Time for change conference accepted abstracts

The following abstracts were accepted as verbal or poster presentations for the Together for Short Lives UK conference *Time for change: A new vision for children's palliative care,* due to take place in March 2020, but cancelled due to the coronavirus crisis.

A New Community Pharmacy Workforce Delivering Paediatric Palliative Care Services Across Scotland

Dr Kate McCusker, Childrens Hospices Across Scotland (CHAS)

Aim: A Paediatric Palliative Care Community Pharmacy Network was conceptualised to deliver three core services: - Medicine Supply Service — to improve access to specialist paediatric palliative care medication in the community - Medicine Information Service — to improve access to pharmaceutical paediatric palliative care advice - Paediatric Palliative Care Advocacy Service — to raise awareness of paediatric palliative care and Children's Hospices Across Scotland (CHAS) in local communities **Background:** A ground breaking paediatric palliative care study in Scotland in 2015 identified that 15,400 babies, children and young people with life-limiting conditions required input from palliative care services. This scale of need is significantly higher than previous estimates and as a consequence, innovative and transformational approaches to palliative care need to be investigated if services are to meet demand. To this end, a new model of care has been conceptualised, which unlocks the clinical expertise of community pharmacists and capitalises on their unique reach across Scotland to deliver palliative care services deep into the heart of communities. **Methods:** Through stakeholder engagement, a service delivery framework was designed. The framework is set out under 3 key domains: (1) Core Services from Community Pharmacies (2) Required Training and Resources for Community Pharmacies, (3) Service Evaluation and Patient Outcomes. **Findings:** Full funding to test the model has been successfully secured. The model is currently being tested in the Forth Valley Health Board in Scotland before full service evaluation and national roll-out. **Conclusions:** A pioneering new model of care, which is the first of its kind in the UK, has been conceptualised. The model capitalises on community pharmacy expertise and reach, with the aim of delivering paediatric palliative care services deep into communities and improve patient outcomes. Testing of the model is underway, with the first evaluation results due to be analysed in the summer of 2020.

A Paediatric Palliative Care Ward Round - Bridging the Gap between General Paediatrics and Community.

Catherine Brown, Dr Stella Yeung, Dr Ross Smith, Heidi Reynolds, Manrita Khatker, Dr Catriona McKeating, Bradford Teaching Hospitals Trust

Aim: To establish a multi-disciplinary paediatric palliative care ward round to improve inpatient care provided to children and young people (CYP) with palliative care needs at a large district general teaching hospital. **Background:** The Bradford Specialist Community Paediatric Palliative Care Team (SCPPCT) provides care to over 80 CYP and families together with two children's hospices. As described by Chambers et al. CYP with life-limiting/life-threatening conditions can have 'Multiple admissions to hospital with transfer between care settings' therefore care providers should 'ensure minimal supporting team changes, timely communication and excellent care coordination'(1). **Methods:** A 4-month pilot project providing a weekly inpatient round was established by the SCPPCT. Attending professionals included a paediatric palliative care nurse specialist, family support worker, children's community nurse, community paediatric physiotherapist, prescribing paediatric pharmacist, medical representative from both local children's hospices, consultant general/community paediatricians and ward nursing coordinator. CYP already known to the SCPPCT were reviewed and other inpatients considered to have potential need for SCPPCT input. CYP who had been discharged within the prior 7 days between ward rounds were also discussed. Each review considered medical, social, emotional/physiological and spiritual needs of the CYP and family. If considered beneficial a physical review of the CYP by the SCPPCT was undertaken. **Findings:** Communication between ward team, community and other specialist areas has improved for each care episode. In 3.5 months a total of 66 CYP were reviewed on ward round (61 inpatient, 5 outpatients). 29 inpatients/families were physically reviewed leading to 4 inpatient prescribing decisions, 3 new advance care decisions, and 3 new referrals to the SCPPCT. **Conclusions:** The pilot has been well received, evidenced by informal verbal feedback from staff and families, in particular visible SCPPCT presence on the inpatient ward. End of pilot feedback via survey monkey questionnaire from hospital staff will be sought.

A service evaluation of the role of hospice and palliative care for boys with Duchenne Muscular Dystrophy (DMD)

Katie Crook, Dr Baba, Ty Hafan Children's hospice and Cardiff Medical School

Aim: Review the role of hospice care and the acceptance criteria at Ty Hafan for DMD boys and consider appropriate care provisions for the boys with DMD. **Background:** Ty Hafan Children's hospice has offered services to many boys with Duchenne Muscular dystrophy (DMD) over the past 20 years. The life expectancy of DMD has increased significantly and most boys now survive into adulthood. **Methods:** Data on referrals and deaths was collected from Ty Hafan's databases and patient files onto an excel table for analysis. Information was also collected from the Neuromuscular Care Advisor and other hospices across the UK. **Findings:** The number of referrals and the average age of referral has increased over the past 20 years. Parents and Neuromuscular Care Advisors were the main referrers. The commonest reasons for referral were family support and respite care. The age of death has increased with no death under the age of 18 since 2010. No other services exist currently that support DMD boys in south Wales. Other hospices in the UK still accept DMD boys and have no plans to change this. **Conclusions:** Most DMD boys no longer meet Ty Hafan's referral criteria however if policies change there will be a significant impact due to the lack of other services available to support DMD boys and their families.

A service evaluation of the Transition Hub: facilitating transition from Paediatric into Adult Palliative Care

Grace Hosking, Dr Megumi Baba, Ty Hafan

Aim: To evaluate the Transition Hub service to identify its strengths and areas for improvement. **Background:** Increasing numbers of children with life limiting conditions are surviving into adulthood, resulting in more patients entering adult palliative care services. The transition process is crucial for ongoing care. Ty Hafan Transition Hub is a charity-funded, time-limited project providing a holistic one stop service to help support children and families in the process. **Methods:** Quantitative analysis of data gathered on the existing database and qualitative analysis of the service user feedback were carried out to evaluate the impact of the service. **Findings:** 38.5% of patients invited attended with 66% of attendees completing the feedback form. Responses were positive. Identified areas of improvement included altering the time, more informative invitation and additional, varied medical support **Conclusions:** The Hub is achieving it's aims of guiding families through the transition process. Some improvement can be made to the future Hub service delivery

Adapting a Long Term Ventilation (LTV) service For Children And Young People (CYP) In A Hospice Care Setting- Development of Senior Care Assistants

Rachel van den Brink-Budgen, Jenna Ridout, Deborah Lynn, Linda Maynard, East Anglia Children's Hospices

Aim: The number of CYP with LTV needs accessing hospice services continues to increase. This paper outlines the provision of a hospice led LTV service initially by specialist nurse roles, evolving further with the development of a novel senior care assistant role (SCA). **Methods:** Current service is delivered to 41 children. Short break care in hospice or home delivered to 61%, 21% of these CYP have Level 1, 55% level 2 and 24% Level 3 ventilation needs. The service supports discharge planning, coordinates care outside of hospital and has provided end of life care to 5 CYP with LTV needs in past 16 months. Care is overseen by 2 clinical nurse specialists (CNS), 2 LTV nurses and 2 senior care assistants (SCA). Full theoretical and practical training is in place with education cascaded by specialist team and tailored to individual hospice staff needs. **Findings:** The development of SCA role was perceived as innovative and cost effective way to support the CNS in delivery of LTV care as the caseload and complexity of LTV CYP developed. From July 2018 to June 2019, SCA's spent 45% on clinical tasks and 28% teaching. Key elements of the SCA role (with CNS oversight) are; - Teaching/training/mentoring nurses and care assistants. Training and supporting families - Developing child specific portfolios - Advocating for CYP in MDTs & professional liaison - Sourcing equipment - Assessment of stable and unstable CYP, planning and evaluating care. **Conclusions:** Developing this innovative SCA role has ensured patients receive increased professional contact, enabled their own personal professional development and makes best use of the organisation's available workforce in a cost effective way. The SCA acts as role model, demonstrating that safe and effective care is possible with the introduction of a skill mix for CYP with LTV needs in the region.

An Audit of Referrals Made to TÅ· Hafan Children's Hospice April 2018-March 2019

Zoe McCarroll, Dr Megumi Baba, Ty Hafan Children's Hospice

Aim: The aim of this audit is to identify the gaps and potential barriers to referral and its process by building on the current Ty Hafan referral audit and to make recommendations for improvement. Ty Hafan has a referral policy and procedure which will be consulted for this audit (1). **Background:** The prevalence of children with life-limiting conditions (LLCs) in the UK has been shown to be rising, from 16 per 10,000 in 2007 to 32 per 10,000 population in 2010 (2). The precise number of children with LLCs is not known in Wales but using the estimated prevalence above, and the population of children in Wales (3), there should be around 3,200. Despite the well-established children's hospice service, the estimate from the national statistics suggests that there are many unreached life-limited children in South Wales. **Methods:** The list of referrals made to TY Hafan between April 2018-March 2019 was gathered from the TY Hafan annual referrals audit database. The file notes for each child on the list was accessed in order to collect data on reason for referral, diagnosis, ACT category, date of referral acceptance and date of first contact with the family after panel decision. Ethical approval was not required as this was an audit using retrospective data and no patient identifiable data was collected. **Findings:** 63 referrals were made during the time period analysed. The number of children referred per Health Board is largely proportionate to the population distribution. Gaps and barriers identified include delays in time from referral to panel acceptance and differences in referrers between Local Health Boards. **Conclusions:** Based on the gaps and barriers identified the next step will be to increase awareness of the referral process between different professionals and to contact referrers where there were delays, exploring reasons in greater depth.

An evaluation of the Advanced Care Planning model use for neonates in the Paediatric Palliative Care service in Cardiff and Vale University Health Board

Natasha Jones, Dr Timothy Warlow, Cardiff University

Aim: To assess the quality of Advanced Care Planning in neonates with palliative care needs referred to the All Wales Paediatric Palliative Care Service **Background:** Advanced Care Planning (ACP) is one of the key principles of good practice within children's palliative care. ACP is a process of discussion regarding wishes for the child, in addition to end of life care and some aspects following death. Alongside ACP, parallel planning, planning for babies lives whilst also being prepared for deterioration or death, is a vital part of managing difficult cases, often involving complex ethical issues and decision making. **Methods:** Retrospective audit of data collected from Welsh Clinical Portal and Ty Hafan Children's Hospice archives between January 2015 and December 2018. Current guidelines on ACP were taken from NICE, Royal College of Paediatrics and Child Health and Together for Short Lives. **Findings:** Data from 26 patients was used in the final audit and analysed. 34.6% of these engaged in formal paediatric advanced care planning (PAC-planning), a written plan serving as a template for discussions with parents. However, a similar percentage engaged in informal discussions that still achieved many of the same criteria. Many aspects of ACP were demonstrated to have been done well, however some were poorly adhered to, for example documentation of discussions regarding organ donation or religious preferences were available in less than 25% of patients. Data highlighted that a stay at Ty Hafan children's hospice had a significant impact on the quality of record keeping and whether the families received extensive holistic support. **Conclusions:** Completion of ACP is variable with low rates of PAC-plan completion. However, many discussions of complex cases do occur informally. Recommendations include: adapting the current PAC-plan tool to keep up with current guidance and improving the documentation of care planning discussions.

Are the emotional needs of staff providing care in a Children's Hospice met?

Dr Katrina Macdonald, Kayleigh Gash, Claire Kilbey, Children's Hospice South West

Aim: To review staff absence with stress, anxiety or depression in a Children's Hospice to determine areas where support could be improved to aid resilience. **Background:** The importance of staff wellbeing is crucial for workforce retention and recruitment and for an organisation's success in providing high quality care (1,2). Work related stress appears to be rising particularly in professional occupations like healthcare with a higher rate overall of work related stress among women (1). Providing palliative and end of life care (EOLC) to children and young adults is stressful so psychological support through reflection to maintain and promote resilience is built into the workforce practice at Children's Hospice South West (3,4). Staff have access to a clinical psychologist who provides regular individual and group sessions. There are staff debriefs after each death and a culture of informal support within the team plus a management "open door" policy to address staff concerns and organisational issues. We reviewed work absence with stress, anxiety or depression to identify times where additional emotional support could improve and maintain staff wellbeing and to aid the development of effective supportive services. **Methods:** Staff absence with stress, anxiety or depression was reviewed retrospectively from July 2018 to August 2019. **Findings:** 170 days (40%) of the total 427 working days had one or more members of staff absent with stress, anxiety and depression. There was no pattern of staff stress, anxiety or depression absence and children receiving EOLC. **Conclusions:** Organisations have a responsibility to safeguard staff wellbeing. Staff absence with stress, anxiety and depression impacts on care provision and workload causing pressure on organisations. Feedback forms are being developed to assess the current system and ask staff how resilience can be improved with a view to developing a supportive environment that meets their emotional needs (5).

Better Together: An evaluation of joint transition clinics, co-facilitated by adult and paediatric palliative care clinicians in Hospice settings

Hannah Williams, Dr Megumi Baba, Ty Hafan

Aim: To capture learning from a pilot project offering joint hospice-based clinics for young people transitioning into adult palliative care **Background:** We recognised young people transitioning into adult services felt a key barrier was familiarity with adult palliative care clinicians and settings. Equally we identified adult clinicians and hospice settings experience barriers by way of a lack of familiarity with the demographic of young people, their conditions and their needs. We instigated a pilot for adult and paediatric clinicians to co-facilitate joint clinics, rotating between children's and adults hospice settings. **Methods:** Structured questionnaires and semi- structured interviews with young people and parents/carers. Reflective frameworks with involved professionals. **Findings:** Young people preferred informal 'drop in' clinics, hosted in hospice settings. They reported this gave them a greater sense of control, determining engagement based on their own assessment of need. - Young people reported now having trusted professionals within adult settings. They reported feeling more confident, building networks of support and feeling a greater sense of agency in navigating decisions regarding their care. - Young people felt they had a different perception of adult hospices, dispelling myths. Professionals reflected that they felt they had a greater understanding of the needs of young people and how to engage effectively. - Joint working enabled an exchange of skills and knowledge. It enabled better information sharing, relationship building and continuity of care. - Joint working led to a high level of responsiveness with effective symptom management and onward referral. It also facilitated end of life planning with a whole team approach to planning follow up. **Conclusions:** - Combining existing staffing and resources enabled effective co-delivery benefiting young people and offering opportunities for teams to share skills and knowledge - Learning from the project identified further barriers to engagement for some young people and also gaps in service offer. This learning was built into the second stage design of the pilot, currently being funded by Together for Short Lives

Bringing the sides together — improving palliative care for infants and their families

Prof Jayne Price, Rosa Mendizabal Espinosa, Kingston University St George's University London

Aim: This presentation examines ways hospital NNUs and children's hospices can work collaboratively to ensure choices, and improve care for infants with life-limiting conditions and their families. **Background:** In the development of palliative care and services — palliative care for babies shortly after or before birth has been described as the final frontier. Within this development some hospices have recently expanded to include care of infants transferred from neonatal units (NNU) and also antenatal referrals. However, evidence suggests hospice care is often not offered to parents in neonatal units (NNU). **Methods:** A part of a larger qualitative study examined experiences of staff (n=17) from 3 children's hospices caring for infants in hospice. Data were collected from 3 focus groups and analysis used a thematic approach. **Findings:** Four distinct but interrelated analytical derived themes arose from the data that enable a better understanding of the challenges and opportunities hospice staff juggle whilst caring for infants transferred from NNU. This presentation unravels one of those themes/challenges that being 'Bringing the sides together' which permeated the data and indicated the notion that the baby and family were betwixt and between hospital and hospice. Such a notion appeared to centre round the referral process from hospital services borne from an apparent reluctance of hospital staff to let go, by referring to hospice. **Conclusions:** Education, partnership working, planning for all possible outcomes seemed crucial to bringing the sides together and enable further development of quality palliative care for infants and their families.

Care after expected death: are we supporting families and staff?

Millicent Perry, Dr Jo Griffiths, Cardiff University/Paediatric palliative care services, Singleton Hospital

Aim: To audit services provided by Swansea Bay Paediatric Palliative care team at end of life, the ongoing bereavement support provided for family and the support available for staff after the death of the child. **Methods:** Information was extracted from medical, nursing and hospice notes of deceased children known to the service between 2013-2018 (n=18). This information was compared against standards from recent NICE guidance and appropriate literature (TFSL 2012; NICE 2016). The audit was undertaken as part of a Cardiff University SSC. **Findings:** In most cases, the team met the standards almost 100% of the time although note keeping hampered findings in some domains. Main findings included discrepancies between the level of information included in conversations that were held with each of the different families, for example, organ donation was only discussed in 4 cases. There was no routine record of which agency was providing bereavement care to families despite being offered through multiple routes. Sibling support was frequently offered, but only in one case was it found that this was accessed. **Conclusions:** There are many areas of good practice occurring in terms of end-of life care, bereavement support for families and support for staff following the death of a child under the care of the team. Clearer documentation is needed in certain areas, to ensure clarity and in order to make sure the children and their families are receiving the best level of support through such a difficult time. Closer communication between NHS and hospice services would assist clarity and reduce duplication for families. Also, staff debriefing after the loss of a child should be more routinely not only offered, but taken up by the MDT. Looking forward, a framework could be created and kept with the child's medical notes in order to make sure every detail is discussed with each family when appropriate.

Children's Rapid Response Team, reassurance, resilience and choice in place of care.

Rachael Williams, Michelle Snipe, Birmingham Community Healthcare NHS Foundation Trust

Aim: To provide effective/appropriate care closer to home reducing the number of emergency department attendances and short stay admissions in hospital for children with complex health care/palliative needs. Often children/young people are admitted to hospital unnecessarily when their care can be delivered at home. GPs can lack skills and confidence to treat children which results in them being referred to hospital for conditions that could be managed in primary care (DH 2010). Noyes et al (2013) support home based palliative care and flexibility that allows families to stipulate their preferred place of care. **Background:** In June 2018 BCHC was commissioned to provide extended hours of service for children and young people known to the existing Children's Community Nursing and Palliative Care Team. It was recognised that a high number of parents/carers of children with complex health care needs could not access the existing teams for support during periods of acute deterioration due to the high number of booked visits these teams had on a daily basis. **Methods:** Hours of service 07.30 to 23.00, overnight telephone advice by existing Children's Community Nurses/Palliative Care Team. Senior Nurse Practitioners holding advanced skills in caring for children with complex health care needs/non medical prescribing qualification. Senior respiratory physiotherapists supporting complex respiratory patients. Parents refer to the service for emergency management around enteral feeding or when their child becomes unwell as an alternative to their GP or hospital. **Findings:** Implementation of enteral feeding clinics and the use of virtual clinics offering safe telephone triage and appropriate allocation of resources maximising the number of children/young people that can be seen. **Conclusions:** In the first year team prevented 2339 A&E attendances, 404 admissions of children on the caseload. Excellent feedback has been received from our families. The team are looking to further develop this new and exciting service.

Children's unmet palliative care needs: a scoping review of parents' perspectives.

Georgina Constantinou, Prof Gurch Randhawa, Dr Erica Cook, Elaine Tolliday, University of Bedfordshire

Aim: To explore the available literature on the unmet needs of children with life-limiting conditions and their families, from the perspective of parents, internationally. **Background:** Providing care for families of children with life-limiting conditions can be difficult, due to the unpredictable trajectory of their conditions. Often services can experience a challenge to meet families needs. Few studies explore how well services are meeting the needs of these families. **Methods:** This study carried out a scoping review of the available literature which explored the unmet needs of families from the parent perspective. Papers included were from the perspective of parents of children aged 0—19 years, who have a life-limiting condition and are receiving palliative care, internationally. PubMed, MEDLINE, CINAHL and PsycINFO were included in the search for papers. Search terms: parent, needs, met/unmet/satisfaction, palliative/supportive/end of life care, life-limiting/life-threatening illness, infants/children/young people. **Findings:** The findings of the scoping review highlighted 5975 papers for screening. 55 papers were selected in line with the pre-approved criteria. These papers used various methods and were sourced from 17 countries internationally. Parents experiences of unmet needs reported in the papers were; respite care, professional communication skills, coordination and organisation of care and psychological support. **Conclusions:** The parent's perspective of unmet need, experienced in palliative care, were shown in many areas of the Quality Standards and Children's Palliative Care Frameworks. This would suggest families needs are not being met by services and need for exploration into children's and their families needs is warranted.

Collaborative partnership between children and adult palliative care/hospice services; A new model of care providing a continuing and comprehensive service to young adults and their families with complex palliative care needs.

Louise Smith, Andrew Curtis, Dr Emma Longford, Helen Parkinson, Claire House Children's Hospice & Wirral St Johns Hospice

Aim: To provide a collaborative service offer for all our Young People (YP), (both with and without capacity), which comprises a 5 year overlap of services in Paediatric and Adult Palliative care services. The plan is to manage palliative care needs jointly, improve symptom management, and therefore quality of life. This collaboration will provide an opportunity for adult services to extend knowledge on conditions previously only seen childhood (1), whilst offering a coordinated, continuous collaboration, with the opportunity to build relations safely. **Background:** Children are living longer, therefore increasing the need for them to access adult palliative care. It has been well documented that transition is a scary, isolating process for YP and their families (2), as they struggle with transition and building relationships with adult services. It is also recognised that there are deficits in awareness and understanding of adult palliative care provision (1), with gaps in knowledge for previously exclusive childhood diseases. **Methods:** Still in its early stages. We have held joint presentation evenings to families, which has facilitated early relationship building. Canvassed opinion of what they want/need (3,4). Agreed to offer joint clinics (5), parallel planning discussions ACP, symptom management, and social events to enable YP to build relationships. **Findings:** Increased quality of life for YP, improved symptom management, less hospital admissions, more support for families both in hospital and the community, greater opportunity to build sustainable relations. We aim to seek purposeful feedback from families at our 6 monthly open evenings, and from our YP as part of their social group. Professional feedback will also be sought. **Conclusions:** Gives YP a choice of services. Offers support to YP and families throughout transition, providing a continuous, collaborative relationship with palliative care services. Enables adult services to gain the right skills to meet the needs of YP with increasing dependencies, and complex needs. Transferable to other adult hospices within our footprint.

Competence, Confidence and Courage : Increasing Clinical Skills in a Children's Hospice

Elli Rushton, Christine Forster, Wessex Children's Hospice Trust

Aim: To plan, develop, and deliver a comprehensive practice development programme within a children's hospice to support the nursing care of clinically complex children and young people. **Background:** Children's palliative care is changing. Medical advances and improved technology, enable an increasing number of children with life limiting conditions to survive for much longer. They are supported by procedures such as long term ventilation, total parenteral nutrition, and peritoneal dialysis. Nurses in Children's Hospices are required to develop a much higher level of knowledge and skills to facilitate the support of these children, young people and their families. **Methods:** Development of the Practice Education Team - Honorary Contracts PICU/HDU/Respiratory Unit - Increase in PE hours from 48 to 104 pw - Collaboration with regional hospitals PE Teams Development of Competency Frameworks & Assessment of Practice - Specialist Study Days : Long Term Ventilation, Intravenous Therapies, Peritoneal Dialysis. - Skills Lab/Simulation - Supervised Practice - Pop up Training Sessions - Clinical supervision , Focus based solutions Joint Posts with Specialist Hospital - Paediatric Palliative Care Consultant - Adult Palliative Care Doctor - CNS Palliative Care - CNS Long Term Ventilation - Physiotherapy rotation - Development of a Long Term Ventilation Unit - Partnership working with Specialist Hospital : Respiratory Consultant, - Specific LTV Competency Framework & Respiratory Workbook - Increased opportunities to develop competence and confidence **Findings:** Staff competencies increased significantly during the seven year periods particularly in the areas of LTV, and IV administration. The consequence of this was an increased ability to support children and young people with very complex clinical needs **Conclusions:** Partnership working with a tertiary Hospital in combination with practice development and the opening of a Specialist Long Term Ventilation Unit resulted in a Nursing team of competent and confident practitioners with the courage develop to meet the needs of those in their care.

Confronting Transitional Challenges in Pediatric Hospice and Palliative Care in Rural Central California

Victoria Cruz Hernandez, MSW, Amy Cadenazzi, MSW, Hinds Kids

Aim: To implement an original, functional, strengths based model of guiding patients and families as they age out specialized pediatric palliative care into the uncharted adult care world in order to minimize gaps in service and ensure the have the greatest chance at overcoming unique hardships not faced in other regions of the United States. **Background:** We are a team of pediatric palliative care nurses and social workers who serve three rural counties in the center of California, and have the ongoing goal of helping our children with significant economic, cultural and social barriers to maximize their comfort and quality of life while facing life limited conditions. **Methods:** A comprehensive review of the literature and studies surrounding the past efforts of assessing needs in transitional care **Findings:** We have assessed and found a significant need to implement our model, both for our patients/families and our team members benefit, to ensure a cohesive and smooth transition plan, and to assist in overcoming unique barriers to California's Central Valley. **Conclusions:** We have found the benefit of developing this transitional model for our patients/families and have the long term goal of sharing findings and contribute to and collaborate with other pediatric health care providers in the community.

Developing a Model of Care: An opportunity to define children's hospice care in Ireland

Bevan Ritchie, Joanne Balfe, Kerry McLaverty, LauraLynn Ireland's Children's Hospice

Aim: To describe the processes by which a model of care for children's hospice services in Ireland was developed, and to define the key benefits of having a clearly articulated model. **Background:** Children's hospices have been providing a range of interdisciplinary care and supports to children with life-limiting conditions and their families since the first children's hospice opened in 1982. In the Republic of Ireland children's hospice care is a relatively new and evolving service; there is only one children's hospice in Ireland*, which developed from a pre-existing children's disability service. Since opening in 2011, it has become apparent that a clearer definition of children's hospice care, it's scope and aims, were necessary for all key stakeholders; families, professionals and staff. **Methods:** In 2015 LauraLynn commenced a project to consider the following in relation to current service provision: - Identify Core Services - Appraise Best Practice - Key Stakeholder Engagement & Evaluation - Define Key Change Objectives The subsequent development of the model of care involved an extensive review of best practice in children's hospice care. **Findings:** The LauraLynn Model of Care presents a framework of service delivery across five pillars — Direct Care, Family Support, Symptom Management, End of Life Care and Bereavement Support. Having a clearly documented model provides a clear focus for service delivery and enables greater understanding of the broad range of interdisciplinary supports on offer. It facilitates appropriate referrals, aids staff recruitment and retention, and guides research, training and education priorities. **Conclusions:** The model of care is a live document. It is both dynamic and evolving in nature, so as to continuously reflect the current services provided by LauraLynn Children's Hospice. It is hoped that the model will support the development of a range of KPIs and outcomes, against which the service can be measured.

Developing National Transition ECHO Networks

Carrie James, Hospice UK

Aim: To improve the process for young people with complex and life limiting conditions who are transitioning from children's to adult hospice and community services. **Background:** Advances in medical and therapeutic technology has resulted in an increasing number of young people surviving into adulthood with a range of complex needs. For many young people, their whole support system collapses as they reach their 18th birthday. Inadequate knowledge about this group can result in uncertainty and a lack of appropriate support/ services. Hospice UK want to utilise ECHO methodology to help to transform the lives of young people with complex needs during this transition period. **Methods:** - Using ECHO Hospice UK aims to bring together regional children's and adult's hospices, local NHS service providers, educators, volunteer groups and the young people themselves, to build a community based 'Transitions Network', forging local networks at the grass roots level across England. - Empowering young people to co-design and co-produce the programme - Engage health professionals and other stakeholders via a Transitions community of practice, to influence and drive change. - Engage & train three ECHO Transitions Hubs, championing the use of the ECHO model across the sector and supporting the networks and groups **Findings:** Anticipated outcomes: - A Transition Network that is designed by and reflects the views of young people living with complex conditions; and is sustainable/ self-managing for the longer term. - Set up a national Transition Community of Practice (COP) - Identify and produce recommendations for managing the Transition process Project ECHO is a popular model for improving patient outcomes through provider education, which has grown rapidly since its initial success in the treatment of Hepatitis C. Now operating in 21 countries covering over 55 complex conditions including neurology and palliative care. **Conclusions:** Hospice UK believes our project to develop national Transition Networks using ECHO can have a far-reaching and transformational impact on the way the Transition process for young people with complex conditions is currently approached within communities.

Development of an innovative new responsive model of care by a children's hospice

Jo Cohen, Dr AK Anderson, Kimberley Burke, Toni Menezes, Shooting Star Children's Hospices

Aim: Our central question was how Shooting Star Children's hospices can identify and support children and families in the child's last year of life and ensure that there is sufficient capacity/flexibility in our service to do this. **Background:** The hospice is working with more children with increasingly complex conditions and has finite resources. Our ethos of equity for all families was limiting our ability to be responsive to those in the last year of life and fully adhere to NICE guidance 61 and QS160. **Methods:** July 2018. Literature review - A desk based review of all current literature on palliative care assessment frameworks was conducted. Sept-Dec 2018. 3 multi disciplinary meetings over a 4 month period to discuss and review options and make recommendations. Detailed option appraisals which included analysis of caseload and existing respite provision. Existing research based, paediatric palliative care assessment tools were agreed, in combination to add an additional level to our referral criteria. Feb 2019 New approach approved by Board of Trustees. March 2019 A panel including the family keyworker met 5 times over a two week period to discuss each of the 500 children/families. **Findings:** 244 families whose children may be in the last year of life were eligible for charitable respite; 221 were no longer eligible and 20 families were given 3 months notice to close due to inactivity. Meetings were arranged for staff and families with the CEO and Director of Each family was sent a letter informing them of the outcome of the review and given 6 months notice until charitable respite services ceased. **Conclusions:** The new care model is due to roll out 1/11/19. By the time of the TFSL conference in March 2020 there will be additional information to present about the results during the Sept 19 — March 2020 period.

Does early introduction of palliative care and advance care planning impact outcomes and experiences of families?

Archana Soman, Linda Maynard, Bluebell Wood Children's Hospice; East Anglia's Children's Hospices

Aim: This study explored a. the main factors that influence the experiences of children who die of life-limiting conditions (LLC) and their families, and b. families' experiences of palliative and end-of-life care, including Advance Care Planning (ACP). **Background:** Children with LLC and their families face multifaceted challenges. Paediatric palliative care (PPC) endeavours to provide holistic family-and-child-centred care, aimed at minimising suffering, and improving quality of life, from diagnosis to death and beyond. Sensitive, open and effective communication between professionals and families that facilitates shared decision-making is essential is pivotal to achieving these goals of care. ACP is widely recommended and is believed to improve outcomes and experience. Practice varied widely within the UK, by geographical region as well as disease **Methods:** This quantitative arm of a mixed-methods study used an anonymous questionnaire offered both online and by post - offered to bereaved parents in the East of England whose children had died between December 2013 and June 2018. Demographic information as well as determine the prevalence of ACP factors that determine occurrence of advance care planning and those impact families' experiences — as measured by variables such as the availability of choice of place of death (PoD) and various subjective perceptions of care. **Findings:** Thirty questionnaires were returned along with 12 interests to participate in the interviews. Nine interviews were conducted; 3 families were excluded as they were known to the lead investigator. 53.3% (16/30) of questionnaire respondents recalled a prognostic discussion at diagnosis - four out of ten families of children with cancer and seven out of nineteen with non-cancer diagnoses. 53.6% (15/28) reported ACP discussion. 10 reported 33.3 documented ACP. Families who remembered advance care planning discussions were more likely to have been offered a choice of PoD (p=0.0107). Parents who reported access to a PPC team were more likely to report that they had been offered a choice of PoD (p=0.01) and that the caring teams respected their wishes and desires (p=0.05) than those who had no PPC. There was no statistically significant effect of parents' educational level, diagnosis of cancer or time elapsed between first prognostic discussion and death on ACP, choice of PoD or subjective experiences. **Conclusions:** Formal ACP and early prognostic discussions are not yet part of routine paediatric practice in the region study. Formal ACP and early integration of palliative care are likely to positively impact subjective experiences as well as outcomes such as realisation of preferred PoD. This study was limited by lack of statistical power, diagnostic heterogeneity and socio-cultural homogeneity of the sample and potential recruitment and recall bias. Further training of paediatric professionals in communication skills and the ACP and improved access to specialist PPC are recommended. Further research is needed into the impact of ACP in different patient groups and to explore professionals' perceptions.

Early referral to palliative care and brave and open conversations can help reduce conflict and improve collaboration in when a child has a life-limiting condition.

Stephanie Nimmo, Freelance

Aim: To enable HCPs to understand the parent's experience of caring for a life limited child, how good communication can enable collaborative decision making and potentially avoid conflict. To demonstrate how, when communication works well ,it can contribute to a parent feeling empowered around end of life planning decisions. **Background:** As a bereaved parent I am an "expert by lived experience" I also have a career focus training and talking about the importance of good communications between parents and HCPs and can provide examples of where things have worked and where they have not worked and have lead to conflict and disagreement **Methods:** By sharing my own story, interwoven with stories of other parent carers I will show the communication tipping points between HCPs and parents which can lead to conflict and communication breakdown. I had a good experience and will demonstrate how early referral to palliative services, framed in terms of improving my daughter's quality of life lead to good collaborative working and end of life planning, which in turn enabled me to grieve properly. I will counter this with examples of where poor communication between parents and HCPs has lead to disagreement and conflict. Sharing real examples and simple tips based on experience will help delegates understand the importance of how they engage with parents and how a simple action or word can make or break a relationship. **Findings:** Early referrals, acknowledging the knowledge and experience a parent brings to the table, open communication and a willingness to admit to not having all the answers can help improve parent/HCP collaboration and potentially avoid escalation of conflict. **Conclusions:** Early referral to palliative services is crucial Asking parents what they would like to be called rather than assuming they want to be called "mum" or "dad" breaks down hierarchies and encourages collaboration and respect Being open about now having all the answers but willing to work to find out engenders trust with parents A positive experience with palliative services enables bereaved parents to grieve fully

Effects of Patient Deaths on Internal Medicine and Paediatric Medicine residents — A Singaporean Perspective

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Aim: To determine and compare the impact of patient death on Internal Medicine (IM) and Paediatric (PD) residents. We also aimed to determine if residents were confident in dealing with practical proceedings and if they had adequate bereavement support following the death of their patients. **Background:** Death is a significant event that brings grief to families and affects healthcare providers emotionally. Death of patients can have adverse effects leading to burnout, especially in inexperienced young doctors. **Methods:** A single centre, exploratory cross-sectional study involving residents from IM and PD was performed in a tertiary academic hospital in Singapore. They completed a questionnaire related to their responses and emotions after encountering patients' deaths; confidence in dealing with dying patients and their families; documentations and death procedures; existing support systems; and what would help them cope with death and bereavement. **Findings:** A total of 122 residents (85 IM and 37 PD) participated in this study with 100% response rate. 82% of these residents were equipped to handle the practical proceedings, e.g. death certification. However, only half of the residents (56.6%) felt they would be comfortable treating a dying patient and 66.4% reported feeling depressed following their patient's death. 79.5% were not aware of available support resources and 82% agreed that formal bereavement training should be included in the residency curriculum. Paediatric residents had more negative symptoms than internal medicine residents with poor concentration (PD 35.1% vs IM 16.5%, p=0.02) and lethargy (PD 35.1% PD vs 9.4%, p<0.01) being the commonest. **Conclusions:** Our residents do have negative experiences following the deaths of their patients, especially in children. These negative emotions and reactions could lead to burn out and low work morale if left unaddressed. There is a need to incorporate relevant bereavement training into the residency curriculum especially in the paediatric residency where death of children often results in more distress.

Empowering nurses to lead sector wide change by recruiting, developing and retaining a resilient children's palliative care nursing workforce which is responsive to patient need.

Katie Stevens, Eileen White, Michele O'Grady, Children's Hospices across London

Aim: In order for the workforce to adapt to the changing nature of children's palliative care they require opportunities to expand, consolidate and validate knowledge and skills. This paper describes an innovative project aimed at offering children's palliative care (CPC) nurses professional development opportunities in a uniquely supportive way. **Background:** In 2016 Children's Hospices across London, supported by local NHS and academic institutions, submitted a bid to the Burdett Trust for Nursing. A major grant was awarded which allowed development of a project entitled 'Empowering nurses to lead sector wide change by recruiting, developing and retaining a resilient children's palliative care nursing workforce which is responsive to patient need.' **Methods:** The 3 year project is run by a Project Manager and commenced in January 2018. To date: - Four Band 5 CPC nurses completed an 8 month programme of clinical experience and education; - Four Band 7 CPC nurses completed a Leadership Programme with associated Action Learning; - Five Band 6 and 7 CPC nurses have commenced cohort 2 of the Leadership Programme with Action Learning. - Participants are supported with regular clinical supervision by the Project Manager. - University of Hertfordshire (UH) completed a literature review exploring the impact of nursing rotation on retention. A literature review of nursing rotation and resilience is underway. - UH have gathered data from 8 participants and 3 managers, thematic analysis continues. Detailed findings will be available for presentation at conference. **Findings:** Initial findings demonstrate: nurses are gaining valuable insight and experience; core CPC competencies maintain a sustained focus; peer support is invaluable; 'impartial' clinical supervision is an advantage; families reassured seeing nurses caring across clinical areas; the need for a programme coordinator is critical.

Conclusions: The strengths and challenges of the programme will be outlined together with lessons that can be learnt to enable the potential application of the project to other areas.

End of Life Care for Children and Young People in Kent and Medway: Who is in Greatest Need?

Dr Melissa Mather, Samantha Bennett, Kent County Council Public Health Team

Aim: - Estimate the prevalence of life-limiting and life-threatening conditions (LLCs) amongst children and young people (C&YP) in Kent and Medway (K&M). - Describe the characteristics of this population by demographics, hospital admission rates, diagnosis and location of death. - Inform the Strategy for End of Life Care (EOLC) for C&YP in K&M. **Background:** The need for EOLC services for C&YP is increasing nationally [2]. A Palliative Care Network (PCN) has been formed in K&M as a proactive response to the escalating need for acute and community services across the area. Up until now, prevalence of LLCs amongst C&YP in K&M has not been estimated. **Methods:** C&YP were defined as people aged 28 days to 19 years. LLCs were defined using ICD-10 codes, derived by Fraser, L. et al, 2016. Two cohorts were identified: - Cohort 1: C&YP coded with a diagnosis of a LLC during an admission to a K&M hospital in 2014-2018 and who were alive as of August 2018 (identified using the Kent Integrated Dataset). - Cohort 2: C&YP resident in Kent who died in 2006 to 2017 and who had a LLC stated on the death certificate (identified using the Primary Care Mortality Dataset). **Findings:** - There were 1,415 living individuals with a LLC in K&M in 2014-18, and 279 C&YP died from or with a LLC in Kent from 2006-17. - Yearly rates of living C&YP with a LLC have significantly increased since 2014-15 and yearly death rates have been declining since 2008. - 15-19-year-olds with a haematological condition had the highest number of admissions per person. - The highest rates of LLCs were seen in the 1-4y age band. Prevalence of LLCs amongst living 15-19-year-olds is growing the most rapidly. - Amongst living C&YP, congenital LLCs were most common across all CCGs. The most common cause of death was cancer. - A higher rate of LLCs was seen in the most deprived deciles than the least deprived deciles. - There has been a general increase in hospital deaths from LLCs since 2008 and a general decline in hospice deaths since 2011. **Conclusions:** To cope with the changing landscape of EOLC, services need to be well-placed, with special consideration given C&YP from deprived backgrounds, and 15-19 year-olds, whose needs fall somewhere between those met by children's and adults' services.

End of Life Care for Children and Young People in Kent and Medway: Can Our Community Services Cope with Future Need?

Dr Melissa Mather, Samantha Bennett, Kent County Council Public Health Team

Aim: - Map current end of life care (EOLC) service provision for children and young people (C&YP) in Kent and Medway (K&M) - Inform the Strategy for EOLC for C&YP in K&M **Background:** The need for EOLC services for C&YP is increasing nationally [2]. There is increasing pressure on acute and community services to deliver good-quality, clinically effective care to C&YP and their families, in the context of C&YP living longer with more complex health needs, and financial and workforce challenges. A Palliative Care Network (PCN) has been formed in K&M as a proactive response to the escalating need for acute and community services across the area. Up until now, EOLC service provision in K&M has not been comprehensively mapped. **Methods:** Service provision in the community was mapped as per meetings with K&M providers for EOLC for C&YP, including Demelza Hospice, Ellenor, KCHFT Community Children's Nursing Team (CCNT), Maidstone Tunbridge Wells Diana Nursing Team, Medway NHS Foundation Trust COAST, Medway Community Healthcare CCNT and Tunbridge Wells Hospital Paediatric Team. Service provision was mapped against the NICE Quality Standard for Palliative Care for Infants, Children and Young People (September 2017).

Recording of service activity data was generally poor and therefore no meaningful conclusions could be drawn. **Findings:** - Some providers struggle to deliver 24-hour EOLC to C&YP and families who need it. - Funding challenges and difficulty in recruiting specialist nurses impact on all aspects of care, particularly OOH provision. Nursing capacity:population served is variable across the area. - Commissioning arrangements have evolved organically, making roles and responsibilities and patient pathways unclear. This has left some areas with overlapping service provision and other areas with gaps. Some providers also do not have formal commissioning arrangements for EOLC, and some rely on outdated specifications. - Co-ordination between providers can be difficult, as not all providers have a formal commissioning arrangement or adequate capacity. Confusion around roles and responsibilities of teams and referral criteria impacts upon acute services and patient pathways. - There is variability in training levels of nursing staff within acute and community settings, which can impact patient pathways and community team involvement. - There is no Specialist Paediatric Palliative Care Team in K&M, alongside a national shortage of SPPC consultants. There is also variable local OOH medical support across the area with the necessary expertise in EOLC. - There is a lack of knowledge around local commissioned bereavement services. - Recording and sharing of service activity across the system is generally poor. **Conclusions:** Nursing teams deliver the best quality care they can to as many C&YP and families as they can, within worsening financial, organisational and cultural constraints. However, the system is complex and fragmented in parts, making it poorly-equipped to cope with the growing need for services in its current form. Important steps for the future include ensuring: - OOH rotas are staffed through collaboration between teams in the immediate-term - commissioning arrangements are revised to meet the needs of the population in the long-term, requiring intensive involvement of all commissioners and service providers across K&M and London - referral criteria of community teams and patient pathways are clarified with all acute and community teams - all acute trusts across K&M and London are engaged with to provide more frequent training sessions in EOLC - all providers are aware of local commissioned services - all providers collect service activity data in a consistent way that can be safely and easily shared between providers and commissioners

Establishing a specialist nurse led symptom management clinic in a children's hospice setting.

Nicola Jane Moriarty, Laura Bunton, Aimee Tyrrell, Linda Manynard, East Anglia Children's Hospice

Aim: The intention of specialist palliative care team is to promote anticipatory management of symptoms and minimise their effect on a child/young person's (CYP) quality of life. Symptom management at home can enhance daily life, although it is specialist resource intensive. This evaluation aimed to assess whether nurse-led symptom management clinics in the children's hospice were acceptable to CYP and families whilst maintaining individualised, high quality, effective symptom management. **Methods:** All new referrals and CYP on the specialist palliative care caseload were invited to a Clinical Nurse Specialist-led clinic. Family feedback was collected electronically post appointment. **Findings:** Thirty four CYP (June-Aug 19) were invited appointments, with 18 attending. Attendees were aged 3 months to 16 years; with diagnoses: cerebral palsy, genetic mutation, brain malformation, chromosomal abnormality, oncology and 1 other. 2 were new referrals. 12 CYP were stable, with 5 deteriorating and 1 in an unstable phase of illness 17 families engaged in other hospice activities 1 Paediatrician attended and 8 hospice practitioners. 1 CYP required symptom management plan amendments. 6 CYP required intervention to manage symptoms. Reasons for cancellation were family related: no transport, other appointments, acute illness of CYP, CYP milestone e.g. first day at school. Benefits were reported as: - Enabled family access to hospice interventions; sensory, play, emotional health and wellbeing. - Reduced wait time for initial symptom management assessment for new referrals - CNSs shared specialist skills and knowledge - Promoted team working and enhanced communications - Cost-efficient use of specialist resource - Enhanced staff wellbeing. **Conclusions:** This approach to symptom management is acceptable to CYP and their families. Attendees were highly likely to recommend this service to another family. Using hospice facilities differently was reported highly beneficial for families wellbeing; CNS team reduced time travelling across a large geographical area and increased their autonomy.

Exploring fathers' experiences of living with a child who has a life shortening condition. A phenomenological approach

Nicky Bridges, Corinna Robertson, Children's Hospices Across Scotland

Aim: To explore: 1. What day to day life is like for fathers when their child has a life shortening condition 2. How it affects them personally 3. How it affects their relationships **Background:** Care for a child with a life shortening condition (LSC)/life threatening condition (LTC) is usually carried out in the family home by parents. It may involve undertaking very complex care, and as such affects the whole family. There is little research focusing on the experiences and needs of fathers of a child with LSC/LTC. **Methods:** A qualitative phenomenological study was carried out using semi structured interviews. Participants were recruited from a children's hospice. Six fathers took part. **Findings:** Interviews provided rich data. Four broad themes emerged: - impact of the child's condition, - experiences of family life, - social isolation - challenges with employment. Fathers spoke of the loss of hope at diagnosis and the challenges of a new world of services and health professionals. They experienced sleep deprivation, with relationships with partners and their other children suffering because of caring for the child with LSC/LTC. Fathers spoke of a lack of support and continuing feelings of guilt and anxiety. Maintaining full time employment was a challenge which subsequently affected family finances. A general perception was that health services are more focused on the needs of mothers. However, all spoke of the positive aspects of caring for such children. **Conclusions:** Fathers have specific needs and there is currently lack of support available to meet this need. Services must consider how to address the needs of this group if they are to reduce suffering for the future. Despite facing adversity, fathers are able to maintain a positive outlook on life. CHAS are now looking to utilise digital technology to provide a network for peer support to help reduce social isolation for fathers across Scotland

"Falling Off The Cliff". Children's and adult hospices working together to provide continuing palliative care support for young adult's.

Sharon Warner, Anne-Marie Murkett, Jo Kavanagh, Rainbows Hospice & LOROS Hospice

Aim: To ensure that young adults and their families receive palliative care support after discharge from children's services. To develop a pathway for transition from children's to adult hospice. To identify and address the issues for young adults, their families and staff in both children's and adult settings. **Background:** Increased life expectancy of young people with life limiting conditions and varying models of care between children's and adult hospices have meant that young adults are being discharged from children's palliative care services with little or no adult palliative care support and was described by one family as "like falling off a cliff". Rainbow's Hospice for Children and Young People and LOROS adult hospice have recognised the need to work in partnership to address this issue. **Methods:** A transition pathway was developed after consultation with families. The initial pathway was designed to run over a two year period and introduce young adults and their families to adult hospice services and staff, in order for them to build relationships and gain confidence prior to discharge from children's services. An introduction to the concept of an adult hospice was made and visits arranged, supported by Rainbows staff. LOROS staff had opportunity to introduce themselves and the services available. The pathway also involved identifying and meeting training needs in both children's and adult services and building staff confidence. Multi-disciplinary team meetings were held to develop partnership working. **Findings:** Evaluation and feedback from young adults and their families has led to a review of the pathway and development of a transition fact sheet. **Conclusions:** Young adults have now been successfully referred to LOROS hospice and discharged from Rainbows. "We feel more secure now". Next steps are planned joint events which will introduce LOROS to all young people in the Leicestershire area, aged 18 and over who access Rainbows.

Long term nurse—parent relationships in the children's hospice setting: A pilot study

Mandy Brimble, Cardiff University School of Healthcare Sciences

Aim: Develop: - An in-depth understanding of how children's hospice nurses manage long term relationships with parents. - An in-depth understanding of how children's hospice nurses maintain professional integrity when providing long term practical, emotional, social and spiritual care to parents. Explore: - Children's hospice nurses' coping strategies for managing emotional labour. **Background:** Children with complex life-limiting conditions are living longer1 so relationships between nurses and families can sometimes span decades. There are tensions between closeness and professional distance in paediatric palliative care2 and emotional labour is high3. Although emotional labour and professional integrity in long term relationships, between nurses and children/families in paediatric palliative care have been researched4,5, studies undertaken exclusively in children's hospices are rare. Therefore the influence of this unique environment on nurse-parent relationships is unexplored. **Methods:** Data were collected via audio diaries, recorded on mobile phones. Participants completed each diary after an episode of caring for a child and family, whom they have known for at least 3 years. Diaries related to short break or day care but not end of life. Data was securely transmitted using 'end to end' encryption via 'Whatsapp'. Each participant was asked to complete 3 diaries, over 3-6 months. Diaries were further explored in telephone interviews. **Findings:** The main findings from the pilot data were that there were some challenges in managing emotional labour. However, the 'home from home' hospice environment and philosophy helped to mitigate this. Where relationships were very lengthy there was a sense of a shared history and at times this led to high levels of personal disclosure. Participants felt compelled to share personal information with parents as a reciprocal gesture for what families had shared with them. The hospice model of care where 1:1 nurse-child allocation is the 'norm' fostered social relationships between nurses and parents. Trust between the nurse and the parent was the overarching concept. Nurses often viewed the personal information they shared as 'snippets' but at times this was personal and highly emotive. **Conclusions:** The pilot demonstrated that the main study is feasible and rigorous. Emotional labour is a feature of hospice work but participants felt this was counteracted somewhat by the social environment of the hospice. Perceived obligations of reciprocity on the part of the nurse may be an indicator of fluid professional boundaries. Nurse-parent relationships in the children's hospice setting require careful management in order to safeguard nurses' professionalism and the therapeutic relationship, thus keeping the child and family at the centre.

Magnolia House. Improving palliative care in an acute children's hospital

Dr Karen Shaw, Dr Carole Cummins, Dr Albert Farre, Dr Gemma Heath, Nicki Fitzmaurice, Jenna Spry, Anna Hilton, Sara Bawa, University of Birmingham

Aim: To explore how Magnolia House impacts on hospital-based palliative care for children and their families, with a particular focus on the role of policy, architecture and design. **Background:** Palliative care in hospitals is often 'problematized'; focusing on preferences for care/death outside hospital and avoiding unnecessary admissions. Less emphasis is placed on improving palliative care within acute settings or developing a positive role for hospitals [1].

Magnolia House addresses this by offering a hospital-based facility that was co-designed with parents and young people to support families who have palliative care needs. **Methods:** Case study design [2] employing qualitative methods (walkabout, photo-voice, focus groups, interviews) to examine (i) how different stakeholders view the role of hospitals in relation to palliative care, and (ii) the early implementation and impact of Magnolia House. Analysis used the framework method [3] and drew on a range of existing frameworks related to organisational change, therapeutic environments and value-based care. **Findings:** Participants described Magnolia House as an innovative and 'therapeutic' approach to care that supported families (and staff) at life-changing moments and had positive impacts on distress and wellbeing. They felt that Magnolia House offered conditions ('time', 'space', 'privacy', 'homeliness') that supported families to draw on their inner resources and find meaning in their experiences. However, the findings also revealed tensions and challenges that may influence how Magnolia House embeds into the wider hospital. **Conclusions:** The findings reveal a set of policy and design decisions that enable staff, in an acute hospital, to create an environment conducive to the delivery of care based on palliative care principles. Work to evaluate the 'routine' implementation of Magnolia House is underway to examine its sustainability and wider impact.

Meeting the challenges of providing palliative care serices to children requiring long term ventilation requires an innovative approach to developing a skilled workforce.

Anna Jones, Chestnut Tree house Childrens Hospice

Aim: To develop a skilled workforce so that children and young people (CYP) requiring long term ventilation (LTV) could access paediatric palliative care services. **Background:** Within the hospice, the lack of staff equipped to care for invasively ventilated children was evident, resulting in a waiting list of children unable to access respite stays. The number of CYP receiving LTV is increasing. Brookes (2019) identifies the increase is disproportionate to population growth demonstrating the changing landscape of paediatric care. The physiological benefits of LTV are evident (Finkel et al. 2017 and Higgs (2015), but alongside this comes immense challenges to ensure an adequately skilled workforce to deliver paediatric palliative care services. **Methods:** An intensive ventilation training month was introduced, delivering over 200 sessions to staff including underpinning theory and practical exposure.Staff were engaged with education about the unique challenges encountered by CYP and families and principles of palliative care. The admission process was changed ensuring regular admissions and purposeful double staffing of CYP's stays, allowing a second nurse to gain skills. PDN's focused on developing community nurses to care for CYP at home resulting in trust and confidence from CYP and families. Community staff were utilised to play a prominent role in the planning and staffing of the CYP's first respite stay. **Findings:** Parents reported positively on the continuity of care and in-house staff gained competence and confidence working alongside community nurses. Staff were able to appreciate and understand the positive benefits of providing this care. All children on the waiting list have been able to access respite stays. **Conclusions:** An intensive and innovative training programme allows for staff to develop skills and confidence to deliver palliative care services within the changing landscape of paediatrics. Challenging and changing practice leads to improved, quality care for CYP.

Oh, I do like to be beside the seaside'

Zoe Workman, Liz Bray, Demelza Hospice Care for Children

Aim: To provide children and families with an opportunity to be themselves, have fun and make memories. **Background:** Objectives of the beach day were to: - Bring families together and reduce social isolation - Engage Dads and extended family members - Build confidence and resilience and social inclusion - Provide a hassle free, everything in place, all services provided, disability accessible fun day - Focus on socialisation and fun, rather than medical needs - Provide partnership working with other providers **Methods:** From an initial pilot event, a business plan and budget were secured to repeat the event, thus increasing numbers and opening opportunities to families at other Demelza sites. The event provided collaborative working opportunities for other departments within Demelza to network on the front line. The area was researched for accessibility including a thorough risk assessment and discussion with local traders building a network of contacts. Market research included the involvement a local mother of disabled child with first-hand experience of the difficulties and what would attract service users to attend. **Findings:** The trend on earlier events showed an increase year on year as shown in data. 35 children and family members attended the pilot beach day in 2017 ,60 in 2018 and 170 in 2019. There was a great deal of interest cultivated by services users through 'word of mouth', social media and publications. Services offered year on year increased and were adjusted accordingly to feedback and requirements. **Conclusions:** All families gave positive feedback about the beach day including: - Something for everyone — Vast array of activities and resources - Mobiloo and Beach within reach wheelchairs - Being with other families on mass with complex needs — building confidence and resilience - All local traders in area supporting and being involved - Great accessibility and well-connected transport links - Excellent engagement with Dads and extended family members - All needs met — overcoming the hurdles — empowering the families.

Our Story': A song writing project with the Teenage Cancer Group at Haven House Children's Hospice

Roxanne Scott, Haven House Children's Hospice

Aim: Music therapy is a well established and increasingly integrated aspect of paediatric palliative care. The relationship between music, identity and adolescence continues to inform music therapy practice. Music therapy is therefore perhaps a well-situated means of offering holistic therapeutic support to adolescents accessing hospice care. **Methods:** This paper describes a song writing project with adolescents attending an oncology group at a children's hospice. The aim of the monthly group meetings is to provide a support network and social activities and for the young people, their siblings and families at a time when they may otherwise be isolated (2003). Music therapy input was initially suggested by the group's lead nurse; subsequently, the idea of a co-created song, featuring lyrics that describe the participant's shared experiences of cancer, arose from the group members. 'Our Story' is the title given by the young people to their original track. **Findings:** An outline of the project is offered in this paper, beginning with the generation of musical material, devising lyrics and formulation of a demo track, through to recording and releasing the final version of 'Our Story'. The group wished strongly to make their track available as a charity release to support the hospice, eliciting significant therapeutic considerations. Feedback gathered from the participants in the project described the development of their confidence, bonding and relationships and self expression. **Conclusions:** This paper offers a summary and reflection of the processes, challenges and approaches of the song writing project, informed at each stage by McFerran's writing (2010). The collaborative and multidisciplinary working between music therapy, play specialisms and bereavement support is described, alongside an outline for the next steps of reviewing and evaluating this project.

Physiotherapists in Paediatric Palliative Care (PPC): what is their role?

Alice Dawson, Richard Hain, AnnMarie Nelson, Cardiff University

Aim: The aim was to define the role of the paediatric physiotherapist and consider limitations of this role in PPC. Standards and guidelines in PPC and for physiotherapists in palliative care were explored. The views of clinical nurse specialists and paediatric physiotherapists currently involved in provision of PPC were established. Findings were collated and suggestions made regarding the future of this role. **Background:** Many standards for paediatric palliative care recommend a specialist multi-disciplinary team (MDT). The role of the physiotherapist in the PPC team is not clearly defined despite its status as a specialist service. **Methods:** Face-to-face semi-structured interviews with 15 professionals (CNSs and paediatric physiotherapists). The interviews were analysed using thematic analysis and reviewed for validity. **Findings:** Three themes were identified. Understanding of palliative care (both what the professionals recognised as the definition of palliative care and the different aspects of MDT working). The clinical role of the paediatric physiotherapist was discussed (general skills, specialist skills and delivery of PPC services across Wales). The final theme was education, training and support required in PPC. **Conclusions:** Although previously not defined, the role of the paediatric physiotherapist in PPC, could be defined referencing current standards for delivery of PPC in Wales. There is a role for physiotherapists working at all three levels, a palliative care approach, general palliative care and specialist palliative care. Currently the role is limited with need of education for physiotherapists on PPC, including the expectations of their role at each and additional skills such as advanced communication. Education at undergraduate and postgraduate level needs to be addressed. Several unmet needs of physiotherapy delivery in PPC could well be met by establishing an all-Wales PPC physiotherapist providing education at postgraduate level, expert clinical skills and advice and emotional support for colleagues delivering general care provision for children with life-limiting conditions and their families.

PICU and Paediatric Palliative Care Teams, working in partnership with families

Dr Sadie Thomas-Unsworth, Dr Charlotte Mellor, Bristol Royal Hospital for Children

Aim: We examine complex decision-making from the perspective of Paediatric Intensivists and ask how a hospital based Paediatric Palliative Care Team (PPCT) can provide support. **Background:** As paediatric healthcare professionals we recognise the challenge of supporting children with complex life-limiting and or life-threatening conditions (LLLTCs). Novel therapies offering hope but uncertainty, changing public expectations and the ability to recruit opinion widely through social media conspire to make working in partnership with families challenging when making healthcare decisions for children. The Bristol Royal Hospital for Children PPCT supports teams and families making decisions regarding initiating or discontinuing life sustaining treatment in the context of LLLTCs. Recent publications have described frameworks for decision-making and advanced our understanding of factors that might make this work challenging. Less has been written about what PPCTs might bring to these situations. **Methods:** This project explored the experiences and perspectives of Paediatric Intensivists on complex decision-making with families when there is disagreement about goals of care and asked what the PPCT brings to this process. Focus group interview transcripts underwent thematic analysis. **Findings:** Like clinical situations, decision-making evolves in its complexity. There is a need to follow a structure to support partnership-working from early on, sometimes before complexity arises The changing way families connect with each other and the outside world impacts on decision-making Regular meetings are key for everyone involved to come together and review decision-making Roles for the PPCT include: o Family support; specifically in advocacy o Bringing externality to the decision-making — challenging and supporting decisions o Communicating the views of the medical team in terms consistent with the legal and ethical frameworks and accepted by families **Conclusions:** PPCTs play a critical role supporting complex decision making in the PICU setting. They provide constructive and supportive challenge to the decisions made, support families and contribute to consensus building.

Providing home-based end of life care for children and their families: a realist evaluation of the Care 24 Lothian service.

Dr Cari Malcolm, Dr Katherine Knighting, Edinburgh Napier University and Edge Hill University

Aim: Employing a realist approach, the evaluation set out to address the following question: 'What are the features of the Care 24 Lothian service that work, for whom, and under what circumstances?' **Background:** The drive to ensure end of life care and death occurs in a child and families' preferred setting, be that home, hospice or hospital, has been set by policy makers across the United Kingdom (UK) (Department of Health 2016; National Palliative and End of Life Care Partnership 2015; Scottish Government 2012) and echoed by Together for Short Lives, the national children's palliative care charity (2015; 2013). In order to deliver on this ambition, appropriate services need to be in place to deliver effective end of life care including access to specialist nursing and medical care and support 24 hours a day and seven days a week (NICE 2017; Together for Short Lives 2013). Few services providing 24/7 access to support within a child's home at the end of life exist within the UK. Within Scotland, NHS Lothian and Children's Hospices Across Scotland (CHAS) set out to address the gap in home-based end of life care services by developing a bespoke model of care that supports families to access specialist palliative and end of life care in their home if that is their wish. **Methods:** The evaluation was conducted in three phases. The first phase involved developing the initial programme theory through a scoping review, document analysis and interviews with programme developers and managers. The programme theory was then tested in phase two through in-depth case studies involving interviews with families who accessed the service and professionals delivering the service. In phase three, the programme theory was refined through analysis, interpretation and synthesis of the data. Findings from the case studies will be presented alone with the final programme theory for service aimed to guide future research, policy and practice. **Findings:** The service 'worked' effectively for families and enabled them to remain in their preferred setting for their child's end of life and after death. Families found particular value in the how the service ensured care was led by the child and family's wishes and how it allowed and encouraged them to be 'parents' at the end of life. Another facilitating mechanism which led to the outcome of effective end of life care included the specialist knowledge and experience of nurses providing care and the 24/7 access to specialist nursing and medical support. This yielded families' confidence and trust in the service and in being at home at this point in their child's journey. **Conclusions:** With the requirement to provide children and families with access to 24/7 end of life care and support in the home, the demand for services like Care 24 Lothian across the UK will increase. This evaluation contributes to the evidence base surrounding home-based end of life care and assesses the effectiveness of the service from the perspectives of both families and professionals.

Reframing the Approach to Advance Care Planning in Children's Palliative Care

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Aim: Through a constructivist grounded theory approach this study aimed to deepen our understanding of the contextual and relational complexities of advance care planning (ACP) for parents of children with life-limiting or life-threatening conditions. **Background:** In the last five years advance care planning for children has evolved as a central part of end-of-life care. It has attracted increasing attention in policy and practice, and identified as a core standard in the guidelines for end-of-life care for infants, children and young people (NICE 2017). However. ACP for children remains largely unexplored through research, and there is little understanding of the experience and perspective of parents. Specifically, there is limited knowledge about the process of ACP, of when and how to talk to parents about end-of-life care for their child. In addition, medical advances and increasing options for health care interventions influence parents' expectations of what might be possible, making choices and ACP more complicated. **Methods:** Methods combined open ended, semi-structured interviews and examination of advance care plans. Thirteen parents were interviewed, nine who were parents of children receiving palliative care and four parents of children who had died. Transcripts of digitally recorded interviews and nine advance care plans were analysed through a constant comparative approach. **Findings:** The study has generated deeper understanding of parents' experience of ACP and provides health care professionals with new ways to think about the needs and experiences of parents as they talk about end-of-life care. The study identified three conceptual components of realisation, reconciling multiple tensions and building confidence and asserting control, which revealed the experience of reconstructing meaning for parents as they engaged in the process of ACP. **Conclusions:** The study challenges health care professionals to reframe their approach to ACP; from being a record of decisions about do-not-resuscitate and treatment options, to a continuous, relational conversation about choices of care that fosters meaning-making.

Research- The experiences of consultant paediatricians involved in end-of-life care for children with a palliative diagnosis

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Aim: The study aims to explore views and experiences of consultant paediatricians who have been involved in providing EOL care with a palliative diagnosis and increase understanding of the facilitators and barriers paediatricians face when delivering paediatric palliative care to their patients. To identify confidence of paediatricians to provide medical advice and symptom management at EOL, to identify the psycho/social impact of providing EOL medicine on paediatricians and to identify learning needs and psychological needs of paediatricians **Background:** : There is limited access to a specialist children's palliative care consultants in England. End-of-life (EOL) care is predominantly led by general consultant paediatricians who have a variance of experience and training regarding palliative care. There is limited literature which considers the experiences of paediatricians in delivering this care. **Methods:** This is a qualitative study using a phenomenological approach. Semi-structured interviews were undertaken with nine consultant paediatricians from three acute district general hospitals in Devon. A purposeful sample was used to identify participants with the relevant experience. **Findings:** The findings are categorised into four themes of; communication with others, confidence to deliver EOL care, making decisions regarding EOL care and the emotional impact of the EOL situation. Barriers identified by paediatricians in providing EOL care include; time constraints, uncertainty of prognosis, infrequency of cases, the coronial process and lack of emotional support. Facilitators include; having a relationship with the child/family and wider healthcare team, peer support and access to specialist advice, shared decision making and EOL planning with the MDT. The emotional and personal burden on paediatricians was found to be significant to all participants and influenced communication, decision making and confidence. **Conclusions:** Paediatricians find EOL situations challenging and emotionally difficult but are in a good position to provide EOL care due to their ongoing relationship with the family and ability to work with wider MDT. Specialist palliative care services should increase training and learning opportunities for health professionals and health organisations must do more to recognise emotional burden and develop strategies to improve formal and informal support strategies for staff working in palliative care.

Re-visioning the definition of Children's Palliative Care to include Sudden Deaths

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Aim: Drawing on findings from qualitative research undertaken in an acute children's hospital in Ireland, this paper aims to explore experiences of sudden death from the perspectives of parents and staff. The objective is to draw implications from these findings in relation to the applicability of the framework for children's palliative care in acute and sudden deaths. **Background:** The current categories defining children's palliative care (Wood et al 2010) do not describe the experience of children whose deaths are sudden, either from acute illness or trauma. These children usually die in Emergency Departments or Intensive Care Units in challenging circumstances for both families and staff. **Methods:** Using a narrative methodology, 15 parents who had experienced the loss of a child six months to two years prior to being interviewed, were invited to share their experiences through the use of a two part in-depth interview. Staff in the hospital were also interviewed using the same methodology in focus groups. A hermeneutic phenomenological approach was used for analysis of the data. **Findings:** The findings highlight the significance for parents of actions taken by staff following the sudden deterioration of their child's health and their subsequent death. Parents emphasise their experience of being told bad news and the trajectory of the development of their understanding that their child will die. The significance of time and the opportunity to be with their child for ordinary parenting tasks as well as "memory making" feature strongly in the findings. Staff too highlight the importance of providing time and personalised care to family experiencing the sudden loss of their child. **Conclusions:** The findings indicate the appropriateness of distinguishing sudden death within the categories of children's palliative care, or expanding the categories to include sudden death. The implications for children, families and staff providing care to them will be discussed

Short breaks - Care at Home pilot - an integrated approach

Liz Bray, Beth Helen, Demelza Hospice Care for Children

Aim: The Demelza Care at Home pilot was implemented to support delivery of Demelza's Strategic Goals to 'do more' and provide 'care at home'. **Background:** Objectives of the pilot were to: - reach more families - test if Care at Home is cost effective - give families a choice of where they want care support - provide the child with an opportunity to play and socialise - reduce social isolation for the child and family - provide partnership working with other providers - test whether staff want to work in the community **Methods:** A 12 week pilot was planned with support from a Business Development Advisor to provide one 2.5 hour session per week to 4 families who met the inclusion criteria (under 5, living in ME postcode area, meet Demelza admission criteria). Staff were recruited from the hospice team. **Findings:** Data was collected from parents and staff. The data collected demonstrated that the pilot was a success, it was well controlled with a small sample size and competent hospice staff delivering the care. **Conclusions:** All families gave positive feedback about the sessions including: - Having a choice of where they received care - Achieving their outcomes - Having a positive effect on their wellbeing - An opportunity to do something they would not normally do - Their child benefiting from the session Parents identified that they liked receiving care from an integrated team, two families accessed the hospice for short breaks and end of life care as a result of the pilot. The staff all felt that they had the correct knowledge, skills and equipment to provide the sessions safely and effectively and felt that the service was beneficial to families. They enjoyed working in the community as well as within the hospice. The service is expanding and we are currently providing the service to 31 children in Kent.

Supporting children to adults living with juvenile forms of CLN disease (juvenile Batten disease) — Working in partnership to build strong networks

Sarah Kenrick, Wendy Thompson, BDFA and SeeAbility

Aim: Seeability's juvenile batten disease outreach liaison nurse and the BDFA's family support officer are working in partnership to provide an advisory and educational support network to professionals, carers and affected families. Demonstrating the innovative collaborative approach they have been developing since July 2019 when the outreach post commenced **Background:** Juvenile forms of CLN are a rare group of progressive neurological diseases extending from early childhood to early adulthood.Children with juvenile CLN diseases face complex patterns of decline in cognitive, visual and physical abilities, with distressing symptoms of epilepsy, hallucinations, panic and agitation. A gradual progression of childhood dementia with a loss of functional skills such as continence, eating and drinking and activities of daily living. **Methods:** Focusing on case studies we will explore how families living with CLN diseases can be supported to feel empowered, more knowledgeable and able to identify what is normal and part of the disease process and what tools and resources they already have within themselves to cope with the challenges faced. **Findings:** Regarding complex behaviours that may challenge, we will demonstrate how helping the child identify what their hopes and fears are and how they can take control, coupled with enabling those around them understanding how their own behaviours can enable the child to feel more valued and safe. **Conclusions:** Working in a person centred way, enabling the clinical and professional network around the child to develop skills and knowledge and supporting the whole family with the outcome aim of maintaining education and improved disease stability.

The H-Word

Rachel Wright, East Anglia's Children's Hospices (EACH)

Aim: The H-Word was a participatory photography project with five parents which enabled sharing their experiences of services and the word 'hospice'. The resulting exhibition aimed to educate the public about children's hospices, challenge prevalent stigma and misconceptions, lower barriers to access for prospective service users, and encourage conversations to reduce loneliness and social isolation amongst parents of ill children. **Background:** The word 'hospice' is often perceived as a barrier for families eligible for palliative care services. Research has demonstrated that the word creates stigma and fear which can contribute to loneliness and social isolation amongst families who have a seriously ill child. **Methods:** Photographs, writings and audio interviews, showing realities of children's hospices through the eyes of those with first-hand experience, formed an exhibition during Children's Hospice Week 2019. Perceptions of 'hospice' amongst exhibition visitors were recorded. **Findings:** There was an increase in positive words used to describe children's hospices after seeing the exhibition, (joyful, bright, happy, fun, warm), and a decrease in negative words (dark, daunting, scary, distressing, upsetting, unknown). The number of people who stated they would be comfortable talking to someone who uses, or had used, a children's hospice, increased after exhibition viewing. Although this project aimed to educate the public, it also showed how Communications and Care teams can work together to enhance service user emotional health. There was demonstrable positive impact on participants' wellbeing and understanding of their experiences and journeys. **Conclusions:** The exhibition continues 'on tour' in public spaces including libraries and hospitals, and feedback is gathered from visitors. We aim to build on collaborations between Care and Communications staff, to better understand how creative participatory projects can contribute to family wellbeing and wider understanding of children's hospice care.

Use of Subcutaneous Fluids in Paediatric Palliative Care: A Case Study

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Aim: The aim of the document was to promote discussion regarding the use of subcutaneous fluids in the care of a child at end of life, revisiting the ethical, legal and practical aspects of providing such care. This also included consideration of the effects n the child and family, along with the effects of a relatively new practice for nursing staff. **Background:** This article discusses a decision to administer subcutaneous fluids to Rosie (pseudonym) at end of life, and describes how this was achieved in the children's hospice setting **Methods:** Research was carried out including contraindications and indications for use of subcutaneous fluids, possible complications , ethical issues (non-maleficence v beneficence), practical guidance. This involved an extensive literature search. **Findings:** The use of subcutaneous fluids can potentially have adverse consequences, as it can be unpleasant, uncomfortable, and at times painful It is necessary to balance the benefits and harms that the treatment may cause. The primary consideration was the risk of dehydration, with no other means of hydration meaning that Rosie could have been admitted to hospital for intravenous fluids, which was not in line with the family's wishes. **Conclusions:** In considering the use of subcutaneous fluids, clinicians must be aware of the relative risks and benefits to the child, and how this will impact on the family as a whole. There must be a team approach to the delivery of care at end of life, and education of staff members in the practical and ethical issues must be made available.

Where do I go now? A mixed-method systematic review into the availability, effectiveness, economics, experience, and policy context of respite care for young adults with complex healthcare needs.

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Aim: To identify, characterise and evaluate respite care provision for young adults with complex healthcare needs (18-40 years); develop a knowledge map of service types and a conceptual framework. **Background:** The number of children with complex healthcare needs (CHCN) due to a life-limiting condition or complex physical disability surviving into adulthood is growing internationally; estimated to be >55,000 and 100,000 respectively in the UK. Respite care and short breaks are an essential component of care for children with CHCN but following transition to adult services provision is often inadequate and inappropriate for young adults and described as 'like falling off a cliff'. Poor continuity of care significantly impacts on the health and well-being of families and can shorten lives. **Methods:** A 2-stage mixed-methods systematic review to identify and select evidence: electronic databases and grey literature searched from 2002-current; evidence selected based on a priori inclusion criteria by two reviewers; data extraction into bespoke forms; and data synthesised according to service type and evidence stream (effectiveness, economics, experience and attitudes, policy and guidelines) using appropriate methods. An overarching synthesis will inform a conceptual framework describing the circumstances and contexts which affect how service types work. Advisory groups of young adults and family members, alongside professionals with service commissioning and delivery expertise have guided the review (Pilkington et al., 2019) **Findings:** To date we have identified and developed logic models for 14 service types across seven categories: planned residential, day care, home-based care, emergency care, holidays, social provision and carers. The synthesis of the evidence streams will be completed November 2019. We will present the full knowledge map of service types, a summary of the identified evidence, including gaps for each evidence stream and service type, and the conceptual model. **Conclusions:** The review will share learning of conducting complex, mixed-method, evidence synthesis. The findings will inform future research agendas and optimal service development for this growing population.