available on skin changes in people with darker skin and we consulted the Ubele Initiative.

Results Preliminary searches found few articles covered descriptions of skin changes at the end of life and contained outdated terms. No studies described the appearance of skin in people with darker skin at the end of life. Information about skin changes relevant to end of life care in people with darker skin found in resources from Wounds UK, National Wound Care Strategy, Mind the Gap and UK Sepsis Trust was used to update resources and website information which were reviewed by experts by experience and professionals.

Conclusion There is a significant lack of robust evidence, information, and guidance on changes of skin tone in people with darker skin at the end of life. There is a need for co-produced, evidence-informed practical guidance for healthcare professionals and informal carers supporting people at the end of life.

Background Service user involvement in design, implementation and evaluation of services is becoming increasingly commonplace (Omeni, Barnes, MacDonald, et al. BMC Health Serv Res. 2014;14, 491). Research also shows that service user involvement has a positive impact on the organisation and the service users (Gordon, Franklin, Eltringham. Res Involv Engag. 2018; 4, 11; Minogue, Boness, Brown, et al. Int J Health Care Qual Assur Inc Leadersh Health Serv. 2005;18(2–3):103–12).

Aims To evaluate and understand what matters to the families, what families with children and young people with life-limiting conditions need to live the best life they can, and what role do the children’s hospices in Wales play in providing this support?


Results Hospice services provide essential support to families and are the main places that families access the support they need. Access to respite/short break care is essential to family coping and wellbeing. Complexity of condition has an impact on care and family life. Support for young people leaving hospice services is lacking and there is a need for bereavement support and counselling.

Conclusion Children’s hospices in Wales are often the only places where families can access the tailored support that they need to care for their child. Including families in service design, implementation and evaluation at all levels is crucial to providing excellent services.

Background With more children with life-limiting conditions surviving into adulthood (Jarvis, Roberts, Flemming, et al. Pediatr Res. 2021; 90(6): 1120–1131) approximately 25% of the overall children’s hospice caseload was of transition age. Families expressed how challenging and stressful this period was, both practically and emotionally. A significant need to transform support was overwhelmingly apparent, particularly in the absence of a national framework alongside a lack of investment and resource. It also became clear there is disparity between services available to a young person (aged 18) in a children’s hospice compared to accessing services from an adult hospice.

Aims To build a transition service informed by a steering group involving hospice Clinical Services Leads and representation of families, to facilitate and inform a review of the current offer of support; to ensure quality improvement and equity of service, with an identified caseload. To review multi-professional approaches and service availability within differing referral criteria.

Methods 1. Extensive research and information gained from the National Institute for Health and Care Excellence, Together for Short Lives and Hospice UK, alongside the lived experiences of families.
2. Development and implementation of unique Transition Framework.
3. Restructure and recruitment of designated posts.
4. To work collaboratively with adult services.

Results Contacting families to provide bespoke support has been key to understanding the needs of families, putting the voice of the young person at the centre. Creating opportunities for peer-to-peer support and developing these support programmes has been invaluable in connecting families, through hybrid engagements and collaborative working.

Conclusions Transition support has been transformed, with increased understanding of legislation, defined support service offer and enhanced communication with social and health providers. Needs of young people have been identified, and support given to all family members moving into adult services. Access to psychosocial Family Support defined after young person’s 18th birthday with start of transition plan in place from 14 years old.

Background You may have special memories from a school trip, whether a first stay away or trying something new. These opportunities are crucial for siblings living with a young person with a serious or life-limiting condition. For the past two years, we have organised a three-day residential for siblings transitioning to secondary school. The need heightened after the pandemic with lockdown affecting the mental health of those living with siblings with disabilities, who have missed out on important opportunities to meet others.

Aims The focus was to provide a fun space, create new friendships, meet others in similar situations and build...