

# Identifying children who may have palliative care needs: A Spectrum of Children's Palliative Care

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# Outline

- Development of the ACT/CH-UK Children's Palliative Care Minimum Dataset (MDS)
- The Children's Palliative Care Supporting Definitions Delphi Study
- The Spectrum of Children's Palliative Care Needs
- Validation & practical implications
- Summary
- Next steps...



# The need for a minimum dataset

- No local data on incidence or prevalence of life limiting conditions
- Only extrapolated national data available
- Need for ongoing data collection
  - “Sudden” availability of funding streams
  - Changes in incidence and prevalence over time
    - Antenatal diagnosis
    - Better treatment
    - New conditions being recognised
  - Need to map service provision against changing population needs



# Minimum dataset pilot

- Commenced in Merseyside and Cheshire September 2005
- 17 data items collected at referral to a palliative care or essential supporting service
- 3 additional data items when a child or young person dies
- Children identified using ACT definitions of
  - Children's palliative care
  - Life threatening conditions
  - Life limiting conditions



# Minimum dataset pilot

- Merseyside and Cheshire data collection ongoing
  - Stepwise rollout to whole of Merseyside and Cheshire
  - Initial report published 2007
- Funding from True Colours Trust for National rollout through ACT/CH-UK 2006 - 2010



# National rollout

- Three rate limiting steps
  - Development of children's palliative care networks
    - Leadership and co-ordination of data collection
  - Consent
  - Definitions
    - Acceptable to patients, families and professionals
    - Consistent application of definitions across the UK



# Consent

- Concern that if consent was required this would prohibit data collection
  - Initial data collection through section 60 Data Protection Act
  - Consistent with Cancer Registry approach
  - Option to opt - out
- Subsequent move towards consent as default position
  - Changes in legislation
  - Professional concerns
  - Alternative to demonstrate that seeking consent is impossible or low accrual rates would significantly affect accuracy of data collection



# Background to Delphi

- Concern that different teams and services were counting differently
- Subjectivity and variation within teams and districts
- Wider variations in different areas of UK
- Need to define more precisely children we want to count in order to compare figures
  - Different areas of country
  - Consistently over time





# Delphi study

- Accept and not alter definition of palliative care for children
- Review definitions for
  - Life threatening condition
  - Life limiting condition
- Greater precision
  - Age
  - Meaning of key words and phrases
- Evaluate alternative methods for identifying children with palliative care needs



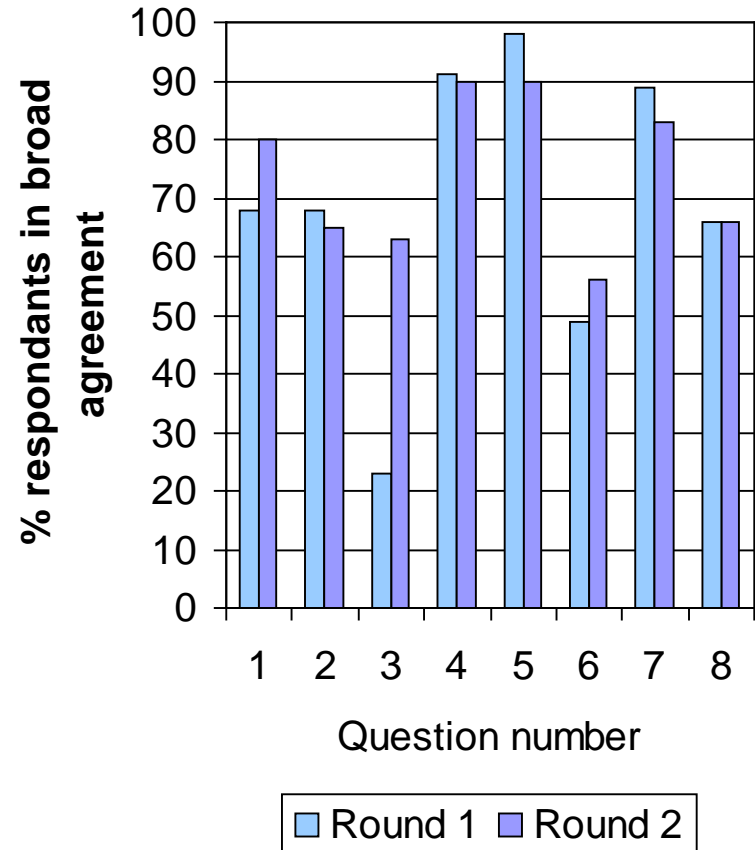
# Delphi study

- **Round 1**
- Distributed to 90 experts in children's palliative care
  - Doctors
  - Nurses
  - Heads of care
- Forty four responses 44 (49%)
- **Round 2**
- Survey simplified and re-designed to incorporate the findings from the first round
- Distributed to 97 experts
- 42 responses (42%)
- **Round 3 – Delphi workshop**

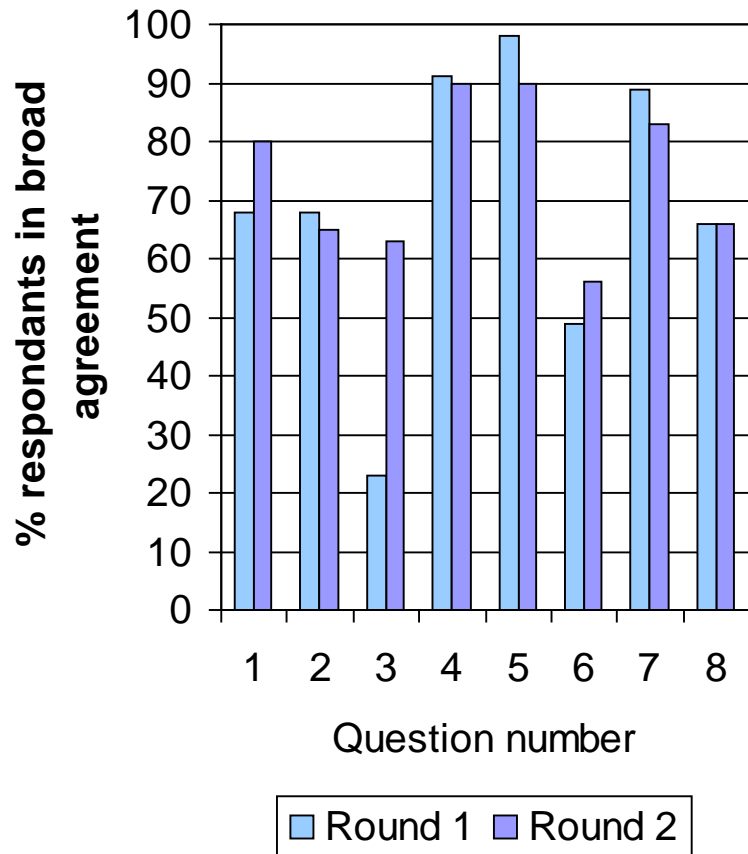


# R1 & 2: quantitative analysis

- “A life-threatening condition is one in which medical intervention may prove successful but by its nature carries a substantial chance of mortality in childhood”
- High consensus
  - Q4 “diagnosed before 18”
  - Q5 “onset before 18”
- Consensus improved
  - Q3 “childhood”



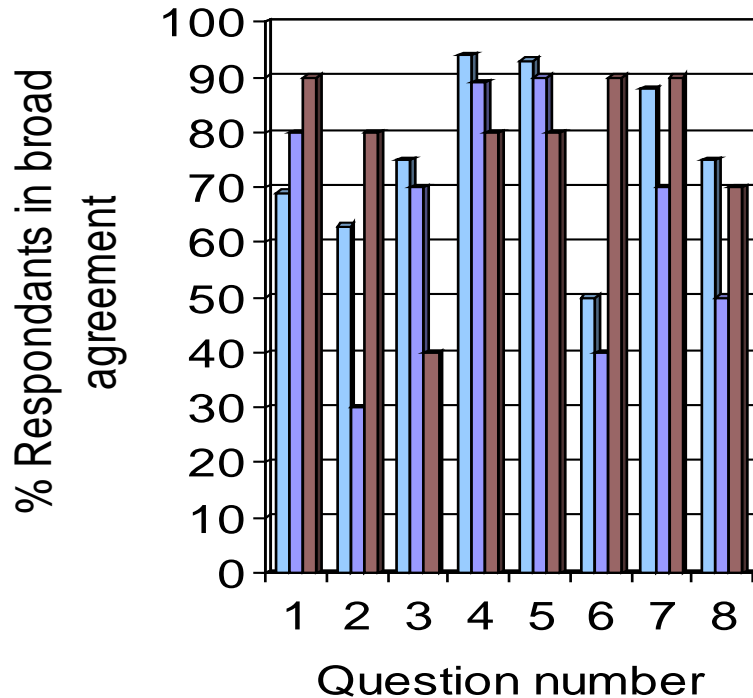
# R1 & 2: quantitative analysis



- “Life limiting conditions are those for which there is no reasonable hope of cure and from which children and young people will die prematurely”
- High consensus
  - Q 7 “Cure”



# R2 Influence of respondent type



■ Nurses ■ Doctors ■ Heads of care

- Marked difference by respondent type:
  - Q2 “substantial chance of mortality”
  - Q3 “Childhood”
  - Q6 “No reasonable hope”
- 75% in broad agreement for all respondent types only for Q4 and Q5



# R2 Qualitative analysis

- Respondents were invited to
  - Add comments
  - Offer revised definitions if they disagreed with the proposed definitions.
- Few respondents offered completely revised definitions
- Many expanded on why they did not agree with a proposed definition.
  - Comments were examined independently by the two researchers and after discussion a system of coding was devised.
  - Quotations were selected on the basis of being indicative of the views expressed.



# R2 Qualitative analysis

- The following themes were identified:
  - Life expectancy in the context of children's palliative care
  - Conditions that carry a risk of mortality
  - Access to services and the transition to adult care
  - Consistency
  - Quantifying hope



# Life expectancy

## (in the context of children's palliative care)

- Issues were raised around the life expectancy of children with life threatening conditions, and how it compares with others of their own age. (Q1; Q3; Q7)
  - “Add in such that the child or young person has a life expectancy comparable with other children or young people of the same age”
  - “The child or young person may still have limited life expectancy even if treatment is successful”
  - “There is an over emphasis on life expectancy and a medical (disease based) model”
  - “Over emphasis on life expectancy”





# Conditions that carry a risk of mortality

- There were observations about the wide range of conditions that carry a risk of mortality, and the number of children that would be included if the definition is too broad or ambiguous.

(Q2)

- “Use of the word substantial denotes a ‘real risk’ as oppose to a potential risk that could be applied to a wider range of conditions”
- “Substantial seems more proportionate and more understandable than ‘any’”
- “Definition is too tight as much depends on care and individual patients. ‘Prematurely’ means before the expected time.”



# Consistency

- The need for consistency of age restrictions throughout this study and with other agencies (Q4; Q5; Q8).
  - “Should aim for consistency with other groups of children and young people e.g. disabled children”
  - “In Scotland if diagnosis after 16th birthday then young person would be in adult services”
  - “Clarify that definition refers to ‘life threatening conditions of childhood’”



# Delphi workshop

- Invitations to all professionals identified through the Delphi survey
- 13 attendees (4 doctors: 8 from hospice background)
- Feedback and discussion of quantitative and qualitative results from Delphi rounds 1 and 2
- Stepwise discussion evaluating potential methods for identifying children with palliative care needs
  - Prognosis or percentage chance of survival
  - ACT groups
  - Surprise question and Colours of Life
- Identification and discussion of other key issues



# Outputs from the Delphi workshop

- Fundamental principles
  - Palliative care is different to other long term conditions: palliative care requires an increased risk of dying compared with the general population
  - Aim to define and hence identify children with palliative care needs
  - Deal separately with operational issues arising from implementation of the definitions



# Palliative care and end of life care

- End of life care describes care during the last hours and days of life: anyone who dies may require end of life care
- End of life care falls into the spectrum of palliative care
- However not all end of life care is provided by palliative care services



# Children with palliative care needs

- Aim to define and hence identify children with palliative care needs
- Scope from antenatal through childhood and adolescence
  - Diagnosis or recognition
  - Possibility of end of life
- Definitions of adulthood vary across the UK and worldwide: need to ensure definitions are as consistent as possible across related work
- Round 1 & 2 Delphi >90% consensus for diagnosis or recognition before 18 years of age (i.e. before 18<sup>th</sup> birthday)



# Palliative care and transition

- Two groups of young people with palliative care needs
  - Survivors who are diagnosed in childhood and live unexpectedly into adulthood
  - New cohort of young people who are diagnosed in early adulthood
    - Needs are important and require consideration but beyond scope of immediate work
    - Not normally eligible for children's hospice or paediatric palliative medicine



# Identifying children with palliative care needs

- Prognosis
  - Original approach taken in Delphi study
    - Consensus decreased on the second round: Conflicting responses
  - Predicting dying or end of life is difficult
    - “None of us can accurately predict the future”
  - Accuracy of prognosis improves with
    - Nearness to end of life
    - Multi-professional approach
  - Professionals are reluctant to give a poor prognosis: reluctant to label or identify children as “palliative”





# ACT groups (current wording)

- Category 1 Life-threatening conditions for which curative treatment may be feasible but can fail. Where access to palliative care services may be necessary when treatment fails or during an acute crisis, irrespective of the duration of that threat to life. On reaching long term remission or following successful curative treatment there is no longer a need for palliative care services. e.g. cancer, irreversible organ failure of heart, liver, kidney.
- Category 2 Conditions where premature death is inevitable, where there may be long periods of intensive treatment, aimed at prolonging life and allowing participation in normal activities. e.g. cystic fibrosis, Duchenne muscular dystrophy.
- Category 3 Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years. e.g. Batten disease, mucopolysaccharidoses
- Category 4 Irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complications and likelihood of premature death. e.g. severe cerebral palsy, multiple disabilities such as following severe brain or spinal cord injury, complex healthcare needs and a high risk of an unpredictable life-threatening event or episode.



# ACT groups

- ACT group is for the child as a whole
- Describes the child's anticipated journey
- Identifies probable palliative care needs when applied to a cohort of children who have died
- Identifies possible palliative care needs when applied to a cohort of children who are currently living
  - Additional information needed to identify children with active palliative care needs
  - Large numbers of children in groups 4, 1 (and to a lesser extent group 2) who may have needs around the time of diagnosis or recognition but then do not have active palliative care needs for many years



# Surprise question

- Would you be surprised if the child died before adulthood?
  - More comfortable to say wouldn't be surprised versus expect
  - Less threatening to talk about and plan for a possibility rather than a certainty
  - Less threatening to ask for consent
  - Hard to write down in a letter of referral but OK if verbal
- Undoubtedly subjective
  - But not necessarily any more than other estimates
  - Accuracy should improve with familiarity with child and experience over time
  - Potential to use multidisciplinary approach to add consensus and validity



# A Spectrum of Children's Palliative Care needs

- Colour groupings used to describe different stages in illness journey and types of palliative care need
  - Gold Standards Framework (adults and children)
  - Colours of Life (N. Harris et al)
  - Classification of children and young adults with life threatening and life limiting conditions (ACT 2009)
- Can we use this to help us identify children who may have palliative care needs?



# A Spectrum of Children's Palliative Care needs

**Children who are diagnosed or recognised to have a potentially life shortening (fatal condition) before their 18<sup>th</sup> birthday.**

Survival into adulthood is likely.

Diagnosis is likely to fit into one of the ACT categories

*Would you be surprised if this child died as a result of this condition or problem?*

**Children whose death before adulthood (18<sup>th</sup> birthday) is not unexpected.**

May live for many years.

Care needs may be similar to children who have complex chronic, but not life-shortening, conditions.

*Would you be surprised if this child died before adulthood (their 18<sup>th</sup> birthday)?*

**Children who have increasing instability or progressive deterioration.**

Death is not unexpected in months to years

*Would you be surprised if this child died within the next five years and possibly within the next few months?*

**Children who are critically ill.**

Survival is not expected beyond the next few weeks

*Would you be surprised if this child was alive in a few weeks time?*

**Children who die.**

# Supporting questions

- **Diagnosis or recognition**
  - Would you be surprised if this child died as a result of this condition or problem?
- **Death before adulthood**
  - Would you be surprised if this child died before adulthood (18<sup>th</sup> birthday)?
- **Increasing instability**
  - Would you be surprised if this child died in the next few months to years? Or
  - Would you be surprised if this child died in the next five years?
- **Critical illness or end of life**
  - Would you be surprised if this child was alive in a few weeks time?

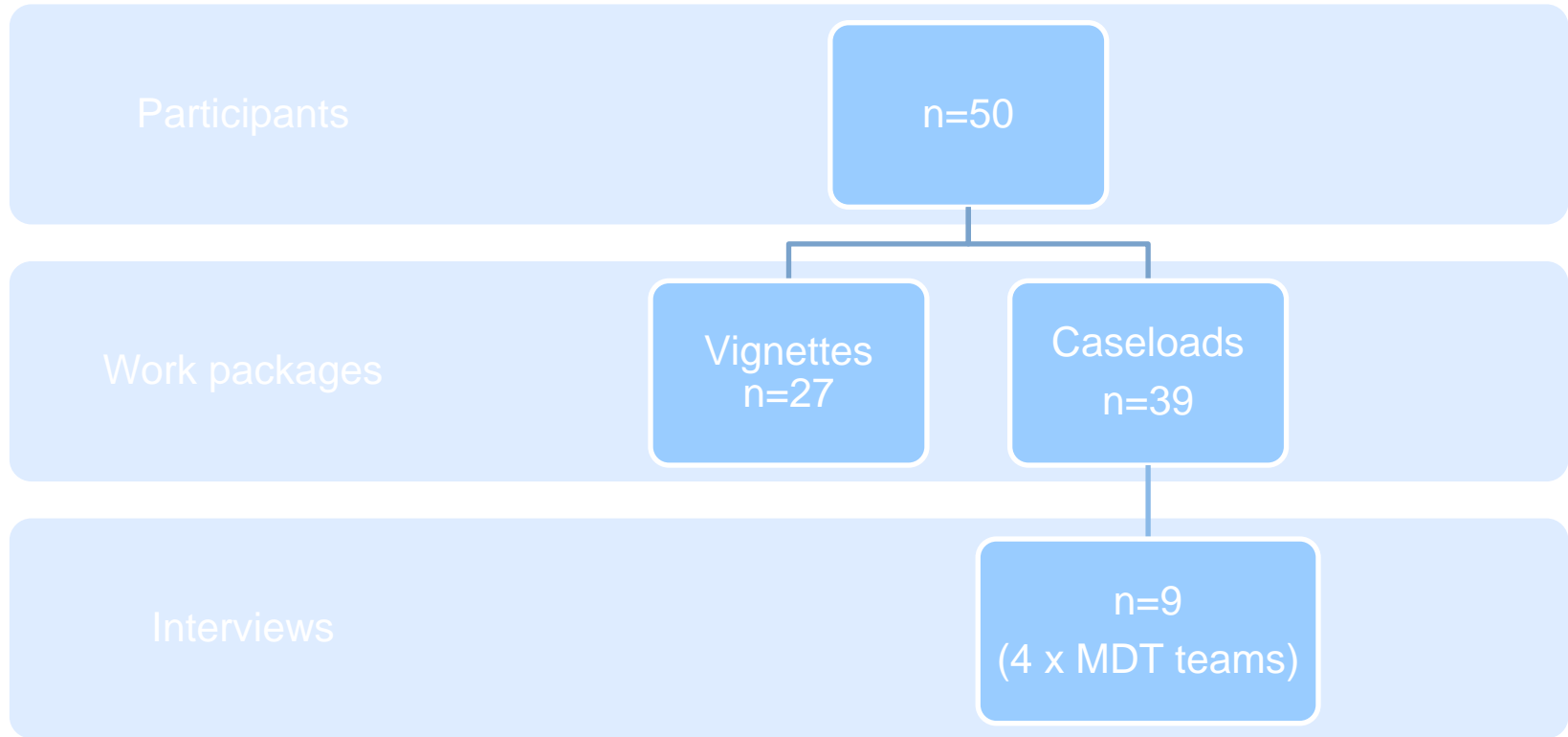


# Initial validation of the Spectrum of Children's Palliative Care Needs

- 10 vignettes (**reliable**)
- 5 consecutive children (**valid; practical utility**)
- Interview
  - Conceptually valid
  - User-friendly
  - Scope and purpose
  - Other frameworks/tools
  - Dissemination strategies
- Recruitment: WMPPCN & email list of MDS meeting



# Study participants



**Over 300 yrs of combined experience in children's palliative care.**





# Key findings

- Acceptable and easy to use by a range of health professionals and care settings.
- Made conceptual sense – applicable to children
  - With a range of life-limiting or life-threatening conditions
  - Across the complete trajectory of illness
- Had good explanatory power

*one of our family support workers who...is very very experienced said ..... that often if a child moves to red, the child may well move as far back as green but the families expectation stays in red and I thought, isn't it interesting that she can use the tool to make a really good point because how else would you explain that, you know.*



# Primary purpose: Service mapping

- Useful for service mapping, clinical audit, epidemiology

*A national tool which captures the child death process and reflects the actual care hours and admin hours required to support dying children, families, colleagues etc would be a very powerful commissioning tool.*

- But concerned about practicalities of data -collecting

*I mean it's fine to say they're orange or yellow or green, at some point but, you know, do you update the database monthly, six monthly, you know, who goes through and audits them and validates them and so on.*



# Other purposes: Clinical working

- Useful clinical framework to facilitate
  - Case review (MDT meetings)
  - Workload assessment/management
  - Communication
- But what do categories mean in real-terms

*An interesting point raised by a colleague was that she thought the time taken to care for each child would be reflected by their colour category i.e. orange = more time than green/yellow, but this is not the case. [It] would be really good to capture some actual time input on a weekly basis for each child/category..... with future commissioning arrangements, this may be very useful.*



# Other purposes: Add value to child & carer experiences

- Potential to:
  - Identifying current care needs
  - Prompt discussions about key transitions and turning points (especially end of life issues) – leading to better anticipatory planning.
  - Identifying disparities in how clinicians and families view care needs and priorities.
- But cautioned against using it directly with families

*Would I use it with families? I guess my hesitation is it's a bit, sort of, in their face when they already know what's going to happen. If they're not quite ready to be told we're moving from the green to the amber, then I think that that could be very difficult visually....I think that it would depend on the family.... There's some families that may find that helpful; there's some families that may lose hope.*



# Next steps...

## Spectrum of Palliative Care Needs

- Predictive validity
  - e.g. Prospective study to determine if categorisations predict prognosis
- Can we identify factors that influence accuracy?
- What are the defining features of each category and are they discriminatory enough?
  - Immediate care needs
  - Future care needs
  - Workload implications
  - Economic implications
- How do the categories relate to child/carer views of their care needs?



## Next steps...

# Spectrum of Palliative Care Needs

- Consultation and consensus building
  - Importance of definitions and data to identify needs not primarily as justification for existing services
  - Identify appropriate census points to support data collection
- Related definitions to support palliative care for young adults
  - Consider how “our” definitions translate into adult care when young people survive



# Next steps: Minimum Data Set

- Consent for registration and MDS collection
  - Education, training and supporting documentation to facilitate seeking consent
  - Emphasise the benefits of data collection for recognising unmet needs and ensuring that they are met
  - Multidisciplinary approach to identification e.g. CAF (Common Assessment Framework) Plus
- Proposed Regional or National Data Hub
- Links with Palliative Care Funding Review



# Summary

- Identification of children who may have palliative care needs is essential but poses some very significant challenges
- The ACT/CH-UK Children's Palliative Care Minimum Dataset supported by the Spectrum of Children's Palliative Care Needs has the potential to allow identification of these children in real time with potential benefits for service planning, delivery and evaluation





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