

## Impact case study (REF3)

<b>Institution:</b> Coventry University		
<b>Unit of Assessment:</b> 3		
<b>Title of case study:</b> Improving Care for Young People with Long-Term Illnesses and Complex Health Needs		
<b>Period when the underpinning research was undertaken:</b> January 2011 – December 2018		
<b>Details of staff conducting the underpinning research from the submitting unit:</b>		
<b>Name(s):</b>	<b>Role(s) (e.g. job title):</b>	<b>Period(s) employed by submitting HEI:</b>
Jane Coad	HLS Honorary Professor Professor in Children and Family Nursing	2020-Present 2011 - 2020
Nicola Thomas (nee Ashley)	Research Assistant	2012-19
Erica Brown	Research Assistant	2011-19
Dawn Coleby	Research Fellow	2017-19
Jasveer Kaur	Research Assistant	2011-14
Samantha Nightingale	Research Assistant	2016-19
Alex Toft	Assistant Professor	2014-19
Elizabeth Bailey	Research Fellow	2014-19
<b>Period when the claimed impact occurred:</b> September 2013 – December 2020		
<b>Is this case study continued from a case study submitted in 2014? Y/N</b> No		

**1. Summary of the impact** (indicative maximum 100 words)

From 2001 to 2020, children and young people (CYP) in England with life-limiting and life-threatening conditions rose from c.33,000 to c.87,000 (Fraser et al, 2020), and advances in treatments mean many highly-dependent CYP now survive longer and live at home with their families. Research led by Professor Jane Coad and Team focused on experiences of this group and their carers, to ensure a stronger choice, voice and better quality of life. Research outcomes have been used by NICE, NHS, and sector charities internationally to develop specialist training, enhance resource allocation, and influence policies and guidelines to improve care services.

**2. Underpinning research** (indicative maximum 500 words)

Since 2011, Professor Jane Coad and team at Coventry University used innovative participatory arts-based methods to explore health and well-being for CYP with complex care needs. Coad began work with UK charity 'Together for Short Lives' (TfSL) to explore how well services in the West Midlands met palliative care needs for CYP and families. Initial research with Anne Hunt (partner UCLAN) established a user-informed picture of the issues facing this group [R1], which led to an extensive multi-partner Big Lottery Funding project (2011-2014, G1) to evaluate national provision.

Coad led Strand 2, an appreciative inquiry (a co-research method enabling stakeholders to explore and self-define care needs) which used arts-based tools to gauge participants' use and response to services. Research indicated that CYP and their families felt medical/nursing needs were well met but provision was needed for broader financial, social and emotional support alongside more responsive specialist therapies [R2]. Findings about perceptions of met and unmet health needs of CYP and families were reported to TfSL [R3], representing applied research in an underexplored area. R1-2 also underpinned a subsequent project with the charity WellChild, evaluating their nursing provision [G2].

Beginning the same year and collaborating with Professor Diane Harcourt (Partner: UWE Bristol), Coad investigated the experiences of CYP living with neurofibromatosis type 1 (a genetic condition resulting in varying degrees of visible difference), and the psychosocial impacts of living with the condition [R5]. Findings underlined a need for trustworthy information and practical advice to support adjustment for CYP with the condition [R5].

From 2012-2015 the CU team including Coad, Ashley and Kaur were also commissioned by the Teenage Cancer Trust (TCT) to conduct an action research project of a new pilot of specialist nurses across the North West of England [G5], which established ways arts-based methods could be used in real-world settings to understand views CYP have of health preferences [R6]. Results integrated young people and families' voices into the care provided for the first time, and led to important changes to service provision.

Drawing on all of this work, from 2015-2018 Coad, Ashley/Thomas and Toft with Joseph Manning (University of Nottingham) led the first UK rapid review investigating the use of a 'blended diet' for CYP fed via a gastrostomy tube, as an alternative to prescribed formula feeds (G3). A controversial and emotive issue for carers, research was carried out with a number of hospices, health trusts, following an initial project with the charity WellChild [G4]. Findings indicated that blended diet could offer health benefits, and supported families' cultural desire to nurture and feed, but that there was no gold standard to help guide choices [R4].

Overall, the research [R1-6, G1-4] revealed new insights into how CYP with complex care needs and their families experience, engage and navigate care services, and highlighted an imperative for:

1. Health professionals to support CYP with complex care needs and their families in offering choice, respecting diversity and enabling their voices in services;
2. All stakeholders to work together, across systems to improve patient-centred services and health outcomes;
3. Health care that is user-led, and user-centred.

### 3. References to the research (indicative maximum of six references)

---

R1. Anne Hunt, Erica Brown, Jane Coad (2015) "Why does it happen like this?" Consulting with users and providers prior to an evaluation of services for children with life limiting conditions and their families. *Journal of Child Health Care*, 19(3), 320-333.  
<https://doi.org/10.1177/1367493513510630>

R2. Coad J., Kaur J., Ashley N. (2014) Exploring the Perceived Met and Unmet Need of Life-Limited Children, Young People and Families. *Journal of Pediatric Nursing*, 30(1), 45-53. DOI:  
<https://doi.org/10.1016/j.pedn.2014.09.007>

R3. Hunt A., Coad J., West E., Hex N., Staniszewska S., Hacking S., Farman M., Brown E., Owens C., Ashley N., Kaur J., May K., Chandler V., Barron D., Wik A., Magee H., Lawson K., Wright D., Gunn, K. (2013) *The Big Study for Life-limited Children and their Families – Final research report, Together for Short Lives*, ISBN: 1 898447 21 7.  
<https://www.togetherforshortlives.org.uk/wp-content/uploads/2018/03/TfSL-A-Guide-to-Children%E2%80%99s-Palliative-Care-Fourth-Edition-5.pdf> [Accessed 26.02.21]

R4. Coad. J; Toft, A et al (2017) Blended foods for tube-fed children – a safe and realistic option? A Rapid Review of the evidence. *Archives of Disease in Childhood*.  
<http://dx.doi.org/10.1136/archdischild-2016-311030>

R5. Barke, J., Harcourt, D. and Coad, J. (2014) 'It's like a bag of pick and mix - you don't know what you are going to get': Young peoples' experience of Neurofibromatosis Type 1. *Journal of Advanced Nursing*. ISSN 1365-2648 <https://doi.org/10.1111/jan.12319>

R6. Jane Coad (2020). Building resilience through listening to children and young people about their health preferences using arts-based methods. In McKay L, Barton G, Garvis et al (Eds) Arts-Based Research, Resilience and Well-being Across the Lifespan. Palgrave Macmillan, London, 47-62. [https://doi.org/10.1007/978-3-030-26053-8\\_4](https://doi.org/10.1007/978-3-030-26053-8_4)

G1. Coad, J. (PI). (2010-2013). 'Association for Children's Palliative Care (ACT) Big Study for Life-limited Children and their Families: Study of West Midlands palliative care needs of children, young people and families'. Big Lottery Fund. Total grant: £499,320.

G2. Coad J. (PI). (2013-2016). 'Through the Eyes of Children, Young People and Families: Evaluation of the WellChild model of care'. WellChild. Total grant: £73,626.74.

G3. Coad J. (PI). (2015-17). 'The Blended Diet Study: the perceived benefits and risk of using a blended diet with children and young people with complex health needs and enteral feeding requirements'. National Institute for Health Research. Total grant: £266, 935.

G4. Coad. J. (PI). (2012-2014). 'Feed Me How? A study of confidence and competence related to gastrostomy care and blended diet'. WellChild. Total grant: £49,000.

G5. Coad J., (PI). (2012-2015). 'North-West Pilot Site Evaluation A participatory action research project and economic analysis in the NW of England of Teenage and Young Adult cancer services'. Teenage Cancer Trust. Total grant: £91.736.

#### 4. Details of the impact (indicative maximum 750 words)

---

The research on CYP with complex care needs has driven changes in three areas: informing national and international policies/guidance, helping develop specialist health services, and enabling CYP and their families to have a greater voice in provision.

##### Policies and Guidelines

Together for Short Lives (TfSL) supports over 50,000 children living with life-limiting conditions and families in the UK. Working closely with TfSL, the qualitative component of The Big Study [R1-3, G2] led by Coad was, according to TfSL Director of Research, 'pivotal in...highlighting the voices of children and their families', providing evidence 'incorporated throughout the work of TfSL', informing palliative care services, and underpinning advice and support offered [S1]. The research also provided 'credible evidence' which 'added weight' to calls for additional funding to develop provision, and informed 'the breadth' of their lobbying work' [S1].

As 'one of the most robust studies... in children's palliative care', its evidence on needs assessment was used to inform the key TfSL publications 'Guide to the Development of Children's Palliative Care Services' and 'Core Care Pathway for Children with Life-limiting and Life-threatening Conditions' [S1, 2]. These continued to be used across the UK by 'a range of providers in hospitals, hospices and community'; the latter 'has been translated and adapted for use' by the International Children's Palliative Care Network, who use it as a 'key tool' in 'countries where children's palliative care is less developed (Africa, Portugal, Norway, Hungary and the Crimea)' [S1].

In 2016 NICE referenced the research in their 'Guidelines on End of Life Care for Infants and CYP' [S1; S3, p.66-68], directly informing guidance concerning effective, timely, and honest provision of information for patients and parents. The document also used the Big Study's identification of significant unmet psychological needs of CYP and carers to justify their recommendation for further research on emotional support in this area [S3, p.258-59].

At a regional level, the NHS Clinical Commissioning Groups for Birmingham (with over 49,000 CYP with life-limiting conditions) used Strand 2 of the Big Study in their published strategy for

## Impact case study (REF3)

developing CYP palliative and end of life services in the region, produced July 2016 [S4]. The strategy drew on CU's work to advocate for 'co-ordinated healthcare, with the option of...care being delivered in the home' and for the centring of CYP and families' wishes regarding needs within service provision, and continues to underpin individual CCG operational planning [S4].

Following research on blended diets (2012-17), the CU team led two national workshops and a number of stakeholder consultations including the British Dietetic Association and British Association of Parenteral and Enteral Nutrition. Having previously firmly recommended against the practice, as a result TfSL and a number of NHS Trusts (including Leicestershire, Isle of Wight, and Torbay and South Devon) shifted policies to better support those wishing to follow blended diets [S5]. In November 2019 the British Dietetic Association released a policy statement with new recommendations for a 'shared decision-making approach' to blended diets, informed by Coad's research [S6].

### Changing practice in specialist services

Every year approximately 2,500 UK 16-24-year olds are diagnosed with cancer. In 2014 Coad and team led an evaluation for a Teenage Cancer Trust (TCT) pilot, aiming to bridge a gap in CYP cancer support by providing specialist nurses to work alongside existing treatment teams [R6, S7]. The 'innovative...pilot and evaluation' won the Nursing Times' inaugural Prince of Wales Award for Integrated Approaches to Care in 2015 [S7]. The evaluation was embedded in TCT's 2016 Blueprint of Care [S7], providing the research base for them to advocate for this specialist nursing provision internally, within the NHS, and funders [S7]. As a result, TCT was able to expand its specialist nursing provision from the North-West pilot, increasing from four nurses to 64 by 2018 to support all of young people with cancer in the UK [S7].

### Giving voice

WellChild is a national charity dedicated to enabling children to be cared for at home via a dedicated nurse network. From 2013 to 2015 Coad evaluated their specialist nursing provision, the recommendations led the charity to shift focus to 'the families' perspective' [S8]. The caring role of families 'had previously been underestimated' by WellChild, so nurses began to focus on training families, allowing 'more children to leave hospital and be cared at home' [S8]. This developed into a 'UK-wide training summit' in 2015, supported by NHS England, and new family training principles were launched by WellChild in 2018 [S8].

The evaluation focused attention on the 24/7 nature of caring for CYP with palliative and complex care needs, which led to the launch of '#notanursebut', a parent-driven campaign to highlight the realities of life for these families and identify gaps in support [S8, 9]. The project also informed the development of the WellChild Family Tree network, launched in 2014: a free-to-join, peer-support network which by 2020 had grown to support over 2500 families across the UK. As one parent testifies, through the network 'You are never alone. There will always be someone else in the WellChild Family tree to offer advice and support' [S9].

## **5. Sources to corroborate the impact** (indicative maximum of 10 references)

---

S1. Testimonial. Director of Research & Programmes, Together for Short Lives.

S2. Collated Guidance, Together for Short Lives. 'Guide to the Development of Children's Palliative Care Services', 4th Edition, 2018; 'Core Care Pathway for Children with Life-limiting and Life-threatening Conditions', 3rd Edition, 2013.

S3. Guidance. 'End of life care for infants, children and young people with life-limiting conditions: planning and management'. National Institute for Health and Care Excellence, December 2016.

S4. Collated documents relating to 'Ambitions for Palliative and End of Life Care for Children and Young People: A Strategy for Birmingham', 2016.

S5. Collated document. Blended Diets - Updated Nutritional Guidelines. Together for Short Lives (November 2019); Leicestershire Partnership NHS Trust. (October 2017); Isle of Wight NHS Trust. (August 2017); Torbay and South Devon NHS Foundation Trust. (March 2017).

S6. Policy Statement. 'The Use of Blended Diet with Enteral Feeding Tubes'. British Dietetic Association, November 2019. <<https://www.bda.uk.com/resource/the-use-of-blended-diet-with-enteral-feeding-tubes.html>> [Accessed 26.02.21]

S7. Collated documents. Testimonial, Former Head of Nursing and Quality, Teenage Cancer Trust; TCT Blueprint of Care (December 2016).

S8. Collated documents. Testimonial, Director of Programmes, WellChild; Guidance Document. '11 Principles for Better Training'. WellChild (2018).

S9. Collated resources on campaigns, WellChild Website.