

# The Spectrum of Children's Palliative Care Needs: a classification framework for children with life-limiting or life-threatening conditions

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## ABSTRACT

**Objectives** This paper examined the potential of a new classification framework, *The Spectrum of Children's Palliative Care Needs*, to facilitate identification of children with palliative care needs for the purposes of minimum data set collection and population needs assessment.

**Methods** Health and social care professionals (n=50) in a range of paediatric palliative care settings applied *The Spectrum* to (i) clinical vignettes and (ii) consecutive children on their caseloads. They also provided confidence ratings and written comments about their experiences. Inter-rater reliability, conceptual validity, acceptability, feasibility and sustainability were examined. A subset of professionals (n=9) also participated in semistructured telephone interviews to provide further insight.

**Results** Inter-rater reliability for the vignettes ( $\kappa=0.255$ ) was fair. However, professionals were more confident applying *The Spectrum* to their caseloads, which included children (n=74) with a range of life-limiting/life-threatening conditions. *The Spectrum* made conceptual sense in relation to these children and was considered to offer a meaningful way to define the eligible population in service mapping. Benefits for clinical work (eg, facilitating patient review, workload management, clinical audit) and research were also identified. However, important threats to reliability were highlighted.

**Conclusions** Preliminary assessment of *The Spectrum* confirms its potential to promote consistent data set collection in children's palliative care. The results have been used to produce a revised version and user guidelines to address issues raised by participants. However, further research is required to further validate the framework and establish its relevance to families' self-defined needs.

## INTRODUCTION

Identification of children with palliative care needs is an essential step in improving service provision.<sup>1–3</sup> However, a major challenge to this is the lack of a robust systems to define the eligible population;<sup>4</sup> an issue that has similarly thwarted adult palliative care.<sup>5</sup> Work to address this has been championed by Together for Short Lives who have developed core definitions for children's palliative care,<sup>6</sup> including a classification criteria for life-limiting/life-threatening conditions (box 1).<sup>7</sup>

These criteria have been instrumental in advancing children's palliative care<sup>8</sup> and are now internationally recognised.<sup>9</sup> However, they are not without limitations (eg, assignment to a group may change as a child's condition progresses).<sup>4</sup> To this end, a Delphi study was commissioned to develop a more robust framework.<sup>4</sup> The result was *The Rainbow of Children's Palliative Care Needs* (figure 1), later renamed *The Spectrum of Children's Palliative Care Needs* and hereafter referred to as *The Spectrum*. This incorporates the existing definitions and categories, but groups children who are diagnosed or recognised to have a life-limiting or life-threatening condition before their 18th birthday into five prognostic-based categories that are considered to have distinct care needs and implications. These are colour-coded for ease of use and supported by a 'surprise question' to prompt professionals to consider the possibility that a child might die within a specified period of time. This was intended to provide clear population criteria for use in minimum

**Box 1 Categories of life-limiting and life-threatening conditions<sup>7</sup>**

**CATEGORY 1:** Life-threatening conditions for which curative treatment may be feasible but can fail.

Access to palliative care services may be necessary when treatment fails or during an acute crisis, irrespective of the duration of threat to life. On reaching long-term remission or following successful curative treatment there is no longer a need for palliative care services.

*Examples: cancer, irreversible organ failures of heart, liver, kidney.*

**CATEGORY 2:** Conditions where premature death is inevitable

There may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities.

*Examples: cystic fibrosis, Duchenne muscular dystrophy.*

**CATEGORY 3:** Progressive conditions without curative treatment options.

Treatment is exclusively palliative and may commonly extend over many years.

*Examples: Batten disease, mucopolysaccharidoses.*

**CATEGORY 4:** Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health complications and likelihood of premature death.

*Examples: severe cerebral palsy, multiple disabilities, such as following brain or spinal cord injury, complex healthcare needs, high risk of an unpredictable life-threatening event or episode.*

data sets and other service-improvement activities and thus help users to quantify the number of children in each prognostic group and facilitate identification of their needs.

Although The Spectrum was developed by experts in palliative care, it has not been tested. The aims of this study, therefore, were to examine the feasibility of using The Spectrum within practice settings and to assess its clarity, content, acceptability, face validity (ie, the extent to which it makes clinical and conceptual sense to those using it) and inter-rater reliability (ie, level of consistency between users). The intention was to use this information to revise The Spectrum prior to any subsequent use and formal validation.

## METHODS

### Sample and setting

Invitations to participate in the project were sent out to clinicians who provide care to children with palliative care needs via the West Midlands Paediatric Palliative Care Network. This was supplemented by a targeted recruitment strategy in which invitations were forwarded to members of relevant national special interest groups, via email distribution lists. We were aiming for coverage of views across a range of

multidisciplinary professionals, working within different specialities, team structures and care settings. This was to allow us to (i) detect contrasting opinions about defining and identifying children with palliative care needs and (ii) examine the extent to which The Spectrum can meaningfully classify the full range of children with life-limiting or life-threatening conditions and its usefulness across different service providers. Consenting professionals were invited to take part in one or both Work Packages. It was hoped that this flexibility would promote participation.

### Work Package 1: vignettes

Professionals applied The Spectrum to 10 vignettes that presented a broad range of children with palliative care needs (box 2). These were developed by the project team and described children at different stages of the patient journey and whose conditions fell within the four standard categories (box 1). They were pretested for authenticity by the project reference group and revised as required.

Participants were asked to:

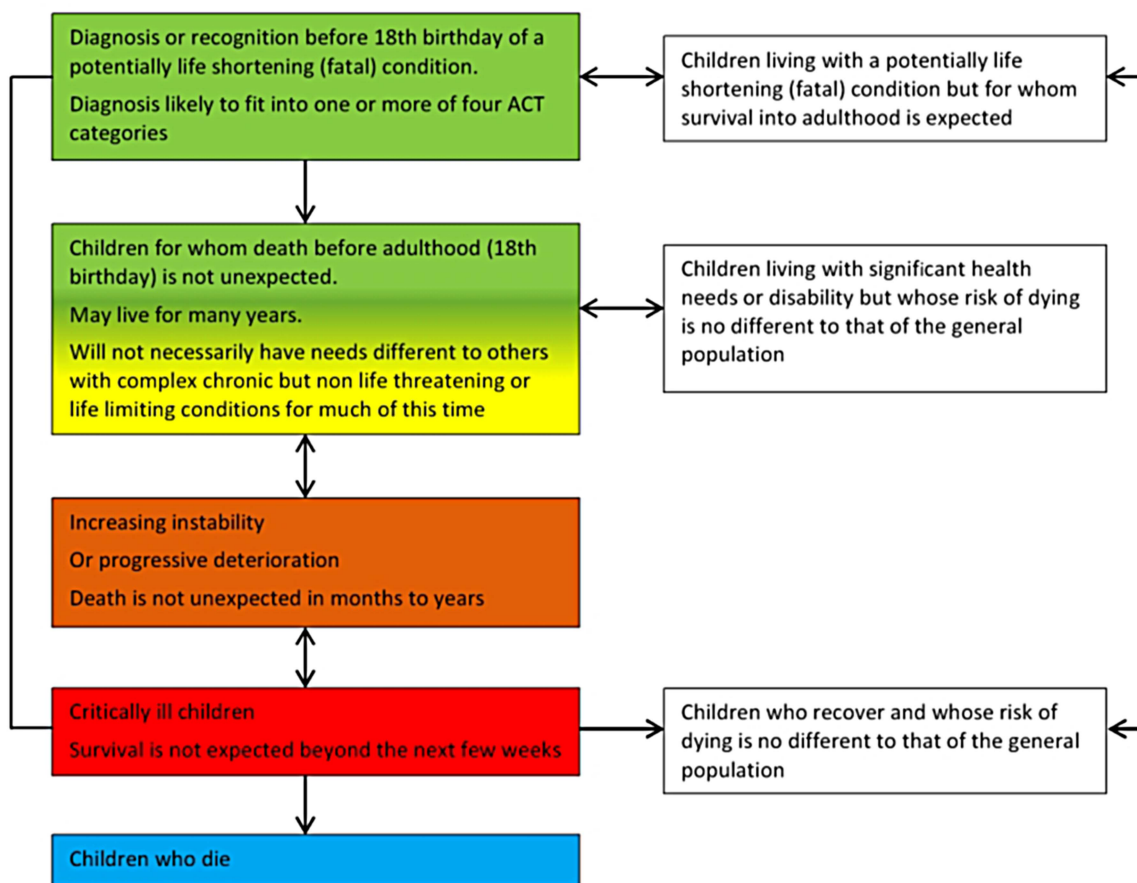
1. indicate which Spectrum colour-coded category best described the child in each vignette
2. rate their confidence-level regarding their decision (response options; 'extremely confident', 'somewhat confident', 'not at all confident')
3. provide written information to explain their decision making.

Participants were instructed to complete the vignettes individually and omit any that fell outside of their expertise.

### Work Package 2: caseloads

Participants were also asked to apply The Spectrum to at least five consecutive children on their caseload (during routine client updates, case reviews, discharge planning, etc). This was to examine its use in 'real-life' settings. As such, participants were asked to use The Spectrum on their own or as part of their usual team, dependent upon their normal working practices. It was felt that this approach allowed examination of the individual/group dynamics that might influence use of The Spectrum and its feasibility within routine practice. They also provided (anonymous) data to describe (i) their personal characteristics and those of other team members, where applicable (eg, clinical role/grade, speciality, setting, number of years working with children who have palliative care needs), and caseload details (eg, age, primary diagnosis, length of involvement, main reason for review and Spectrum allocation).

Participants of this Work Package were subsequently invited to participate in a semistructured telephone interview to reflect on their experiences of using The Spectrum. These were undertaken within 3 days of use of The Spectrum to minimise recall bias and sought to ascertain health professionals' (i) general



### The revised definitions

#### Diagnosis or recognition before the child's 18th birthday of a potentially life shortening (fatal) condition

- "Would you be surprised if this child died as a result of this condition or problem?"
- It is anticipated that diagnosis or recognition will facilitate identification of one or more relevant ACT groups

#### Death before adulthood is not unexpected

- "Would you be surprised if this child died before adulthood (18th birthday)?"

#### Children with Increasingly 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?"

#### Children experiencing Critical illness or end of life care

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

**Figure 1** The (original) Rainbow of Children's Palliative Care Needs.

views about identifying children with palliative care needs and (ii) specific views about The Spectrum, including strategies for improvement and dissemination. Interviews were audio-recorded and transcribed verbatim.

### Analysis

Standard descriptive statistics were used to summarise participant/caseload characteristics and the distribution

of Spectrum and confidence ratings. Inter-rater reliability was assessed using Fleiss' kappa statistical measure ( $\kappa$ )<sup>10</sup> and interpreted using guidance from Landis and Koch.<sup>11</sup>

Qualitative data (from the interviews and questionnaire comments) were analysed using Directed Qualitative Content Analysis,<sup>12</sup> in which the initial codes are derived from theory or relevant research findings. Data were coded to reflect their assignment

**Box 2 Sample vignette**

Age: 16 years

Diagnosis: Duchenne muscular dystrophy

ICD 10: G71

Category: 2

George is ventilated via a tracheostomy. He requires supportive ventilation 24 h a day; off the ventilator he has a weak respiratory drive but can manage for 6–8 h before he starts to become tired and his saturation levels start to fall. In the past few days he has developed a chest infection for which he has received broad spectrum antibiotic therapy for the past 5 days. His breathing is laboured with a respiratory rate of 80 resp/min and a pulse rate of 110 bts/min. He is pyrexial 38°C, has a Glasgow coma score of 5 and is responsive to painful stimuli. He is receiving 75% of his fluid allowance via a gastrostomy and has a reduced urinary output.

to content and conceptual themes and established processes were employed to ensure trustworthiness (eg, ‘constant comparison’, ‘negative case analysis’).<sup>13</sup>

**Ethical considerations**

The project was given service development status by the National Research Ethics Service in England and received ethics approval from the University of Birmingham. Research governance and data protection principles were adhered to throughout.<sup>14 15</sup>

**RESULTS****Participants**

Fifty professionals participated (figure 2); 17(34%) on an individual basis and 33 (66%) as part of their routine team.

They represented a range of disciplines/specialities, with 532 years of combined experience in children’s palliative care (table 1).

**Work Package 1: vignettes**

Work Package 1 was undertaken by 27 (54%) participants (table 2). Agreement and confidence in decision making was best for children considered to be in their last few weeks/days of life (ie, V2, V3 and V7). Participants were less confident applying The Spectrum to other children, and while agreement was reasonably high for some vignettes (V6, V9 and V10), there was no majority agreement for others (V1, V4, V5, V8). This is reflected in the overall measure of inter-rater reliability ( $\kappa=0.255$ ), which is considered *fair*.<sup>9</sup> Clarifying comments (n=161) were provided by 24 (89%) participants. These indicated that agreement and confidence were influenced by where the child is in their disease trajectory, the level of information available (considered to be limited in many vignettes)

and judgements regarding the relevance of clinical indicators.

**Work Package 2a: caseloads**

Participants (n=39, 78%) applied The Spectrum to 74 children (aged >1–18 years) with a wide range of life-limiting/life-threatening conditions. Median length of involvement with children was 2.25 years, (range 0–16 years). Over half of the children (n=42, 57.5%) were categorised as orange. However, all Spectrum categories were used with 2 (2.7%) children classified as green, 20 (27.4%) as green/yellow, 8 (11.0%) as red and 1 (1.4) as blue. Clarifying comments were made in relation to 52 (70%) cases and indicated that categorisation often depended upon a careful synthesis of information about clinical symptoms, treatment outcomes, dependency indicators, psychosocial factors and patient/carer priorities.

**Work Package 2b: interviews**

Nine health professionals participated in interviews (table 1), four of whom had applied The Spectrum within a multidisciplinary team (figure 2).

Several themes were identified, and triangulation with the numerical data regarding agreement and confidence in categorisation showed much concordance. This allows a number of statements to be confidently made.

The Spectrum makes conceptual sense and is easy to use

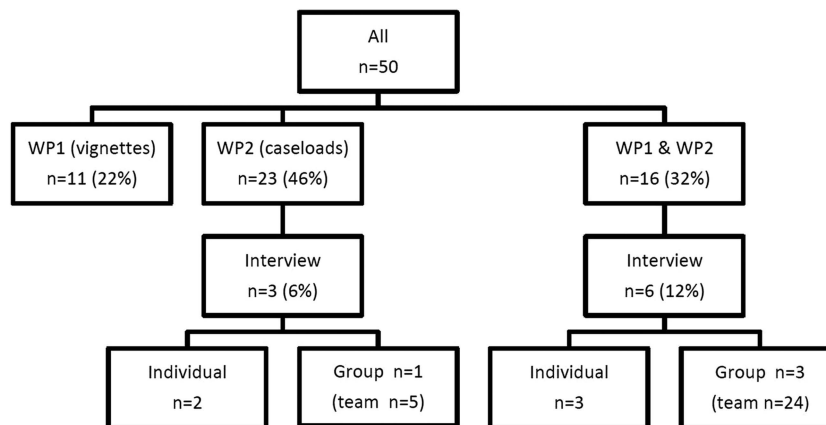
Participants felt that The Spectrum made intuitive sense and was relevant. It was considered to be acceptable and comprehensive, covering all areas of the disease trajectory. Participants found it much easier to apply The Spectrum to their caseloads than to the vignettes and attributed this to the greater availability of information.

I found it much easier to apply to my own case...

I either knew instinctively where I would put them because it was somebody I had seen recently or I was able to ask somebody from the care team who had had contact with that family [participant 7].

They felt that access to up-to-date information from multiple perspectives was critical to the framework’s reliability and reported that consensus regarding a child’s categorisation was easily achieved in such circumstances.

It was easier than we thought it was going to be.... we’d allowed some extra time because we thought it might take us a while....but in fact we found that because the tool was quite clear...and with the prior knowledge that we’d got of those particular children, that actually [it] was quite a quick process to come to an agreement about where we felt they [the children] sat [participant 14].



**Figure 2** Summary of participation in relation to Work Packages (WPs).

The Spectrum has the potential to identify children with palliative care needs, but its usefulness is dependent on the system of data collection. Participants acknowledged that children require individualised care but clearly understood the need to identify the eligible population. The Spectrum was felt to provide a useful framework for this, enabling the number of children in each category to be quantified and supporting assessment of their needs and evaluation of service provision. They also highlighted the value of having a universal system to collect these data; in that having a nationally agreed framework would enable comparisons to be made between settings, regions and populations.

I can see clearly what we are trying to achieve from this, you know, we are trying to categorise children to give us a picture, give us a snapshot of what the demand is and what the needs are at any one given time. So, for me it works well and you know, I think using these sorts of visual coloured tools where you can sit down and say, right okay, where are you going to place them, it is an easier tool than it is to go through a series of questions with tick boxes with scores attached to them...So, I like this actually [participant 5].

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 [participant 13].

However, some participants raised concerns about the ability of The Spectrum to contribute fully to this agenda. In part, this was related to the framework itself. They felt that while the colour-coded categories provided a useful way to group children, it could not provide accurate assessment of their care needs; only an approximation. Thus, the framework would need to be closely tied to measures of service requirement. Participants' comments also reflected wider concerns about the complexities of collecting reliable data and recounted experiences of failed initiatives to develop minimum data sets in children's palliative care. Thus,

the usefulness of The Spectrum framework in service mapping was considered dependent upon having robust data collection systems, which would need to be well-funded, appropriately staffed and regularly updated.

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 [participant 8].

The Spectrum is clinically relevant and has practical utility

Participants placed most emphasis on using The Spectrum within clinical settings (eg, to facilitate case review, manage workload, support consistency). It was considered to have good explanatory power to help professionals understand families' palliative care journeys and anticipate their care needs.

Interestingly one of our family support workers who...is very very experienced said that she felt the families' coping mechanisms, 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. And I thought that was a really clever observation that perhaps that then explains some of the mismatch between professionals' expectations and families' concerns, doesn't it? [participant 7].

Participants also felt that The Spectrum offered a powerful way to share information with colleagues and support mutual understanding, delineation of collaborative roles and earlier referral to specialist providers.

I would be quite keen for us to see some of those referrals earlier....Oncologists particularly come to me usually well into amber, if not red...Wouldn't it be nice to have something like this to say to them, 'I think I am seeing most referrals from you in red and amber, quite late in amber. Is there any chance where you might be able to identify some of the families for whom treatment is now only going to supported on

**Table 1** Participant characteristics

	All (n=50)	Vignettes (n=27)	Caseload (n=39)	Interviews (n=9)
<b>Professional status: count (%)</b>				
Medical doctors				
Consultant community paediatricians/hospice doctors	6 (12)	6 (22)	4 (10)	1 (11)
Consultants in paediatric specialities	5 (10)	4 (15)	2 (5)	1 (11)
General practitioners	3 (6)	2 (7)	2 (5)	0 (0)
Nurses				
Children's nurses	9 (18)	7 (26)	8 (21)	1 (11)
Specialist/consultant nurses*	7 (14)	3 (11)	3 (8)	2 (22)
Heads of care (children's hospices/children's community nursing teams)	4 (8)	2 (7)	4 (10)	4 (44)
Other (unspecified members of care team, PhD nurse researcher)	4 (8)	0 (0)	4 (10)	0 (0)
Allied health professionals/social care				
Social worker	3 (6)	0 (0)	3 (8)	0 (0)
Physiotherapist	2 (4)	1 (4)	2 (5)	0 (0)
Family support worker	1 (2)	0 (0)	1 (3)	0 (0)
Play therapist	1 (2)	0 (0)	1 (3)	0 (0)
Others				
Hospice manager/administrator	2 (4)	1 (4)	2 (5)	0 (0)
Hospice at home coordinator	1 (2)	0 (0)	1 (3)	0 (0)
Transition manager	1 (2)	1 (4)	1 (3)	0 (0)
Community worker	1 (2)	0 (0)	1 (3)	0 (0)
<b>Speciality: count (%)</b>				
Paediatric palliative care	21 (42)	12 (41)	19 (50)	4 (44)
Allied health professionals/social care	8 (16)	1 (4)	8 (21)	0 (0)
Paediatrics (general)	5 (10)	4 (15)	4 (10)	1 (11)
General practice	3 (6)	2 (7)	2 (5)	0 (0)
Other/not specified	3 (6)	1 (4)	3 (8)	0 (0)
Paediatric inherited metabolic disorders	2 (4)	1 (4)	0 (0)	1 (11)
Paediatric intensive care	2 (4)	2 (7)	0 (0)	0 (0)
Community nursing	2 (4)	0 (0)	2 (5)	2 (22)
Paediatric neurology	2 (4)	2 (7)	1 (3)	1 (11)
Paediatric oncology	1 (2)	1 (4)	0 (0)	0 (0)
Neonatal	1 (2)	1 (4)	0 (0)	0 (0)
<b>Setting: count (%)</b>				
Children's hospice	32 (64)	16 (59)	29 (74)	5 (56)
Acute children's hospital	12 (24)	6 (22)	6 (15)	2 (22)
Community	2 (4)	2 (7)	2 (5)	1 (11)
Hospital and community	2 (4)	1 (4)	2 (5)	1 (11)
Education and clinical setting (children's hospital/hospice)	2 (4)	2 (7)	0 (0)	0 (0)
<b>Professional experience: median (min, max) sum</b>				
Years working with children who have life-limiting or life-threatening conditions	11 (0.5 to 30) 532	12 (0.5 to 30) 332	10 (1 to 25) 390	13 (5 to 25) 90

\*Caseload data missing for one specialist nurse who participated in an interview.

palliative when they are yellow?' and we might be able to put in more family support [participant 7].

However, perhaps the most recurrent theme was the value of The Spectrum in managing workload.

You could probably use it to guide on what staffing requirements were. So, you know if we had all eight of our beds, with green patients who were here for elective respite, we might feel more comfortable with the lower staffing ratio than if we had, you know, two or

three children in red category who were here for end of life care and I think it would give some little measure about the amount of work that we might need to do on shift because you can see how that would up-scale the type of commissioning [participant 7].

The Spectrum is relevant to families, but health professionals advocate caution

Participants cautioned against using it directly with families and felt that labelling children in

**Table 2** Summary statistics for the vignettes

Vignettes	Participants Count (%)	Spectrum category ratings Count (%)				Participants Count (%)	Confidence ratings Count (%)		
		Green	Green/ yellow	Orange	Red		Extremely confident	Somewhat confident	Not at all confident
V1: Alice (6 years) Medulloblastoma	19 (63.0)	7 (36.8)	8 (42.1)	4 (21.1)	0 (0.0)	18 (66.6)	3 (16.7)	13 (72.2)	2 (11.1)
V2: George (16 years) Duchenne muscular dystrophy	22 (81.5)	0 (0.0)	0 (0.0)	8 (36.4)	14 (63.6)	22 (81.5)	10 (45.5)	11 (50.0)	1 (4.5)
V3: Ibrahim (14 days) Hypoplastic left heart syndrome	22 (81.5)	1 (4.2)	0 (0.0)	1 (4.2)	22 (91.7)	22 (81.5)	16 (66.7)	8 (33.3)	0 (0.0)
V4: Sarah (12 years) Cerebral palsy	24 (88.9)	12 (50)	12 (50)	0 (0.0)	0 (0.0)	22 (81.5)	6 (27.3)	16 (59.3)	0 (0.0)
V5: Parveen (3 years) Cirrhosis of the liver secondary to biliary atresia	21 (77.8)	2 (9.5)	6 (28.6)	11 (52.4)	2 (9.5)	19 (63.0)	1 (5.3)	14 (73.7)	4 (21.1)
V6: David (9 years) Epilepsy	23 (85.2)	0 (0.0)	9 (39.1)	14 (60.9)	0 (0.0)	22 (81.5)	3 (13.6)	18 (81.8)	1 (4.5)
V7: Halima (4 years) Acute myeloid leukaemia	18 (66.7)	1 (5.6)	0 (0.0)	0 (0.0)	17 (94.4)	18 (66.7)	10 (55.6)	6 (33.3)	2 (11.1)
V8: Harvey (7 years) Batten disease	24 (88.9)	0 (0.0)	2 (8.3)	12 (50.0)	10 (41.7)	22 (81.5)	7 (31.8)	11 (50.0)	4 (18.2)
V9: Ellen (7 years) Cystic fibrosis	21 (77.8)	14 (66.7)	7 (33.3)	0 (0.0)	0 (0.0)	20 (74.1)	9 (45.0)	11 (55.0)	0 (0.0)
V10: Joshua (10 years) Down's syndrome	23 (85.2)	17 (73.9)	4 (17.4)	2 (8.7)	0 (0.0)	20 (74.1)	4 (20.0)	15 (75.0)	1 (5.0)

such a reductionist way could cause significant distress.

That's okay if families recognise where their child is, but that's quite difficult for families to see that, you know, it's obvious when they're critically ill, but it's working with the families to see that their child's condition is changing, and I think lots of families see that but do they want to see it in black and white on a bit of paper? [participant 12].

However, they did highlight the importance of including families in further development of The Spectrum, including its potential to facilitate shared understanding and decision making.

The Spectrum can be enhanced to understanding, reliability and practical utility

No significant training issues were identified. However, it was clear that operationalisation of The Spectrum would benefit from supporting documentation to outline its purpose, relevance and use. Overall, they liked the graphical format, but felt the diagram could be simplified to make it more self-evident and indicate that a child's progression through the categories is not necessarily linear. They were generally happy with the differentiation of categories, although the orange category was considered the most difficult to apply, given the wide time frame (months to

5 years). However, there was no consensus about appropriate subdivision.

Much of the debate focused on the 'surprise' questions. These were considered helpful prompts, but participants expressed opposing views about the conceptual validity of being 'surprised'. Some felt this reflected the uncertainty inherent in many life-shortening conditions. In contrast, others felt 'surprise' was inappropriate, given that decision making should be based on 'professional expertise'. Participants also noted that an individual's level of 'surprise' could be influenced by experience and the availability of information.

Your element of surprise depended on your background ... for instance, one of the oncologists that I discussed this with was saying that well actually, you know, your element of surprise and my element of surprise is very different because I see the survivors, you in the hospice only see the ones who deteriorate and die. So of course when you see such and such a scenario or diagnosis, you expect they're gonna die and I will tell you that actually, only a quarter of mine will die so therefore I would be surprised and when talking to some of the nurses, they said very often they are coloured by their most recent experience of a child in a similar position. I mean we had a leukemic a while ago who died very early on, having got a massive infection and then multi organ failure, and

died, which is a very unexpected early death from leukaemia. But having seen that once, the nurses were then saying well for my next child, if you ask me would you be surprised if this child died, I would say well no, I wouldn't be surprised 'cause I've seen it happen before even though it's very unlikely [participant 9].

There was also debate about the inclusion/exclusion criteria. Participants highlighted that professionals do not always recognise that a child has palliative care needs and that could lead to differential use of The Spectrum and under-representation. Some participants also questioned the rationale for excluding children with complex care needs who may use palliative care services but are not necessarily life-limited.

you absolutely need to know if a child has a life limiting condition and that's fine for three of the four categories,...but when you come to the children with cerebral palsy and conditions that...or something or a one off event like a post surgery, you know, post cardiac surgery stroke or something where you're left with quite a disabled child. Those children, you know, which ones go into the palliative care, those are the ones that cause the difficulty because their life may be limited by their degree of disability but you would not necessarily expect them to die. So I think you need to know how many children there are in a given area because any one of those children will cost a fortune in terms of services needed, so I think it's quite important to know that [participant 8].

The Spectrum should be developed further to optimise the benefits for families, health professionals and commissioners

Participants suggested that it would be extremely important to establish the tangible meaning of each category. This was particularly important if The Spectrum was to be used in clinical settings to review care needs and manage workload.

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 equals 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.

When asked whether it would be possible to develop a framework that was suitable for use by commissioners, health professionals and families, most felt that a universal tool with agreed definitions would be preferable to aligning separate models. However, it was suggested that any such framework should adopt a bottom-up approach to reflect the needs of the service users.

## DISCUSSION

This study provides preliminary support for The Spectrum's potential to promote consistent data set

collection in children's palliative care. A revised Spectrum (see web-only files 1 and 2) is now available from Together for Short Lives, <http://www.togetherforshortlives.org.uk>. This includes a simplified diagram to reflect participants' comments and user guidelines to improve understanding and consistency. In addition to good practice points, these guidelines provide a rationale for using 'surprise questions' to prompt professionals to consider whether a child may die within a specified period of time. Participants had mixed feelings about their use, which reflects similar debates about 'surprise questions' that have occurred in adult end-of-life care.<sup>16 17</sup> However, given that uncertainty is a major stressor for families and a known barrier in managing the transition from curative to palliative care,<sup>18-20</sup> the Researchers and Project Steering Group agreed with the view that 'surprise questions' provide a useful heuristic function in identifying individuals who may benefit from palliative care.<sup>17</sup> Their inclusion in The Spectrum also recognises that professionals are often more comfortable with the uncertainty implicit in 'not being surprised' than 'expecting' a child to die.<sup>4</sup>

The importance of adopting a broad approach (in which the possibility of death is acknowledged alongside possible cure or transition to adult care) is also highlighted by Borgesteede *et al*,<sup>5</sup> who compared criteria for defining the adult palliative care population. They concluded that the most appropriate approach should 'describe differences between sub-populations without omitting any potential palliative care patients' and include 'palliative care as labelled by (professional) carers, the intention of treatment provided, and an assessment of the patient's life-expectancy, not meant to predict because this is rather difficult, but as an indicator of the possibility of a palliative care trajectory' (p.68).<sup>5</sup> The Spectrum is largely consistent with these recommendations, although it does not include care goals. This was also highlighted by participants who suggested that identifying best practice standards for each of The Spectrum's categories, and linking them to appropriate palliative care pathways, would support better quality and more timely care. This is important as professionals' uncertainty about prognosis and reluctance to label children as 'palliative' has been shown to delay anticipatory planning with families.<sup>18</sup>

Participants also emphasised The Spectrum's potential to facilitate workload management. Their focus on this is not surprising, given an increasing number of children and young people with palliative care needs,<sup>21</sup> a reduced global economy and competing demands in healthcare. To this end, it will be important to explore the similarity/diversity of families' care needs within each group and what this means for service provision (eg, resource requirements). Related to this, there were concerns that The Spectrum would not reflect needs (and associated workloads) of



children who have complex, but not life-limiting/life-threatening, conditions who may also use palliative care services (eg, for respite). While The Spectrum is primarily a framework for children who are likely to die before their 18th birthday, it does allow identification of other children. As such, it may also provide a useful tool to help palliative care professionals examine the remits and limits of service delivery and highlight where consultative relationships with other service providers should be developed or strengthened.

As a clinical tool, The Spectrum was considered a useful framework to improve care, although participants were reluctant to use it directly with families. Families often have different views to professionals about their child's health status, level of need and preferences for treatment.<sup>8</sup> It will be valuable, therefore, to map The Spectrum to milestones in the disease trajectory that are known to be important to families,<sup>8</sup> other needs-based measures (eg, Colours of Life)<sup>22</sup> and its potential to support decision making.

### Limitations

The findings of this project also need to be interpreted in relation to a number of caveats. Inter-rater reliability was investigated using clinical vignettes that provided only brief patient histories with no opportunity for clarification. This may have limited the extent to which participants could make informed decisions about categorisation. Indeed, participants found it much easier to apply The Spectrum to children on their caseloads, suggesting that the true level of inter-rater reliability may be higher than that reported in this study. While the project revealed a number of consistent findings, it is possible that the participants are not fully representative of the entire children's palliative care community or the children and families that they serve. Unfortunately, most organisations that supported recruitment were unable to provide accurate response rates, and the characteristics of non-responders are not known. The small sample size (particularly in the interviews) may further limit transferability. However, the credibility and diversity of participants and consistency in their views suggests a good level of trustworthiness, although wider participation may have produced additional insights.

### CONCLUSION

Despite these limitations, The Spectrum appears to have a heuristic value that allows health professionals to describe a child's journey in a way that conveys likely prognosis, changes in trajectory and approximate care goals. It requires minimal support to use and is applicable across conditions, age groups and care settings. The results provide new insights about developing and evaluating classification systems in paediatric palliative care and confirm that The Spectrum may be a valuable framework to improve the quality of data collection. The results also suggest that The Spectrum has great

potential to improve clinical care more directly. This undoubtedly warrants further research, but promises to facilitate greater recognition of care needs, more joined-up care, earlier referrals to specialist providers and better use of resources.

An important outcome of this project is that The Spectrum has been included in the UK Palliative Care Funding Review, which has selected several pilot sites to gather information to inform the creation of a new National Health Service palliative care tariff for adults and children.<sup>23</sup> This recommends a classification system based on phases of illness; *stable*, *deteriorating*, *unstable* and *dying*,<sup>23</sup> which have been used elsewhere to evaluate and improve adult palliative care.<sup>24</sup> However, these phases have not been devised specifically for children. Inclusion of The Spectrum by some of the children's pilot sites recognises that the disease trajectories of children with life-shortening conditions are variable and can extend over many years, with repeated movement between these phases. It will be interesting to see which of these two frameworks provides the most robust data and whether they may be usefully combined for added benefit. Other important next steps will be to assess The Spectrum's predictive performance, identify the factors that influence accuracy and consistency, and establish its ability to distinguish between children who have different outcomes, in ways that are conceptually and clinically valid. Indeed, results from the clinical vignettes showed that consistent categorisation requires the availability of sufficient information and may be best achieved within a multidisciplinary context. However, it was also apparent that there was a degree of differential interpretation and weighting of information between individuals. As such, The Spectrum is likely to have a margin of error that may be influenced by setting, speciality and level of experience. Further work will therefore be important to understand and minimise any threats to reliability. International validation will also be important. Although developed in the UK, it is hoped that The Spectrum will have a wider relevance and facilitate transfer of knowledge between countries.

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co-designed the methods, co-designed the data-collection tools, supported analysis and contributed to the paper. CK supported data-collection and analysis and contributed to the draft paper. NH and SL supported development of the data-collection tools, helped analyse the data and revised the draft paper. All members supported participant recruitment and were members of the project steering group.

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**Data sharing statement** There is little unpublished data from this study, but what exists is available from the authors by request. The outcomes of the project (ie, The Spectrum of Children's Palliative Care Needs) is available from Together for Short Lives; <http://www.togetherforshortlives.org.uk>.

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# The Spectrum of Children's Palliative Care Needs: a classification framework for children with life-limiting or life-threatening conditions

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