I’ll now be tweeting from the first of three concurrent sessions today, sitting in on the first Paediatric PalliativeCare session, chaired by Lisa Cuddeford from the WA Paediatric Palliative Care Service #21OPCC

First presenter is Adjunct. Assoc. Prof. Claire Treadgold @Starlight_star talking about ‘Rosie’s story’. Rosie is a palliative child with chronic kidney disease who was supported by the Starlight Moments program #21OPCC

@Starlight_star Sadly, Rosie died a month ago 😞 Claire says the family are happy to share Rosie’s story #21OPCC

@Starlight_star Rosie was diagnosed with Bardet Biedl Syndrome, and went on to get chronic kidney disease #21OPCC. Her mum says "she was full of life" and a "great lover of unicorns"

@Starlight_star And particularly a love of lego - more on this later #21OPCC

@Starlight_star Starlight Moments developed after research to explore the needs of families with children who have palliativecare needs. Small, positive moments to distract from serious life events #21OPCC

@Starlight_star Starlight Moments are small, ongoing moments, tailored to the family #21OPCC

@Starlight_star Rosie loved lego - Starlight Moments created a lego treasure hunt for Rosie and family to take part in during COVID19 #21OPCC
@Starlight_star Lego treasure hunt designed with the whole family involved - it's not just about the patient, but whole family #21OPCC

@Starlight_star Self-care for parents important - Starlight Moments gives them an opportunity to do activities they may not otherwise #21OPCC

@Starlight_star Siblings can often fly under radar - Starlight Moments create special moments for siblings also, and recognise family milestones #21OPCC

@Starlight_star The impact of #COVID19 - added an extra layer of isolation for the family, who already were quite isolated #21OPCC. Starlight Moments put together happiness hampers to help get through #COVID19

@Starlight_star Starlight Moments program extended to a year post-bereavement to help support the family while grieving #21OPCC

@Starlight_star "Ultimately the program is all about making memories" - Claire. #21OPCC

@Starlight_star Second presentation in this session is by Angela Delaney & Penelope Slater @childhealthqld - they are talking about their research exploring the experiences of families who have received paediatric #palliativecare in Qld #21OPCC

@childhealthqld What is Paediatric #palliativecare? Definition here #21OPCC

@childhealthqld One of the challenges delivering paediatric #palliativecare in Australia is the vast distance to services #21OPCC

@childhealthqld Research part of QuoCCA project (Quality Of Care Collaborative Australia (QuoCCA) Home #21OPCC quocca.com.au

@childhealthqld They interviewed 11 parents of children with life limiting conditions who received paediatric #palliativecare #21OPCC

@childhealthqld Key findings from interviews incl: integration of child and family within health system inseparable, and informed decision making vital #21OPCC
Two videos were developed based on the findings of the research #21OPCC - unable to share during presentation due to tech difficulties. I'll share links at the end of the session

Third and final presenter in this session, @StuartEkberg @QUT is sharing key findings from a rapid review that helped inform a National Paediatric Palliative Care Action Plan for Australia. #21OPCC @Pall_Care_Aus

The plan follows from @Pall_Care_Aus being awarded funding for a Paediatric #palliativecare project #21OPCC

Paediatric #palliative care aims to improve the quality of life for families and children with life limiting conditions. Complex care. #21OPCC

Specialist #palliativecare services needed due to complex needs of children with life limiting conditions. #21OPCC

369 sources identified in the review (That is a lot of full-texts to read!) #21OPCC

Key findings include: quality of specialist paediatric #palliativecare needs to be improved. Continuity of care one way care can be improved, and multidisciplinary approach another #21OPCC

Improving advance care planning another key finding, can be done by early integration of specialist paediatric #palliativecare and patient and family focused interventions #21OPCC

Limitations highlighted in optimal education approaches published in the literature - a focus on clinicians; and little rigorous evidence available #21OPCC

QuoCCA a key resource in Australia, with their aim to deliver education in paediatric #palliativecare #21OPCC quocca.com.au

Inclusion of wide range of stakeholders important in paediatric #palliativecare, incl families (and siblings) #21OPCC

Major findings from the literature review help inform policy with priority in improving paediatric #palliativecare. #21OPCC

Gaps in knowledge remain, including research about paediatric #palliativecare in Aboriginal and Torres Strait Islanders #21OPCC

More info about the Paediatric Palliative Care Project can be viewed online @Pall_Care_Aus
Introduction The Paediatric Palliative Care National Action Plan project received grant funding from the Australian Government as part of the Supporting Children with Life Threatening Medical Conditions program.


@StuartEkberg @OUT @Pall_Care_Aus Copy of rapid review can be found here #21OPCC

Paediatric Palliative Care National Action Plan Project Background Lit...
The Paediatric Palliative Care National Action Plan Project (Project) team is excited to announce that the Paediatric Palliative Care Literature Review is now complete. We would like to acknowledge t...

https://palliativecare.org.au/paediatric-palliative-care-national-action-plan-project-background-lit...

@StuartEkberg @OUT @Pall_Care_Aus Q and A #21OPCC Paediatric #palliativecare session
Q for @StuartEkberg - are there plans in place in the Northern Territory?
A - understanding is that it remains the case that families in the NT can access care in SA.

Q for Angela and Penelope - how did the families feel about the interviewing process? (sorry, not verbatim)
A - the families found the interview process therapeutic, valued telling their story #21OPCC #qualitativeresearch

Q for Claire - is there a dedicated person for each family in Starlight Moments
A - one person starts off process of getting to know family really well, but is a collaborative process. Relationship with initial contact very important #21OPCC

The two videos developed from the findings of the QuoCCA research #21OPCC
Both beautiful - recommend viewing.
'Meeting Paediatric Palliative Care'
Meeting Paediatric Palliative Care
This is “Meeting Paediatric Palliative Care” by #Quocca #Paedpc on Vimeo, the home for high quality videos and the people who love them.
https://vimeo.com/499870982

‘Life with a child who has a life limiting condition’ #21OPCC

Life with a child who has a life limiting condition
This is “Life with a child who has a life limiting condition” by #Quocca #Paedpc on Vimeo, the home for high quality videos and the people who love them.
https://vimeo.com/499869110

plz unroll
@threadreaderapp