

CLIC SARGENT CHILDREN'S KEY WORKER SERVICE EVALUATION PROJECT

In 2010 CLIC Sargent proposed a UK-wide project to help the NHS understand and implement the specialist nurse key worker model of care, recommended in NICE Guidance¹ and CLIC Sargent's *More than my illness*² report, with an independent evaluation to test the model and evaluate service user outcomes.

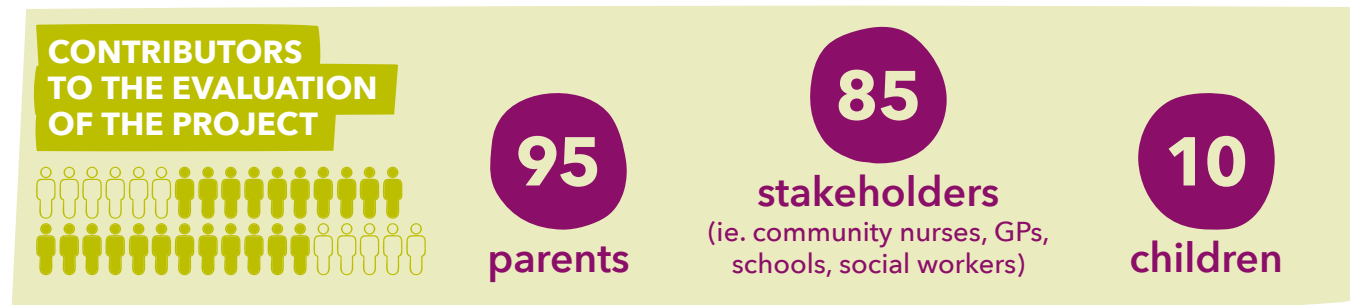
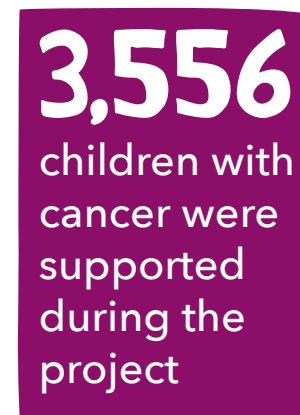
1. National Institute for Health and Clinical Excellence (NICE). Improving Outcome Guidance for Children and Young People with Cancer; 2005.

2. CLIC Sargent. More Than My Illness: delivering quality care for children with cancer. Report; 2009.

THE PROJECT








THE KEY WORKER PROJECT RAN FROM OCTOBER 2011 TO MARCH 2015



FINDINGS AND LEARNING

The evaluation demonstrates that the specialist key worker role can and, when it works well, does achieve the following outcomes:

-  Improvement in the child and family's experience of their care and treatment
-  Improved emotional wellbeing
-  Families are able to spend more time at home, and children with cancer can be cared for closer to home
-  Children are better able to participate in education
-  Best practice and learning is adopted by local hospital teams.

KEY WORKING EFFECTIVENESS IS BUILT ON THREE PILLARS:

A BETTER QUALITY FAMILY EXPERIENCE CAN BE ASSURED

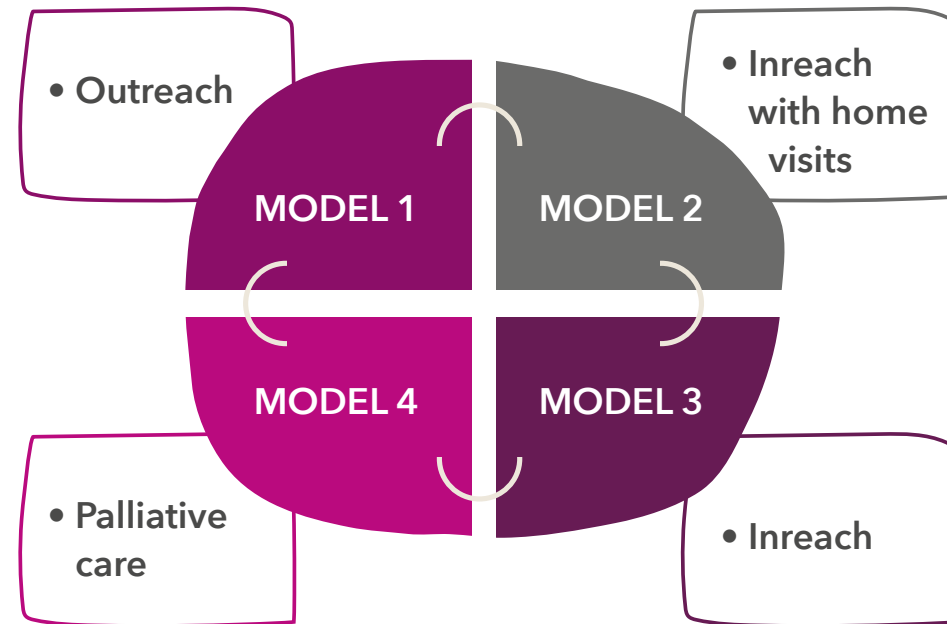
KNOWLEDGE

RELATIONSHIP

COORDINATION

When these three pillars are in place and the role is embedded in the children's cancer multi-disciplinary team (MDT), and is understood and supported, the key worker can make a better contribution to achieving these outcomes for children with cancer and their families.

"My key worker makes my life easier and explain things to make me feel less worried, less scared."



Key workers developed their role within a continuum of inreach and outreach (models 1-3). Model 4 only applied to palliative care where the model adjusts to accommodate families' additional needs.

The key worker role works best when matched to family and service need; variations in model delivery should be welcomed.

1,745

episodes of care given in school during the project

RELATIONSHIP

Value of the relationship between the key worker and the family over a period of time enabled **trust** to grow, scaffolding information over time, and helped families to feel they were supported by someone who knew them. The relationship between the key worker and other health, social care and education professionals was identified as being able to facilitate greater understanding and clarification of roles, and ensured the child and family had the **right support at the right time**.

KNOWLEDGE

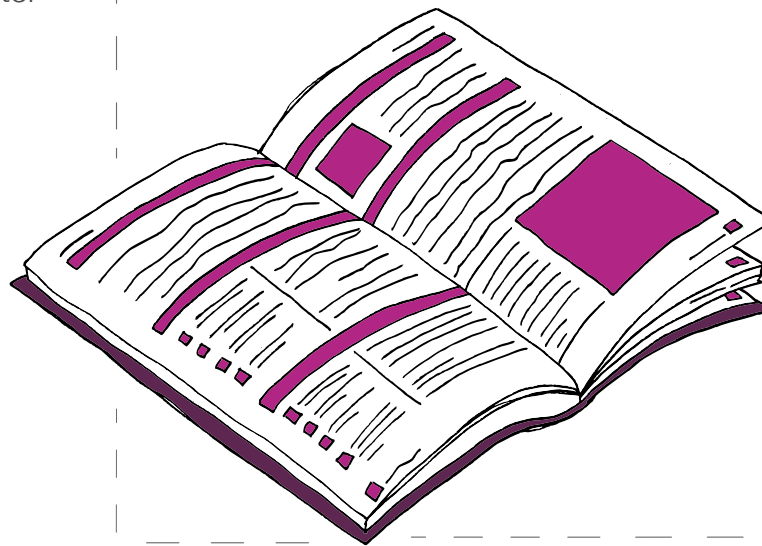
The key worker was a specialist nurse with knowledge, experience and expertise in childhood cancer that led to a higher standard of care, and helped families have the **confidence to care for their child** at home.

COORDINATION

The key worker was a main point of contact for a family and supported a seamless service between specialised hospital services, community care and home, enabling families to navigate the system.

IN CONTRAST

In some circumstances there were also **challenges** to the role working well. The synergistic effect of the three pillars resulted in positive outcomes; if anything was missing or limited the experience of the family was diminished.



"A stunning piece of work putting children with cancer and their families at the very heart of the project."

J Whittome NHS-IQ August 2015

7,417

key worker home visits undertaken during the project

"The key worker understood us as a family (...) it's such a personal time and it's such an intense time."

Parents, children, key workers and stakeholders (health, social care and educational professionals) shared their views about the core responsibilities and roles of a specialist nurse key worker.

The key worker project was created and delivered by CLIC Sargent and independently evaluated by Professor Faith Gibson, Dr Ana Martins, Dr Rachel Taylor and Mrs Susie Aldiss from London South Bank University. The project was funded by Tesco's Charity of the Year partnership in 2010 and the evaluation was funded by the former Department of Health National Cancer Action Team.

London South Bank University

Children & Young People Now Awards 2015
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