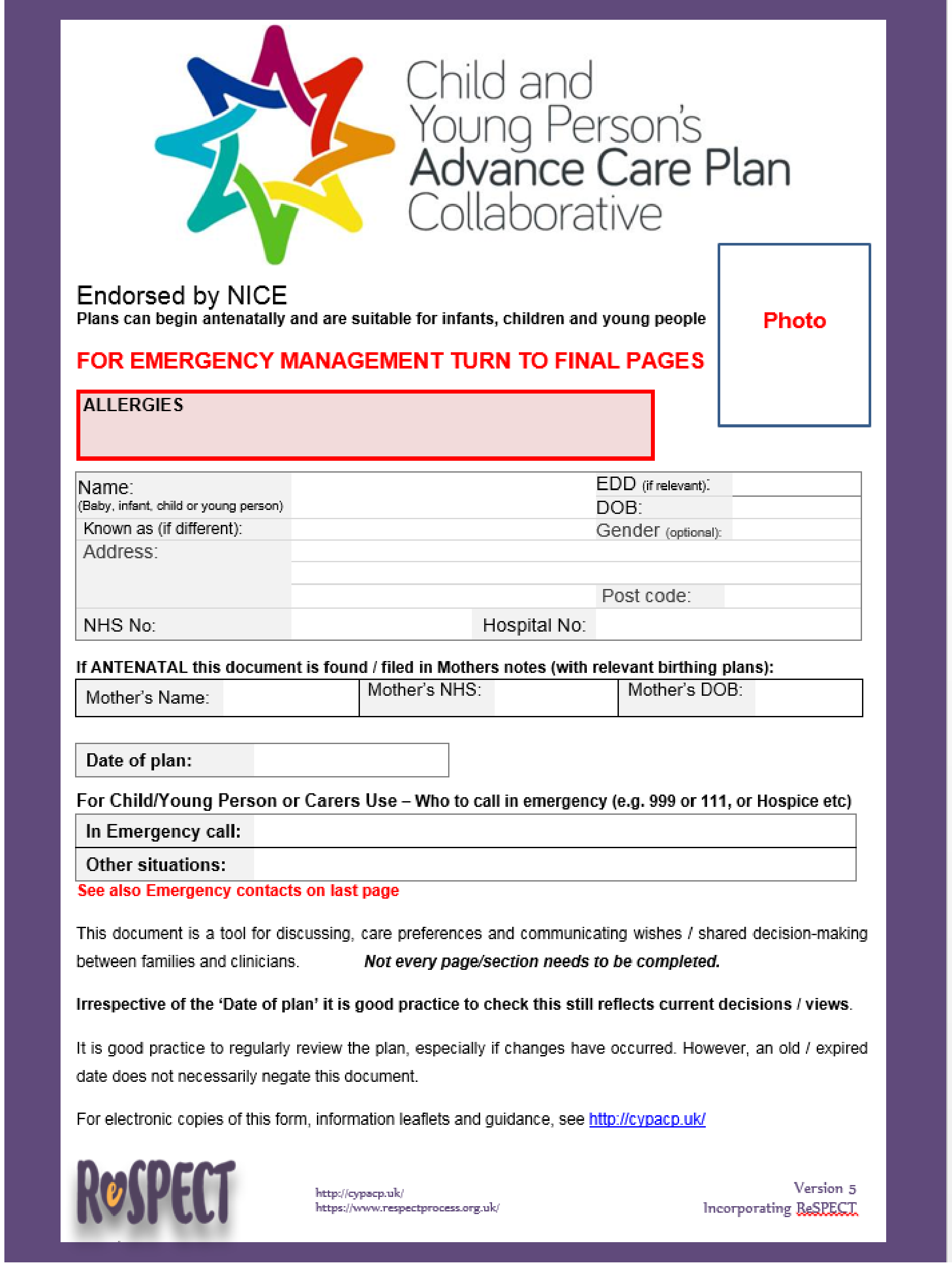
The Advance Care Plan should include:

- **demographic information** about the child or young person and their family
- up-to-date **contact information** for:
  - the child or young person's parents or carers **and**
  - the key professionals involved in care
- a statement about **who has responsibility for giving consent**
- a **summary of the life-limiting condition**
- an agreed **approach to communicating** with and providing information to the child or young person and their parents or carers
- an outline of the child or young person's **life ambitions and wishes**, for example on:
  - family and other relationships
  - social activities and participation
  - education
  - how to incorporate their **religious, spiritual, and cultural beliefs and values** into their care
- a **record of significant discussions** with the child or young person and their parents or carers
- agreed **treatment plans and objectives**
- **education plans**, if relevant
- a **record of any discussions** and decisions that have taken place on:
  - **preferred place of care and place of death**
  - **organ and tissue donation** (see recommendation 1.2.17)
  - **management of life-threatening events, including plans for resuscitation or life support**
  - **specific wishes**, for example on **funeral arrangements and care of the body**
- **distribution list**

https://www.nice.org.uk/guidance/ng61/chapter/recommendations



- PLANNING AND DECISION-MAKING
  - INTER-PERSONAL RELATIONS
    - Caring involvement
    - Staff behaviour and communication style
    - Lack of rapport
    - Getting information from staff/ empowerment
    - Fearing disagreement with staff
    - Trust in staff/ feeling supported by them
  - BARRIERS FOR DISCUSSION
    - Time constraints
    - Lack of privacy
    - Generation gap
    - Not wanting to see reality
    - Reluctance to talk about end of life issues
    - Parents and children having different opinions
    - Burden for parents
  - ILLNESS AND TREATMENT
    - Nothing more to do
    - Preserving quality of life/ avoiding side-effects
    - Uncertainty about diagnosis, prognosis
    - Still trying for cure/ wanting any available treatment
    - Not having a real choice
  - FACTORS RELATED TO THE PROCESS
    - Timing to initiate discussions
    - Ongoing process
    - Deviations from the plan
    - Holistic planning
    - Formal document
    - Standardised guidelines and protocols
  - PERCEIVED BENEFITS
    - Ensuring best care for the child
    - Having time to plan
    - Communicate desired care/ respect of wishes
  - CULTURAL, RELIGIOUS & PERSONAL VALUES
    - Ready to die and go to heaven
    - Altruism
    - Cultural differences
    - Being helped by faith
  - ACTIVE INVOLVEMENT
    - Collaborative decision-making
    - Multi-professional process
    - Involvement from parents
    - Involvement from children and young people
    - Final decision



Child and Young Person's Advance Care Plan Collaborative

Endorsed by NICE

Plans can begin antenatally and are suitable for infants, children and young people

FOR EMERGENCY MANAGEMENT TURN TO FINAL PAGES

Photo

ALLERGIES

Name: (Baby, infant, child or young person)		EDD (if relevant):	
		DOB:	
Known as (if different):		Gender (optional):	
Address:			
		Post code:	
NHS No:		Hospital No:	

If ANTENATAL this document is found / filed in Mothers notes (with relevant birthing plans):

Mother's Name:		Mother's NHS:		Mother's DOB:	

Date of plan:	

For Child/Young Person or Carers Use – Who to call in emergency (e.g. 999 or 111, or Hospice etc)

In Emergency call:	
Other situations:	

See also Emergency contacts on last page

This document is a tool for discussing, care preferences and communicating wishes / shared decision-making between families and clinicians. ***Not every page/section needs to be completed.***

Irrespective of the 'Date of plan' it is good practice to check this still reflects current decisions / views.

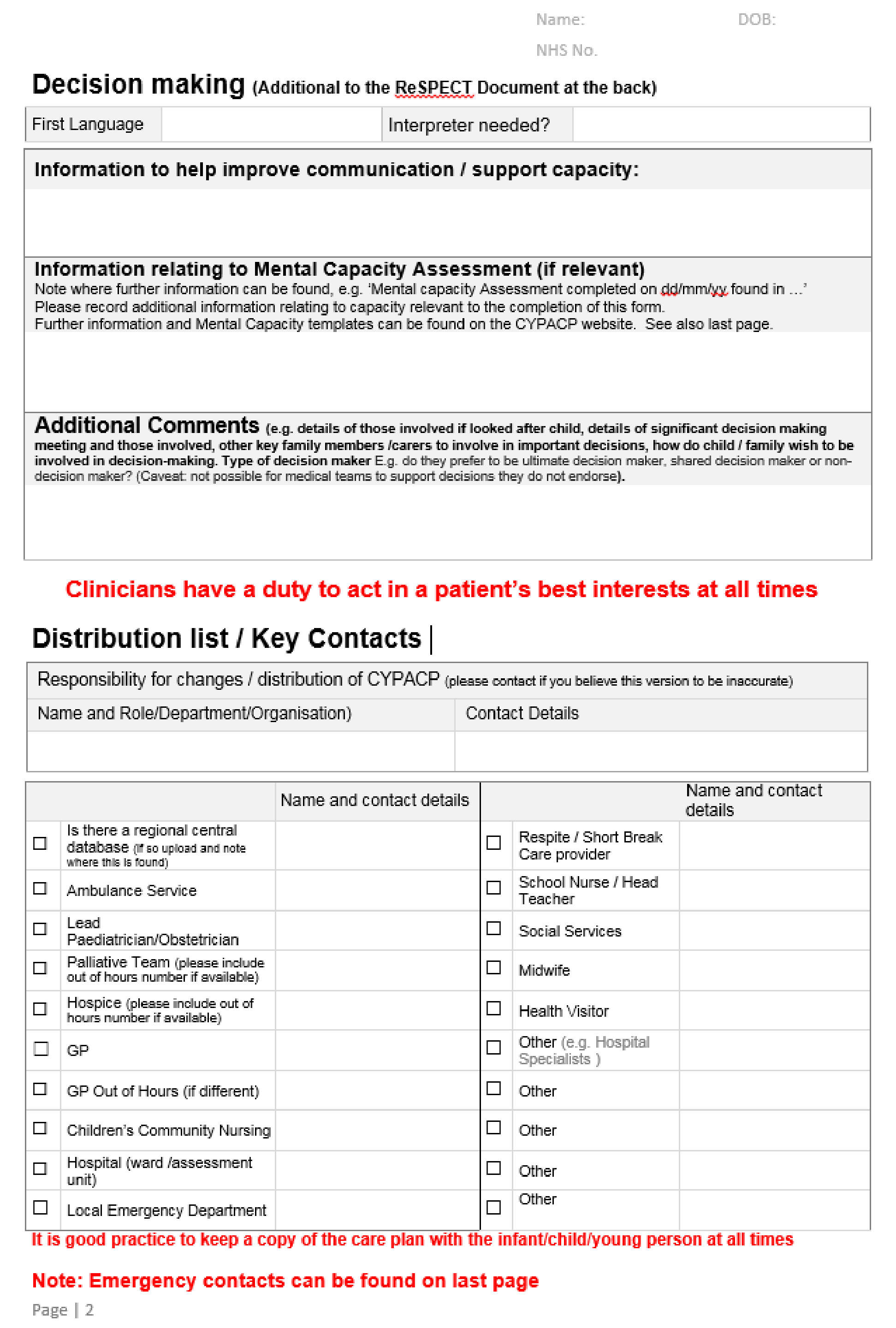
It is good practice to regularly review the plan, especially if changes have occurred. However, an old / expired date does not necessarily negate this document.

For electronic copies of this form, information leaflets and guidance, see http://cypacp.uk/

ReSPECT

http://cypacp.uk/
https://www.respectprocess.org.uk/

Version 5
Incorporating ReSPECT



Name: DOB:
NHS No.

Decision making (Additional to the ReSPECT Document at the back)

First Language		Interpreter needed?	

Information to help improve communication / support capacity:
Information relating to Mental Capacity Assessment (if relevant) Note where further information can be found, e.g. 'Mental capacity Assessment completed on dd/mm/yy found in …' Please record additional information relating to capacity relevant to the completion of this form. Further information and Mental Capacity templates can be found on the CYPACP website. See also last page.
Additional Comments (e.g. details of those involved if looked after child, details of significant decision making meeting and those involved, other key family members /carers to involve in important decisions, how do child / family wish to be involved in decision-making. Type of decision maker E.g. do they prefer to be ultimate decision maker, shared decision maker or non-decision maker? (Caveat: not possible for medical teams to support decisions they do not endorse).

Clinicians have a duty to act in a patient's best interests at all times

Distribution list / Key Contacts

Responsibility for changes / distribution of CYPACP (please contact if you believe this version to be inaccurate)	
Name and Role/Department/Organisation)	Contact Details

		Name and contact details			Name and contact details
☐	Is there a regional central database (if so upload and note where this is found)		☐	Respite / Short Break Care provider	
☐	Ambulance Service		☐	School Nurse / Head Teacher	
☐	Lead Paediatrician/Obstetrician		☐	Social Services	
☐	Palliative Team (please include out of hours number if available)		☐	Midwife	
☐	Hospice (please include out of hours number if available)		☐	Health Visitor	
☐	GP		☐	Other (e.g. Hospital Specialists)	
☐	GP Out of Hours (if different)		☐	Other	
☐	Children's Community Nursing		☐	Other	
☐	Hospital (ward /assessment unit)		☐	Other	
☐	Local Emergency Department		☐	Other	

It is good practice to keep a copy of the care plan with the infant/child/young person at all times

Note: Emergency contacts can be found on last page

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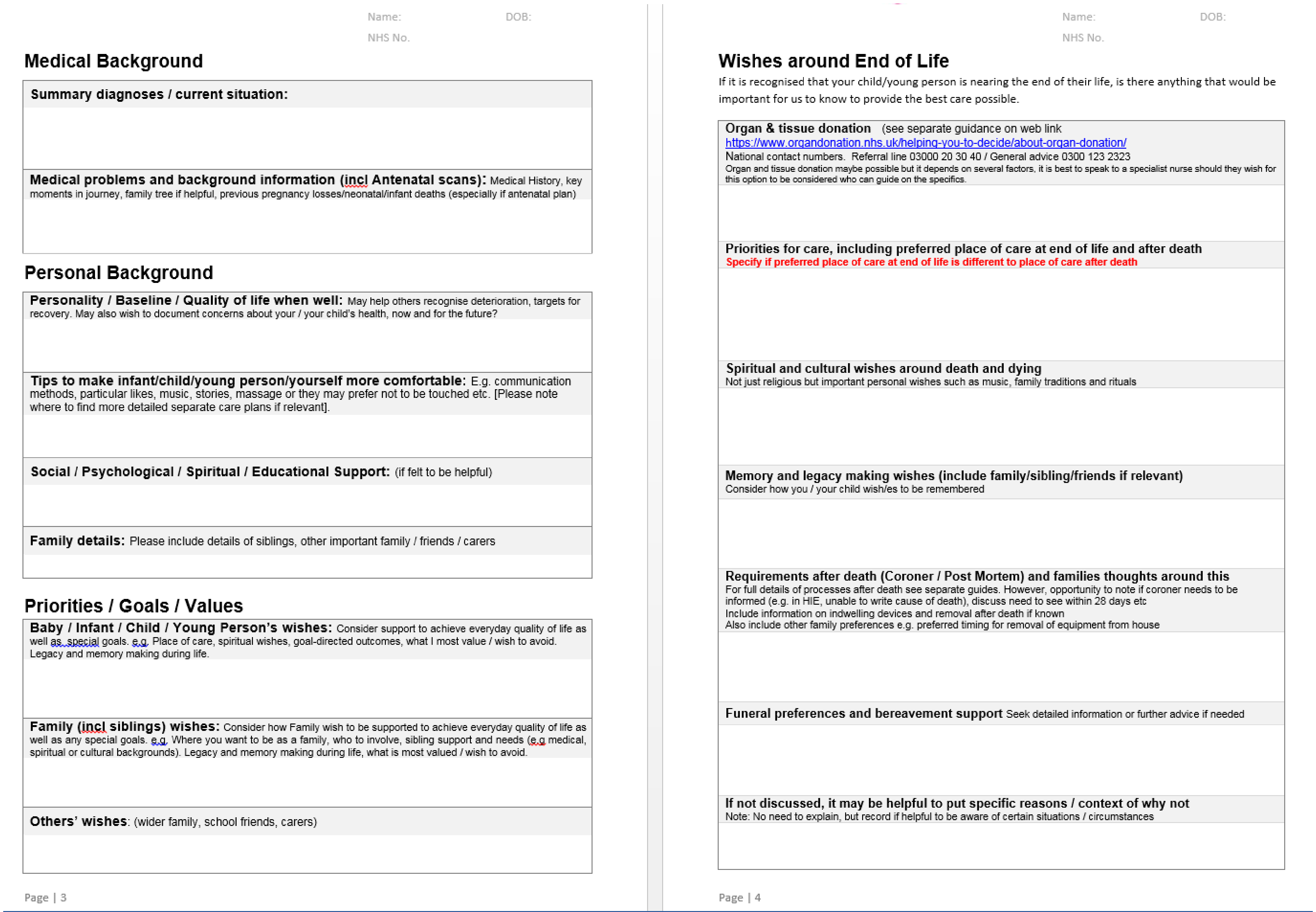


Name: DOB:

NHS No.

Medical Background

Summary diagnoses / current situation:

Medical problems and background information (incl Antenatal scans): Medical History, key moments in journey, family tree if helpful, previous pregnancy losses/neonatal/infant deaths (especially if antenatal plan)

Personal Background

Personality / Baseline / Quality of life when well: May help others recognise deterioration, targets for recovery. May also wish to document concerns about your / your child's health, now and for the future?

Tips to make infant/child/young person/yourself more comfortable: E.g. communication methods, particular likes, music, stories, massage or they may prefer not to be touched etc. [Please note where to find more detailed separate care plans if relevant].

Social / Psychological / Spiritual / Educational Support: (if felt to be helpful)

Family details: Please include details of siblings, other important family / friends / carers

Priorities / Goals / Values

Baby / Infant / Child / Young Person's wishes: Consider support to achieve everyday quality of life as well as special goals. e.g. Place of care, spiritual wishes, goal-directed outcomes, what I most value / wish to avoid. Legacy and memory making during life.

Family (incl siblings) wishes: Consider how Family wish to be supported to achieve everyday quality of life as well as any special goals. e.g. Where you want to be as a family, who to involve, sibling support and needs (e.g medical, spiritual or cultural backgrounds). Legacy and memory making during life, what is most valued / wish to avoid.

Others' wishes: (wider family, school friends, carers)

Name: DOB:

NHS No.

Wishes around End of Life

If it is recognised that your child/young person is nearing the end of their life, is there anything that would be important for us to know to provide the best care possible.

Organ & tissue donation (see separate guidance on web link https://www.organdonation.nhs.uk/helping-you-to-decide/about-organ-donation/

National contact numbers. Referral line 03000 20 30 40 / General advice 0300 123 2323

Organ and tissue donation maybe possible but it depends on several factors, it is best to speak to a specialist nurse should they wish for this option to be considered who can guide on the specifics.

Priorities for care, including preferred place of care at end of life and after death

Specify if preferred place of care at end of life is different to place of care after death

Spiritual and cultural wishes around death and dying

Not just religious but important personal wishes such as music, family traditions and rituals

Memory and legacy making wishes (include family/sibling/friends if relevant)

Consider how you / your child wish/es to be remembered

Requirements after death (Coroner / Post Mortem) and families thoughts around this

For full details of processes after death see separate guides. However, opportunity to note if coroner needs to be informed (e.g. in HIE, unable to write cause of death), discuss need to see within 28 days etc

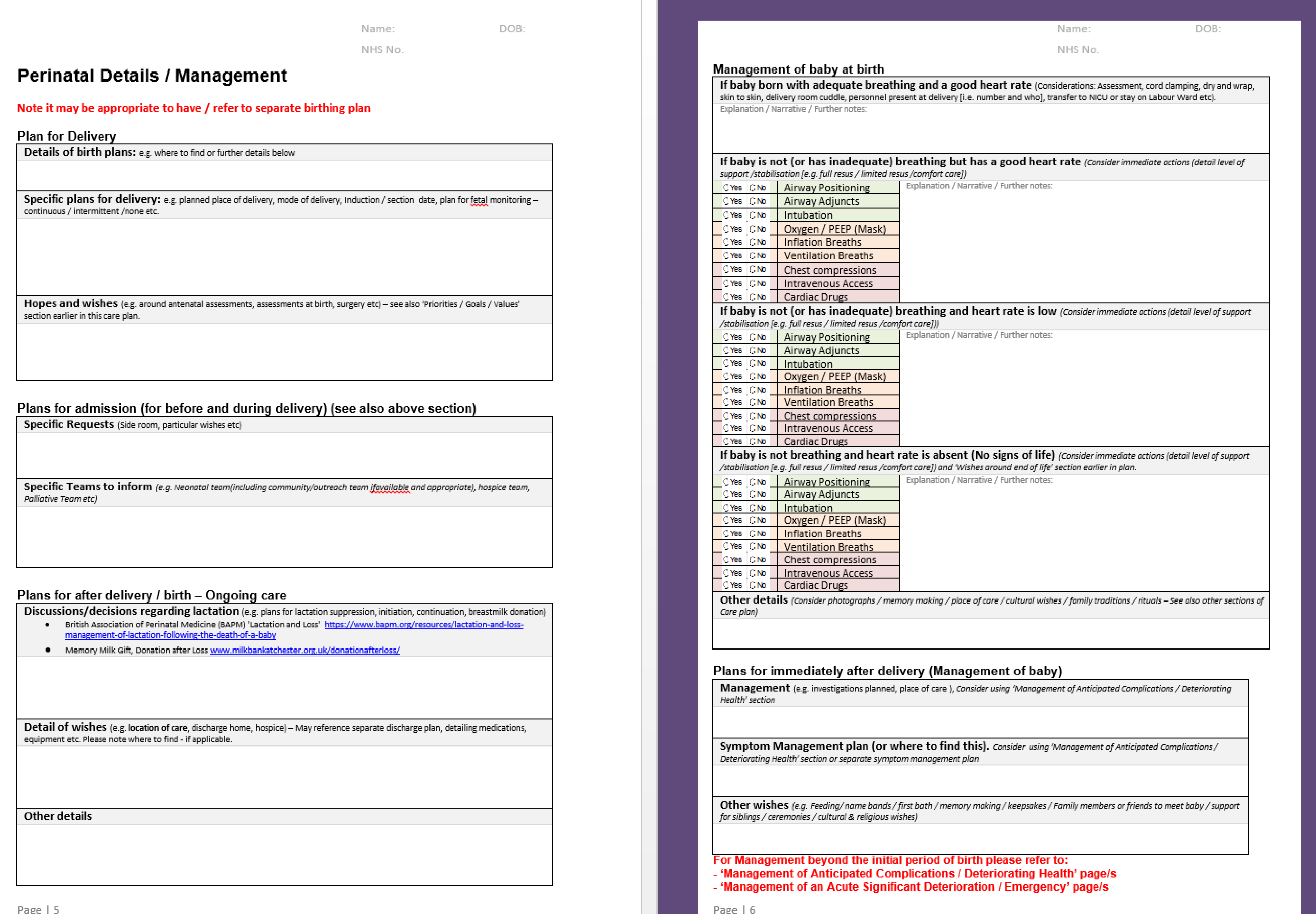
Include information on indwelling devices and removal after death if known

Also include other family preferences e.g. preferred timing for removal of equipment from house

Funeral preferences and bereavement support Seek detailed information or further advice if needed

If not discussed, it may be helpful to put specific reasons / context of why not

Note: No need to explain, but record if helpful to be aware of certain situations / circumstances



Perinatal Details / Management

Note it may be appropriate to have / refer to separate birthing plan

Plan for Delivery

Details of birth plans: e.g. where to find or further details below

Specific plans for delivery: e.g. planned place of delivery, mode of delivery, Induction / section date, plan for fetal monitoring – continuous / intermittent /none etc.

Hopes and wishes (e.g. around antenatal assessments, assessments at birth, surgery etc) – see also 'Priorities / Goals / Values' section earlier in this care plan.

Plans for admission (for before and during delivery) (see also above section)

Specific Requests (Side room, particular wishes etc)

Specific Teams to inform *(e.g. Neonatal team(including community/outreach team ifavailable and appropriate), hospice team, Palliative Team etc)*

Plans for after delivery / birth – Ongoing care

Discussions/decisions regarding lactation (e.g. plans for lactation suppression, initiation, continuation, breastmilk donation)

- British Association of Perinatal Medicine (BAPM) 'Lactation and Loss' https://www.bapm.org/resources/lactation-and-loss-management-of-lactation-following-the-death-of-a-baby
- Memory Milk Gift, Donation after Loss www.milkbankatchester.org.uk/donationafterloss/

Detail of wishes (e.g. **location of care**, discharge home, hospice) – May reference separate discharge plan, detailing medications, equipment etc. Please note where to find - if applicable.

Other details

Management of baby at birth

If baby born with adequate breathing and a good heart rate (Considerations: Assessment, cord clamping, dry and wrap, skin to skin, delivery room cuddle, personnel present at delivery [i.e. number and who], transfer to NICU or stay on Labour Ward etc).

Explanation / Narrative / Further notes:

If baby is not (or has inadequate) breathing but has a good heart rate *(Consider immediate actions (detail level of support /stabilisation [e.g. full resus / limited resus /comfort care])*

○ Yes	○ No	Airway Positioning	Explanation / Narrative / Further notes:
○ Yes	○ No	Airway Adjuncts	
○ Yes	○ No	Intubation	
○ Yes	○ No	Oxygen / PEEP (Mask)	
○ Yes	○ No	Inflation Breaths	
○ Yes	○ No	Ventilation Breaths	
○ Yes	○ No	Chest compressions	
○ Yes	○ No	Intravenous Access	
○ Yes	○ No	Cardiac Drugs	

If baby is not (or has inadequate) breathing and heart rate is low *(Consider immediate actions (detail level of support /stabilisation [e.g. full resus / limited resus /comfort care]))*

○ Yes	○ No	Airway Positioning	Explanation / Narrative / Further notes:
○ Yes	○ No	Airway Adjuncts	
○ Yes	○ No	Intubation	
○ Yes	○ No	Oxygen / PEEP (Mask)	
○ Yes	○ No	Inflation Breaths	
○ Yes	○ No	Ventilation Breaths	
○ Yes	○ No	Chest compressions	
○ Yes	○ No	Intravenous Access	
○ Yes	○ No	Cardiac Drugs	

If baby is not breathing and heart rate is absent (No signs of life) *(Consider immediate actions (detail level of support /stabilisation [e.g. full resus / limited resus /comfort care]) and 'Wishes around end of life' section earlier in plan.*

○ Yes	○ No	Airway Positioning	Explanation / Narrative / Further notes:
○ Yes	○ No	Airway Adjuncts	
○ Yes	○ No	Intubation	
○ Yes	○ No	Oxygen / PEEP (Mask)	
○ Yes	○ No	Inflation Breaths	
○ Yes	○ No	Ventilation Breaths	
○ Yes	○ No	Chest compressions	
○ Yes	○ No	Intravenous Access	
○ Yes	○ No	Cardiac Drugs	

Other details *(Consider photographs / memory making / place of care / cultural wishes / family traditions / rituals – See also other sections of Care plan)*

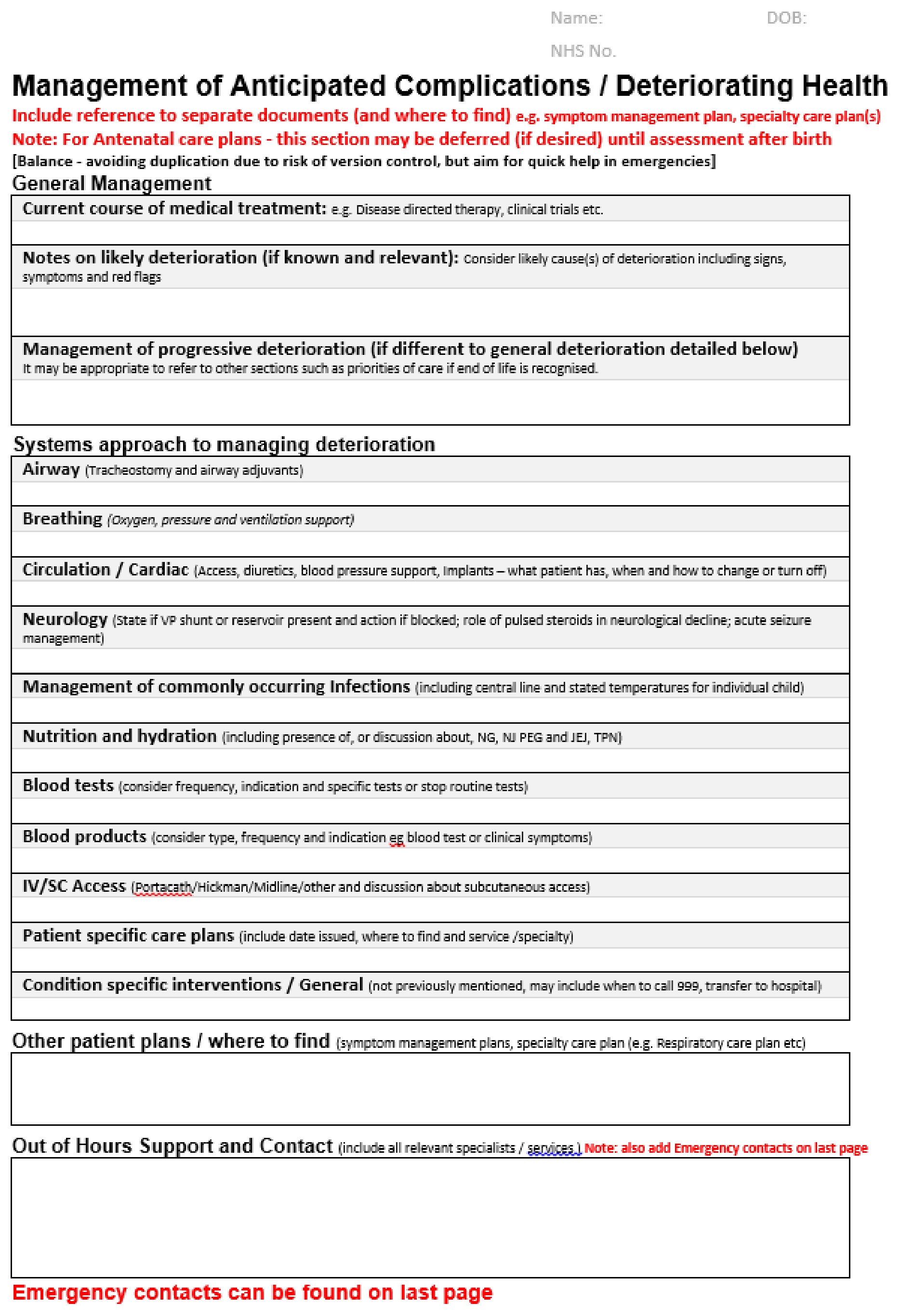
Plans for immediately after delivery (Management of baby)

Management (e.g. investigations planned, place of care), *Consider using 'Management of Anticipated Complications / Deteriorating Health' section*

Symptom Management plan (or where to find this). *Consider using 'Management of Anticipated Complications / Deteriorating Health' section or separate symptom management plan*

Other wishes *(e.g. Feeding/ name bands / first bath / memory making / keepsakes / Family members or friends to meet baby / support for siblings / ceremonies / cultural & religious wishes)*

For Management beyond the initial period of birth please refer to:
- 'Management of Anticipated Complications / Deteriorating Health' page/s
- 'Management of an Acute Significant Deterioration / Emergency' page/s



Name: DOB:

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Management of Anticipated Complications / Deteriorating Health

Include reference to separate documents (and where to find) e.g. symptom management plan, specialty care plan(s)

Note: For Antenatal care plans - this section may be deferred (if desired) until assessment after birth

[Balance - avoiding duplication due to risk of version control, but aim for quick help in emergencies]

General Management

Current course of medical treatment: e.g. Disease directed therapy, clinical trials etc.

Notes on likely deterioration (if known and relevant): Consider likely cause(s) of deterioration including signs, symptoms and red flags

Management of progressive deterioration (if different to general deterioration detailed below)
It may be appropriate to refer to other sections such as priorities of care if end of life is recognised.

Systems approach to managing deterioration

Airway (Tracheostomy and airway adjuvants)

Breathing *(Oxygen, pressure and ventilation support)*

Circulation / Cardiac (Access, diuretics, blood pressure support, Implants – what patient has, when and how to change or turn off)

Neurology (State if VP shunt or reservoir present and action if blocked; role of pulsed steroids in neurological decline; acute seizure management)

Management of commonly occurring Infections (including central line and stated temperatures for individual child)

Nutrition and hydration (including presence of, or discussion about, NG, NJ PEG and JEJ, TPN)

Blood tests (consider frequency, indication and specific tests or stop routine tests)

Blood products (consider type, frequency and indication eg blood test or clinical symptoms)

IV/SC Access (Portacath/Hickman/Midline/other and discussion about subcutaneous access)

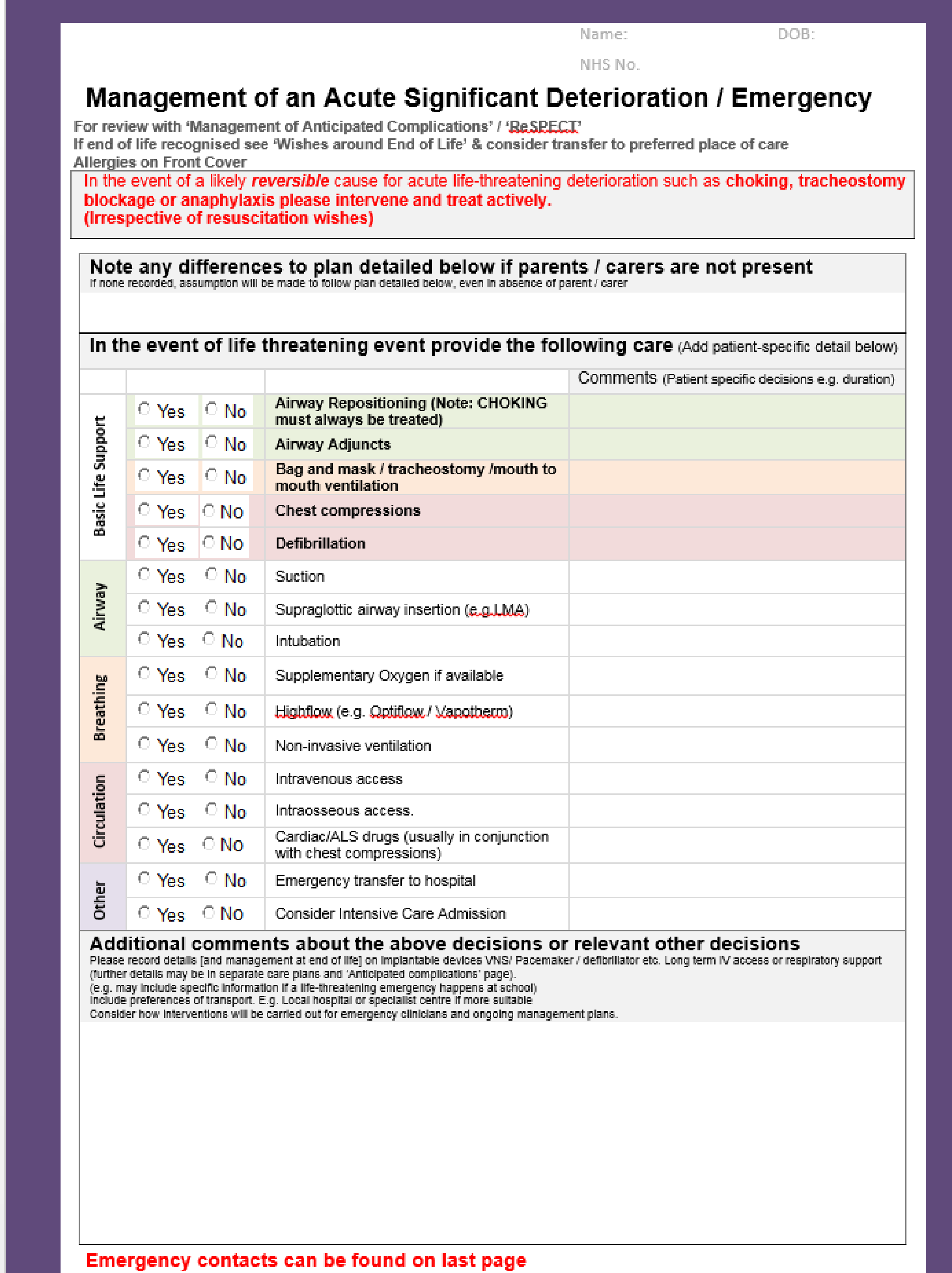
Patient specific care plans (include date issued, where to find and service /specialty)

Condition specific interventions / General (not previously mentioned, may include when to call 999, transfer to hospital)

Other patient plans / where to find (symptom management plans, specialty care plan (e.g. Respiratory care plan etc)

Out of Hours Support and Contact (include all relevant specialists / services.) Note: also add Emergency contacts on last page

Emergency contacts can be found on last page



Name: DOB:

NHS No.

Management of an Acute Significant Deterioration / Emergency

For review with 'Management of Anticipated Complications' / 'ReSPECT'
If end of life recognised see 'Wishes around End of Life' & consider transfer to preferred place of care
Allergies on Front Cover

In the event of a likely ***reversible*** cause for acute life-threatening deterioration such as **choking, tracheostomy blockage or anaphylaxis please intervene and treat actively.**
(Irrespective of resuscitation wishes)

Note any differences to plan detailed below if parents / carers are not present

If none recorded, assumption will be made to follow plan detailed below, even in absence of parent / carer

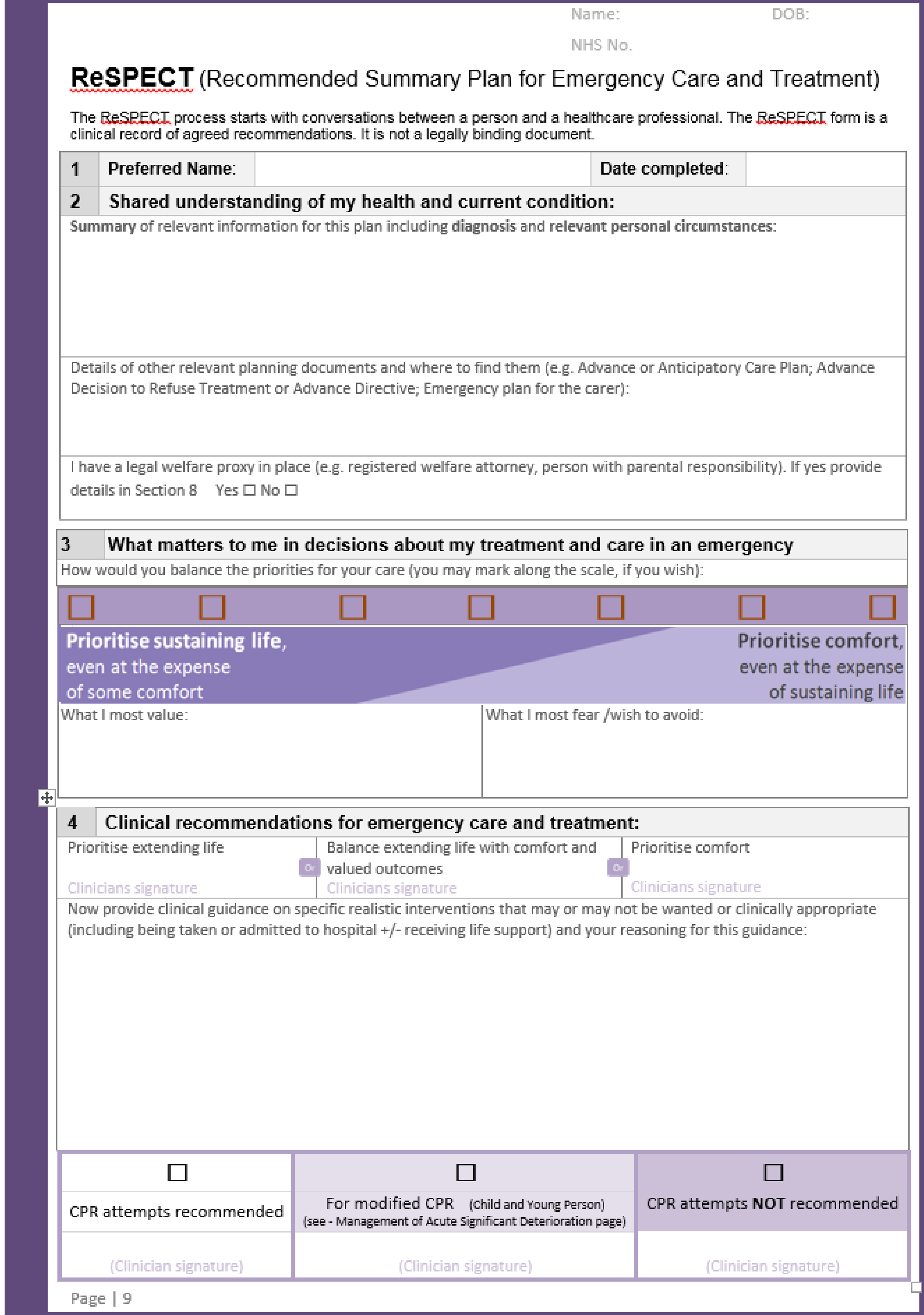
In the event of life threatening event provide the following care (Add patient-specific detail below)

				Comments (Patient specific decisions e.g. duration)
Basic Life Support	○ Yes	○ No	**Airway Repositioning (Note: CHOKING must always be treated)**	
	○ Yes	○ No	**Airway Adjuncts**	
	○ Yes	○ No	**Bag and mask / tracheostomy /mouth to mouth ventilation**	
	○ Yes	○ No	**Chest compressions**	
	○ Yes	○ No	**Defibrillation**	
Airway	○ Yes	○ No	Suction	
	○ Yes	○ No	Supraglottic airway insertion (e.g.LMA)	
	○ Yes	○ No	Intubation	
Breathing	○ Yes	○ No	Supplementary Oxygen if available	
	○ Yes	○ No	Highflow (e.g. Optiflow / Vapotherm)	
	○ Yes	○ No	Non-invasive ventilation	
Circulation	○ Yes	○ No	Intravenous access	
	○ Yes	○ No	Intraosseous access.	
	○ Yes	○ No	Cardiac/ALS drugs (usually in conjunction with chest compressions)	
Other	○ Yes	○ No	Emergency transfer to hospital	
	○ Yes	○ No	Consider Intensive Care Admission	

Additional comments about the above decisions or relevant other decisions

Please record details [and management at end of life] on implantable devices VNS/ Pacemaker / defibrillator etc. Long term IV access or respiratory support (further details may be in separate care plans and 'Anticipated complications' page).
(e.g. may include specific information if a life-threatening emergency happens at school)
Include preferences of transport. E.g. Local hospital or specialist centre if more suitable
Consider how interventions will be carried out for emergency clinicians and ongoing management plans.

Emergency contacts can be found on last page



Name: DOB:

NHS No.

ReSPECT (Recommended Summary Plan for Emergency Care and Treatment)

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.

1	**Preferred Name**:		**Date completed**:	

2 Shared understanding of my health and current condition:

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

Details of other relevant 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

How would you balance the priorities for your care (you may mark along the scale, if you wish):

☐ ☐ ☐ ☐ ☐ ☐ ☐

Prioritise sustaining life, even at the expense of some comfort	**Prioritise comfort,** even at the expense of sustaining life
What I most value:	What I most fear /wish to avoid:

4 Clinical recommendations for emergency care and treatment:

Prioritise extending life Clinicians signature	Or	Balance extending life with comfort and valued outcomes Clinicians signature	Or	Prioritise comfort Clinicians 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	For modified CPR (Child and Young Person) (see - Management of Acute Significant Deterioration page)	CPR attempts **NOT** recommended
(Clinician signature)	(Clinician signature)	(Clinician signature)

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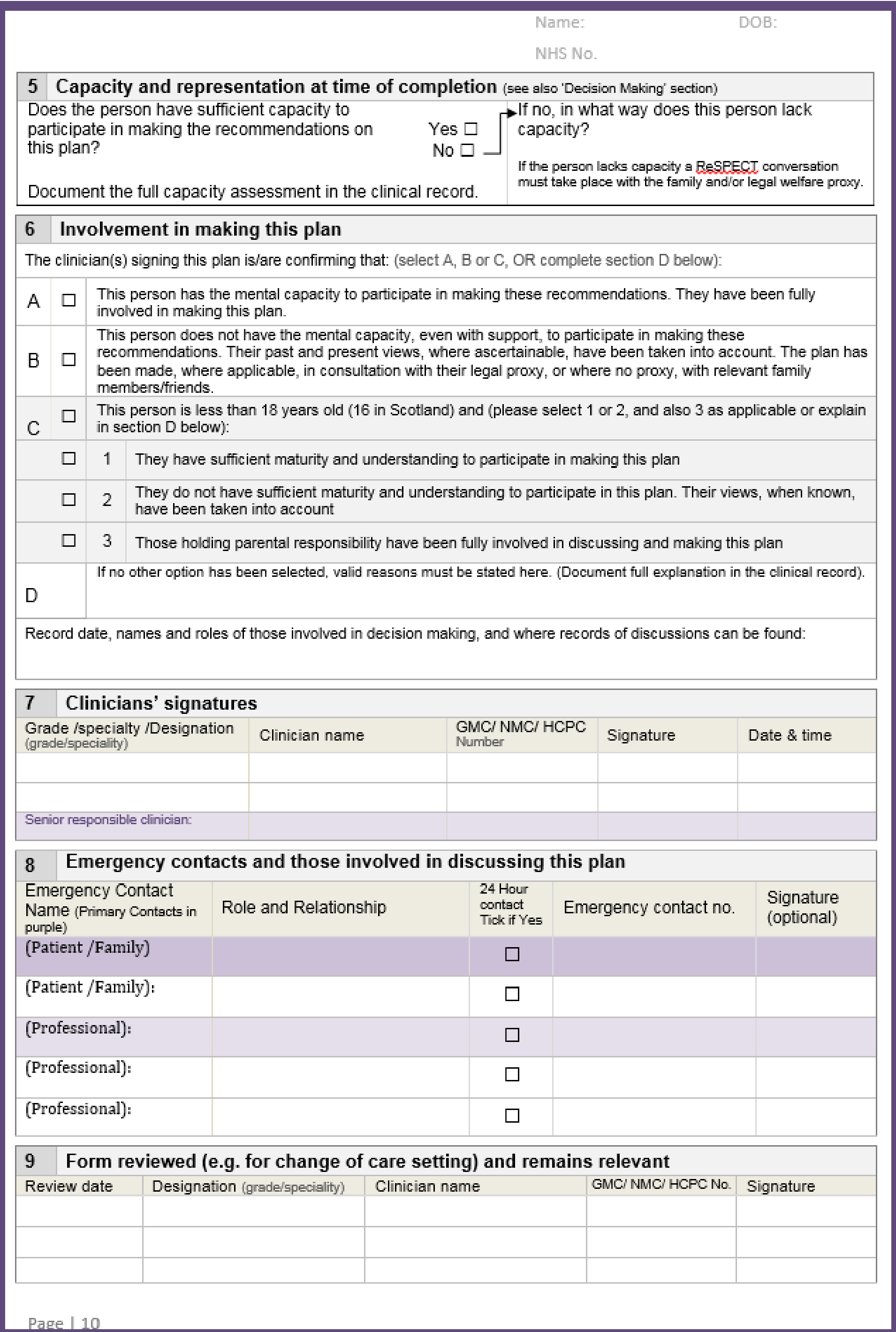

Name: DOB:

NHS No.

5 Capacity and representation at time of completion (see also 'Decision Making' section)

Does the person have sufficient capacity to participate in making the recommendations on this plan? Yes ☐ No ☐ Document the full capacity assessment in the clinical record.	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 making 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).

Record date, names and roles of those involved in decision making, and where records of discussions can be found:

7 Clinicians' signatures

Grade /specialty /Designation (grade/speciality)	Clinician name	GMC/ NMC/ HCPC Number	Signature	Date & time
Senior responsible clinician:				

8 Emergency contacts and those involved in discussing this plan

Emergency Contact Name (Primary Contacts in purple)	Role and Relationship	24 Hour contact Tick if Yes	Emergency contact no.	Signature (optional)
(Patient /Family)		☐		
(Patient /Family):		☐		
(Professional):		☐		
(Professional):		☐		
(Professional):		☐		

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

Review date	Designation (grade/speciality)	Clinician name	GMC/ NMC/ HCPC No.	Signature

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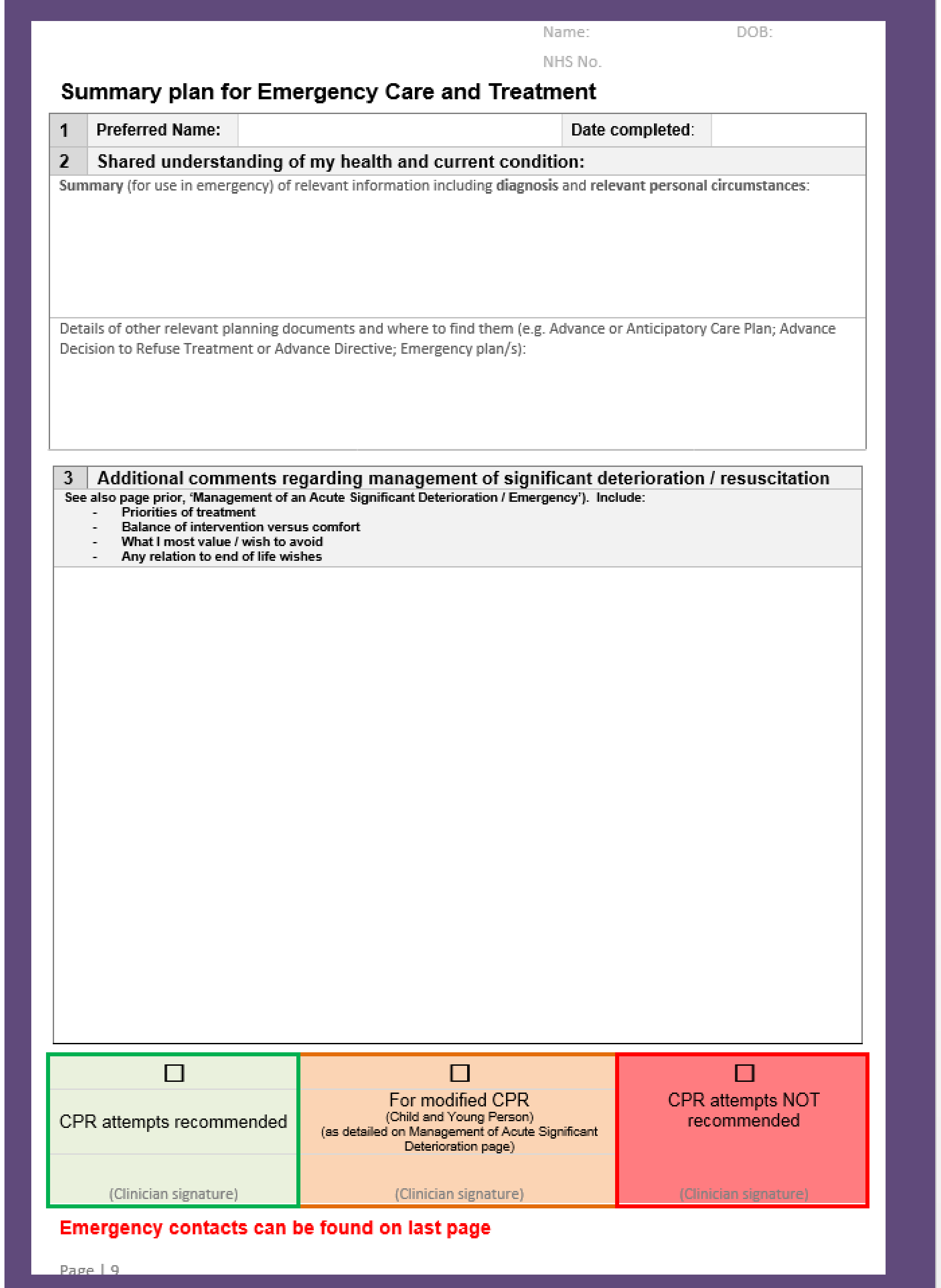


Name: DOB:

NHS No.

Summary plan for Emergency Care and Treatment

1	**Preferred Name:**		**Date completed**:	

2 Shared understanding of my health and current condition:

Summary (for use in emergency) of relevant information including **diagnosis** and **relevant personal circumstances**:

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

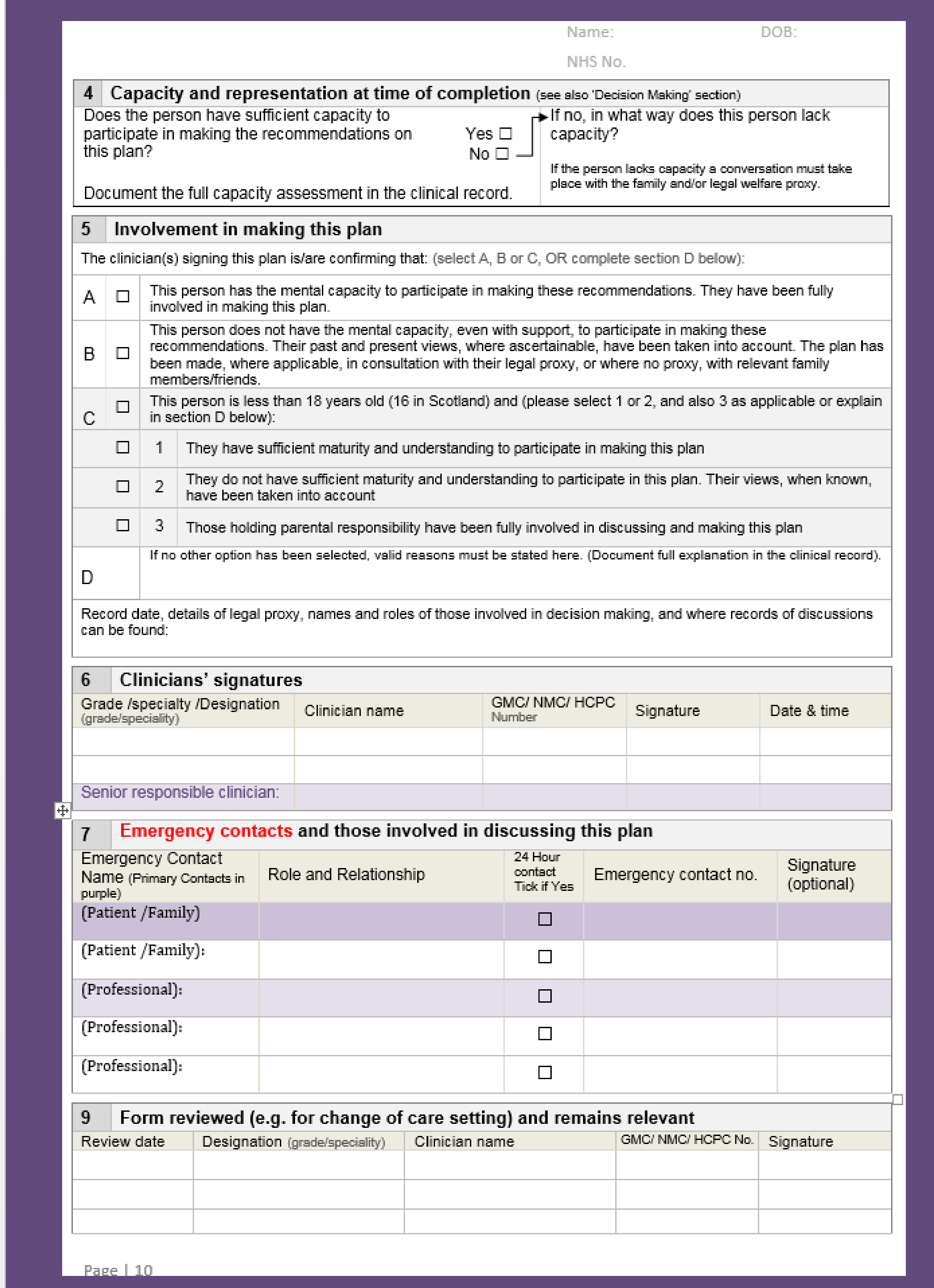
3 Additional comments regarding management of significant deterioration / resuscitation

See also page prior, 'Management of an Acute Significant Deterioration / Emergency'). Include:

- **Priorities of treatment**
- **Balance of intervention versus comfort**
- **What I most value / wish to avoid**
- **Any relation to end of life wishes**

☐	☐	☐
CPR attempts recommended	For modified CPR (Child and Young Person) (as detailed on Management of Acute Significant Deterioration page)	CPR attempts NOT recommended
(Clinician signature)	(Clinician signature)	(Clinician signature)

Emergency contacts can be found on last page



Name: DOB:

NHS No.

4 Capacity and representation at time of completion (see also 'Decision Making' section)

Does the person have sufficient capacity to participate in making the recommendations on this plan? Yes ☐ No ☐ → If no, in what way does this person lack capacity?

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

Document the full capacity assessment in the clinical record.

5 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 making 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).

Record date, details of legal proxy, names and roles of those involved in decision making, and where records of discussions can be found:

6 Clinicians' signatures

Grade /specialty /Designation (grade/speciality)	Clinician name	GMC/ NMC/ HCPC Number	Signature	Date & time
Senior responsible clinician:				

7 Emergency contacts and those involved in discussing this plan

Emergency Contact Name (Primary Contacts in purple)	Role and Relationship	24 Hour contact Tick if Yes	Emergency contact no.	Signature (optional)
(Patient /Family)		☐		
(Patient /Family):		☐		
(Professional):		☐		
(Professional):		☐		
(Professional):		☐		

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

Review date	Designation (grade/speciality)	Clinician name	GMC/ NMC/ HCPC No.	Signature

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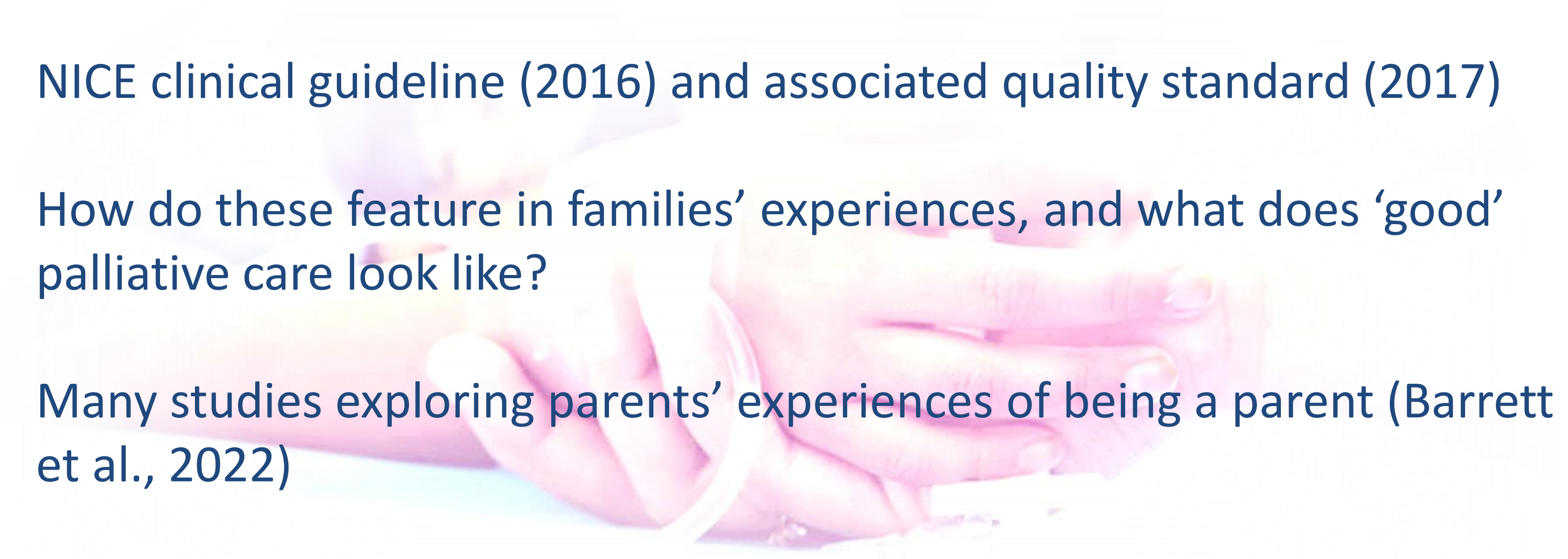
The Martin House RESEARCH CENTRE

In partnership with UNIVERSITY of York

What does 'good' palliative care look like for children and young people? A qualitative study of parents' experiences and perspectives

Diana Fields, Jo Taylor, Lorna Fraser, Julia Hackett

Background



- Around 4,500 infants and children die in England and Wales every year (Petrou et al., 2014)
- Known barriers to accessing palliative care (Constantinou et al., 2019; Noyes et al., 2013)
- NICE clinical guideline (2016) and associated quality standard (2017)
- How do these feature in families' experiences, and what does 'good' palliative care look like?
- Many studies exploring parents' experiences of being a parent (Barrett et al., 2022)

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NICE quality standards for end-of-life care for infants, children and young people

Statement 1	Infants, children and young people with a life-limiting condition and their parents or carers are **involved in developing an advance care plan**.
Statement 2	Infants, children and young people with a life-limiting condition **have a named medical specialist** who leads and coordinates their care.
Statement 3	Infants, children and young people with a life-limiting condition and their parents or carers are given **information about emotional and psychological support**, including how to access it.
Statement 4	Infants, children and young people with a life-limiting condition are cared for by a **multidisciplinary team that includes members of the specialist paediatric palliative care team**.
Statement 5	Parents or carers of infants, children and young people approaching the end-of-life are offered **support for grief and loss** when their child is nearing the end of their life and after their death.
Statement 6	Infants, children and young people approaching the end-of-life and being cared for at home have **24-hour access to both children's nursing care and advice from a consultant** in paediatric palliative care.

Methods

- Multi-site qualitative study
- In-depth semi-structured interviews:
    - parents or legal guardians of CYP (aged 0-17 years) who were receiving palliative care;
    - or bereaved parents (between 3 months and 3 years ago);
    - palliative care had been discussed
- Parents offered choice of video call or telephone interview (data collected during COVID-19 pandemic)
- Data were analysed using reflexive thematic analysis

Results

- Charity organisations social media, 4 hospices, and 1 hospital supported recruitment

- 16 interviews completed (9 video-call and 7 telephone)

- Mean interview length was 77mins

- 14 mothers and 3 fathers:
  - 7 bereaved parents
  - Age of children: 7 weeks – 17 years
  - 12 had siblings
  - 13 were engaged with a hospice
  - 15 had ACPs

NICE Statement 1: infants, children and young people with a life-limiting condition and their parents or carers are involved in ***developing an advance care plan***

Introducing an Advance Care Plan

- Lack of clear communication and avoidance of difficult conversations

- Need to be optimistic, focus on improving quality of life, rather than end-of-life

> The first time I met the palliative care consultant she had that brightness and sparkle about her, the same as the hospice. I think the introduction from her was in a very positive light. (0602)

- Timely conversations were important

> *She doesn't [have an ACP], but that is on our list of things to do, we've talked about looking at it, but it's been difficult because it's something that I want to do, but her mum won't want to do it. She doesn't feel comfortable, or like the idea of doing an ACP, because it seems, kind of, final, and it's not something she wants to think about. It was a very abstract idea, and at the time it didn't really bear any relation to the reality of our daughter being that ill. (0601)*

Developing and reviewing of Advance Care Plans

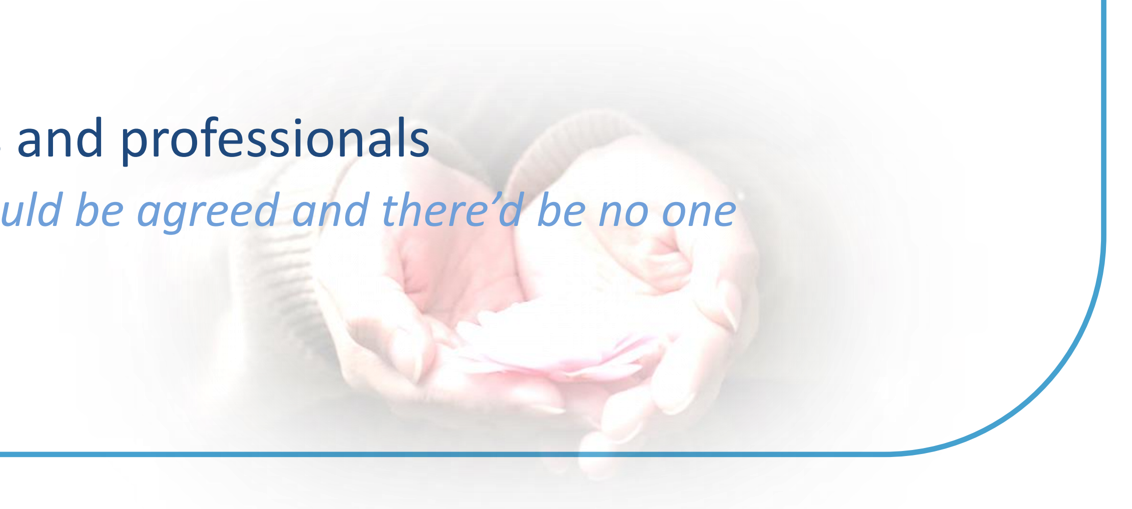
- Parents *advocating for and driving* their child's care

- Reduces fear of the unknown and brought a semblance of calm

  We welcome anything that is trying to plan round something that you can't control.... and his needs and his future is something we have no control over whatsoever. All that we can do is try and plan as best we can. So having a plan in place means that you have some semblance of control in a way. Having a plan means that you know at least people will do the right thing and it can happen quickly. You don't have to explain everything. It's I suppose, reassuring. (0414)

- ACPs mitigate conflicts between parents and professionals

  However heart-breaking that would be, it would be agreed and there'd be no one blaming you. (0510)



- For those with medical complexity, there was difficulty and a fight, to get and maintain services and support
- Parents whose babies had died felt "*very well supported and informed*" (0308)
- Important to encompass the whole family

  It's for us as a family unit, not just this is what [child] needs, but this is what the family needs, and the family's needs will help [child] achieve her needs by providing her a calmer, happier environment without additional stresses and worries of everything else. (0601)

NICE Statement 2: Infants, children and young people with a life-limiting condition have a ***named medical specialist who leads and coordinates their care***

Lack of a coordinator

- Numerous professionals and services involved, but *no key person in charge*

  My son would not have lived as long as he did without us taking some responsibility…we effectively case managed our child. (0606)

- Parents valued professionals supporting them in decision-making

  The paediatrician was extremely good at explaining the benefits and the drawbacks of certain offerings, certain interventions. He explained to us in a way we actually understood. We found him to be really excellent in making clear what our decisions would mean. But we always felt that we were the ones in charge in making those decisions. We never felt pushed... Everyone was always really respectful of our wishes. (0308)

- Contributing to multiagency meetings provided parents with "*more of a concrete plan about what things are available and what next steps to take*" (0601)

NICE Statement 3: Infants, children and young people with a life-limiting condition and their parents or carers are ***given information about emotional and psychological support, including how to access it***

Mixed experiences accessing support

- Some needed psychological support but were not offered this

  The doctors are sometimes matter of fact and very clinical, and the offer of, "do you need support afterwards", as in parents. After the conversation, say "do you need to talk to somebody", because sometimes that gets overlooked. Sometimes parents end up with a bombshell in their lap, their child is possibly going to die, and they just get left to deal with it. (0601)

- Where parents were offered support, this empowered them

- Parents valued memory-making activities before and after their child's death

  [Name of hospice] said to us from the very beginning that their support would never expire. It would always be available, we would always be a family. (0308)

NICE Statement 4: Infants, children and young people with a life-limiting condition are cared for by a ***multidisciplinary team that includes members of the specialist paediatric palliative care team***

‘Luck’ and ‘guilt’ accessing care

- Parents experienced a combination of emotions

  The hard thing is there are families out there that don’t get the referral through to the hospice and if we didn’t have the hospice I’m really not sure what we would do. There's no government funding for them and they provide an enormous service that is so exceptionally valuable for people. That’s done entirely out of funding they have to generate themselves. If we lived in another area, potentially we wouldn't get those services. (0414)

- Older children required unplanned for, longer term support, services and funding

- Multidisciplinary team working provided good palliative care

  We all sit around the table, and that has been really helpful, because a lot of the time it is always a fight, it is always a battle... But when you have a whole group of professionals sitting around a table, it keeps everybody on the same page. (0619)

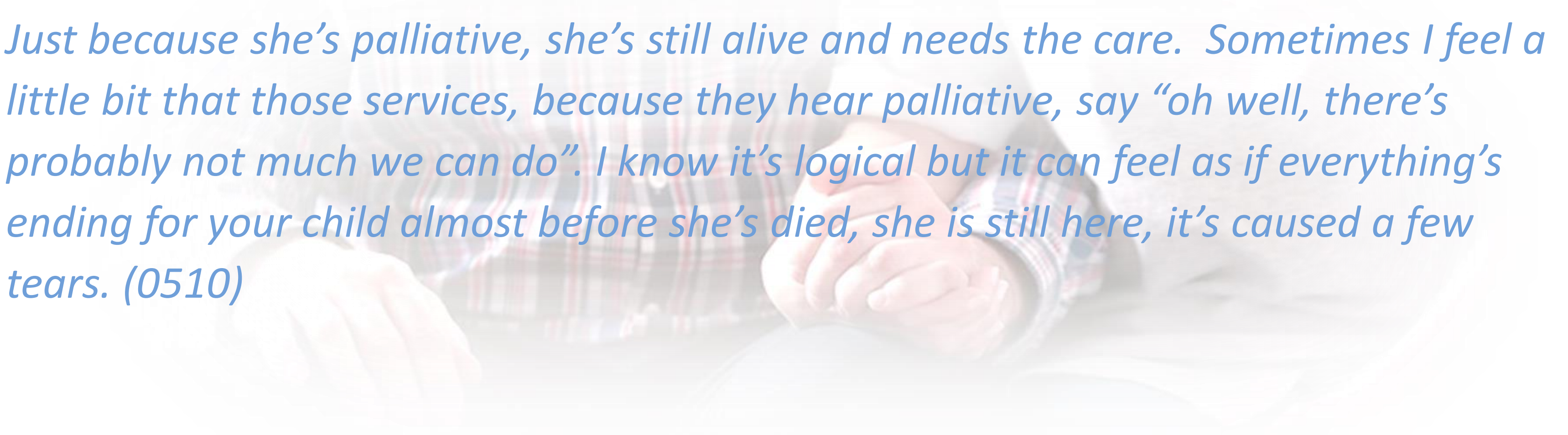
Treated like you matter

- Palliative care specialists skilled in having difficult conversations, treated parents with respect and compassion

  The people who work within those services are amazing because it must be a very difficult job to do. But it does make a massive difference to how we feel about it. Because somebody smiling at you, somebody cracking a joke, they work to make the best of what you have. (0414)

- Non-specialists could lack skills and confidence to navigate conversations

  Just because she's palliative, she's still alive and needs the care. Sometimes I feel a little bit that those services, because they hear palliative, say "oh well, there's probably not much we can do". I know it's logical but it can feel as if everything's ending for your child almost before she's died, she is still here, it's caused a few tears. (0510)



NICE Statement 5:Parents or carers of infants, children and young people approaching the end-of-life are ***offered support for grief and loss*** when their child is nearing the end of their life and after their death

Diverse experiences of support for grief and loss

- Mixed experiences of being offered and accessing bereavement support

  I asked for bereavement support and I was told that it was too early…And then my first telephone conversation with them was, "Well, do you really still need it?" because it was a year since she died. (0602)

- Making lasting memories of their child worked well

  I think on the first or second day we were there we did footprints with [name of child]. They took the little clay moulds of her hands and her feet which are just so beautiful. They helped us take photos of her first bath. We have access to the memorial garden, which we visited on her first birthday, it was lovely to be part of that. (0308)

NICE Statement 6: Infants, children and young people approaching the end-of-life and being cared for at home have ***24-hour access to both children's nursing care and advice from a consultant in paediatric palliative care***

Diverse perspectives of end-of-life care at home

- Choice over preferred place of care was important

  Keep her at home. It's where she loves, it's her domain, it's familiarity in her own environment that really helps her but also, I think the starkness of hospitals, it's not what you really want… We'd rather prefer to do it at home unless it got to a certain point that it was really unmanageable. (0510)

- 24/7 care was crucial to enabling preferred place of care

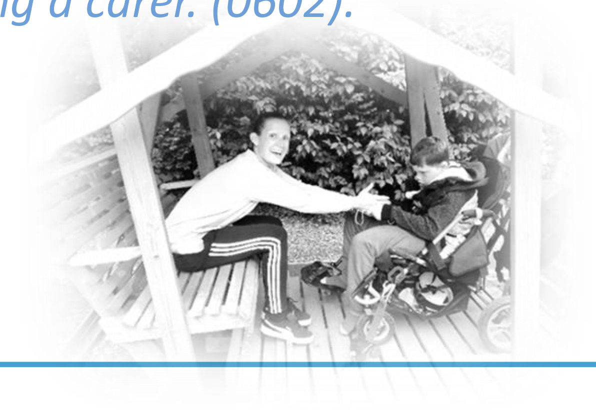
  I got comfort in the fact that people were there 24/7 to look after [child] and to provide the medication because [at home] they don't provide 24 hour care. They're just 9:00 to 5:00, so if we got [child] home then we would have to do the medications and stuff and I couldn't live with myself if I gave him the last shot of Morphine. I just never thought about it really, what that would mean. (0103)

- COVID-19 restrictions influenced preferred place of care

Parental unmet needs and wishes

- More information on resources and financial support
- Introduce palliative care in a consistent, timely and positive manner
- A named coordinator to help consistency and continuity
- At end-of-life, parents wished to be *parents* and move away from their role as carers

I was able to have quality time with [name of child]. And I could join in with all the activities as well. It was like being a mum, instead of being a carer. (0602).



Conclusion

- Considerable variations in parents' experiences
- Aspects of care not working adequately, or translating into practice
- Issues more prominent for parents of older children
- Parents' valued integrated, responsive, flexible palliative care, which enabled them to parent their child at end-of-life
- Good bereavement care starts before a child dies

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Understanding advance care planning: a survey of healthcare professionals in Northwest England

Dr Ben Hughes[1], Dr Matthew Philips[2], and Dr Vanessa Holme[3]

[1] Lecturer, University of Bolton

[2] Paediatric Registrar ST7, Royal Blackburn Hospital

[3] Consultant Paediatrician, East Lancashire Hospitals NHS Trust

Background

- Practice and the use of documentation in paediatric advance care planning is evolving and inconsistent across the United Kingdom (Fraser *et al.*, 2012; Kimmel *et al.*, 2015; NHS inform, 2022).
- The aim of advance care planning is to allow patients to share their personal wishes and goals for future care (Sudore *et al*., 2017; Hughes *et al*., 2022).
- Policy, procedures, and practice have historically focused on advance care planning with adults rather than with children and young people (Benini *et al*., 2013; Hughes *et al*., 2022).
- There are inconsistencies in the use of advance care planning with children and young people (Hughes *et al*., 2022).
- Consequently, there is a lack of understanding about how healthcare professionals view and use advance care planning for young people (Hughes *et al.*, 2022).

Why this is

https://openclipart.org/detail/286088/important

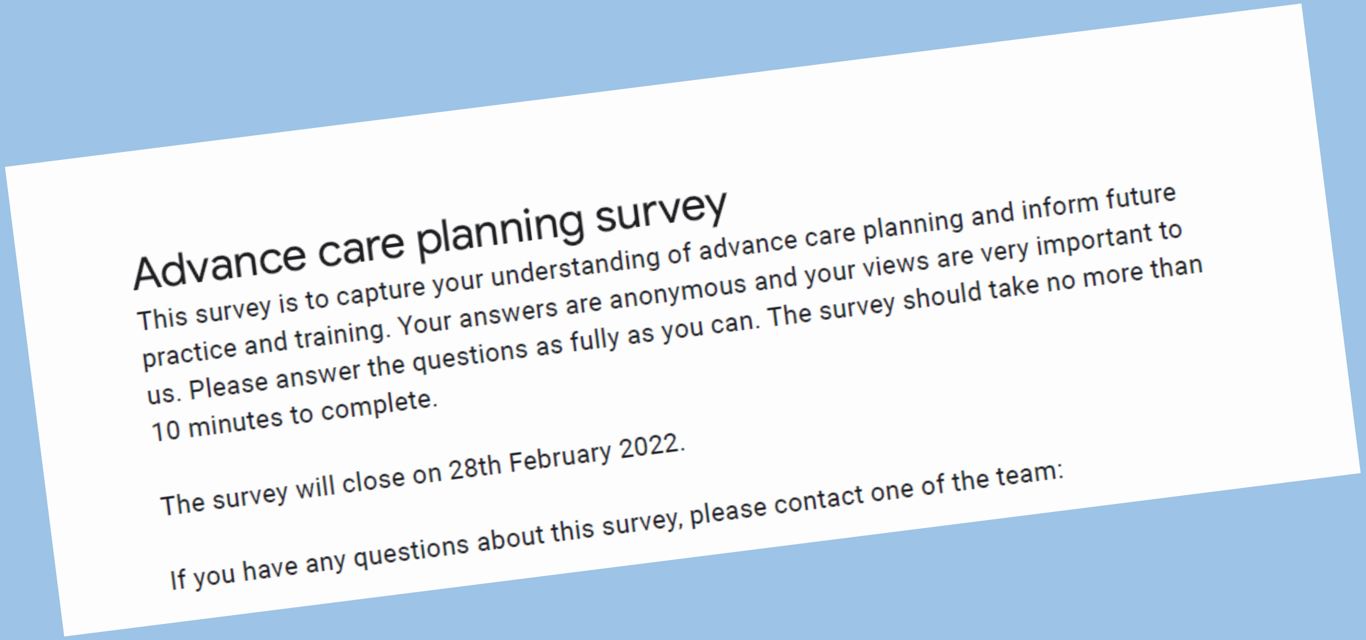
- Up to 99,000 CYP with a life-limiting or life-threatening condition in the United Kingdom may benefit from ACP (Fraser, L. K. *et al.*, 2020).

- Life expectancy of CYP with life-limiting or life-threatening conditions is also increasing (Fraser, J. *et al.*, 2010).

- Understanding ACP from the perspective of HCPs can help improve the experiences of the increasing number of CYP in the care planning process by supporting the initiation and use of ACP (Hughes *et al.*, 2022).

Method

- Convenience, purposive sampling methodology.
- An online questionnaire was used to collect data from healthcare professionals to understand their views and experiences of using advance care planning with children and young people.



Advance care planning survey

This survey is to capture your understanding of advance care planning and inform future practice and training. Your answers are anonymous and your views are very important to us. Please answer the questions as fully as you can. The survey should take no more than 10 minutes to complete.

The survey will close on 28th February 2022.

If you have any questions about this survey, please contact one of the team:

Results

- 122 completed questionnaires across Northwest England
- 5 themes identified in the data

Theme 1 – Understanding of ACP

- The most popular terms used to define ACP included ‘plan’ or ‘planning’; providing care; and including wishes.

‘[ACP is a] *document that includes the complexity of their situation to prevent them having to retell their story…*[but] *allowing them to them* [patients and family to] *concentrate on making the most of living time*’ (Participant 94).

- Broad consensus ACP should involve different people
- Significant a focus on end-of-life care.
- Legal basis to ACP?

https://openclipart.org/detail/330374/ive-got-it-17

Theme 2 – ACP in practice

- HCPs felt the key triggers are:
    - A change or deterioration in the illness/condition of the patient
    - Diagnosis or an illness/condition
    - When the patient initiates the conversation
    - A change in the patient's personal circumstances, such as the hospitalisation or death of a relative/friend
    - Routine review of the patient

- A variety of documentation is used
- Significant lack of confidence initiating and using ACP

https://www.flickr.com/photos/froboy/6514466773

Theme 3 – Professionals involved in ACP

- The most commonly identified professional job roles were consultants, nurses, doctors, hospice staff, community nurses/nursing team, the hospice/community palliative care team, the specialist nurses/nursing team, and paediatricians.
- Some HCPs recognised a non-clinical/non-medical role in ACP
- ACP was generally recognised as a multi-disciplinary process
- HCPs felt ACP should involve a wider multi-professional team

https://www.publicdomainpictures.net/en/view-image.php?image=372467&picture=we-are-a-team

Theme 4 - Training

- The most popular training was related to a specific illness/condition and was offered online, face-to-face, close to where HCPs worked, and delivered by someone they knew.
- Lack of knowledge of accessible training
- HCPs would like a range of training including, but not limited to:
    - Completed forms
    - Mentoring and training from experienced colleagues
    - Information
    - How to have difficult conversations

https://www.picpedia.org/keyboard/a/accredited-training-courses.html

Theme 5 – Facilitators and barriers to ACP

Facilitators	Barriers
Up-to-date information and knowledge	Organisational constraints
Professional skills and personal qualities	Professional relationships

https://freesvg.org/vector-drawing-of-thumbsup-smiley-face

https://publicdomainvectors.org/en/free-clipart/Thumbs-down-smiley-vector-image/7286.html

Conclusion

- HCPs would benefit from additional training to minimise misperceptions of ACP and instil greater confidence in discussing and documenting wishes
- ACP may be more widely used and better communicated with a greater input from a larger and more proactive MDT
- Standardised documentation would also help develop confidence and understanding the process in discussing and documenting ACP and the sharing of plans
- Need to recognise the value of all professional roles in the MDT

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Contact

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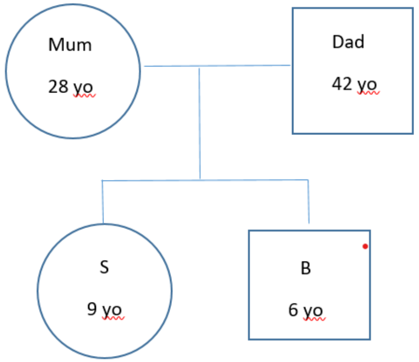
Lost in Translation: Working with interpreters in Paediatric Palliative Care

Jennifer Melville, Clinical Psychologist
Katie Lewis, Palliative Care Nurse
Diana Paediatric Palliative Care Team, Newham

East London NHS
NHS Foundation Trust

Case Context



- Child is now 9 year old girl, 7 years old when moved into our area
- Has hyperplastic left heart syndrome and parents moved from Austria to UK in December 2019 expecting the third stage heart operation to occur at GOSH.
- Referral into Diana Paediatric Palliative Care team in February 2020. Initially engaged with nursing team and then with psychology team.
- At original time of referral, neither parent spoke English, although mum had some oral comprehension.

- J had echo in April 2020 and GOSH Cardiac Team decided surgery was too risky given condition of heart.
- Parents informed that J could not have operation due to deterioration of heart. This happened via video call as the pandemic restrictions were in place. At the time, the family were living in a basement apartment with mould and infestations and no furniture. The context for these consultations was really difficult, and the children were in the next room and able to overhear their parents’ distress if not the details of the conversations.

Impact

On parents:

High levels of parent distress and confusion as felt that the surgery had been scheduled for Spring 2020.

Described feeling abandoned and like their child was being left to die.

Repeatedly saying to professionals "you promised to do the operation". Parents expressing their belief that "doctors have changed their minds, they are doing something different than what they said they would."

In each subsequent medical consultation, parents would return to the first conversation and express confusion, "why aren't they doing the operation?"

On professionals:

Clinicians distressed by high levels of parental distress.

Expressing frustration that parents were "not understanding" or in "denial" about child's condition, frustration that same information had to be repeated in each consultation with same levels of parental (particularly maternal) distress in each session.

Impression amongst professionals that **"each time was like it was the first time parents were hearing this information".**

“It keeps being like it is the first time hearing the information”

- Noticed that it was very difficult for the interpreter to work on zoom with the family given high levels of distress and poor connectivity.
- Noticed that at times professionals spoke for a long period of time and the interpreter appeared to struggle to remember all of the content and also seemed to struggle with the painful things that were being discussed.
- We became curious about “how much has been understood by mum and dad in these and earlier consultations?”; “how difficult is it for the interpreter to discuss risk to the child when death and dying are around?”; “how prepared were the interpreters for the content of what they were going to discuss?”
- We genuinely started to wonder: “is it the first time that parents are hearing that the operation was always conditional on the state of J’s heart?, did this information get lost in translation in earlier consultations?”

Psychology Sessions

- Started to explore how interpretation was working for parents
- Key practical themes that emerged:
  - Often the interpreter speaks a dialect less familiar to parents and they struggle to understand and be understood.
  - Difficult that it is a different interpreter in each session.
  - If don’t understand interpreter, do not want to say this because they do not want to hurt interpreters feelings.
  - Noticed that doctors speak for a long time and then interpreter says a sentence or two, parents anxious about what is missed.
  - Don’t want to complain because they “do not want to make trouble” and have this affect how professionals act towards their daughter.
  - Very grateful for help, unsure how to ask for something different than being offered.

Broader themes

- **Power** – Parents feeling that if professionals become annoyed with them for being “demanding” they will withdraw care
- **Entitlement** – Parents not understanding what is reasonable to expect/ask for
- **Gratitude** – Parents showing and expressing heartfelt gratitude for care of their child and wanting professionals to know that they are grateful (i.e., not critical)
- **Fear** – If parents get things wrong, it will have an impact on care child is offered.

What did we do to address some of these difficulties?

- Found an interpreter that both parents understood and trusted and have tried to only book that interpreter, and provided details for other professionals.
- Made professionals aware the meetings would take longer with interpreter involvement.
- Explored concerns about alienating professionals by “being demanding” and came up with the idea of a “letter of introduction” to send to services prior to appointments explaining how they best work with interpreters and professionals.
- Parents, particularly Dad, decided that they needed to help professionals understand that they need to speak in chunks and allow time for interpreter to speak. At first this was very uncomfortable, now Dad is very confident about explaining at the time of introductions that this is best for their understanding.

Where are we at now?

- Overall, parents have a better level of understanding in all of the different meetings they attend.
- Dad remains very confident about stopping professionals when they are speaking for too long, including me in our psychology sessions (he raises his eye brows at me).
- Recently parents had a cardiology consultation without an interpreter and the outcome of this appointment was a return to high levels of confusion, misunderstanding and parental distress. Parents have subsequently returned to their confusion and distress about why the third stage operation was not offered in April 2020. This appointment seemed to re-create some of the professional and parental frustration about "getting information for the first time" again.

- Parents had stopped sending “letter of introduction” before appointments but will do so again as result of their confusion and distress after this appointment.
- Issue unresolved: When I asked why parents did not feel able to say that they “must have an interpreter”, they explained “that is our time for our child to be seen by the cardiologist and if we don’t go to the appointment we don’t know when they will send us another one. We were afraid she would deteriorate and we would be responsible because we refused to have the appointment without an interpreter.”

Things parents would like to share with us all

- Paediatric palliative care appointments involve discussions about highly painful topics and sometimes highly technical aspects of a child’s condition. Distress, anxiety and fear are around in these conversations which can get in the way of understanding, this is even more challenging when the conversation is happening in a second language.
- It is important for professionals to hold in mind how power and gratitude may stop parents explaining what they need.
- Interpretation takes a lot longer, please book longer appointments.
- The most effective intervention for us was supporting us to explain to professionals what then need (the “letter of introduction” and setting out how talking is most useful to them in chunks, etc.)
- When the above are not taken into consideration, “this results in us being confused and not understanding and this results in us being afraid and panicking.”

Appendix: “Letter of Introduction”

Dear Professionals

We are writing to ask for your help. Thank you very much for helping us and caring for J. We are getting more familiar with big meetings with many professionals and are starting to understand what would be helpful to us.

We would like to request if the following things could happen in our meetings to help us understand what is being talked about:

- We always need a professional interpreter.
- We find it easiest to really understand if professionals:
  - Introduce the topic area that we are about to discuss
  - Speak in short sentences and, most importantly, pause to allow the interpreter to tell us what has been said. We really want to understand everything you are saying, so if you take breaks the interpreter has a better chance of remembering everything and telling us.
  - When professionals talk amongst themselves, that the interpreter is given time to relay to us what has been said.

We know how hard you all work to help J and us and we really want to understand as much as possible so we can help in planning but also problem solving.

We also realise that all of this will take longer than a meeting without interpreting and would appreciate it if this is taken into consideration so that there is enough time for us to hear all that you are saying. We know how much expertise you all have and we want to make sure that we hear everything you have to say as you work to help our daughter.

Sincerely
S’s Parents

UWE Bristol | University of the West of England

Presented by

Nicky Harris
Research Fellow,
Centre for Health
and Clinical
Research,
UWE Bristol

Supervisors:
Toity Deave,
Andy Gibson,
Antonia Beringer

8/9/22

E-health, communication and the delivery of person-centred care – what works, for whom, and why?

MyQuality
My life, my measure

Why does this matter?

Complexity: Children requiring palliative care often have multiple complex health care needs. Their lived experience may include a variety of physical or emotional consequences of their condition, raising a range of psychological, social or existential challenges.

Complexity: Children who need palliative care are not cared for in isolation, but as part of a larger unit including other members of their immediate family, extended family, and wider community. The impact of a health-related problem may have effects much more broadly than just the affected child.

Complexity: Caring for a child with complex needs has been described as “intensive parenting” (Woodgate 2015), as parents incorporate roles ranging from nurse to physiotherapist to OT to counsellor, plus case manager, teacher, detective, guard, and advocate for their children.

Solution?

Person-centred care (PCC) by healthcare professionals and support services could alleviate some of the challenges faced by children and families.

i. Principles (Scholl 2014): see the patient as a unique person; supportive clinician-patient relationships; biopsychosocial perspective.
ii. Focus on individualising care, encouraging autonomy, sharing power and responsibility in a culture of mutual respect
iii. Enabled by good communication and teamwork

MyQuality – an ehealth intervention to support the delivery of person-centred care – www.my-quality.net

1. Website that incorporates individualised outcome measurement, tracking and data sharing options, for use by children/families with LLC and their healthcare professionals (HCPs)
    i. Personalised, meaningful data entry by patient/parent user
    ii. Data entry and access to it is led and controlled by the patient/parent user

MyQuality

My life, my measure

www.my-quality.net

Measure What Matters to You

1. IDENTIFY YOUR PRIORITIES:

Ask yourself:

"WHAT IS STOPPING ME FROM DOING WHAT I WANT TO DO TODAY?"

"WHAT IS AFFECTING MY QUALITY OF LIFE THE MOST?"

"WHAT COULD BE IMPROVED THAT WOULD MAKE THE BIGGEST DIFFERENCE TO ME, OR MY FAMILY?"

2. DESCRIBE THE IMPACT THEY HAVE ON YOU:

0.00	Not at all
1.00	Slightly - but not bothered by this
4.00	Moderately - limits some activity or concentration
7.00	Severely - markedly affects activity or concentration
9.00	Overwhelmingly - unable to think of anything else

3. CHECK-IN AND RECORD HOW YOU FEEL EVERY DAY

How are you doing today?

4. MONITOR CHANGES OVER TIME

5. SHARE YOUR CHARTS WITH YOUR CARE TEAM, OR KEEP THEM PRIVATE—IT'S UP TO YOU

CREATED by Dr Nicky Harris, IT SUPPORT by Agile Mediaware. MyQuality is owned by MyQuality Ltd.

MyQuality – an ehealth intervention to support the delivery of person-centred care – www.my-quality.net

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   i. Personalised, meaningful data entry by patient/parent user
   ii. Data entry and access to it is led and controlled by the patient/parent user

2. Preliminary research in a children's hospice setting suggested that it was easy to use, welcomed by parents, clinically useful, and the process was empowering (Harris, Beringer, Fletcher 2015).
   i. But: not everyone engaged, and no feedback from staff accessing data

3. Further enquiry needed to understand what worked, for whom, under what circumstances, and why.

→ Realist Evaluation

Realist Evaluation – What works, for whom, under what circumstances, how and why?

- Aim is to generate theories to explain how complex interventions work in real life (Pawson and Tilley 1997)

- Realist methodology is not methods specific:
  - Data from literature – what can be learned from similar interventions elsewhere?
  - Quantitative data from observation
    - Website use, Empowerment Questionnaires
  - Qualitative data from interviews with key participants
    - Cycles of exploration for theory development, theory testing and refinement

- Theories presented as context-mechanism-outcomes to illustrate underlying processes

Project Design

Teams supporting children with LLC approached, demo given, interview about MyQuality use – motivations, concerns, practical issues

- 10 teams, 47 HCPs – mixture of professionals, mixture hospital/hospice/community settings

Teams identified children/families to use MyQuality (15) – paired case studies Pt/HCP

- Pt/family: interviews and empowerment scales, pre and post use, observation of use of website
- 7/15 – extensive use; 3/15 – intermittent or temporary use; 5/15 – registered, but didn't subsequently use it

Interviews with HCPs about their experience of using MyQuality and any challenges encountered.

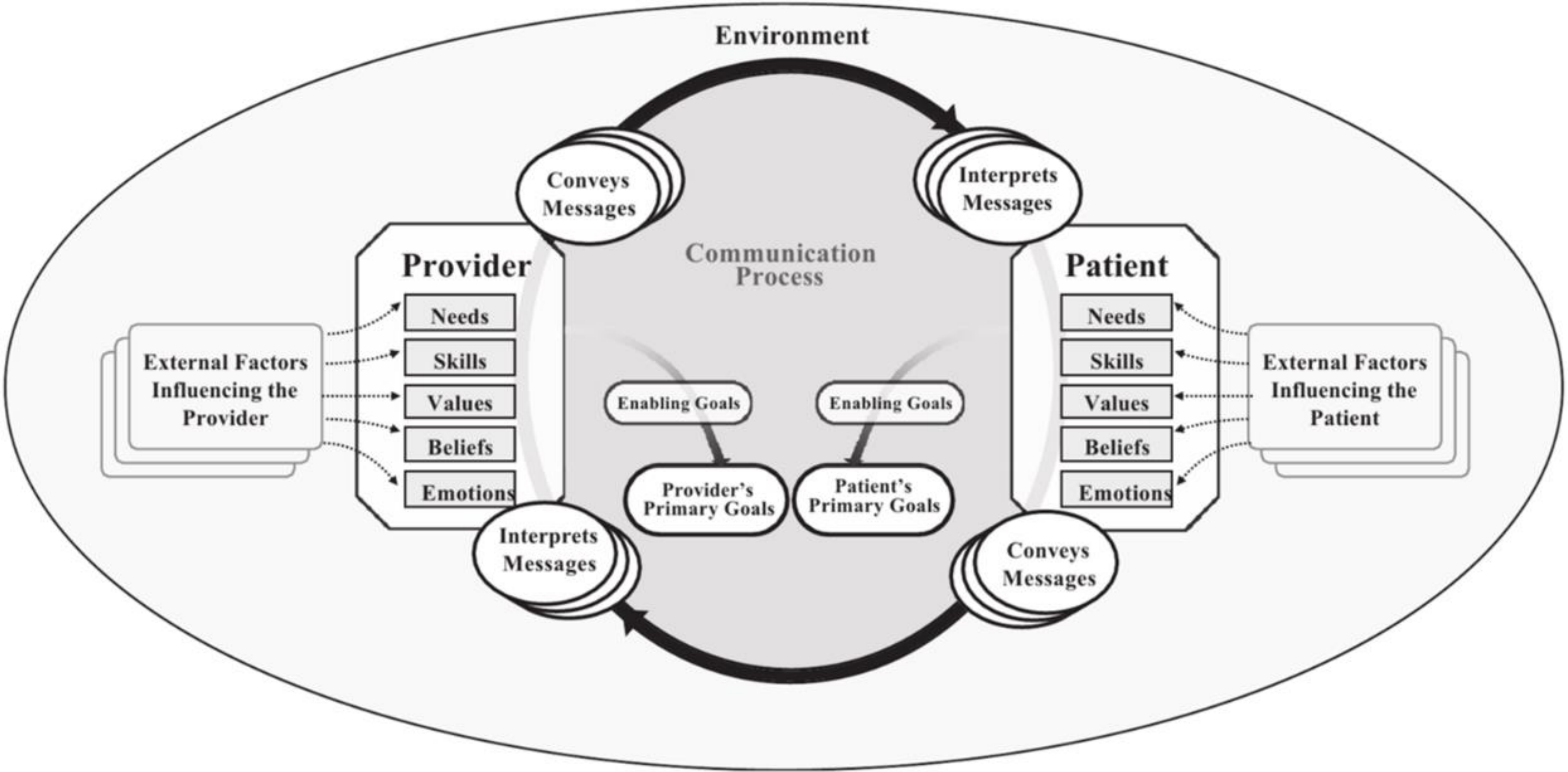
- Total 38 interviews, 1800+ days of MyQuality data documented

Effective communication between patients/families, and their health and social care professionals, is the bedrock of helpful palliative care

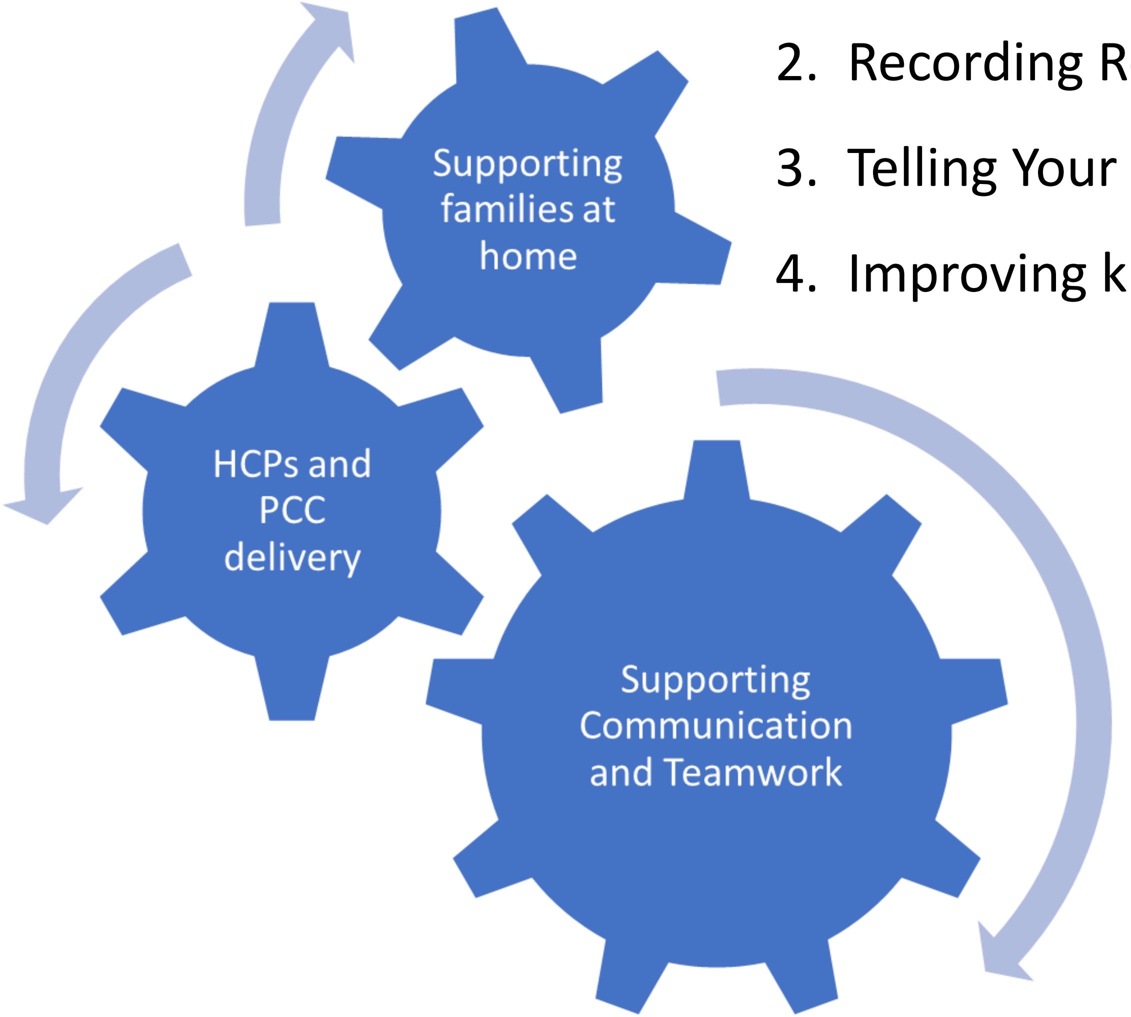
But: communication can be difficult

- Exchange of information
- Understanding perspectives
- Defining roles and responsibilities
- Collaboration and Respect

Brundage et al. (2010) Communications Model: How do interventions designed to improve provider-patient communication work?



Outline of theories



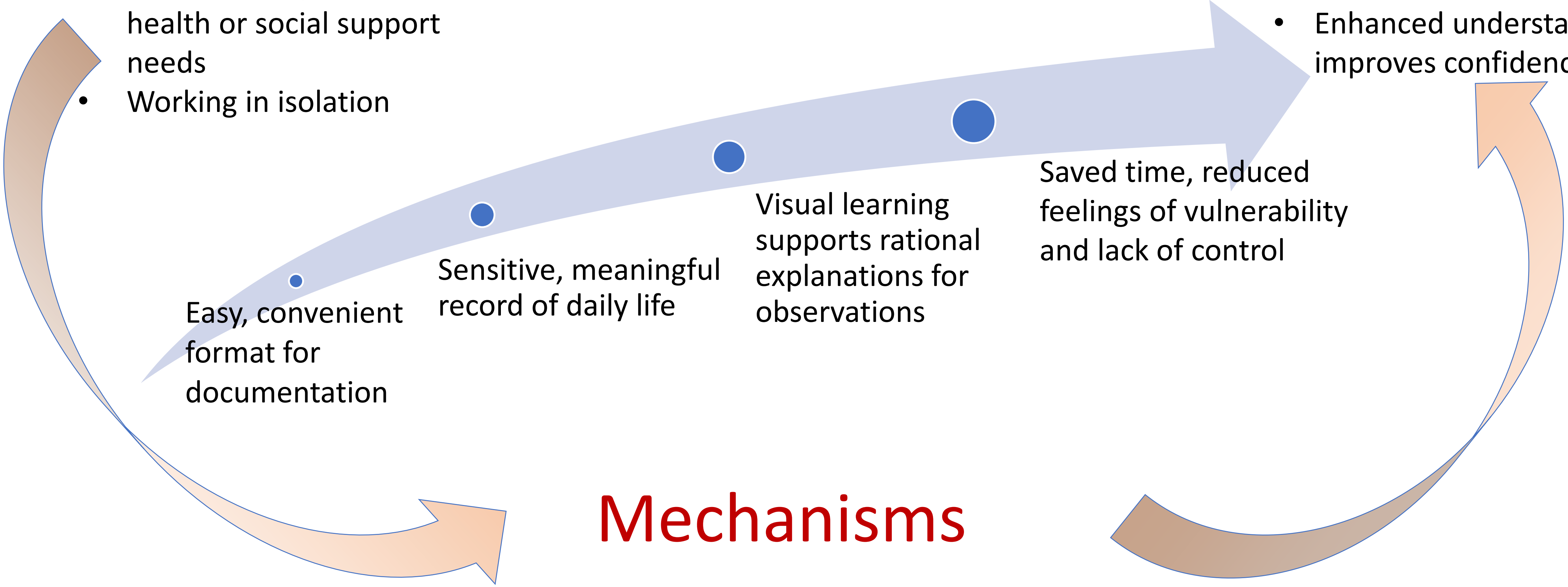
Supporting families at home

HCPs and PCC delivery

Supporting Communication and Teamwork

1. Simplifying intensive parenting
2. Recording Real Life
3. Telling Your Story
4. Improving knowledge and understanding

Supporting patients and their parents at Home - Overview



Context

- Multiple roles and responsibilities
- Rare &/or unpredictable health or social support needs
- Working in isolation

Outcome

- More "quality time" for parents to spend with their children
- Enhanced understanding improves confidence

Easy, convenient format for documentation

Sensitive, meaningful record of daily life

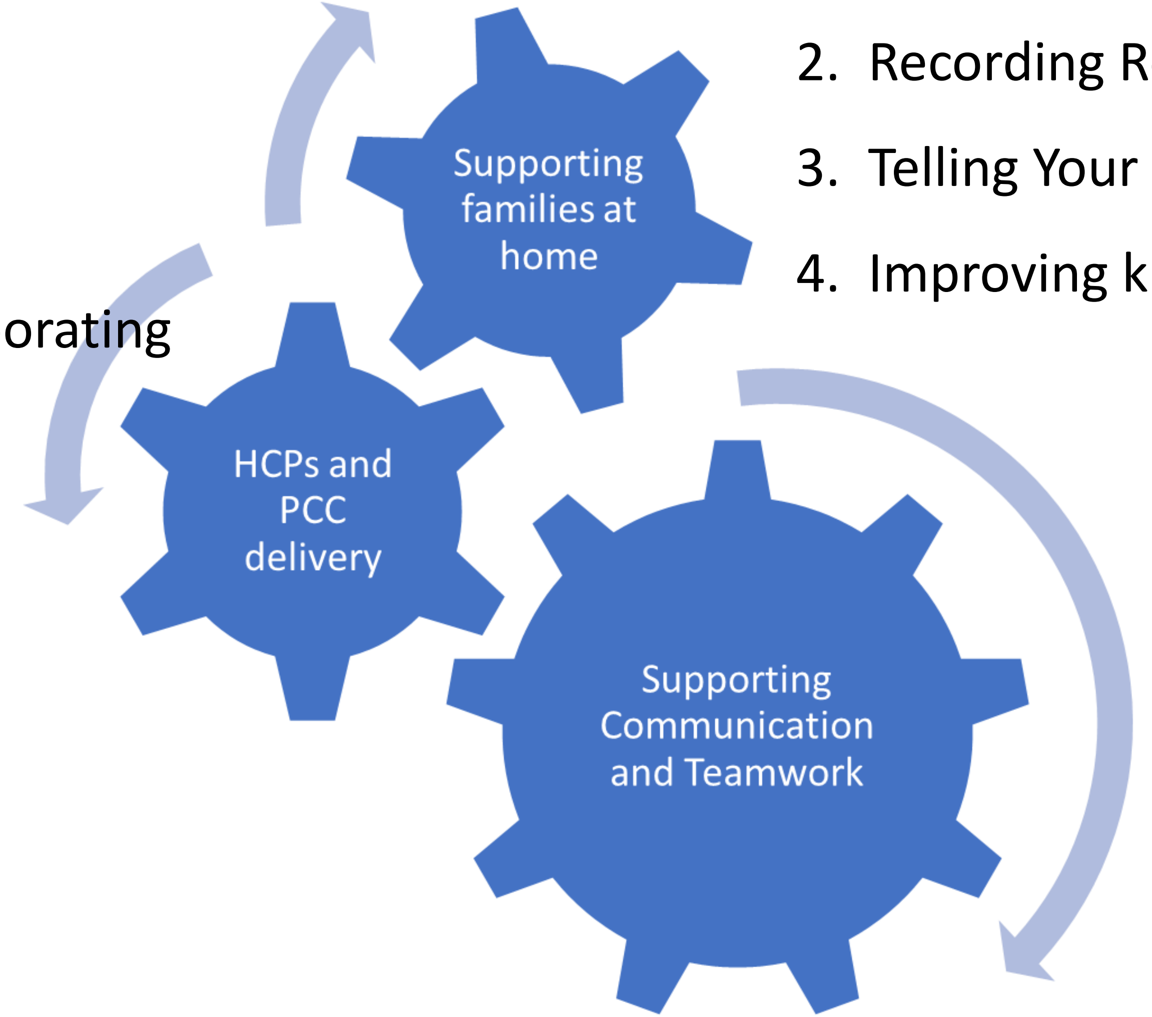
Visual learning supports rational explanations for observations

Saved time, reduced feelings of vulnerability and lack of control

Mechanisms

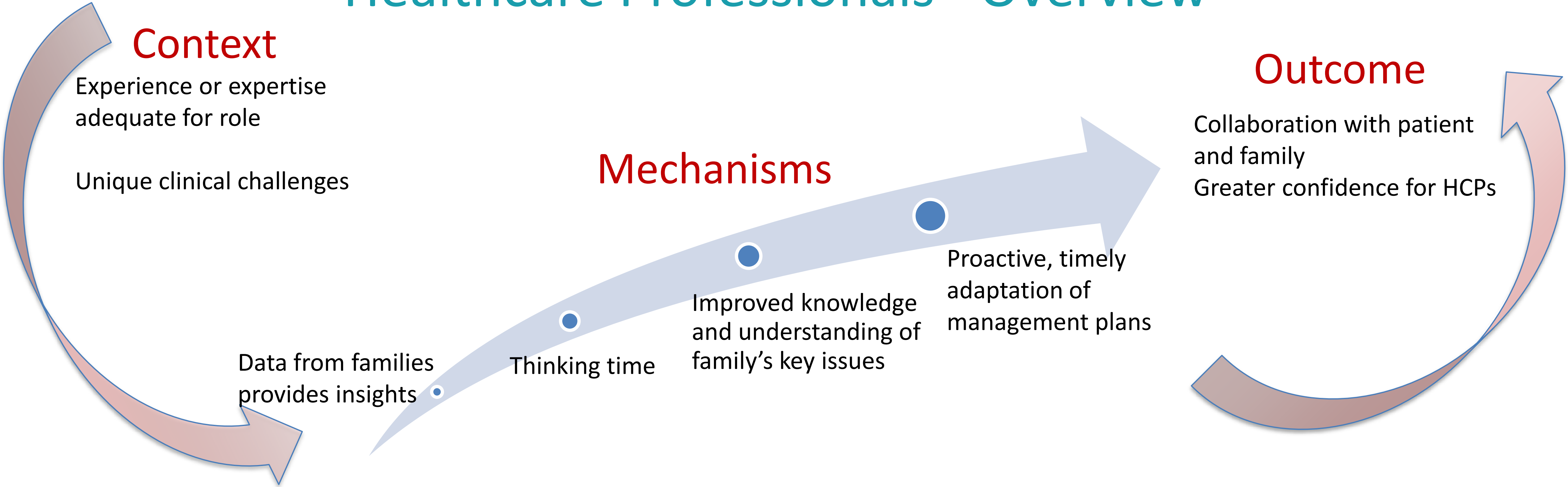
Outline of theories

1. Simplifying intensive parenting
2. Recording Real Life
3. Telling Your Story
4. Improving knowledge and understanding



5. Listening and Collaborating
6. Being Proactive

Healthcare Professionals - Overview



Context

Experience or expertise adequate for role

Unique clinical challenges

Mechanisms

Data from families provides insights

Thinking time

Improved knowledge and understanding of family's key issues

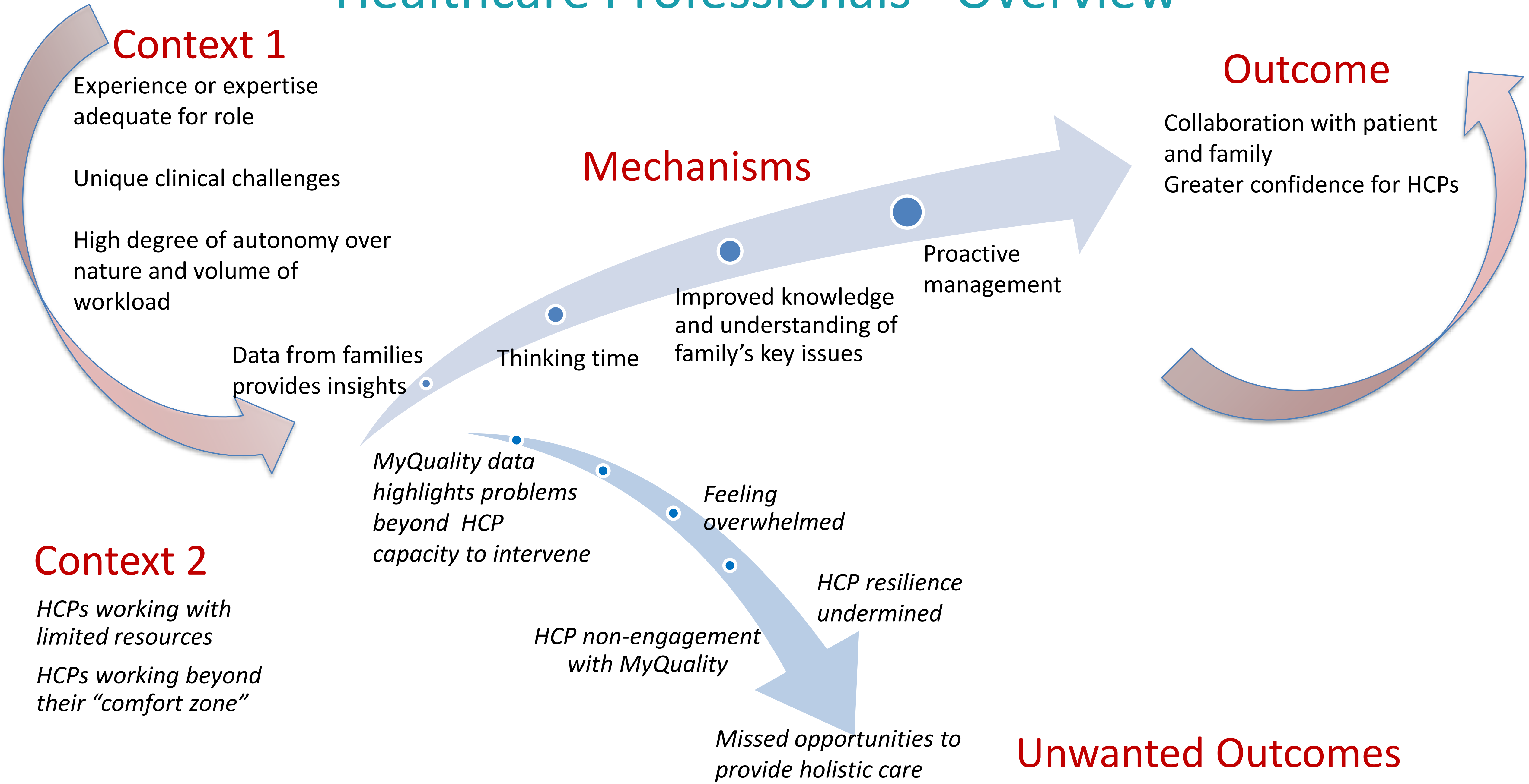
Proactive, timely adaptation of management plans

Outcome

Collaboration with patient and family

Greater confidence for HCPs

Healthcare Professionals - Overview



Context 1

Experience or expertise adequate for role

Unique clinical challenges

High degree of autonomy over nature and volume of workload

Mechanisms

Data from families provides insights

Thinking time

Improved knowledge and understanding of family's key issues

Proactive management

Outcome

Collaboration with patient and family

Greater confidence for HCPs

Context 2

HCPs working with limited resources

HCPs working beyond their "comfort zone"

MyQuality data highlights problems beyond HCP capacity to intervene

Feeling overwhelmed

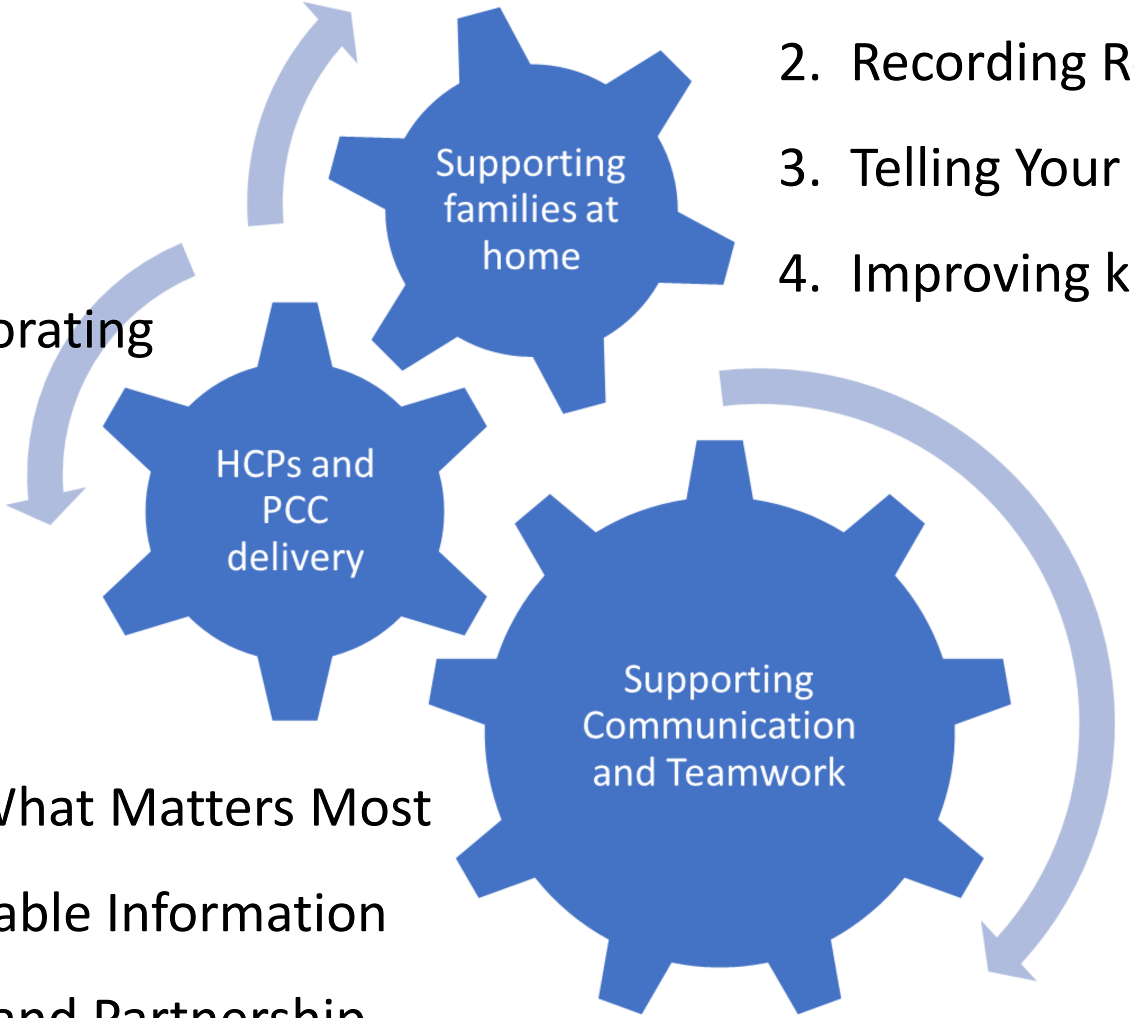
HCP resilience undermined

HCP non-engagement with MyQuality

Missed opportunities to provide holistic care

Unwanted Outcomes

Outline of theories

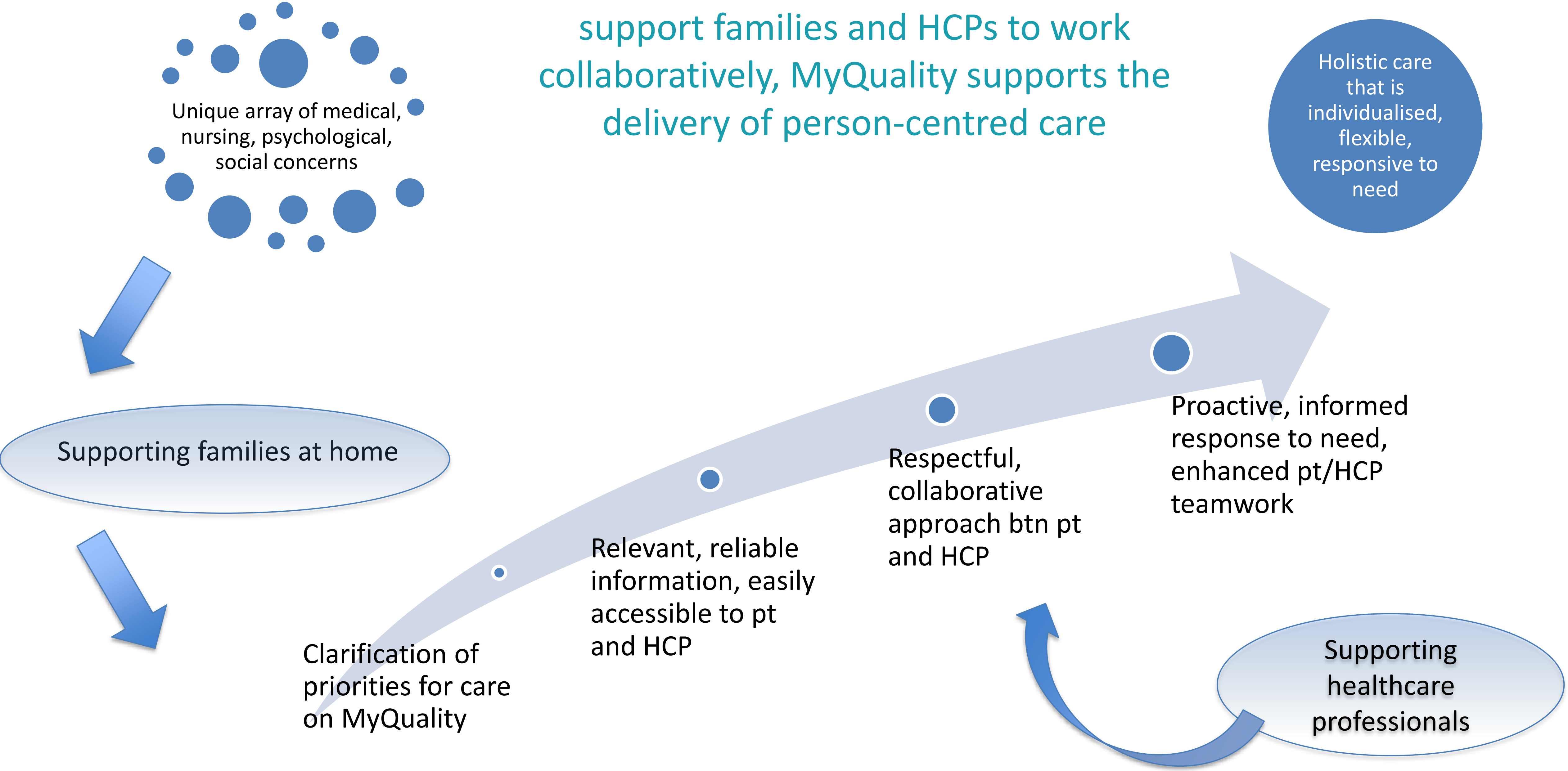


1. Simplifying intensive parenting
2. Recording Real Life
3. Telling Your Story
4. Improving knowledge and understanding

5. Listening and Collaborating
6. Being Proactive

7. Clarifying What Matters Most
8. Having Reliable Information
9. Teamwork and Partnership

Overarching theory: by providing resources to support families and HCPs to work collaboratively, MyQuality supports the delivery of person-centred care



Unique array of medical, nursing, psychological, social concerns

Supporting families at home

Clarification of priorities for care on MyQuality

Relevant, reliable information, easily accessible to pt and HCP

Respectful, collaborative approach btn pt and HCP

Proactive, informed response to need, enhanced pt/HCP teamwork

Holistic care that is individualised, flexible, responsive to need

Supporting healthcare professionals

What works best for whom?

- For patients and families: independent use has been welcomed
  - Computer literate, organised...
  - Curious mindset
  - Multiple symptoms, multiple questions

  - Less good for those who are overwhelmed already, or where symptoms are stable and show no change (ie recording is boring)

  - Deteriorating symptoms?

What works best for whom?

- For HCPs:
  - Curious mindset
  - Multiple symptoms, multiple questions, uncertain management, try-it-and-see situations …
  - robust and professionally resilient, clear ideas about boundaries

Suggest:

- Open discussions about managing expectations from the outset.

For further information about the MyQuality project, please contact nicky.harris@uwe.ac.uk

Neonatal Palliative and End of Life Care (NPELC) course

Dr Jennifer Peterson

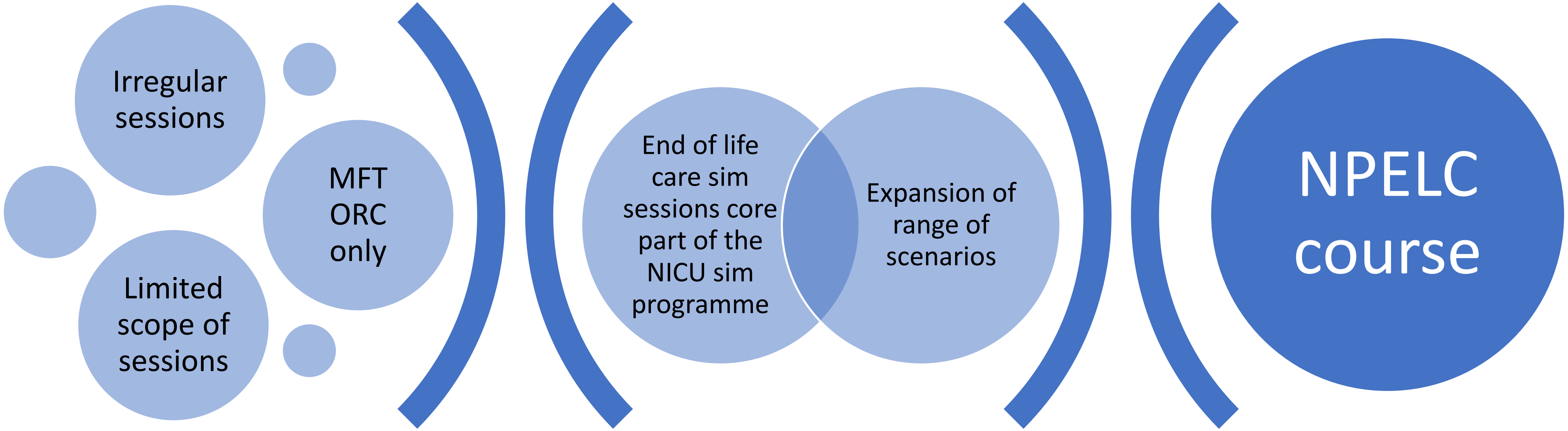
Manchester University NHS Foundation Trust

Starting Point

- Tertiary NICU
- Had 2x end of life care simulation scenarios from prev simulation fellow and NICU bereavement team
- Running intermittently within MFT NICU sim training sessions

Limitations

- End of life scenarios only
- Faculty
- In-house programme
    - Restrictive
    - Psychological safety
    - Support options



Irregular sessions

MFT ORC only

Limited scope of sessions

End of life care sim sessions core part of the NICU sim programme

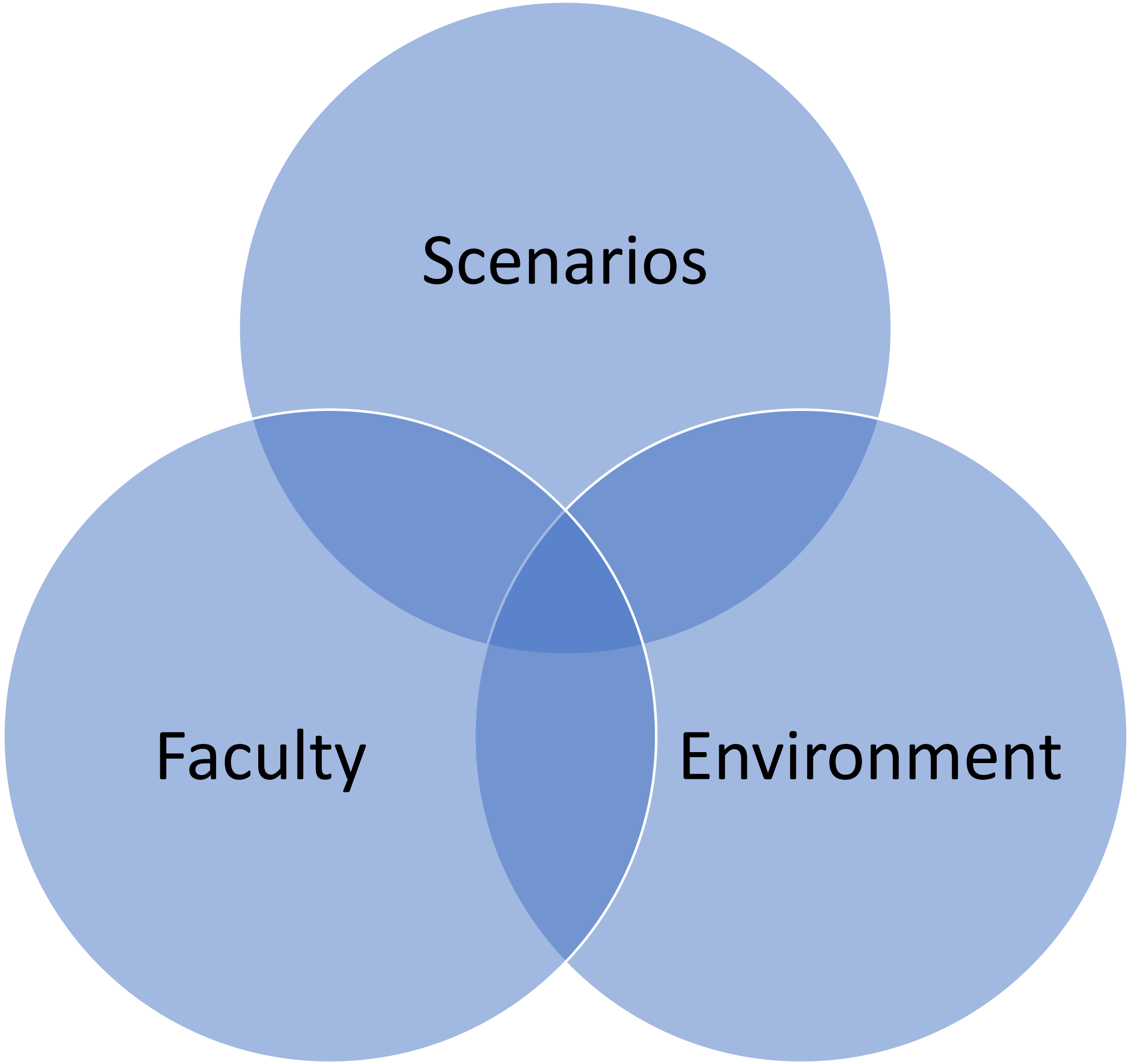
Expansion of range of scenarios

NPELC course

Starting Point

Development

Launch



Scenarios

Faculty

Environment

Scenarios
- Own experiences
- Risk reports
- Inclusion of bereavement midwifes

Faculty
- Inclusive
- Counsellors
- Parents
- COVID-19

Environment
- Dedicated simulation suite
- Spare room
- Video and audio live feed
- Separate debriefing room

NPELC Simulation scenarios
Unexpected term death in the delivery room
Broaching reorientation of care
Transfer to bereavement suite
Compassionate extubation
Medical cause for death certificate workshop
Periviable delivery
Complex abnormalities in antenatal clinic
HIE deterioration on NICU during therapeutic hypothermia
Twin memory making
Bereavement clinic

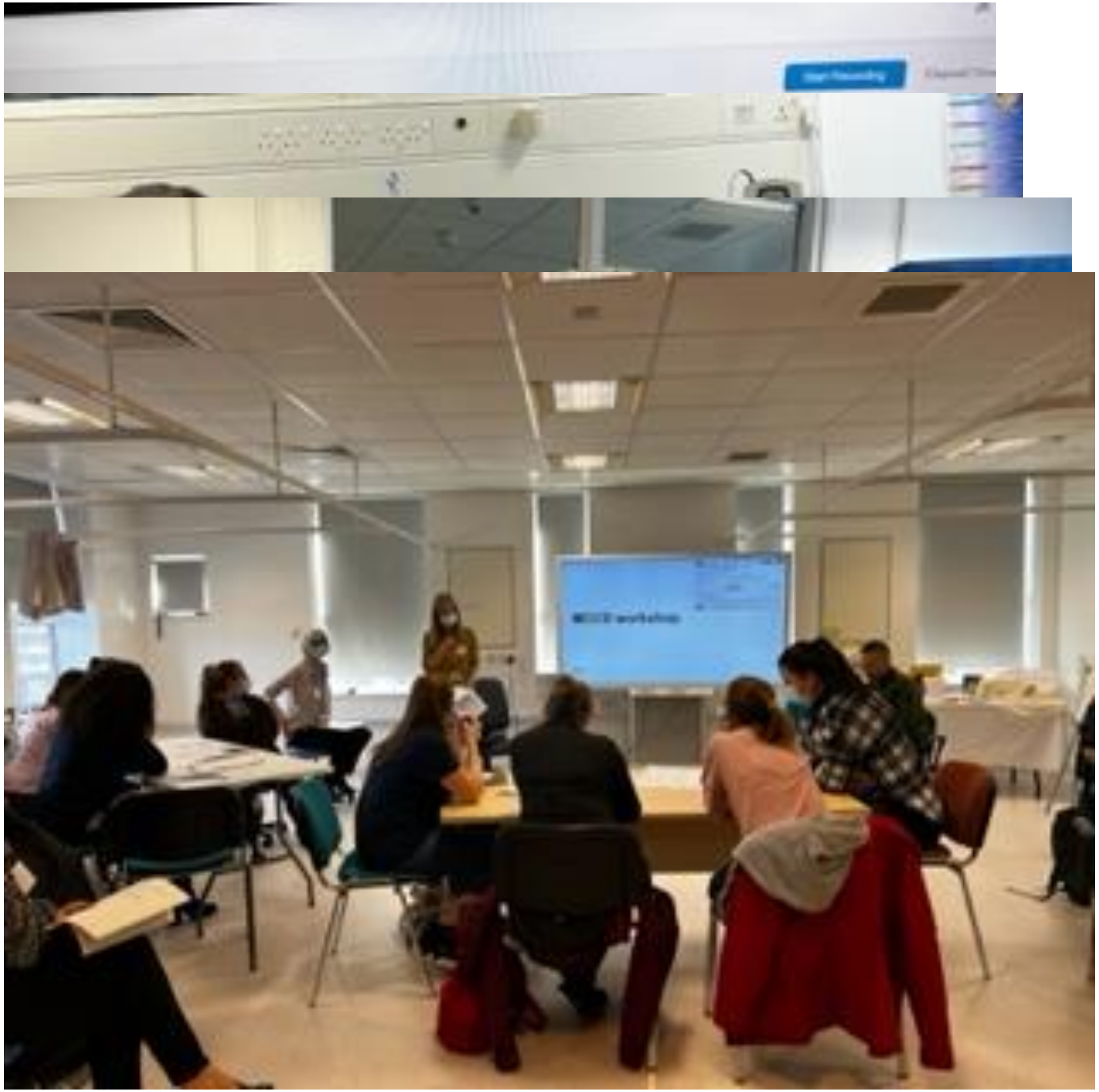


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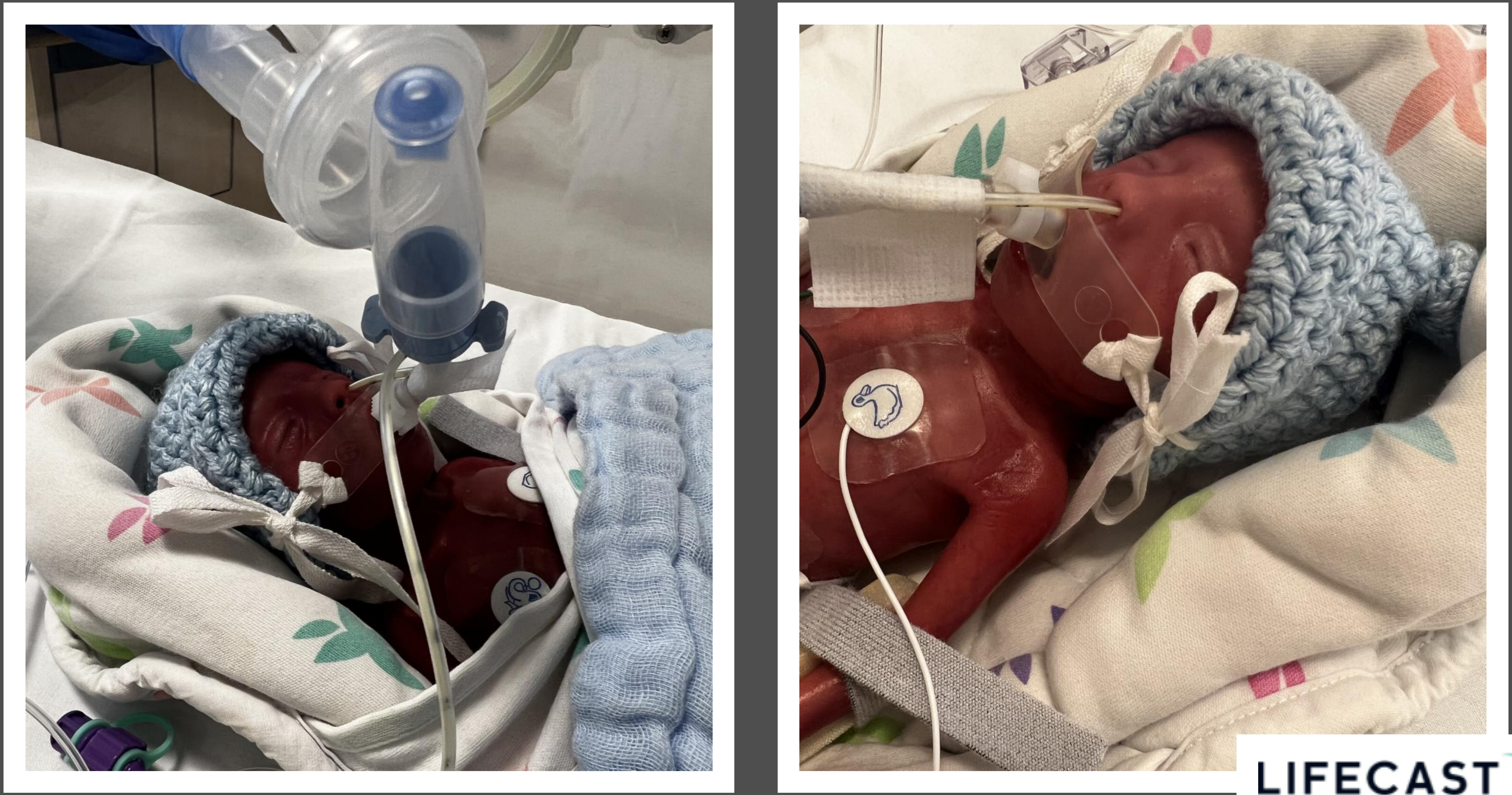
Figure 1. Photo from NPELC extreme preterm infant delivery scenario

Figure 2. Photo from NPELC Positive Palliation Twin Memory Making in Theatre scenario

LIFECAST
·BODY SIMULATION·

LIFECAST
·BODY SIMULATION·



LIFECAST
·BODY SIMULATION·

Nov 2020

- Wythenshawe
  - MFT Staff

July 2021

- Wythenshawe
  - MFT Staff

March 2022

- Whiston
  - Regional attendees

Nov 2022

- Whiston
  - National advert

100% participants rated course as worthwhile

100% participants would recommend to colleagues

“I’ve learnt so much and its clarified/consolidated queries and questions”

“Excellent! Thank you. I have learnt lots and it was really diverse”.

“Great course! Thank you. I would definitely recommend”.

“Amazing actors!”

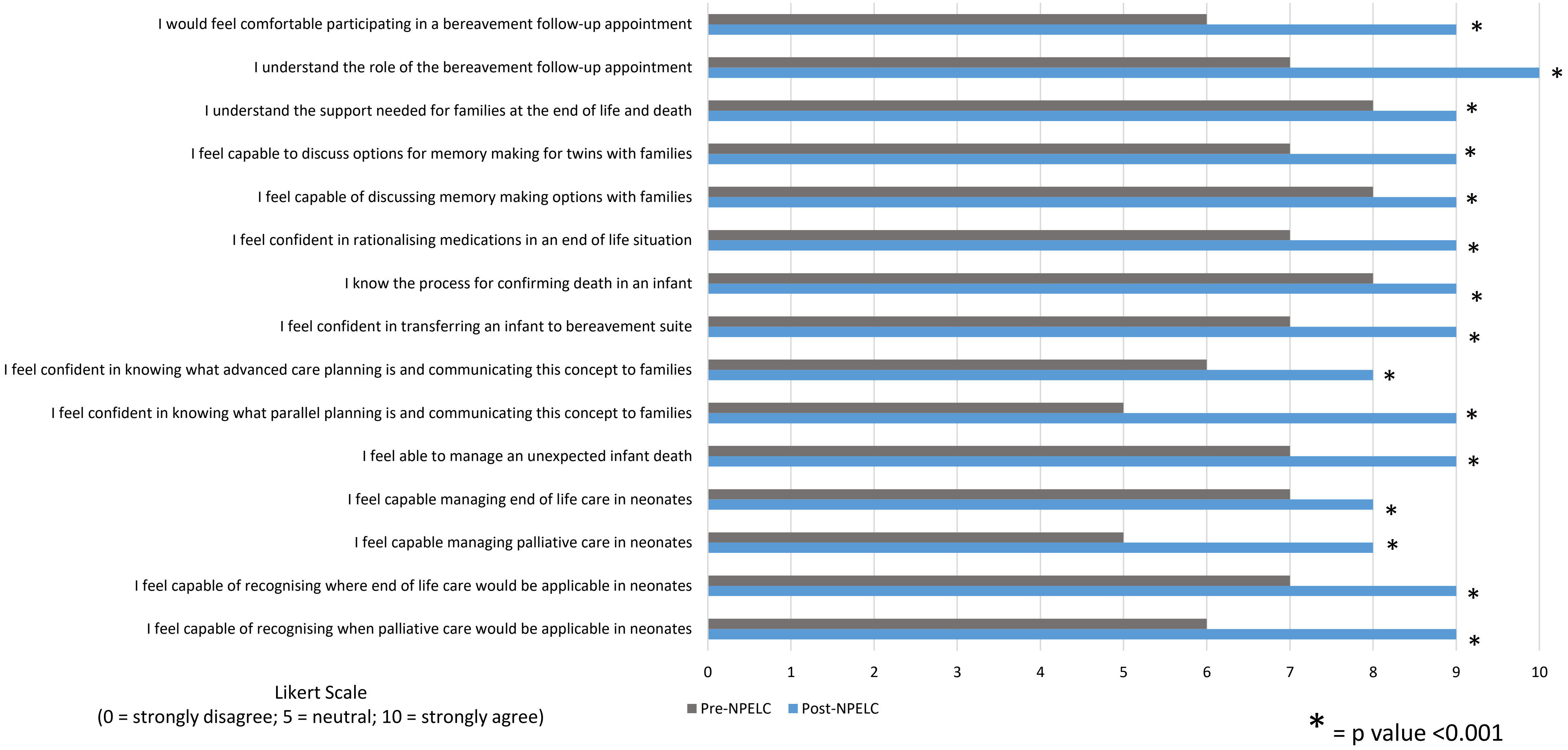
“This course is very worthwhile! So interesting and a great learning experience towards career development”

“Fantastic!”

“The course was excellent – I learnt so much about an area that I’ve not had much exposure to but may be expected to be involved in”

“Surpassed expectations!”

Participant Feedback on Neonatal Palliative and End of Life Care simulation course

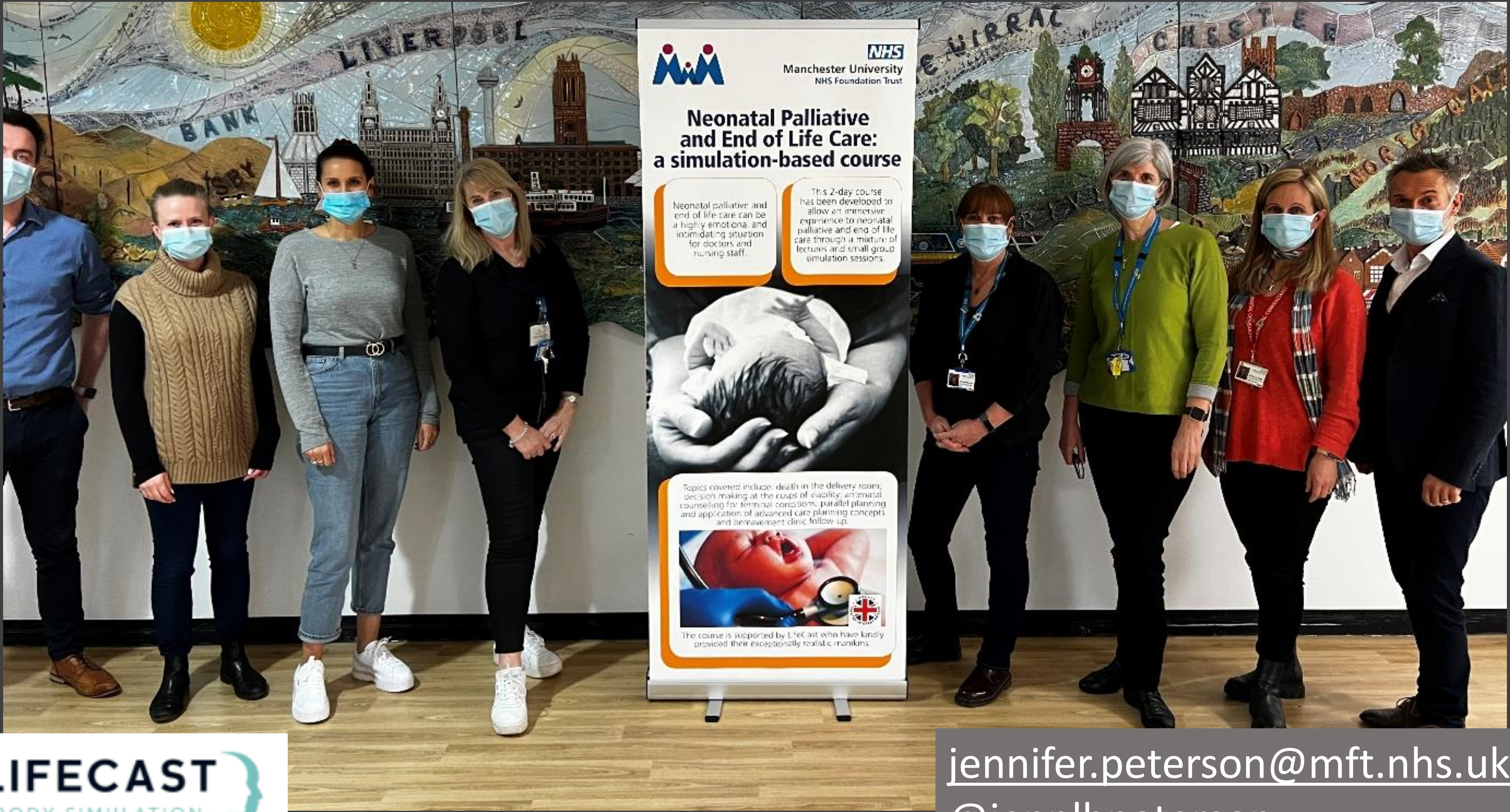


Final Thoughts

Simulation is an excellent tool to learn about P&ELC

Need comprehensive plan for managing psychological safety pre-, during and post-sessions

Great potential to improve the quality of P&ELC delivered to infants and their families.



Manchester University
NHS Foundation Trust

Neonatal Palliative and End of Life Care: a simulation-based course

Neonatal palliative and end of life care can be a highly emotional and intimidating situation for doctors and nursing staff.

This 2-day course has been developed to allow an immersive experience to neonatal palliative and end of life care through a mixture of lectures and small group simulation sessions.

Topics covered include: death in the delivery room; decision making at the cusps of viability; antenatal counselling for terminal conditions; parallel planning and application of advanced care planning concepts and bereavement clinic follow up.

The course is supported by LifeCast who have kindly provided their exceptionally realistic manikins

LIFECAST
·BODY SIMULATION·

jennifer.peterson@mft.nhs.uk
@jennlhpeterson

Unlocking the potential of simulation

Promoting confidence in staff in a children’s hospice - a pilot project

Rebecca Whiting, Geraldine Sheedy, Anna Chadwick, Sally Richardson, Jayne Price

Kingston University London

Burdett Trust for Nursing

Shooting Star Children’s Hospices

Together for Short Lives - Manchester 7-8 September 2022

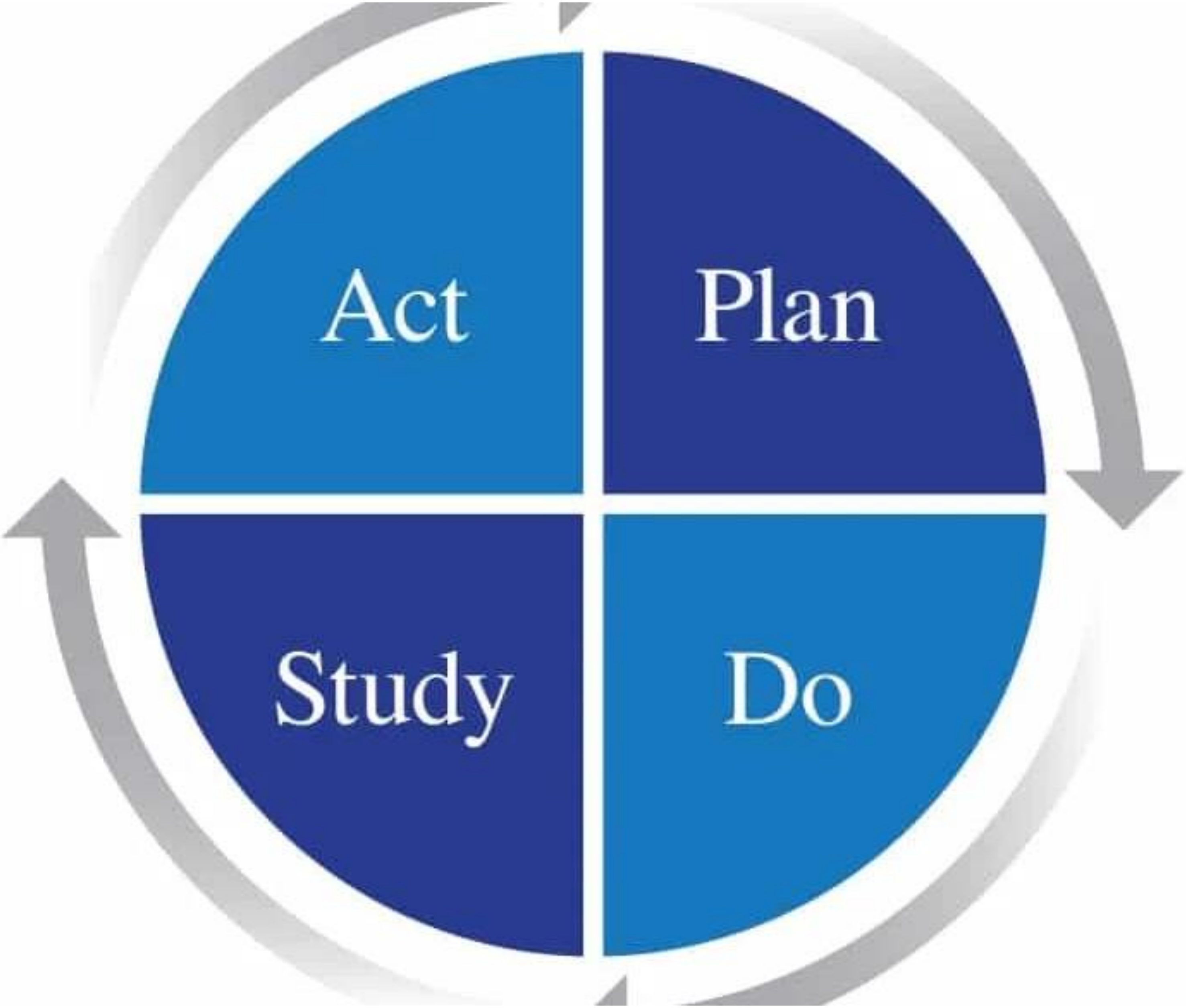
Safe and Effective Care in Children’s Hospices

Inspected and rated

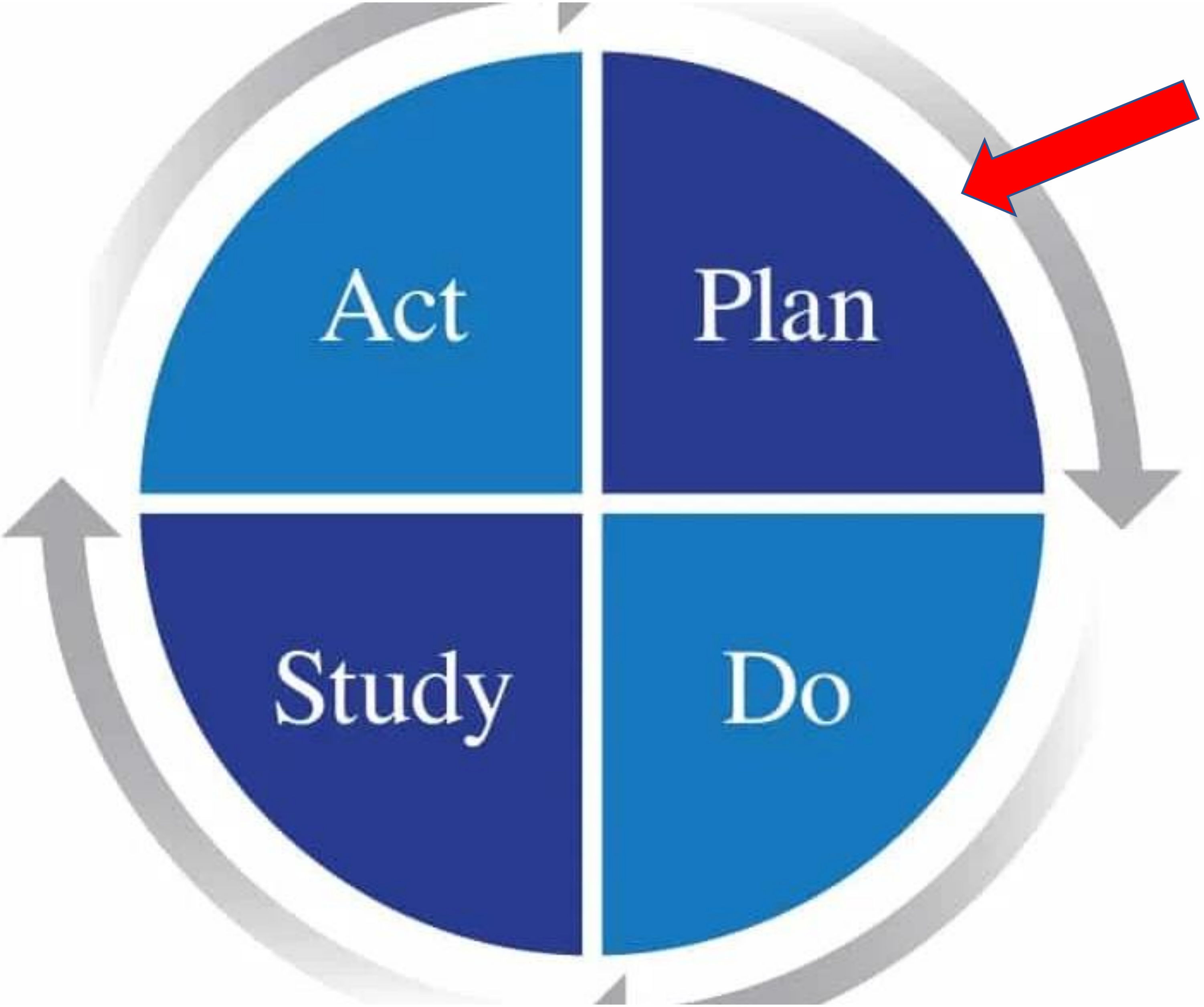
Outstanding ☆

Care Quality Commission

- Children with life limiting illnesses and their families are a vulnerable population with increasingly complex needs.
- Education is central to quality care within children’s hospices.
- Simulation training promotes efficient, safe, effective healthcare provision.


Act
Plan
Study
Do

Burdett Trust
for Nursing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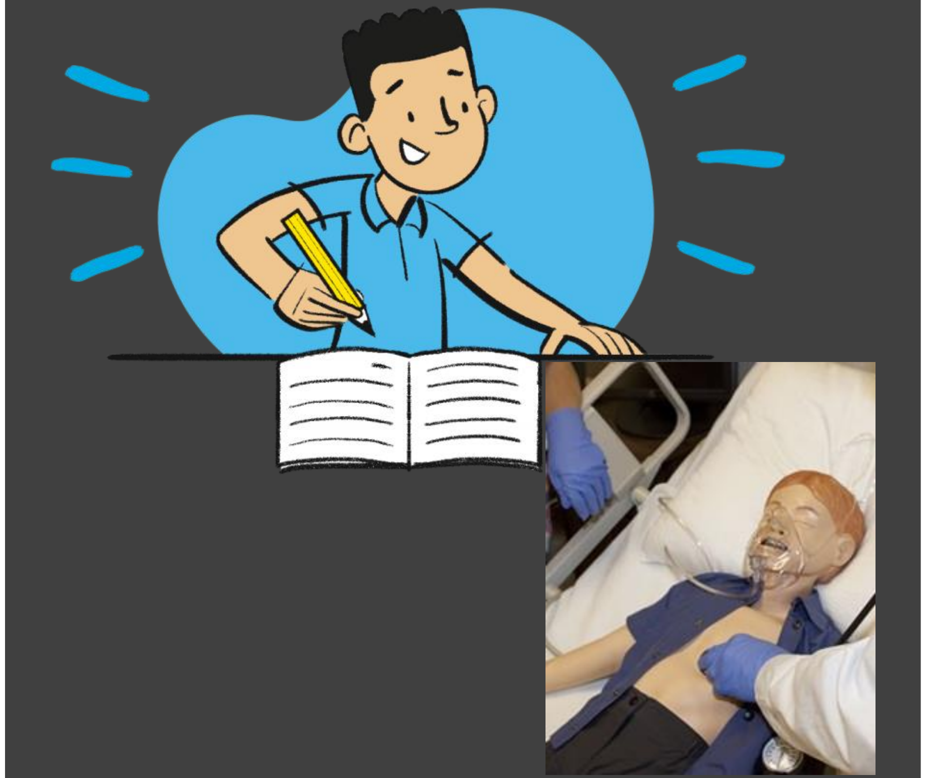
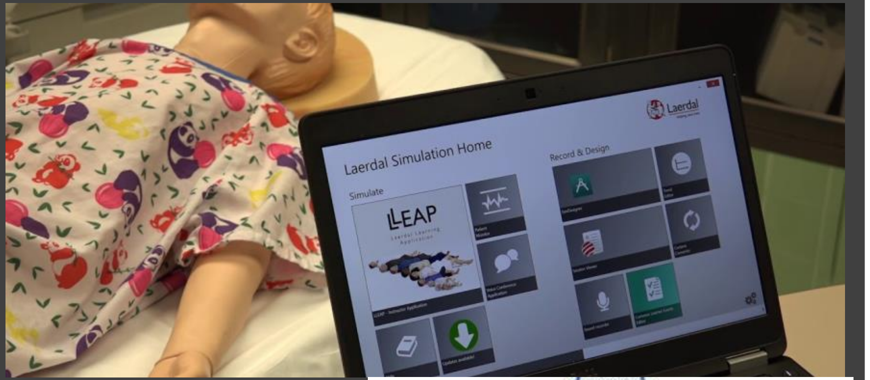
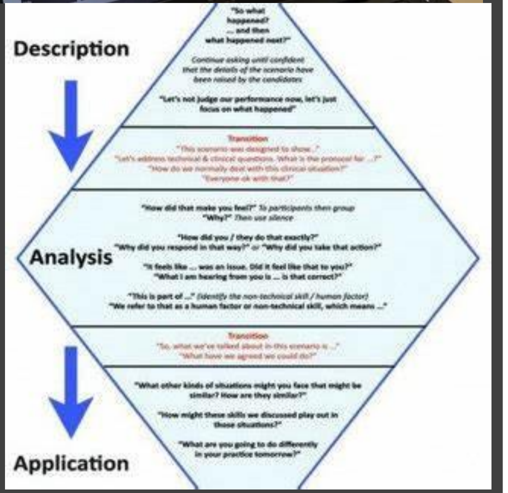


PLAN

Scenario Writing





Description

"So what happened? ... and then what happened next?"

Continue asking until confident that the details of the scenario have been raised by the candidates

"Let's not judge our performance now, let's just focus on what happened"

Transition
"This scenario was designed to show..."
"Let's address technical & clinical questions. What is the protocol for ...?"
"How do we normally deal with this clinical situation?"
"Everyone ok with that?"

Analysis

"How did that make you feel?" *To participants then group*
"Why?" *Then use silence*

"How did you / they do that exactly?"
"Why did you respond in that way?" *or* "Why did you take that action?"

"It feels like ... was an issue. Did it feel like that to you?"
"What I am hearing from you is ... is that correct?"

"This is part of ..." *(identify the non-technical skill / human factor)*
"We refer to that as a human factor or non-technical skill, which means ..."

Transition
"So, what we've talked about in this scenario is ..."
"What have we agreed we could do?"

"What other kinds of situations might you face that might be similar? How are they similar?"

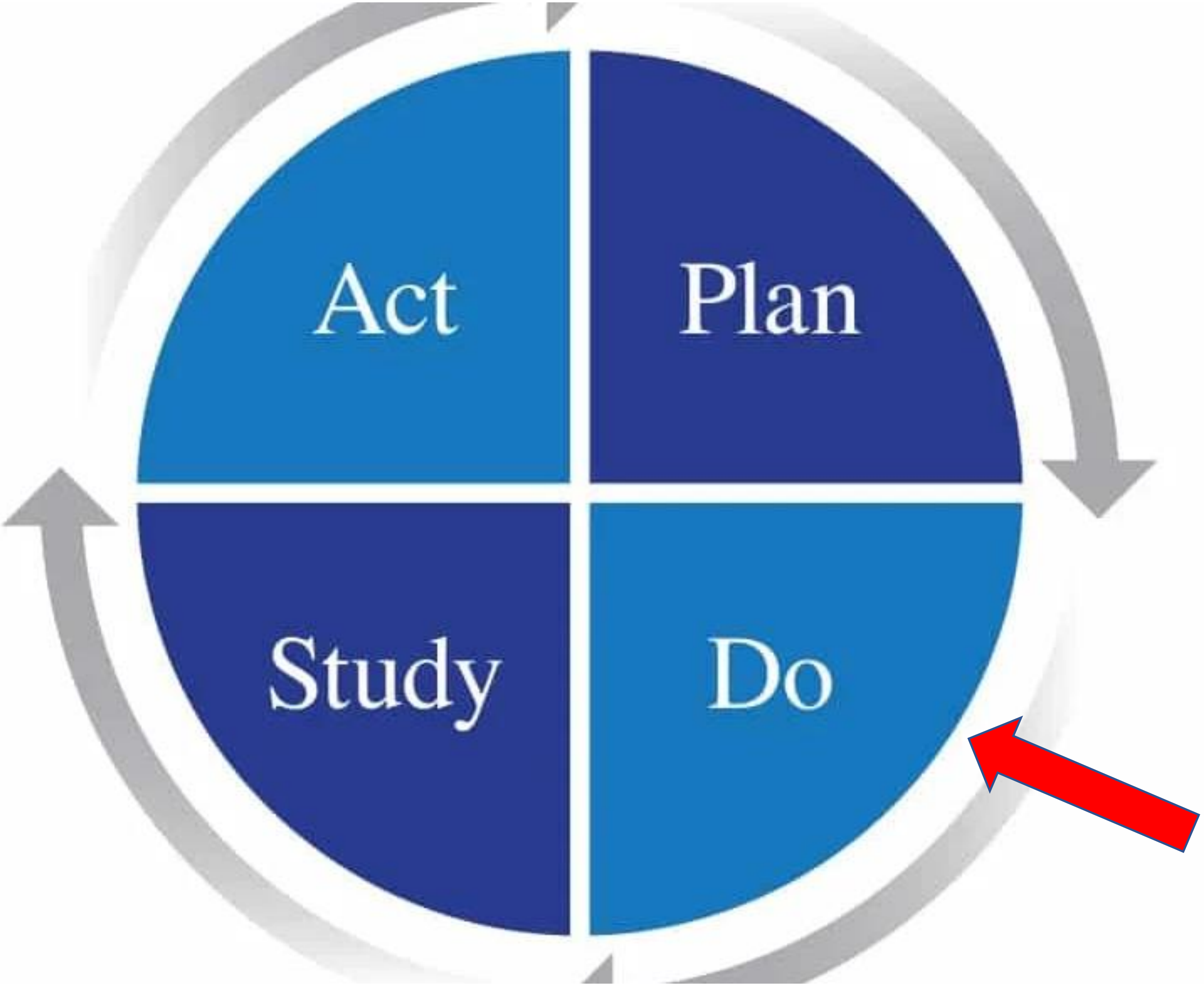
"How might these skills we discussed play out in those situations?"

"What are you going to do differently in your practice tomorrow?"

Application

PLAN

Train the Trainer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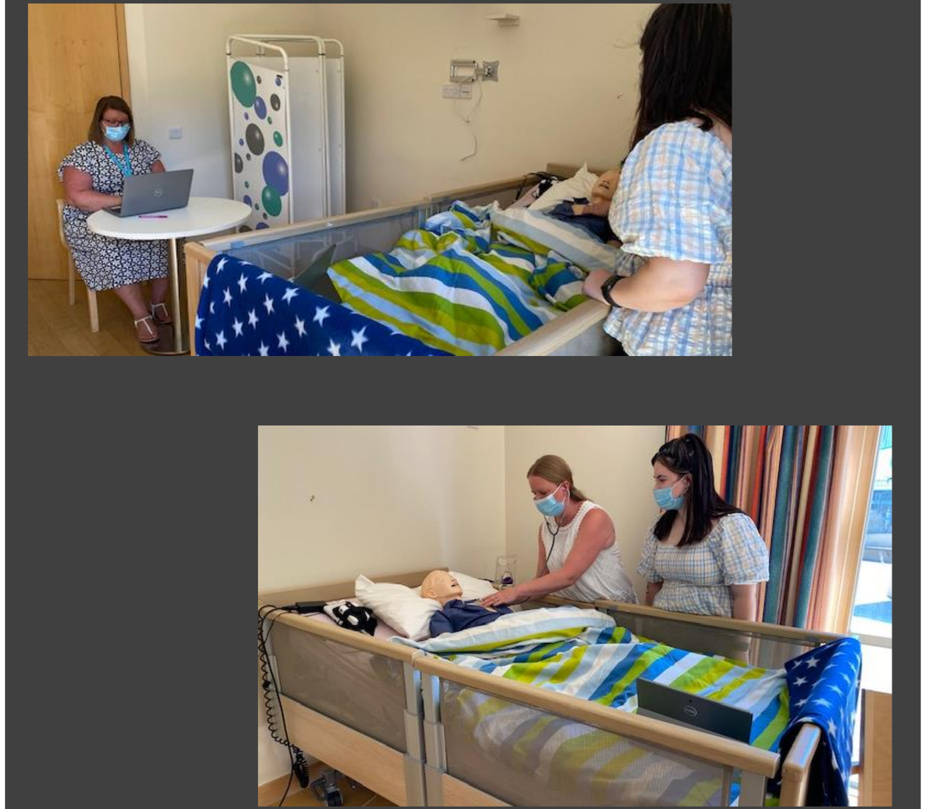
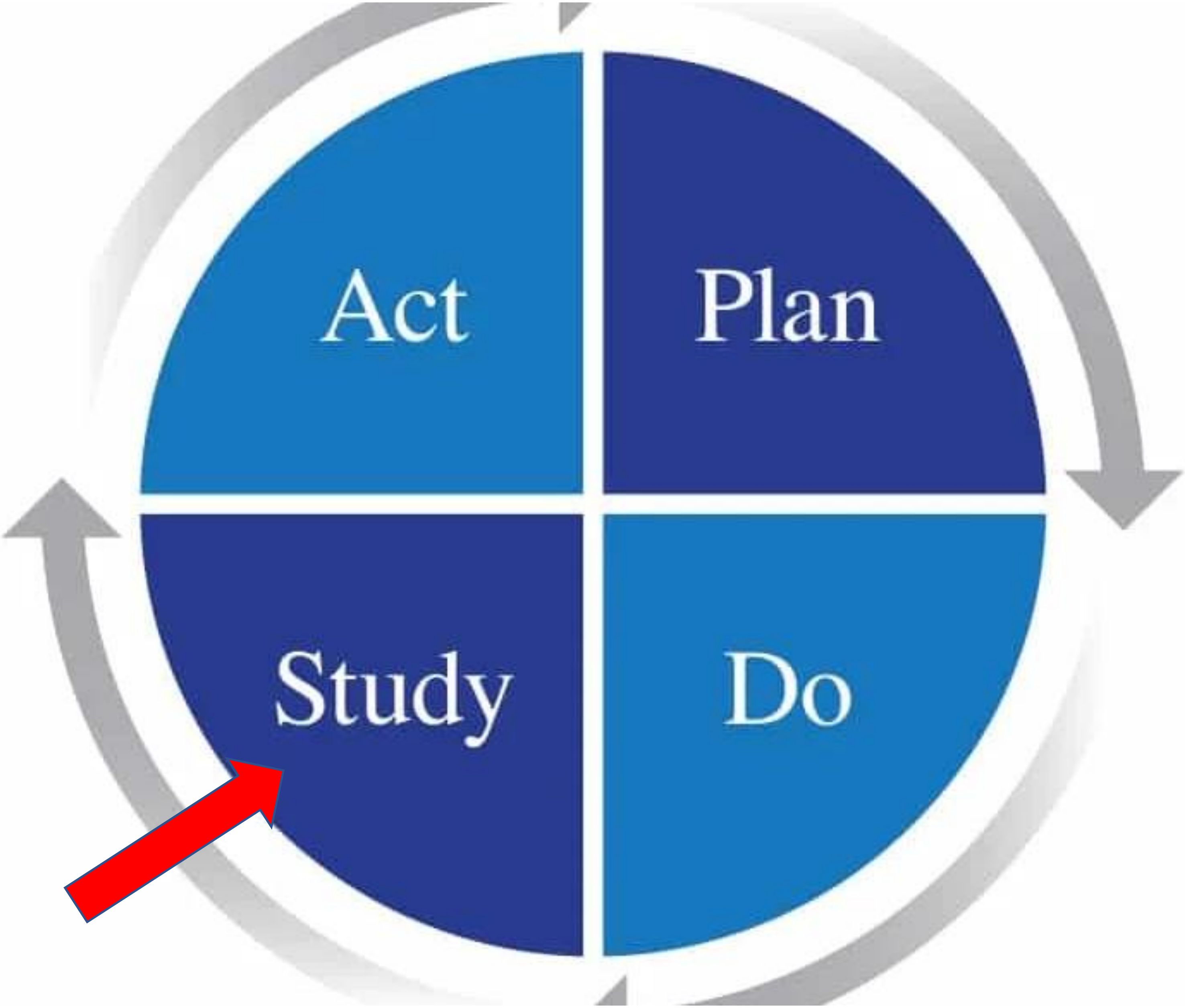


DO

Delivering the workshops



Act

Plan

Study

Do

SLinCH Study

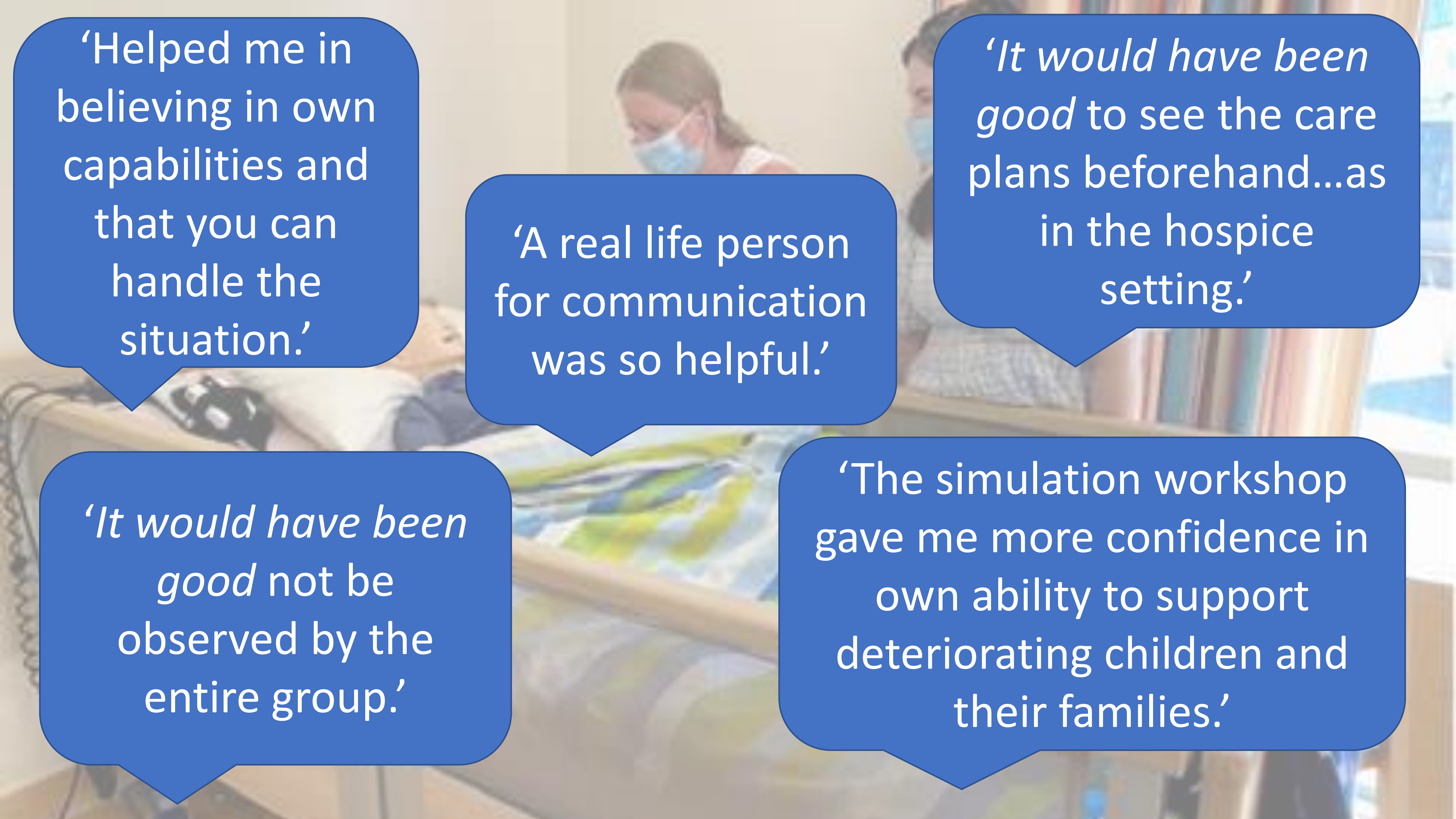
STUDY

Evaluation

The SLinCH study aims to establish the impact and potential value of simulation workshops within a children’s hospice

Data collection at 2 time points once immediately after attendance (via a questionnaire) and secondly over a period of 4 months via a reflective diary.

Ethical approval has been granted through KUREOS Kingston University Ethics System – February 2022.



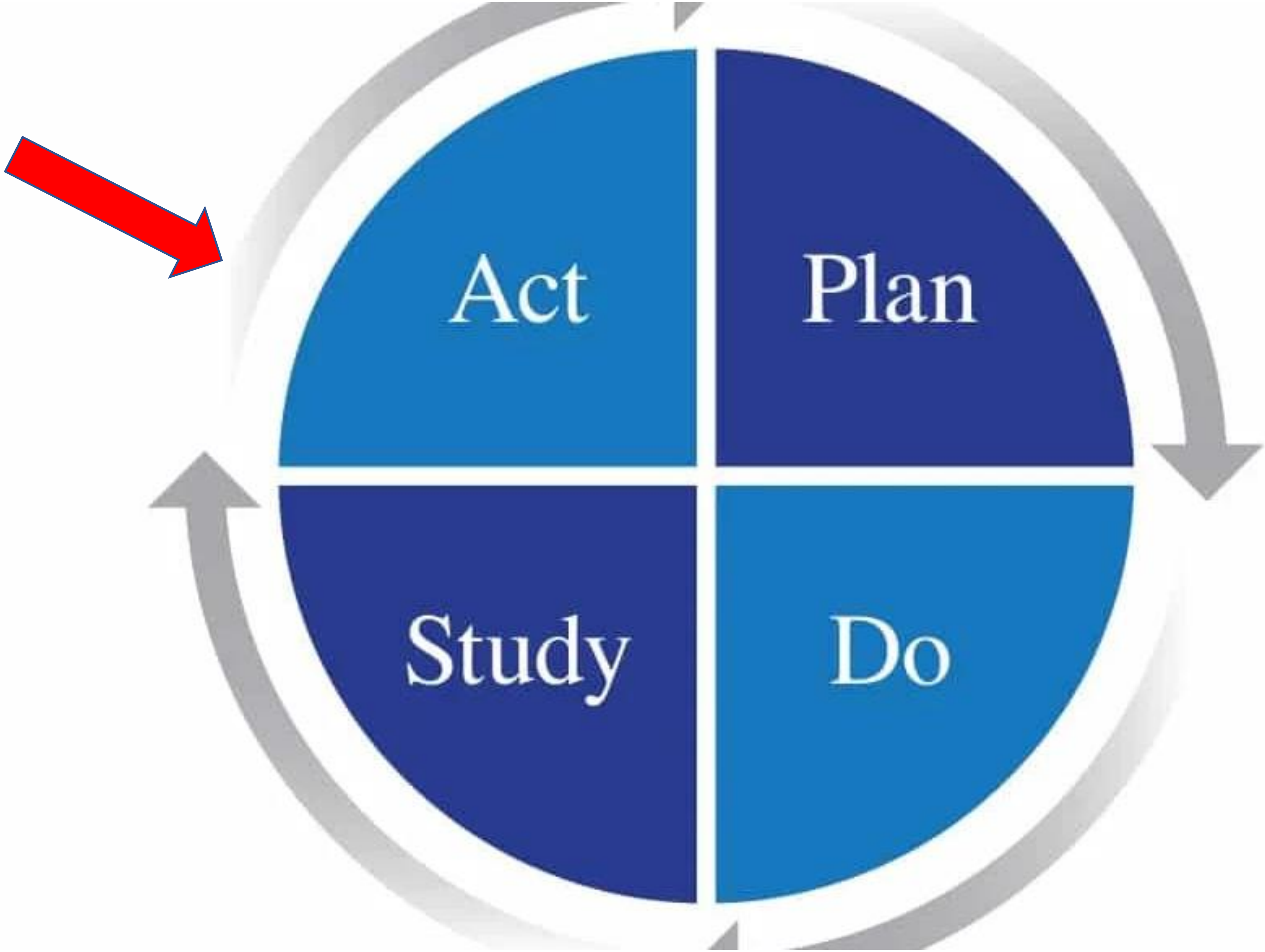
‘Helped me in believing in own capabilities and that you can handle the situation.’

‘A real life person for communication was so helpful.’

‘*It would have been good* to see the care plans beforehand…as in the hospice setting.’

‘*It would have been good* not be observed by the entire group.’

‘The simulation workshop gave me more confidence in own ability to support deteriorating children and their families.’


Act
Plan
Study
Do

ACT

Next Steps

TOP TIPS

- Developing expertise
- Selecting a manikin
- Managing anxiety
- Making it ‘real’
- Flexibility and change

REFERENCES

With thanks to Charlotte Martin – Role Player

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Randall, D, Garbutt, D and Barnard, MC (2017) 'Using simulation as a learning experience in clinical teams to learn about palliative and end of life care : a literature review.' Death Studies 42 (3) Pg 172 - 183

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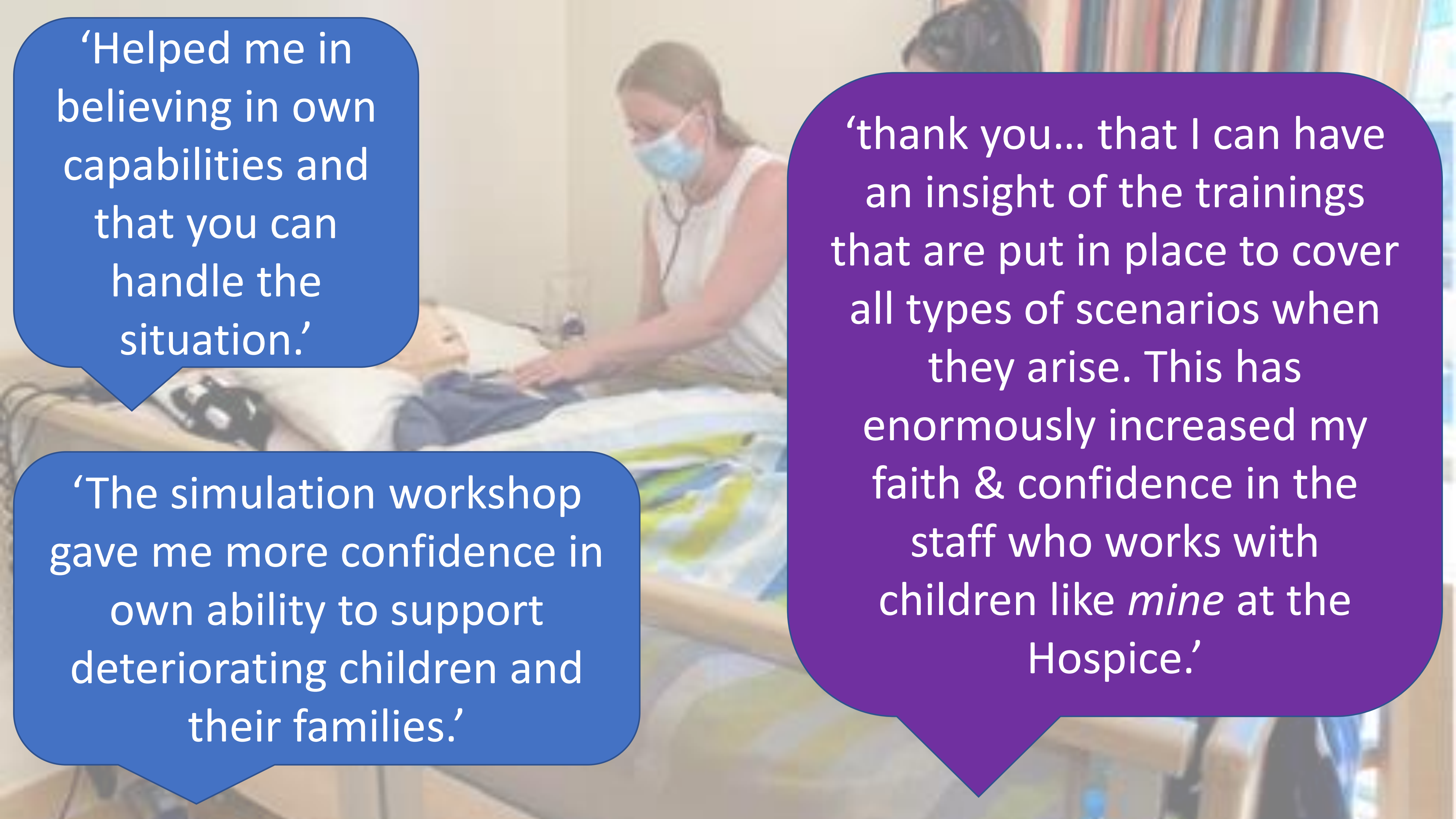


‘Helped me in believing in own capabilities and that you can handle the situation.’

‘The simulation workshop gave me more confidence in own ability to support deteriorating children and their families.’

‘thank you… that I can have an insight of the trainings that are put in place to cover all types of scenarios when they arise. This has enormously increased my faith & confidence in the staff who works with children like *mine* at the Hospice.’

How do children's nurses working in hospices manage emotional labour and professional integrity in long term relationships with parents?

Dr Mandy Brimble

Senior Lecturer in Children and Young People's Nursing,
Cardiff University School of Healthcare Sciences

Together for Short Lives Conference, September 2022

Background

Children with complex life-limiting conditions are living longer (Cooper, 2017), so relationships between nurses and families can sometimes span decades (Maunder, 2013). Although long term relationships between nurses and children/families in paediatric palliative care have been researched (Maunder, 2013 & 2016, Erikson and Davies, 2017), studies undertaken exclusively in children's hospices are rare. Therefore, the influence of this unique environment on nurse/parent relationships is unexplored (Brimble et al. 2019).

Aims of the Study

CARDIFF UNIVERSITY
PRIFYSGOL CAERDYDD

- Develop an in-depth understanding of how children's nurses manage long term relationships with parents in the children's hospice setting.
- Develop an in-depth understanding of how children's hospice nurses maintain professional integrity whilst providing long term practical, emotional, social and spiritual care to parents.
- Explore the coping strategies used by children's nurses to manage emotional labour whilst working in the children's hospice setting.

Key Concept: Emotional labour

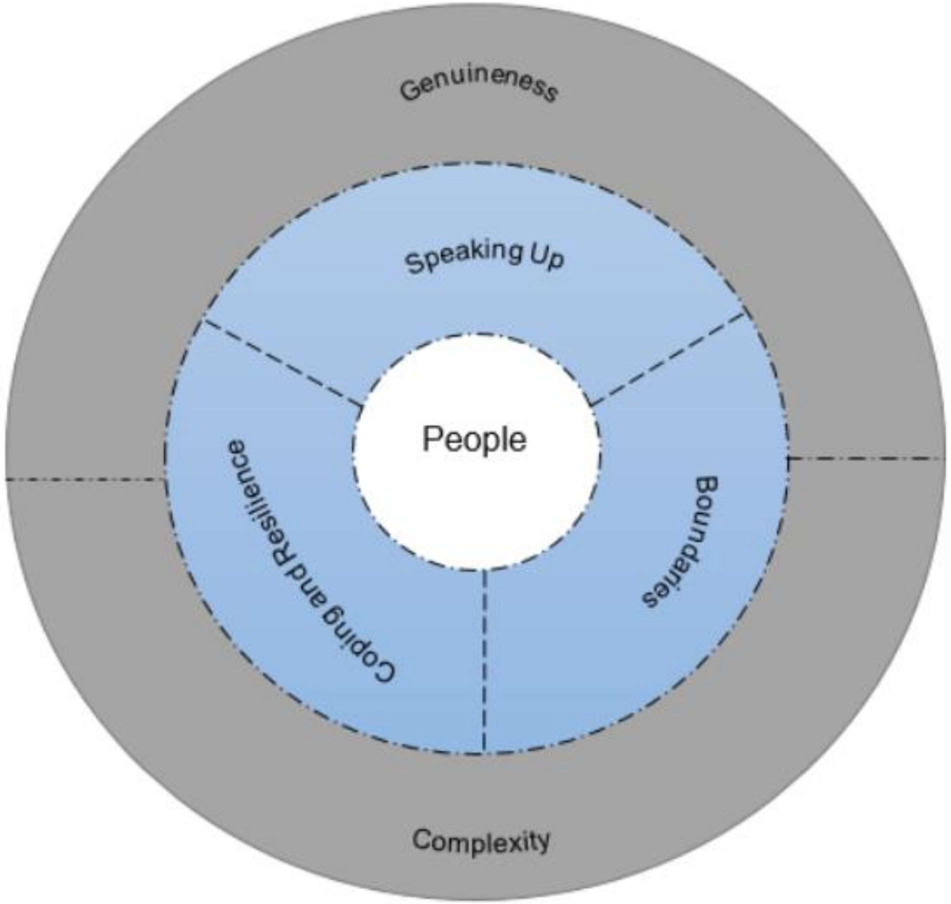
***Emotional labour** requires one to induce or suppress feeling in order to sustain the outward countenance that produces the proper state of mind in others- in this case, the sense of being cared for in a convivial and safe place. This kind of labour calls for a coordination of mind and feeling, and it sometimes draws on a source of self that we honour as deep and integral to our individuality.*

(Hochschild 1983, p.7)

Key Concept: Professional Integrity

- Most definitions of **professional integrity** in nursing refer to moral values and beliefs. However, Tyreman (2011) states that although integrity relates to the personal values and beliefs of the individual, **in healthcare this relates more closely to the professional community the individual is representing and the basis on which they form their identity**. Nursing models of professional integrity appear to be largely absent from the literature. However, Blowers (2016) provides one based on her work with students, mentors and lecturers

Key Concept: Professional Integrity Blowers (2016) Model of Professional Integrity



Preparation

- Children's Hospice Stakeholder Consultation on Research Proposal : Director of Care, Senior Nurse, Community lead (social worker), Former CEO.

- Pilot study (feasibility) to test data collection method and evaluate (Brimble et al. 2022)

Data Collection

- Purposive sample of 6 registered children’s nurses, employed at hospice 4 years minimum. Previously worked in another paediatric clinical environment for 1 year minimum.
- Asked to tell the story of a shift spent delivering day or short-break care to a child and family they had known for at least 3 years.
- Audio diaries recorded on mobile phones
- Data securely transmitted to the researcher via ‘Whatsapp’ (University and hospice ethics approval given).
- Diaries explored in telephone interviews.
- Participants asked to complete 2 recordings over a 1-3 month period

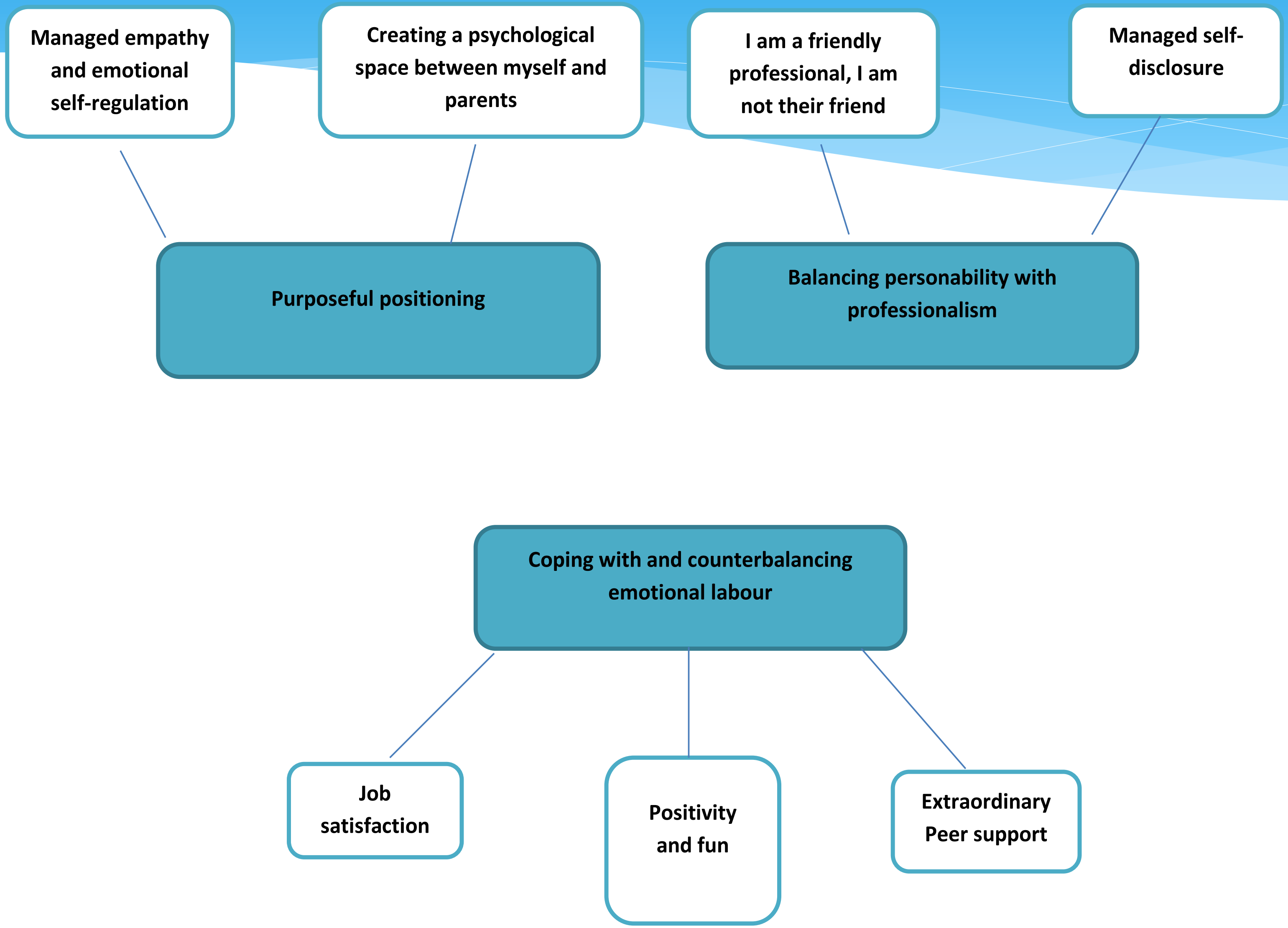
Data

- 6 participants
- 3 completed two audio diaries and two telephone interviews
- 3 completed one audio diary and one telephone interview
- So, nine shift stories in total, complimented by further exploration and adjuncts during telephone interviews

Analysis

- Thematic Analysis of audio diary narratives and telephone interviews using Braun and Clarke's framework (2006)
- Individual (20 individual themes) : types of empathy (using cognitive, compassionate and avoiding emotional), emotion management/self-regulation, counterbalances to emotional labour –features integral to the hospice.
- Whole Group (3 main themes, 7 sub themes)

Whole Group Themes and sub-themes



Managed empathy and emotional self-regulation

Creating a psychological space between myself and parents

I am a friendly professional, I am not their friend

Managed self-disclosure

Purposeful positioning

Balancing personability with professionalism

Coping with and counterbalancing emotional labour

Job satisfaction

Positivity and fun

Extraordinary Peer support

Purposeful positioning

- **Creating a psychological space between myself and work**
  - *'So I've got a separate life to nursing and that's really good for my mental health I suppose because it keeps me grounded and I don't just surround myself with nurses, otherwise I would go insane I think, because that's all you would talk about, because when you are with fellow nurses and your colleagues all you talk about is work but my social life doesn't involve that so I don't, I have a break from it.'* (Chris, telephone interview, p.4)
  - *'Well I think it has a lot to do with how you look at what you are trying to achieve and the best way I think I can explain it is, um, for children we're looking after there is no chance … they're not going to get better, they are going to have shortened lives. So what we are trying to achieve with them … is to give them the best quality care….. So I think it's all about the expectations that you have ….'* (Pat, interview 1, p.14-15)
  - **Managed empathy and emotional self-regulation**
  - *'… you know it doesn't matter how bad we feel … You know that's nothing compared to what it is for his nearest and dearest. I think it's about keeping that perspective really and not allowing, I think it's ok to show a bit of upset so long as you know …* (trails off) *… This social worker was sat sobbing on the settee all of the time. You know, and that's not right either.'* (Ashley, telephone interview 1, p.1-2)

Balancing personability and professionalism

- **I am a friendly professional, I am not their friend**
  - *‘I think it’s about your boundaries really. You’ve got, for me, I give 100% when I’m at work but I am very much there as the nurse, I’m not your friend, I’m not. I’m a friendly professional but I’m not your friend.’* (Alex, telephone interview 2, p. 4).
  - *‘… this perception that we’re their friend but it’s not a mutual thing. Because their world is professionals and no one else really. Some of the children with complex needs, all they’ve got is professional people and I think that their perception is that we are their friend… I don’t view them as my friends at all. So therefore, it I wouldn’t be on the same level as a real friend.’ (*Chris, telephone interview, p3).

- **Managed self-disclosure**
  - *‘…you do share some things don’t you, like you might talk about perhaps my kids. I’ve taken the kids to a concert or something as a way to connect um or you might share something which was perhaps a commonality… perhaps about a school or something’.* (Alex, telephone interview 1, p17-18).
  - *‘Come on now, I can’t be telling you that, I’m your nurse!’* (Les, telephone interview, p.8).
  - *‘No, but I wouldn’t say ‘I’m not going to answer that’ either. I would just try and find the right words to make a pleasant conversation and not, not have difficulties … I would just rather have pleasantries all the time. Yeah. Make a nice atmosphere and make them feel welcome really. So yeah, I’m quite good at small talk, that’s what I consider it as (laughs).’* (Chris, telephone interview, p.3).

Coping with and counterbalancing emotional labour

- **Job satisfaction**

- *'For me it's the type of nursing that I love … I mean when I worked on the wards and they were well staffed it was fine (laughs) but for me it was 'I'm going to be there in a minute' and I wasn't going to be there in a minute and so as a nurse I wasn't achieving what I want to do and the hospice nursing gives me enough of a balance.'* (Jo, telephone interview, p.5)

- **Positivity and fun**

- *'I think that little things like that's kind of magic isn't it. Like sometimes you think gosh those couple of minutes are really magic and how many people get that from their jobs? I think that's quite lucky. … So you've provided the child and the family with a memory but actually you've also done something that impacts on your own life in a lot of ways …, that memory it sorts of sticks in your head as well.'* (Alex, telephone interview 2, p.8.)

- **Extraordinary peer support**

- *I think being in the hospice rather than the acute hospital setting, we as a team, have got more time to be supportive of each other …you've got more time to be aware of each other's support needs and just vocalise your own feelings about how you feel things have gone and what your needs were and what you think we did well and what didn't go so well.* (Ashley, audio diary 1, p.2)

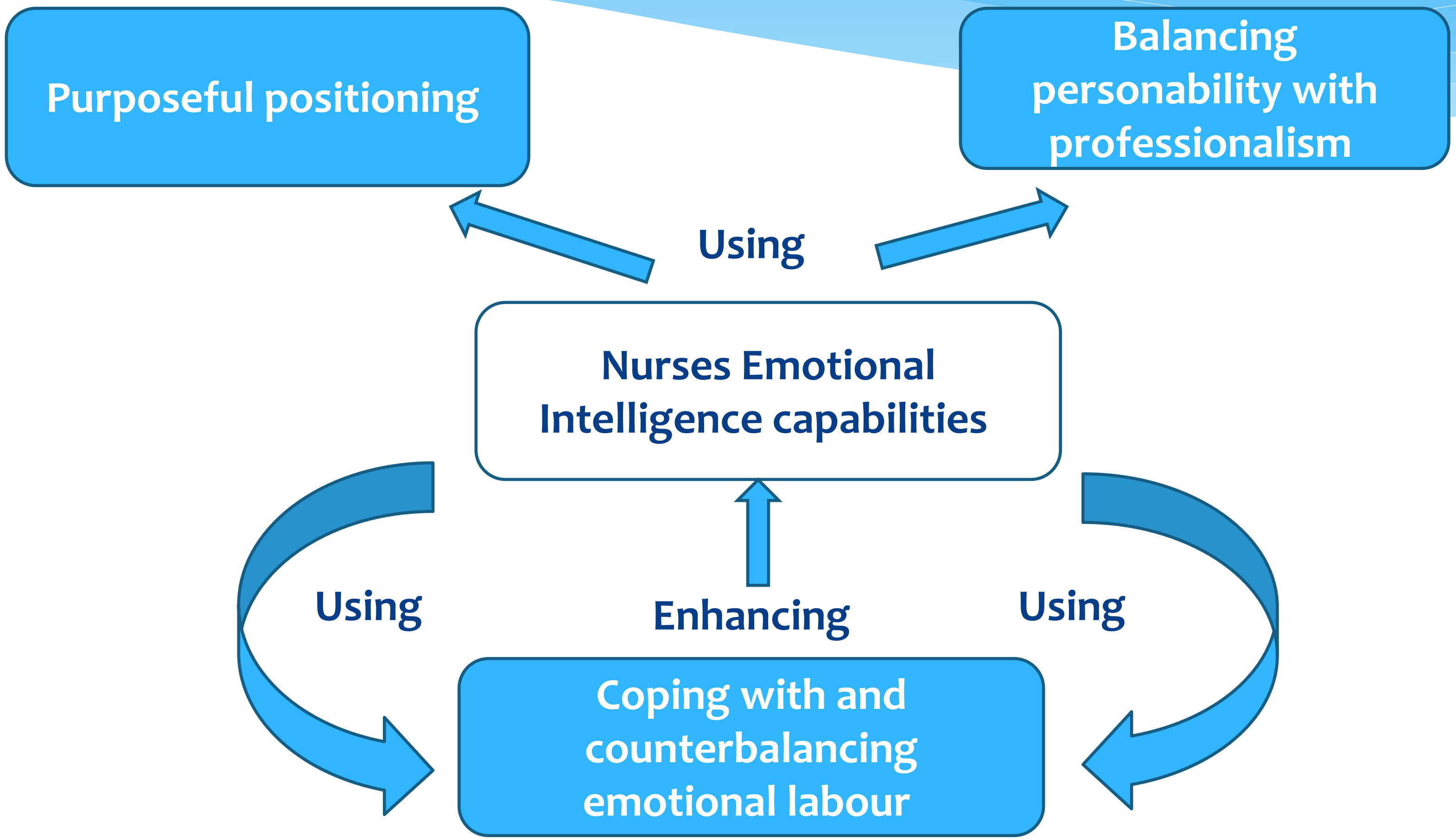
Using emotional intelligence (EI) theory to explore the findings

Goleman’s (1998) constructs of Emotional Intelligence

Type of Competency	Construct	Definition and Characteristics
Personal competencies (intrapersonal intelligence): knowing and managing emotions in oneself	Self-Awareness	the ability to know one's emotions, strengths, weaknesses, drives, values and goals and recognise their impact on others while using gut feelings to guide decisions.
	Self-Regulation	self-control, controlling or redirecting one's disruptive emotions and impulses, respond rather than react, think before acting, comfortable with ambiguity and ability to adapt to changing circumstances, trustworthiness and integrity.
	Intrinsic motivation	a passion to work for reasons beyond money or status, an awareness of personal motivators, optimism and perseverance in the face of adversity, organisational commitment.
Social competencies (interpersonal intelligence): knowing and managing emotions in others.	Empathy	ability to understand other people’s emotions and reactions (only possible if self-awareness is achieved) considering other people's feelings especially when making decisions.
	Social Skills	managing relationships to get along with others, communication skills, finding common ground with others, building a rapport, conflict management.

(Adapted from Goleman 1998)

The Themes:
Using and enhancing EI in Children's hospices



Purposeful positioning

Balancing personability with professionalism

Using

Nurses Emotional Intelligence capabilities

Using

Enhancing

Using

Coping with and counterbalancing emotional labour

Proposed framework for children's hospice nursing practice:

Combining Goleman's constructs (1998) and my research findings

Using EI to Navigate Relationships in Children’s Hospices:
A framework for nurses ©

ENRiCHn© .

Using EI to Navigate Relationships in Children's Hospices: A framework for nurses (ENRiCHn) ©.

Relationships with colleagues (based on Goleman 1998)			Relationships with families (based on study findings)	
Characteristics		Construct	Children's Hospice specific considerations (in addition to Goleman 1998)	
the ability to know one's emotions, strengths, weaknesses, drives, values and goals and recognise their impact on others while using gut feelings to guide decisions.	Personal (intrapersonal) competency	Self-Awareness	Be aware that relationships with families in children's hospices have a different dynamic to elsewhere. This is likely to affect you emotionally and influence your interactions. Sharing thoughts with peers and getting their feedback will help you develop self-awareness[2]	Personal
self-control, controlling or redirecting one's disruptive emotions and impulses, respond rather than react, think before acting, comfortable with ambiguity and ability to adapt to changing circumstances, trustworthiness and integrity.		Self-Regulation	Create psychological space between yourself and families in and out of work. Use appropriate types of empathy[1] to regulate emotional involvement with families. Carefully manage self-disclosure. Experienced peers can advise and help you [3]	
a passion to work for reasons beyond money or status, an awareness of personal motivators, optimism and perseverance in the face of adversity, organisational commitment.		Intrinsic motivation	The opportunity to deliver good care, spend time with families and help them make the most of the time they have together is motivating and satisfying. Recognise the things that motivate you and enjoy them. Positive (memory making) and fun activities can increase your motivation and help to counteract the emotional demands of the role [2 & 3]	
ability to understand other people's emotions and reactions (only possible if self-awareness is achieved) considering other people's feelings especially when making decisions.	Social (interpersonal) competency	Empathy Managed Empathy	You need to understand other people's and your own emotions and reactions. Empathise but do this carefully by using appropriate types of empathy.[1] You need to be self-aware to achieve this. [2 & 3]	Personal & Social
managing relationships to get along with others, communication skills, finding common ground with others, building a rapport, conflict management.		Social skills	The unique hospice environment will influence your interactions with families. Engage with them on a social level but be mindful of your role and professional responsibilities, manage self-disclosure carefully, be a friendly professional not a friend. Experienced peers can support you with this. [2 & 3]	Social

1.Types of empathy appropriate to a professional role: Cognitive (see a situation and the associated feelings from the other persons perspective) and Compassionate (understand, care and help) identified as the 'ideal' (Goleman et al. 2017). Inappropriate in a professional role: Emotional empathy (physically feeling alongside the other person, almost as if their emotions were contagious). 2. Recognition: Who I am. 3. Regulation: What I do (Cherniss & Goleman 2001)

Implications and recommendations for children's hospice nursing practice

- Findings indicate that EI is likely to be an important component of successfully managing the emotional and relational challenges of children's hospice nursing
- Recruitment: test EI - may help to recruit those most suited to manage the emotional and relational aspects of the role and address retention difficulties (TfSL, 2019)
- Staff development: raise awareness of EI (Wilson, 2014), identify EI constructs requiring development, target training to develop individual EI constructs (Clarke, 2010).
- Internal Leadership development - High levels of EI has been identified in successful leaders (Goleman, 1998).
- Formal Education and Practice : Use findings alongside EAPC (2007, 2013) and CPCET (2020) and RCN (2018) standards and competencies to formulate pre and post registration education programmes (Kang and Choi, 2020) .

Future plans/ possibilities

- Use knowledge of EI to underpin my teaching as a CYP nursing lecturer
- Develop EI teaching resources for CYP nursing students (and others)
- Trial and evaluate the framework with children's hospice nurses
- Trial and evaluate the framework with other children's hospice staff
- Trial and evaluate the framework with other children's nurses who have long term relationships with parents, e.g. Oncology
- Adapt the framework following further research/consultation with nurses from other fields of practice, e.g. adult and mental health.

Acknowledgements

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Thanks to……..

- The children’s hospice staff past and present who were involved in consultations about the project and helped refine the research proposal.
- The hospice children’s nurses who participated in the feasibility pilot and its evaluation.
- The participants who gave up their time to record audio diaries and engage in telephone interviews.
- To Cardiff University School of Healthcare Sciences for funding and study leave.
- To my doctoral supervisors Dr Sally Anstey, Dr Jane Davies and Dr Catherine Dunn.
- Everyone who has supported me.

Thank you

Questions?

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Welcome to together for short lives