8: Appendices

Appendix A – Palliative and End of Life Working Group Members

Name	Organisation	Role
Ed Manning	NHS England and Improvement	Data and Intelligence Workstream Lead, Palliative and EOLC Care
Barry James	NHS England and Improvement	Senior Programme Manager, Palliative and EoLC
Kath Lambert	Harrogate District NHS Foundation Trust	Consultant in Palliative Medicine
Rob Moriarty	NHS England and Improvement Personalised Care Coproduction Group	Person with lived experience
Colin Royle	NHS England and Improvement Personalised Care Coproduction Group	Person with lived experience
Marie Hancock	NHS England and Improvement	Project Manager Personalised Care (Palliative and End of life)
Jeremy Wilkinson	NHS Digital	Senior Clinical Business and informatics Lead. (Occupational Therapist) & Clinical Safety Office
Nicola Bowtell	Public Health England	Analytical Programme Manager (NEoLCIN)
Andy Pring	Public Health England	Public health intelligence analyst
Dr Sinead Clarke	NHS South Cheshire CCG	GP, Clinical Director and Lead for end of life care
Davina Hehir	Compassion in Dying	Director of Partnerships and Information
Dr Kathryn Hal	Collingwood Surgery	GP Clinical Lead for Palliative Care
Loraine Foley	Professional Record Standards Board	Chief Executive
Helene Feger	Professional Record Standards Board	Project manager
Kasmyn Chen	Professional Record Standards Body	Project Analyst
Maria Griffin	Professional Record Standards Body	Project Analyst

Dr Sam Edwards	North London Hospice	Medical Director and Consultant in Palliative Medicine
Dr Sarah Wells	Marie Currie West Midlands Hospice	Consultant in Palliative Medicine and Medical Director
Anita Hayes	Hospice UK	Head of Learning and Workforce
James Cooper	Together for Short Lives	Head of Public Affairs and Policy
Dr Helena Dunbar	Together for Short Lives	Director of Service Development
Katherine Selman	Kings College London	Consultant in Palliative Medicine
Matthew Allsop	University of Leeds	Researcher - NIHR EPaCCs
Professor Julia Riley	The Royal Marsden	Consultant in Palliative Medicine

Appendix B – Key Stakeholder Organisations

At the outset of the project PRSB identified organisations with a key role in palliative and end of life care to endorse the standard and support its implementation.

Organisation
Faculty of Public Health
Royal College of Anaesthetists
Royal College of Pathologists
Royal College of Radiologists
Royal College of Surgeons of England
Chartered Society of Physiotherapy
Royal College of Occupational Therapists
Royal College of Speech and Language Therapists
British Dietetic Association
British Psychological Society
Queen’s Nursing Institute
Royal College of Psychiatrists
Royal Pharmaceutical Society
Association of Directors of Adult Social Services
Association of Directors of Children’s Services
Joint GP IT Committee
College of Paramedics
British Geriatrics Society
Royal College of Physicians and Surgeons of Glasgow
Faculty of Intensive Care Medicine
Hospice UK
Sue Ryder
The Good Grief Trust
CRUSE bereavement
The Association of Palliative Medicine
Association of Palliative Care Social Workers

Appendix C – Webinar Attendees

Organisation	Title/Role
Compassion in Dying	Service user
	Service user and Chaplin
Compassion in Dying	Service user
Leeds Palliative Care Network	Clinical Service Manager (Palliative Care and Neighbourhood Night Service)
St Helena Hospice	Chief Executive
St Peter's Hospice	Head of Community Nursing
Shooting Star Children's Hospices	Interim Director of Care – Business Management
Royal College of Physicians	Cardiac Electrophysiologist, Clinical Director Digital Health
Southern Health	Consultant in Palliative Care
Newcastle Upon Tyne NHS Foundation Trust	Consultant in Palliative Medicine
Harrogate District Hospital	Consultant in Palliative Medicine
Black Pear	Chief Project Officer and Nurse
Yorkshire Ambulance Service NHS Trust	Lead Nurse - Urgent Care
Martin House Children's Hospice and Leeds Teaching Hospitals NHS Trust	Consultant in Paediatric Palliative Medicine
Northern Lincolnshire and Goole NHS Foundation Trust	Consultant Paediatrician
SCW NHS	GP and Clinical Lead for CHIE & WCR
St Helena Hospice	GP
NHS Vale of York CCG	GP Macmillan Cancer and End of Life lead
Ashley Centre Surgery	GP
North Lincolnshire CCG Primary Care Team	GP
Devon and Cornwall	Macmillan GPA
Scarborough	Macmillan GP
British Psychological Society	Policy Advisor
Chartered Society of Physiotherapy	Health Informatics Lead
South London and Maudsley NHS Foundation Trust representing RCSLT	Head of Speech and Language Therapy
Compassion in Dying	Director of partnerships and information
Compassion in Dying	Policy and Research Assistant
Together for Short Lives	Head of Public Affairs and Policy
Hospice UK	Head of learning and workforce
Sue Ryder	Chief Medical Director and Consultant in Palliative Medicine
techUK	Head of Health and Social Care

EveryLIFE technologies	User experience researcher
Graphnet	Project Manager
Ideal Health Consultants Ltd	HCV EPaCCS Training Lead
Ideal Health Consultants Ltd	Digital consultant
HL7 UK	Chair
Lancashire Teaching Hospitals NHS Foundation Trust	Service user involvement manager
NHS England/ Improvement	Covid-EOLC Response Team member
NHS England/ Improvement	Project Manager Personalised Care (Palliative and End of life)
NHS England/ Improvement	Personalised Care Programme Manager (interim) Palliative and End of Life Care programme
Lancashire Teaching Hospitals NHS Foundation Trust	Project Manager
NHS England/ Improvement	Communications Manager
NHS England/ Improvement	North East and Yorkshire Regional Director
Scottish Government	Division Digital Lead
Public Health England	Analytical Programme Manager (NEoLCIN)
Leeds City council	Senior Business Analyst
University of Basel	Health ethics expert
University of Leeds	University academic fellow
St Gemma's Academic Unit of Palliative Care, University of Leeds	Research Fellow (Palliative Care)
Department of Health Sciences, University of York	Professor of Epidemiology
PRSB	Director of strategy, communication and engagement
PRSB	Membership manager
NHS Dorset CCG	Business Analyst
North West London Health and Care Partnership	Quality Improvement Lead – Older People’s Care & Last Phase of Life
NHS Surrey Heartlands CCG	Business Analyst
Leeds Community Healthcare NHS Trust	
NHS Hull CCG	Strategic Lead for Children Young People and Maternity and Senior Commissioning Manager
NHS Surrey Heartlands CCG	
NHS Surrey Heartlands CCG	
Thames Valley and Surrey LHCR	Business operations lead
Humber Coast and Vale EPaCCS	Project lead

Appendix D – Webinar breakout sessions feedback

Part of the webinar on the development of the information standard held by PRSB on 11th December 2020 involved participants including people using services, carers, professionals and others breaking out into two discussion groups. Following is a record of the question-and-answer sessions during these discussions.

Group 1 discussed palliative and end of life care for children and young people with life limiting and life-threatening conditions.

Group 2 discussed personalised care and support planning.

Group 1 - children and young people.

A children & young people's information standard should align with which current frameworks?

Any proposed Information Standard should align with other appropriate frameworks including, NICE guidance, Children and Young People Advance Care Plan and the ReSPECT form.

Development of an information standard should include learning from good practice

How does EPaCCS record information and which healthcare professionals supporting children & young people does it share data with?

- Lead Consultant
- Key worker / care coordinator

EPaCCS in adults is often driven by primary care. This is not the case for children and young people which may be led by a palliative care worker, Macmillan team or a palliative community worker. There needs to be the flexibility to assign a lead role to someone other than in primary care.

Who should have an EPaCCS record?

Those who have an advance care plan?

Those who meet the Together for Short Lives categories?

Those with a clear end of life care plan?

Where you wouldn't be surprised if the C&YP died in the next 12 months?

What key information should be included in an EPaCCS:

Key information includes data on carers, patient demographics, etc.

Also, data that aligns with the CYPACP (Children and Young People's Advance Care Plan?) and ReSPECT form. However, CYPACP can be very lengthy.

It is important to record and share that a person is receiving full active treatment.

Leeds Teaching Hospital has an electronic ReSPECT form, but it is not interoperable, just on the main acute system.

In London Coordinate My Care is being used for children and young people but may not capture all the required information.

For children and young people, the terminology for Lasting Power of Attorney needs adapting.

A summary output from any information standard must include the content of ReSPECT not just that it exists and where it is.

Children often have multiple copies of a DNACPR. There is a difficulty with version control, particularly if people upload a photo of a (potentially out of date) document. We need one source of the truth.

The DNACPR plan for children is more detailed and complex than for adults. It is widely accepted that ReSPECT have got this right.

The plan needs to include date and frequency of renewal. How often should an end of life care plan/EPaCCS be updated & can they go out of date?

Who needs to see EPaCCS data?

The same types of healthcare professionals that see the adult EPaCCS but also paediatrics.

Educational, respite services, other services should see the data. It is up to the family to choose to share this information.

Social care may need to see it?

You could base the information standard on the CYPACP framework i.e. maybe just an awareness of its existence rather than access to the full information?

Who should have access to a C&YP information record?

Who should see C&YP information is different compared to adults because of child competency & parental responsibility.

There is an issue for children and young people on their capacity and ability to contribute.

What are the issues on transition into adulthood ?

There needs to be coordination & involvement by the appropriate healthcare professionals.

People may meet the criteria for EPaCCS in children but wouldn't as an adult.

We need to ensure that EPaCCS information transitions with the person and is either updated or deprecated.

We don't want out of date information on record after the person has left children &young people services.

We need to have a frequency of renewal and update of information schedule.

Group 2 – personalised care and support planning

What is important for personalised care?

The person (sic) knowing what options they have. The difference between needs and wants. (sic) Really important to ascertain what is important to the person and what really matters to them.

Doctors are very good at addressing the medical or surgical needs of a person, but they don't often know which family members are involved or want to be involved. Contact details for family members involved in care decisions needs to be captured not just next of kin.

There needs to be a main place where information is stored and shared, and the patient has to own this. It needs to be accessible, as hospital staff need to be able to see it and amend it when necessary.

One example of a key piece of information is an advance directive - a decision to decline a treatment.

Staff need to know what medicines a person is taking.

We need to move away from needs/wants to what really matters to me conversations and documentation of those conversations. Knowing what really matters and understanding this can help the person make the right decisions for them.

To be able to deliver high quality end of life care we need to really understand what matters.

A lot of effort is put into person centred care plans, but these cannot always be seen or edited and often they cannot be accessed when they are really needed e.g. in an emergency.

Broadly speaking people want to be involved in designing their care package. They want healthcare professionals to make decisions about their medical and surgical care.

It is important in any planning that professionals and patients/carers can communicate effectively.

What information is required in a CRISIS situation

What treatment do you or don't you want.

DNACPR, advance decisions.

Even if the person has capacity, they can't always make a decision/preference at that time. It is not easy in these circumstances.

Information is often not passed down in hospital.

Who is the care giver including their telephone number and name. They will be the patients VOICE in a crisis situation. This is not necessarily known.

How the person best communicates e.g if they are deaf how do they communicate?

It's about me and having control.

What information is necessary on a day to day basis?

Can the person providing the care answer the question: **“** Do you know what matters to me?”

Social and personal information, non-medical.

Have you any suggestions to improve information collection?

Allow patients to contribute to case notes with a booklet to support this. This gives control back to the patient and can reduce complaints.

Creating a one-page profile is another way of capturing this information.

PRSB has a standard for recording things that are personalised.

It is imperative that we capture what is most important and what matters. This needs to be stronger.

What does high quality personalised care at end of life look like from a patient viewpoint?

The plan needs to be accessible at the point of care delivery e.g A&E, ambulance, hospital and hospice. The patient should not have to repeat themselves giving the same details over and over. It needs to be front and centre.

The patient must be the owner.

Appendix E– Adult and Carer Survey with Compassion in Dying

The following analysis is from responses to a survey carried out by Compassion in Dying and the Professional Record Standards Body in February 2021. The insights are drawn from 1,031 free-text responses, which asked people to share their experiences or priorities for and concerns about end of life records.

The quotes used are taken directly from the experiences people shared.

Summary People's experiences demonstrated five clear themes:

1. People experienced considerable anxiety about their wishes and health information not being known or acted upon when it mattered. People's worries were based on: a. previous bad experiences b. a general lack of trust in NHS IT systems c. their information not travelling between care settings or across geographical boundaries.

2. People wanted to be more involved in viewing and editing their end-of-life records

3. People had bad experiences of end-of-life care when their wishes and health information were not known or acted upon by healthcare professionals.

4. People had good experiences of end-of-life care when their wishes and health information were known about and respected.

5. Recording their wishes was not always enough – many people needed 'advocates' to ensure their health information was known about and their wishes acted upon.

A significant majority of responses fell into the categories of either having concerns that end-of-life records would not work in the way people needed them to or having an experience which showed that end-of-life records did not enable key information to be known and shared when someone was at the end of life. However, despite this, the people who responded to the survey were clear that it was incredibly important to them that healthcare professionals in various settings had access to their end-of-life records and knew what their wishes and preferences were.

For some, having their wishes and health information known about was important to them because they had strong personal views about death and dying. Some people wanted the comfort of knowing that what mattered to them would be understood by everyone. Others stressed the importance of their wishes and health information being known because of previous experiences of illness or of caring for a loved one at the end of life - experiences which had made them realise what they would or would not want to happen to them, and the impact that not having this information recorded could have on their care.

When thinking about how to improve Electronic Palliative Care Coordination Systems (EPaCCS), it is vital to keep in mind why getting it right is so important to people and what difference this will make to their experiences at the end of life.

What people said they needed from their electronic end-of-life record

People expressed very clearly what they needed an electronic end-of-life record to do in order for them to have peace of mind in the present and have what they considered to be a ‘good’ experience when receiving care and treatment in the last years, months or weeks of life:

- Electronic records need to communicate people’s health information and end-of-life wishes seamlessly across care settings. People used the word ‘seamless’ frequently, and specifically mentioned sharing information between GP surgeries, paramedics, hospitals and care homes.
- Electronic records need to travel between geographical boundaries. People cited experiences of receiving care and treatment at more than one hospital in different Clinical Commissioning Groups or moving house or visiting family and needing to know that their health information and wishes would be instantly available if someone needed it in this new area.
- At a minimum, people want to be able to view their end-of-life record to see what information is available to healthcare professionals. Some also want to be able to edit and update the information either themselves or alongside a healthcare professional. People expressed that being able to do one or both of these things would give them peace of mind, alleviate anxiety and enable them to live well with their condition.
- Paper documents such as Advance Decisions or Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR) forms must be easily visible in someone’s electronic end-of-life record to all healthcare staff. Furthermore, when people complete documents such as Advance Decisions to Refuse Treatment and share them with their GP, they want their GP to ensure that these documents are uploaded to their end-of-life record
- People want to feel reassured that a healthcare professional will have the time to look at their electronic record and that doing so is a routine part of their practice.

A note on terminology: Throughout these findings different terms are used to mean the same thing. For example, DNACPR (Do Not Attempt Cardio Pulmonary Resuscitation), DNR (Do Not Resuscitate) and DNAR (Do Not Attempt Resuscitation). We have deliberately kept quotes in people’s own words, to reflect the language they use.

Findings

- **People experienced considerable anxiety about their wishes and health information not being known or acted upon when it mattered**

This was the most common theme to emerge from the survey. People voiced serious concerns about their end-of-life wishes and health information not being known about when it mattered. This left people with anxiety about what treatment and care they would receive in emergency situations, for example, if paramedics were called to an accident. People were also concerned about what treatment and care they might receive if they lost capacity at the end of life or were unable to speak for themselves. These concerns were present in people with existing conditions as well as people who identified as currently healthy.

For some people, anxiety about their wishes not being known came from having a bad experience in the past of their own or a loved one’s wishes and/or health information not being known or followed. For other people, anxiety about their wishes not being known came from a general lack of trust in the record-sharing systems currently in place. People specifically worried about whether their health and care records would ‘travel’ with them between care settings e.g., between a GP surgery and a hospital, and between different areas in the UK. Again, some voiced this concern based on a previous bad experience of healthcare information not being available in different care settings, and others just had a general lack of trust in IT systems.

Numerous people also reported that they had no idea what happened to documents that they had completed which detailed their wishes for end-of-life care, once they had given those documents to a healthcare professional. This in turn caused anxiety. Several people reported experiences where they had given documents to their healthcare professional, but they were then lost, forgotten about or not uploaded properly onto their electronic end-of-life record. A lot of the worry expressed came from not being able to ‘see’ their medical notes or end-of-life care record, and people reported that if they could access the information in their record more easily it would give them peace of mind, which in turn would help them to live well now.

- **People had concerns based on previous bad experiences**

“I cared for my terminally ill husband until his death. I often felt there was a gap as to the information available to GP, palliative care and other healthcare professionals especially when out of hours care was needed. It was distressing to have to constantly be checking and checking again that the information was correct. It has not given me much confidence for my own end-of-life care. I’m a Stage IV cancer patient and this is a constant worry.”

“I reviewed my end-of-life plan with my GP 2 years ago, he was happy for my wife to be involved in the process & was supportive & reassuring that a) My wishes were important; and b) That he would abide by them… My concern is that I do not have much faith in the NHS when it comes to sharing information digitally, so if I was in an emergency situation, I’m not confident my wishes would be known or adhered to. On 2 occasions I was in a situation where records had been misplaced, lost & the professionals involved with me at that time had great difficulty admitting this.”

“When my father died, his wishes, and the wishes of the family, were ignored by hospital staff. I was a lecturer in palliative and end-of-life care at the time and was able to successfully challenge this. Had I not been able to he would have had interventions to prolong his life against his express wishes. I am personally worried that my Preferred Priorities and Advance Decision will not be considered if I lose capacity. I have a Lasting Power of Attorney for health and welfare, but I am aware of how healthcare teams can, if not managed well, fail to seek information that is recorded.”

“I have made a living will and would like to be sure that those wishes followed me to hospital should I be admitted and didn’t just stay with my GP, as this happened to a relative of mine and her wishes were not followed.”

“Having dealt recently with staff in primary and secondary care who are dealing with my father, I don’t have a great deal of confidence that medical records and sharing of information about patients is particularly good.”

“When my mother was suffering from dementia in 2019, communication between hospitals and departments about her end-of-life care was poor. A digital, shareable record might have helped to avoid this, and I would hope that, when my time comes, my wishes would be clear to all concerned.”

- **People had concerns based on a general lack of trust in NHS IT systems**

"I live on my own and have no family. My GP has a copy of my Advance Decision and I have a printed copy which I keep in a file marked "Emergency File". This is placed in a prominent position in my home. I am still worried that, in the event of, for example, a serious fall or a stroke, the emergency services would not have a system to be able to easily access the information."

"I have RLS (Willis-Ekbom Syndrome) which can make life almost unbearable at times. I'm concerned that, if I couldn't talk about it for any reason, it would not be noticed and cared for. I am also worried that my very specific sleep needs would go unnoticed or unmet if I was unable to discuss my problems because it is not recorded in an accessible way."

"I have 2 daughters who are my next of kin and have a Power of Attorney for my health. I am concerned that, if I have an accident or a sudden heart attack, I won't be able to express my wishes to healthcare professionals, and my daughters won't be consulted. I have registered my wishes with my GP but I'm not confident that this aspect of my medical record will be flagged to other healthcare professionals."

"I am concerned about the lack of communication in the NHS - underfunding resulting in outdated computer systems and overworked staff. It puts the onus on me to co-ordinate and check everything. If I am not well enough to do that in future, or have dementia, I don't at the moment have confidence that my carefully prepared Advance Decision and Power of Attorney will be accessed."

"I have made a Living Will and discussed this with my GP and gave him a copy which he has told me will be placed on the GP's database, but I am not confident that it would be available to other bodies (e.g. a hospital) and could therefore be valueless leading to inappropriate decisions made with good intentions but in ignorance of my wishes." "I have multiple issues relating to my Spina Bifida & I'm anxious that decisions will be taken out of my hands. I've made an Advanced Decision which I lodged with my GP but she said that paramedics would not have access to it so I'm concerned that attempts to resuscitate me will take place."

"I have a DNAR in place and always carry documentation with me and even have a tattoo across my chest as a belt and braces action in the hope people would see it and look in my bag. Before every surgery or test I have, I need to tell the consultant this and show my documentation. I wish with permission it could just stay on my records so everyone treating me now and, in the future, can know just by looking at my records. I have a Lasting Power of Attorney but what if something happens to me and they can't get hold of my attorneys and do actions I don't want? It really worries me."

- **People had concerns based on their information not 'travelling' between care settings or across geographical boundaries**

"My concern is that my wishes will not easily be accessible to healthcare professionals. I live between two cities, and it seems the hospitals at each do not necessarily share medical records so I am not confident that they would share end-of-life wishes."

"I have made an Advance Decision and lodged it with my GP in Somerset. Having moved to Hampshire I'm not at all certain my GP here has that information."

"I am concerned that, although I have made a statement of preferences and lodged this with my GP, it will not 'travel' with me if I was admitted to hospital."

“It concerns me that my doctor’s records are not going to be available at a hospital that I may need to go in to as the 2 centres work on different computer systems.”

“My mum had a DNR on her records but every time she either went to hospital or changed care home it didn’t appear. We ended up carrying a copy around. Not satisfactory at all.”

2. People wanted to be more involved in viewing and editing their end-of life records

Not being able to ‘see’ information on their end-of-life record resulted in anxiety and people wanted to be more involved in this. People specifically said that having access of some description to their end-of-life record would make them feel more in control and reduce anxiety. Some raised the idea of having an online tool or app where they could check details of their end-of-life wishes and health information and potentially edit them as they grew older, or as their health condition changed.”

“As much as I've tried to make my wishes clear, I worry that this information won't be seamlessly available. There seem to be a lot of shortcomings in the NHS regarding IT and the ability to share information between entities. Also, as a person with complex health and personal needs, that some important aspect won't be passed on is a worry. I'd like to have the information in one place that I can see and amend if necessary and be confident that everyone is on the same page.”

“I have given copies of my Advance Decision to Refuse Treatment to both my GP practice and a nurse in the Cardiology Department of the local hospital where my condition is monitored. I have no means of satisfying myself that the document has been uploaded onto my hospital file or the GP notes and am very anxious that my wishes will not be carried out.”

“I want the option to change my mind on refusing treatments etc as I go along and to have this updated information available to those who should be aware of it. I like the idea of an online system where I can make updates easily.”

“I could carry a note saying that this information is available from my GP, but it might be better if there was a standard card or notification that would be recognised by any healthcare professional. Ideally it should be available online so that they can access it at any time. I don't know how much of my medical record and wishes are currently available in this way - I should like to know, and to be able to see it myself.”

“I feel all practices should have the death discussion when they take on new patients from 18 upwards and enable them to air their voices and note them. After that each patient should have access to their notes and be able to change their end-of-life choices as they themselves age.”

“My mother deteriorated rapidly and died unexpectedly. There was not much information being acknowledged such as DNR requests – a central file or app would have made her passing easier and caused less stress to the family.”

3. People had bad experiences of end-of-life care when their wishes and health information were not known or acted upon by healthcare professionals

Significant numbers of people told us about a bad experience of a loved one's previously expressed wishes and health information not being known about or respected at the end of life. This often resulted in traumatic experiences for both the dying person and their loved ones.

Sometimes this was due to problems with paper forms detailing people's wishes or health information being lost, or not being uploaded to an accessible electronic record which was transferrable between care settings.

For others, even if their detailed plans were known about, it did not guarantee them getting the care that was right for them. Sadly, recorded wishes were sometimes not acted upon by healthcare professionals. This caused distress particularly to family and friends witnessing their loved one's wishes being overlooked and subsequently receiving treatment they would not have wanted. This is significant because it shows that getting EPaCCS 'right' on its own is not necessarily enough to ensure that the information in such a record is acknowledged and used.

- **People had bad experiences as a result of wishes and health information not being known**

> *"The paramedics repeatedly resuscitated my mother after a stroke despite her clear wishes and a DNR - I was present (and I have Power of Attorney). Because neither of us had paper copies of these documents with us, they and the hospital kept treating her invasively. She had signed the DNR at the same hospital before surgery a year before, but it wasn't on record. This was 2 years ago. She has been in a nursing home ever since and regrets daily, how, in her view, I failed her."*

> *"I was responsible for the care of my mother and aunt prior to their deaths 5 and 3 years ago. They were cared for in good-quality sheltered housing and nursing homes. Both had Advance Decisions and Advance Statements. They both had multiple admissions to hospital in their final few years. Their Advance Decisions NEVER got effectively communicated to hospital staff except when I physically gave a copy to them. In one case this resulted in treatment being given which should have been refused. I repeatedly tried to get the care home to instigate a better system. They did eventually manage to get the Advance Decision transferred to the hospital in a bag with other essential things for my aunt. (Both my mother and aunt suffered from dementia and could not deal with these things themselves.) The hospital staff failed to find the Advance Decision. I had to track it down and bring it to their attention, which I was unable to do until the next day, which was too late for it to be effective as emergency life-preserving interventions had been carried out which should have been refused."*

> *"My mum lived with me during her end of life period. Our biggest issue was that her previous oncology care was provided in a neighbouring CCG area, so none of their records were available to anyone. Nor were the local hospital records, where she had been admitted briefly before her end-of life care commenced. This caused a lot of additional work for me, as the various teams did not seem to communicate at all together and relied on me to provide answers and information. I feel this did compromise care significantly, as my mum experienced complex and apparently rare symptoms during end of life which were never really managed adequately. If a single end-of-life record had been available, I think at the very least this would have improved communication between the disparate teams and would have improved the*

management of the difficult symptoms, making her end of life much less distressing and more peaceful than it was."

"My grandparent was transferred from one ward to another. Their DNR was not transferred and they were resuscitated. They then spent 2 years unable to speak, in a care home crying every day."

"With my dying father, I was shocked how poor the central records were. Despite receiving hospital treatment regularly, each time he was admitted there seemed to be no joined-up thinking."

"I was the only paid carer for my friend, an elderly lady, for 3 years. She had had a major stroke, and I visited her 5-7 days a week. I co-ordinated all her support and we were very close. She trusted me with everything and had given written permission to the GP, through a small form at the surgery, for me to act on her behalf. Two months before she died she was moved to a nursing home and her GP practice was changed. In the process, her GP records were sent to a central records office. Along with these records went her permission for me to act on her behalf. This made supporting her in the hospital, in the move to the nursing home, and during her brief stay in the nursing home very difficult. The home was not good and she died a miserable death without appropriate palliative care. To this day I am haunted by not having been able to help her fully at the end. The loss of that piece of paper with her signed permission was critical."

- **People had bad experiences as a result of wishes and health information not being acted upon**

"With my husband's end-of-life care, even when records (digital or otherwise) were available, none of the healthcare staff had the time to read them properly and absorb the information provided, so you cannot assume that providing information will cause it to be acted upon."

"When my wife was rushed to hospital with a bad stroke last August, I found that the Doctor treating her in A & E was not overly interested in the fact that she had a proper Advance Decision and the NHS ReSPECT Form."

"Despite my husband having Power of Attorney for welfare and finance, he was frequently not consulted when his father who had advanced dementia was admitted to hospital."

"My late husband's end-of-life wishes were made available to the hospital. Sadly they were `lost' and when replaced they were ignored. He died 2 years ago and I remain saddened that things he thought long and hard about were considered 'not important'."

4. People had good experiences of end-of-life care when their wishes and health information were known about and respected

There were also a significant number of responses detailing good experiences of record sharing. When wishes were recorded and respected, people were able to have what they would describe as good deaths. For example, some people explained how having records shared meant not having to repeatedly talk to healthcare professionals across different settings about their loved one's wishes at a time that is already stressful and upsetting. Others spoke about how having their own wishes shared effectively (e.g. when having an operation) has meant they trust that their wishes would be known about and respected in the future.

This demonstrates the importance of getting EPaCCS ‘right’. The impact on someone witnessing the death of a loved one whose wishes were known about and followed were in stark contrast to the experiences of those outlined in the ‘bad experiences’ section, and resulted in peace of mind for dying people and a more positive bereavement experience for their loved ones.

“My late wife and I were very pleased and relieved that her clinical details and personal preferences could be recorded and shared across the organisations that might be involved in her end-of-life care. There was peace of mind that, if things happened at speed in an emergency, the records would be there for the professionals to access and understand without either of us having to give repeated instructions and so also alleviating the fear that personal preferences would not be implemented in a situation where the focus was on urgent care and care for the rest of our family in emotional and upsetting times.”

“My ReSPECT form was set up with my local practice so that emergency services could see it straight away if needed. This was recommended by my excellent MS specialist nurse; I was then able to let Page 8 her view this electronically when she asked if that would be ok. Seems to have worked well....”

“As my wife's life was coming to an end it was very comforting to know that the Marie Currie nurse attending was able to access all the information she required and see the DNR records.”

“My father was in a care home and nearly sent to hospital but they saw that was against our wishes in the care plan and kept him at the home - thank goodness.”

“My father was able to receive the end-of-life care he needed in the way he wanted without being transferred to hospital and without any of us having to worry that we didn’t know if this was his choice. We knew we were supporting the choices he made when he was able to make them and as a result we spent time with him rather than battling the healthcare system. Having his wishes pre documented also ensured the staff were able to act confidently on his behalf too. Also none of us felt guilty or worried that we weren’t doing right for dad.”

5. Recording their wishes was not always enough – many people needed ‘advocates’ to ensure their health information was known about and their wishes acted upon

Some people said that recording their wishes for treatment and care was not always enough as they needed an informal advocate, like a family member or friend, to ensure their wishes were followed and key information known about. For example, many respondents detailed how they had to keep repeating what was in their loved one’s recorded care plan to healthcare professionals. For some, this was a difficult and stressful experience.

“My parents died 2013 and 2017. My sister and I were able to ensure that the healthcare professionals who were helping them knew what their end-of-life wishes were but only because of our physical presence. I have no confidence that reliance on the very limited existing paper or electronic systems would have worked.”

“The only way the hospital A&E knew my father's wishes was because I was there. I got there before my sisters and I felt a huge responsibility on my own even though my father had shared his wishes with us in advance. It would have been much easier if the hospital had access to his recorded wishes independently. It felt awful having to agree/say he shouldn't be resuscitated etc especially when it was just me on my own without my sisters there.”

“My late husband had MND. The care he received in our local hospital was poor, nobody was prepared to look at his notes. I created and carried with me a folder with end-of-life stuff, DNR, Power of Attorney etc and made sure I watched as it was copied every time he was admitted then returned to me, to be sure it was all there and all in one place.”

“When I cared for dad, I had to rush after him to hospitals and clinics clutching the Advance Decision and Lasting Power of Attorney papers and making sure the carers passed them onto the hospital etc. It would have been so much easier if I could just have told them to check his records; the GP had them but they were rarely uploaded or updated. I’ve given my signed papers to the GP surgery but never heard if they have been uploaded to their system, I suspect not.”

“During the last year of his life 2004/05, my father aged 88/89 had a couple of admissions to his local hospital A&E. I was amazed how they seemed to have no ready access to his medical records of any sort. Had I not been with him on each occasion, they would effectively have been dealing with a blank sheet of paper.

Appendix F– Children & Young Person Interviews

PRSB working with Together for Short Lives carried out a series of interviews with five parents and 1 young person, with life-limiting conditions. The participants were interviewed via Zoom/Teams by Helena Dunbar, Director of Service Development and Improvement for Together for Short Lives. An analysis and feedback of the finding from this consultation is included here.

Participants were asked to consider the following themes:

- Terminology in use around children and young people palliative and end of life care, including ensuring that aspects of children and young people specific needs are clearly defined, captured and understood especially by clinical professionals, carers and key workers

- What can be done to aid difficult discussions around end of life with parents and young people. This includes ensuring mechanisms are in places that allow for difficult discussions, communication is clear and understood especially by parents/ legal guardians and young people and care records reflect all decisions made especially those by parents/guardians

- What is important in a children and young people's advance care plan and how to ensure all aspects of the plan reflect the care required and the decisions taken.

- What are the key anxieties that children, young people and their parents have around palliative and end of life care planning

- Any other concerns and issues that need raising around advance care planning and the information requirements that need to be considered to support parents/guardians, young people and children

Feedback of the themes discussed includes

- Terminology

  When considering an information standard for end of life and palliative care, for children and families there is a need to consider a plan for living which will include end of life but the focus also needs to be on quality of life.

  Many children don't have a clear diagnosis and an advanced care plan needs to reflect treatment and care like the template used by Children and Young People Advance Care Planning Group http://cypacp.uk/

  "Keeping a child as well and as comfortable as possible for whatever their time frame is"

  There is a perception that a palliative care pathway only gets looked at, at end of life. "What matters most is not when I die its the lead up to that, general care, hospital stays"

For children longevity is an issue. The palliative care pathway for children may go on for years into adulthood. System needs to plan for life and not focus only on end of life

There was a view that the end of life pathway for children and young people should be much wider and be much more widely used, then it becomes less of a "Scary document" to professionals and parents. People need to get better at talking about death and dying.

- Having difficult discussions

All participants need to instigate the plan and asked questions. It should not only come from professionals Sometimes there is a battle to get an advance care plan done . While it is important to have a tool/pathway professionals need skills to engage and complete a plan. Many participants expressed frustrations that professionals do not have the right competencies.

Immediate reaction from professionals towards a palliative care pathway is sometimes that parents are giving up hope, this is not the case. There is a perception that the request to do a plan takes professionals by surprise.

Information standard needs to come hand in hand with education package for professionals "A long bitter battle between professionals and parents trying to do a plan!"

A plan is a care document that does not need every part completed at the one time, The end of life section may be completed later. We need to ensure the document is editable. If plan is led and supported by a consultant then it is easier for parents

- Various end of life templates including Respect, Children and Young People Advanced Care Plan, Dying Matters

It may be easier to document what you don't want.

There needs to be in-depth discussions around care – e.g. not just 'CPR - yes or no?' but the level of resuscitation required. Need to discuss all the options that are available for parents including the details of a persons' life , how far parents want to go, how to optimise time at home, how to keep a child out of hospital, etc

What to do when a child deteriorates ?

A document needs to have the right information, nuances of care so professionals can recognise and understand the child

It needs to be akin to a birth plan, be prepared for change, flexible, iterative "living document" with lots of options and scenarios for parents, "May go several ways, not easy to predict with children".

We need a hard and electronic copy. Parents like hard copy to carry with the child

Who leads?, When to review and update the plan ?. Essential plans are updated at least annually

Being able to transition with the plan into adult hood is vital for a young person and their family

Having sections to the data which are accessible to certain professionals at certain times and for certain episodes of care is important

Electronic documentation should stop the need for repetition from parents on the needs of their child

- Anxieties

Even with a plan parents are still concerned that a professional on the day may decide not to follow the plan and try one more test! One example given was when doctors have not looked at the plan when a child presents. It is so important to flag that a child has an advance care plan in place .

There needs to be a transition from a child plan to an adult plan . A person needs to carry through plan into adulthood not move to just a respect document.

Parent were anxious about the legality of an advance care plan – on transition and when capacity changes – how will the plan will be followed?

One young participant carries a pen drive with her with her advance care plan on it. She had researched this

- Other points raised

A point was raised on the importance of information on the a child's death review so that parents can have their wished maintained.

Some people expressed concerns surrounding an advanced care plan and wondered if it was the same as the Liverpool pathway and expressed fears that parents will be made to make decisions.

Electronic document needs to be accessed and owned by parents. There could be a QR code to access the document and to protect access for certain groups. Parents need to understand choices available to them to be able to populate plans

Appendix G– Explanation of Palliative and End of Life Care Terms

Term	Explanation
Advance Care Plan	Advance care planning is a voluntary process of discussion and review to help an individual who has capacity to anticipate how their condition may affect them in the future and, if they wish, set on record: choices about their care and treatment and/or an advance decision to refuse a treatment in specific circumstances, so that these can be referred to by those responsible for their care or treatment (whether professional staff or family carers) in the event that they lose capacity to decide once their illness progresses. https://www.england.nhs.uk/improvement-hub/wp-content/uploads/sites/44/2017/11/ACP_Booklet_2014.pdf
Advance Decision to Refuse Treatment	This is a decision to refuse specified treatment made in advance by a person who has capacity to do so. This decision only applies at a future time when that person lacks capacity to consent to, or refuse, the specified treatment. This is set out in section 24 (1) of the Mental Capacity Act. Specific rules apply to advance decisions to refuse life-sustaining treatment. An advance decision to refuse treatment: It can be made by someone over the age of 18 who has mental capacity Is a decision relating to refusal of specific treatment and may also include specific circumstances. It can be verbal, but if an advance decision includes refusal of life-sustaining treatment, it must be in writing, signed and witnessed and include the statement ‘even if life is at risk’. It will only come into effect if the individual loses capacity. It only comes into effect if the treatment and any circumstances are those specifically identified in the advance decision. It is legally binding if valid and applicable to the circumstances. Sources https://www.nhs.uk/conditions/end-of-life-care/what-it-involves-and-when-it-starts/ Mental Health Capacity Act 2005 https://www.legislation.gov.uk/ukpga/2005/9/pdfs/ukpga_20050009_en.pdf
Advance Directive	An advance directive is sometimes called a living will. It is a written statement of your wishes to refuse a certain treatment. It may also include the specific situation in which you wish to refuse the treatment. It is a way of making sure that everyone knows what treatment you do not want to have, if you become unable to make your own decisions in the future. For example, you may decide one of the following things:

	• If your illness cannot be cured and you become very unwell after having all possible treatment, you do not want to be kept alive by being fed through a feeding tube or drip. • If your condition and quality of life is not improving and is getting worse while you are being fed via a feeding tube or drip, you do not want these treatments to continue. • If you are very ill and only expected to live for a few days, you do not want to be given antibiotics for an infection. You can only make an advance directive if you live in Scotland. If you live in England or Wales, please see our information about an advance decision to refuse treatment. Source https://www.macmillan.org.uk/cancer-information-and-support/treatment/if-you-have-an-advanced-cancer/advance-care-planning/advance-directive
Advance Statement	These are written statements (either written down by the person themselves or written down for them with their agreement) the person might make before losing capacity about their wishes and feelings (Mental Capacity Act Code of Practice 2007, P291) regarding issues they wish to be considered in the case of future loss of capacity due to illness, such as the type of medical treatment they would want or not want, where they would prefer to live or how they wish to be cared for. Advance statements should be used to help find out what somebody’s wishes and feelings might be, as part of working out their best interests when they have lost capacity to decide. They are not the same as advance decisions to refuse treatment and are not binding Source https://www.nhs.uk/conditions/end-of-life-care/advance-statement/
Cardiopulmonary resuscitation decision	**Cardiopulmonary resuscitation** Emergency treatment that supports the circulation of blood and/or air in the event of a respiratory and/or cardiac arrest. **Cardiopulmonary resuscitation decision** A clinical opinion, for or against an attempt at cardiopulmonary resuscitation. Such decisions only apply to attempts to restore circulation or breathing. They do not decide the suitability of any other type of treatment, and never prevent the administration of basic comfort and healthcare needs. **Do not attempt cardiopulmonary resuscitation** (DNACPR) decision Only covers views about withholding attempts at cardiopulmonary resuscitation in the event of a future arrest. It is made by the clinician responsible for care. This decision can also be made by the person themselves as part of ADRT.

	Sources https://www.resus.org.uk/library/publications/publication-decisions-relating-cardiopulmonary https://www.resus.org.uk/library/quality-standards-cpr
End Of Life	NICE Quality Standard (QS13) includes the following definition for adult approaching end of life Adults in the final weeks and months of life, although for people with some conditions, this could be months or years. This includes people with: • advanced, progressive, incurable conditions • general frailty and coexisting conditions that mean they are at increased risk of dying within the next 12 months • existing conditions if they are at risk of dying from a sudden acute crisis in their condition • life-threatening acute conditions caused by sudden catastrophic events. Source National Institute of Care and Excellence *https://www.nice.org.uk/guidance/qs13*
Gold Standard Framework	A recommended end of life care tool developed originally for use in primary care; it can also be used in care homes. It helps to identify people who are approaching the end of life, assess their needs and preferences, plan care and communicate across agencies. Source www.goldstandardsframework.org.uk
Lasting Power of Attorney	Different types of power of attorney There are different types of power of attorney and you can set up more than one. **Ordinary power of attorney** This covers decisions about your financial affairs and is valid while you have mental capacity. It is suitable if you need cover for a temporary period (hospital stay or holiday) or if you find it hard to get out, or you want someone to act for you. **Lasting power of attorney (LPA)** An LPA covers decisions about your financial affairs, or your health and care. It comes into effect if you lose mental capacity, or if you no longer

	want to make decisions for yourself. You would set up an LPA if you want to make sure you're covered in the future. **Enduring power of attorney (EPA)** EPAs were replaced by LPAs in October 2007. However, if you made and signed an EPA before 1 October 2007, it should still be valid. An EPA covers decisions about your property and financial affairs, and it comes into effect if you lose mental capacity, or if you want someone to act on your behalf. Source https://www.ageuk.org.uk/information-advice/money-legal/legal-issues/power-of-attorney/
Palliative Care	End of life care includes palliative care. If you have an illness that cannot be cured, palliative care makes you as comfortable as possible, by managing your pain and other distressing symptoms. It also involves psychological, social and spiritual support for you and your family or carers. This is called a holistic approach, because it deals with you as a "whole" person, not just your illness or symptoms. Palliative care is not just for the end of life – you may receive palliative care earlier in your illness, while you are still receiving other therapies to treat your condition. Source https://www.nhs.uk/conditions/end-of-life-care/what-it-involves-and-when-it-starts/
Personalised Care and Support Plan	Personalised Care and Support Planning is a series of facilitated conversations in which the person, or those who know them well, actively participates to explore the management of their health and well-being within the context of their whole life and family situation. This process recognises the person's skills and strengths, as well as their experiences and the things that matter the most to them. It addresses the things that aren't working in the person's life and identifies outcomes and actions to resolve these. Personalised Care and Support Planning is key for people receiving health and social care services. It is an essential tool to integrate the person's experience of all the services they access so they have one joined-up plan that covers their health and wellbeing needs. Source https://www.england.nhs.uk/ourwork/patient-participation/patient-centred/planning/
ReSPECT	The ReSPECT process creates personalised recommendations for a person's clinical care and treatment in a future emergency in which they are unable to make or express choices.

	These recommendations are created through conversations between a person, their families, and their health and care professionals to understand what matters to them and what is realistic in terms of their care and treatment. Patient preferences and clinical recommendations are recorded on a non-legally binding form which can be reviewed and adapted if circumstances change. The ReSPECT process can be for anyone but will have increasing relevance for people who have complex health needs, people who are likely to be nearing the end of their lives, and people who are at risk of sudden deterioration or cardiac arrest. Some people will want to record their care and treatment preferences for other reasons. Source https://www.resus.org.uk/respect
Treatment Escalation Plan	Treatment Escalation Planning is a clinician-led process which is helpful when a person with serious illness has the potential for acute deterioration or may be coming towards the end of their life. It provides the opportunity for the clinicians to agree a plan for with the person, or if they lack capacity, with their LPA, advocate and those important to them, to guide decision making about what treatments the person would receive should their condition deteriorate. A documented Treatment Escalation Plan is a useful communication tool between different clinicians and teams involved in the care of the person, especially in a crisis or urgent situation, where the person is unable to participate in shared decision making. Source Universal Advance Care Planning Principles