

Table 3: Chameleon Illustrative Case Studies

Setting	Before Chameleon Project	During Chameleon Project
PICU	<p>Female infant, born 2 months preterm with a major congenital abnormality which at first seemed amenable to surgical correction. She had two surgical repairs but remained ventilator dependent and developed chronic lung disease.</p> <p>She was ventilated for 3 months on the neonatal intensive care unit and then was transferred to the paediatric intensive care unit where she was ventilated for another 4 months. She had life threatening complications and despite continuing intensive care she deteriorated and died at 7 months of age on PICU.</p>	<p>Male infant, born 2 months preterm in 2018 with a major congenital abnormality. The surgeons were initially hopeful that this could be corrected if he could be kept alive and if he could grow bigger. He was ventilated on the neonatal intensive care unit for three months and then transferred to the paediatric intensive care unit.</p> <p>He was having recurrent life-threatening deteriorations and discussions with parents regarding personalised care planning and parallel planning were led by the Chameleon team. After 2 weeks his parents and the medical team agreed that it was in his best interests to stop the ventilation and he died on the unit at 4 months of age.</p>
PICU Bed days	134	17
Actual Costs	£238,536	£30,567
Oncology	A 6-year-old male was diagnosed with a diffuse brain tumour, of a type that is universally fatal. The tumour progressed on treatment. He was admitted for investigations and supportive care for his deterioration	A 5-year-old female was diagnosed with diffuse brain tumour. Her oncologist held early discussions with the family about the nature of her illness and that this was incurable.

	<p>and his parents then did not want to leave the hospital. There were a number of attempts to introduce the idea of hospice or home care, but they did not want this. Partly this stemmed from not being able to accept that his disease was not treatable.</p> <p>The child deteriorated to the extent that he lost all ability to communicate, eat and drink and was lying passively in bed, with fluid and nutrition via nasogastric tube. His parents were reluctant to stop this as they felt he may suffer. A number of tests and opinions were sought to assess what brain function remained. Hospice and home were introduced again but declined. He had a long inpatient stay on the oncology ward in the children's hospital for 4 months.</p> <p>After death, he and his family were transferred to the cold room at the hospice. Parents expressed regret at not having been to the hospice before he died.</p>	<p>As her diagnosis was known to be life-limiting she was highlighted to the Chameleon team. When she had a deterioration the Chameleon champion oncologist was able to have end of life care discussions with the family including the benefits of hospice care. A personalised care and resuscitation plan was documented with the help of the Chameleon team, who also helped to arrange her transfer to the hospice within 48 hours of her emergency admission. Her symptoms were brought under better control, and she remained at the hospice, with some days at home, until her death 4 months later.</p> <p>She had many good experiences during her last months, including swimming in the hospice pool and regular visits to the garden. The environment was also much better for her family to visit. Because of the advanced care planning it was possible to make arrangements for research donation of her organs, which was some comfort to the family.</p>
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DGH	<p>A male infant was born with multiple congenital abnormalities including a severe congenital cardiac defect which was confirmed to be inoperable shortly after birth. The baby spent 13 days on the neonatal unit of the DGH where he was assessed by several different teams. The parents were told that his prognosis was likely death in the first 12 months of life and he went home with a follow up appointment in the general paediatric clinic and support from the community nurses for nasogastric tube feeding. Referral to the hospice was offered but the parents felt it was too far away from home. The community nursing team were not able to offer face to face support for end of life care at home outside normal working hours, but did provide regular home visits for practical and emotional support. He was admitted to the general paediatric ward six times for a total of 76 days before he died as an inpatient at seven months of age. Post death care was provided by the community nurses.</p>	<p>Female infant was found to have a lethal congenital abnormality antenatally. Her parents were counselled about the poor prognosis and that she was most likely to die at the time of birth or soon after. She breathed at birth and was nursed in the birthing unit overnight with expectations that she would not survive, however she remained stable and the Chameleon team were asked to support her paediatrician to discuss discharge home and ongoing palliative / end of life care.</p> <p>The project DGH paediatrician met with parents to make the resuscitation plan, organise end of life support and prescribe medication (morphine and midazolam) to take home. She liaised with the local community nursing team who were unable to provide face to face home support over the weekend. The hospice team were contacted by the project DGH paediatrician and they provided outreach support to the home and support with memory making.</p> <p>The project DGH paediatrician worked with the children's community nurse to provide nursing and paediatrician home visits during the next weeks. Advice</p>
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		<p>was provided by the project lead paediatrician regarding anticipatory symptom management plans.</p> <p>The baby deteriorated at home and the choice of place of death was revisited. Her parents wished to stay at home with telephone support from the project DGH paediatrician and the community nurse. No face to face children's community nursing service was available outside normal working hours. When she was dying her parents chose to bring her in to the ward where the project DGH paediatrician provided the medical care. Her parents remained with her after death overnight in the parents' suite, using a cool cot obtained from the maternity unit. Post death care was provided by the community nurse.</p>
NICU bed days	13	0
DGH bed days	76	1
Estimated costs	£ 44,960 £1,120 /day on NICU £30,400 £400 /day on ward £14,560	£400