

# 2<sup>nd</sup> International Children's Palliative Care Conference



**Building Bridges - Home, Hospital and Hospice  
An Interdisciplinary Conference**

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# Conducting a Delphi study in Irish Children's Palliative Care- *a collaborative research initiative*

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PALLIATIVE CARE)



# Why identify Research Priorities for Irish CPC?

**Aims: To inform the development of a research agenda for children's palliative care**



# National Policy

- In 2010, the [national policy](#) on children's palliative care was published (Department of Health and Children).
- This policy made key recommendations resulting in changes to CPC provision in Ireland. Additionally, the national policy made recommendations for the development of a [research culture](#) to ensure evidence based practice.

***“All health care professionals working in palliative care should have the opportunity to engage in research in order to develop evidence based practice, leading to improved quality of care for children with life-limiting conditions and their families.”***

(Department of Health and Children, 2010, p. 37)



# Characteristics of the Delphi Method

- Originally developed by the RAND Corporation in the 1960s, the Delphi method is a consensus building approach to data collection.
- The Delphi technique affords participants the opportunity to reflect on their answers and suggestions and enables them to see where their opinion sits within the frame of a group of experts (Malcolm et al. 2011).

## Four characteristics to the technique:

- *Anonymity of the participants*
- *Iterative process with controlled feedback via 'rounds'* (Blackwood, Steele et al 2008, Albarran W., & Latour M., 2011; Bolger & Wright, 2011; Hanafin, 2004a; Hasson, Keeney, & McKenna, 2000)
- *Statistical group response*
- *Expert input* (Goodman, 1987)

**'Participants (as experts) produce an informed group judgment'** (Steele et al 2008).



# Delphi in the National & International Context

## EXAMPLES:

- ✓ **Irish Department of Health and Children and Brenner et al 2014** -identified and ranked research priorities for nurses delivering care to children in acute settings.
- ✓ **Canada (Steele et al., 2008)**. Following three rounds of data collection, consensus among the expert panel for CPC reduced 74 identified research areas down to 4 key priority topics. These were in the areas of *family experiences, pain and symptom management, bereavement, and alleviating suffering at end of life* (Steele et al. 2008).
- ✓ **UK study (Malcolm et al., 2009)**. Despite the participation of three very different groups, a high level of consensus (76-91%) was achieved on 15 priority topics for future research (Malcolm et al., 2009). *Three main themes- hospice and respite care needs of children and young people; pain and symptom management and bereavement and end of life care support.*

Following a research proposal, ethical approval was granted by UCD, LLCH and OLCHC



# Stages and Findings:

## *Round One*

- ✓ A purposive sampling strategy identified a total of **23 health professionals** nationally with high level knowledge/ expertise in the area of PPC.
- ✓ Interviews were transcribed and analysed using content analysis. Five themes emerged and **72 research priorities** were identified by this expert group. The emerging themes were grouped into:
  - Needs Assessment
  - Service Development
  - Policy
  - Education and Training
  - Support



# Round 2

- Based on the findings from round one, an online survey was developed using *SurveyMonkey*. All 72 research priorities were listed, and the survey was circulated to Irish professionals working in the speciality (n=54) via email. Participants were asked to review each of the research priorities and rank them on a Likert scale in order of importance, from 'Not at all Important' to 'Extremely Important'.
- A total of 47 surveys were completed, giving a response rate of 87%.
- Descriptive analysis of data was undertaken using SPSS. The rankings of the research priorities were examined
- The results were ranked in order of highest mean rating (Felicity Hasson et al., 2000; Keeney et al., 2006; Loughlin & Moore, 1979; von der Gracht, 2012). All 23 research priorities listed achieved a consensus level of 67% or above, indicating a high level of agreement on the items identified in round 2



## ROUND 2:

1. What are the **needs of families** caring for a child with a LLC in Ireland? 88.9%
2. Development of an accurate **data base** on children and families with a LLC in order to support service development 88.9%
3. What are the **palliative needs of children** with a LLC in Ireland? 88.6%
4. **Prevalence** study of children and families with a LLC in Ireland 84.4%
5. What are the **support needs** of parents? 82.2%
6. **Bereavement** 82.6%
7. The **inclusion of parents in planning** and managing PPC strategies 81.4%
8. **Symptom** management 80.0%
9. What are the support needs of **siblings**? 73.9%
10. **Care planning**: what are the **challenges** in developing, maintaining and communicating care plans when care is provided in the home? 73.3%
11. Development of a national **strategy for intra-agency service provision** in PPC 82.2%
12. **Care planning: what is best practice** in developing, maintaining and communicating care plans in PPC 77.3%
13. What is good **clinical governance** when care is provided in the home? 75.0%
14. Development of appropriate **screening** process for children with LLC in order to **identify individual care needs** 77.8%
15. Development of an **evidence based standard of bereavement support** for families 78.3%
16. Development of **on-going assessment** process to identify and monitor the needs of children with LLC over the life of the child 77.3%
17. What is **needed to support the roll out of the preferred model of PPC as identified by families**? 68.2%
18. Development of specific **training programmes for nurses** in PPC 73.9%
19. Is **home still the preferred location** of PPC provision for families in all scenarios? 71.1%
20. What are the **geographical challenges** of PPC provision? How can these be addressed? 75.0%
21. **Children's Rights** Perspective: including the voice of the child in PPC 72.1%
22. Are the **rights of children to be cared for by professionals trained in children's care being met**? 67.4%
23. Creating **linkages between maternity services and PPC** to better support new families 67.4%



# Round 3

- In order to increase consensus on the research priorities identified in round 2, a second survey (Round 3) was circulated. The 23 items were included.
- Analysis of round 3 showed **some changes** in the consensus- only 14/23 items included from Round 2 received an average rating of 4 or above.



# Round 3 Findings

1. **Development of specific training programmes** for nurses in PPC 85.3%
2. What are the **needs of families caring for a child with a LLC in Ireland?** 80.0%
3. Development of an accurate **data base** on children and families with a LLC in order to support service development 74.3%
4. **What are the palliative needs** of children with a LLC in Ireland? 85.7%
5. What are the **support needs of siblings?** 80.0%
6. Development of a **national strategy for intra-agency service provision** in PPC 80.0%
7. **Bereavement** 73.5%
8. **Care planning: what is best practice in developing**, maintaining and communicating care plans in PPC? 82.9%
9. **Care planning: what are the challenges in developing**, maintaining and communicating care plans when care is provided in the home? 74.3%
10. What are the **support needs of parents?** 74.3%
11. What is good **clinical governance when care is provided in the home?** How can good clinical governance be maintained without increasing levels of bureaucracy for families? 71.4%
12. Development of **on-going assessment process** to identify and monitor the needs of children with LLC over the life of the child 68.6%
13. **Children's Rights Perspective**: including the voice of the child in PPC 74.3%
14. Creating **linkages between maternity services** and PPC services 74.3%



# Round 4

- Round 3 demonstrated changes in the rankings “*Development of specific training programmes for nurses in PPC*”, which went from 18 to number 1
- Due to this instability between rounds, a fourth round was undertaken (von der Gracht, 2012).
- The process from previous rounds was repeated, 41% response rate. The majority of items (9:14, 64%) were ranked at 4 or above in Round 4.
- A total of 5 research priorities were removed from the final list as they failed to achieve a mean ranking of 4 or above. The consensus level was higher than in previous rounds, with between 73% and 82% of all respondents rated each priority at 4 or above



# Round 4 Findings:

1. What is **good clinical governance** when care is provided in the home? How can good clinical governance be maintained without increasing levels of bureaucracy for families? 81.8%
2. Development of a **national strategy for intra-agency service provision** in PPC 77.2%
3. Development of specific **training programmes for nurses** in PPC 81.9%
4. **Children's Rights Perspective**: including the voice of the child in PPC 81.9%
5. Creating **linkages between maternity services and PPC services** to better support new families 72.7%
6. What are the **needs of families** caring for a child with a LLC in Ireland? 81.9%
7. Development of an **accurate data base** on children and families with a LLC in order to support service development 72.7%
8. **Care planning**: what are the challenges in developing, maintaining and communicating care plans when care is provided in the home? 72.8%
9. Bereavement 76.2%



# Key areas for future research

## **1. Needs Assessment**

Respondents highlighted the needs of families as a research priority including a database (consider 2015 prevalence estimates, Ling et al 2015)

## **2. Service Development**

The need for effective clinical governance for children with a LLC was identified as the primary research priority. Also identified in the 2005 needs assessment

## **3. Policy**

In line with the National Children's Strategy (2000), the inclusion of the voice of the child in PPC was identified as an area where research is needed.

## **4. Education and Training**

The need for the development of specific training programmes for nurses working in PPC was identified as a key research priority in this study.

## **5. Support**

Bereavement support and a need for greater links between maternity and paediatric palliative services was also identified as an area in need of further research



# Limitations of the study

- Professionals engaged in full time paediatric palliative care is low
- The high attrition rate between Round 3 and Round 4 should be noted
- The use of online technology and control = instability between rounds in terms of the rankings
- The evolvment of the speciality of PPC within Ireland is still a relatively new discipline, with influences & shifts in research priorities as knowledge and awareness grows.



# Acknowledgements

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