

## Abstracts

**Introduction** This paper will explore the role of the Assistant Practitioner (AP) in an innovative a 6 month collaborative pilot project between Leicestershire Partnership Trust and the Leicestershire and Rutland Hospice to test a model of care delivery through AP's working across the hospice and community settings as an integral part of both health care teams.

### Approaches Used

- 2 trainee assistant practitioners from each setting (n = 4), with the support of mentors, undertook 4 rotational work placements between the hospice and community, supplemented by monthly study days
- An action research model was used to evaluate the pilot and support a real-time development of the role and included qualitative interviews and focus groups (n = 4) with assistant practitioners, mentors (n = 5) and managers (n = 3), alongside analysis of the adopted competency framework and reflective diaries

**Findings** The AP's : were skilled and able to provide continuity of care following patients through from home to hospice and back; they helped develop inter-organisational understanding of ways of working; freed – up registered nursing time, offered support to HCA's. The main challenge related to changing policies during the life of the pilot to allow the AP's to fully embrace an extended role. This presentation will focus on the success and challenges in the development of the cross organisational working and the AP role, the views of stakeholders and the benefits to patients.

**Conclusion** Hospice and community settings were convinced of the value and utility of the role and are looking to recruit AP's as part of their long term staffing policy. However, each organisation sees a different focus for the role and they are not yet ready to embrace the concept of shared posts working across organisational boundaries.

## Treatment, care and patient perspectives

### P102 INFLUENCING NATIONAL POLICY AND PRACTICE FRAMEWORKS – A HOSPICE PERSPECTIVE

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10.1136/bmjspcare-2013-000591.124

**Background** As a national organisation providing specialist palliative care for children and young people, we have a responsibility to share skills and experience with colleagues in other sectors, and to develop strong partnerships to shape the development of palliative care for this group across all settings. This session will explore the development of a national palliative care framework for children and young people <sup>1</sup>.

**Aim** The aim of the project was to:

- develop a mechanism to support and develop best practice
- establish recognised pathways of palliative care within and between health boards for every child and young person with a diagnosis of a life-shortening condition
- outline the available support at all stages through to the end of their lives, developing equitable, sustainable, age appropriate support, independent of the geographical area in which they live.

**Approach** The Framework<sup>1</sup> was developed through a clinical network: Scottish Children and Young People's Palliative Care

Executive (SCYPPEX) in consultation with paediatricians and lead children's nurses throughout Scotland.

**Outcomes** The Framework<sup>1</sup> was launched at a National Square Table event in November 2012. Dissemination is being achieved through an NHS Chief Executive's Letter and three regional workshops attended by professionals from many services contributing to palliative care for children in Scotland. A case study approach was used to explore the opportunities and challenges for implementation.

**Application to practice** This is an important development in children's palliative care in Scotland and has positioned children's hospice care as having a central role. It will contribute to improving care for children and young people with life-shortening conditions.

### P103 THE DAILY EXPERIENCES OF LIFE LIMITED CHILDREN AND THEIR FAMILIES

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10.1136/bmjspcare-2013-000591.125

**Introduction** This is a society in which children are expected to live into adulthood. Not much is known about the long-term needs of children, who will not reach adulthood, but who may live with their conditions for many years.

**Aims** To hear directly from life limited children and their families about their day-to-day experiences.

**Methods** Case study provided the overarching strategy combined with participant observation, interviews and an invitation for young participants to use their own artwork and photographs to help them explain their day-to-day experiences. Eleven children, parents and siblings from ten families took part (39 participants).

**Findings and discussion** Children diagnosed early in babyhood seemed to have an identity within which the illness was integrated, perhaps because they were growing children hardly able to remember a time before their illness.

The children who took part were going to lead short lives. Families tried to shut away this fact to get on with daily life and live life to the full for and with the child.

Common elements ('moments of realisation') in the children's life stories emerged:

- Questions of inheritance
- Diagnosis and prognosis
- Acute loss of abilities
- Slow deterioration
- Life threatening surgery
- The cycle of crisis and survival
- The child's life and death.

These elements followed similar patterns across cases despite the range of diagnosis; they ebbed and flowed throughout the child's life generating fear and uncertainty for the child and their family.

Care implications

Families lived day-to-day in a society that expects children to live into adulthood. Participants felt alone with the knowledge that their child would die young, aware of the wider social context Professionals should be aware that 'moments of realisation' in the child's unfolding life might highlight times when pressure on family communication is heightened.