



THE DONNA LOUISE CHILDREN'S HOSPICE TRUST QUALITY ACCOUNTS 2013 – 2014

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"The quality of the service is excellent" and, "I have been made to feel welcome here. Every time I visit the nurses give me an update of what has been going on so I am up to date with everything".

Welcome to our Quality Accounts 2014/15.

In our first Quality Account document last year, we set out our priorities for quality improvement for 2013/14. These priorities are reviewed against our performance in this document. During the past 12 months, the hospice has continued to provide a high quality service and remains financially sound. We have achieved this by providing high quality, cost – effective services to our service users and their families.

We have ambitious plans to extend our services – and these are set out as new priorities for 2014/15.

The Chief Executive and senior management team have been closely involved in this review and in developing these priorities which have been ratified by the Board of Trustees and we support our aspirations through a robust clinical and corporate governance framework. This enables us to seek continuous development locally, as well as responding effectively to national changes.

Our regulators the Care Quality Commission (CQC) have made one unannounced visit and inspected the hospice during 2013, with no compliance issues identified. The hospice was fortunate to receive a substantial grant from the Department of Health during the year to enable our facilities to be revitalised after 10 years continuous use.

Equally, we pride ourselves on developing a culture of continuous quality monitoring, in which any shortfalls are identified and acted upon quickly. The Donna Louise Children’s Hospice is committed to finding ways to improve the services we provide to our service users and their families and the way in which these services are delivered, including our physical environment.

To the best of my knowledge, the information reported in this Quality Account is an accurate and a fair representation of the quality of services provided by our organisation. The safety, experience and outcomes for all our children, Young people and families remain of paramount importance to us and our driving goal. With that in mind, we will continue to actively seek the views of our service users and to engage fully with professionals and partner organisations.

Mike McDonald

Chief Executive

VISION

To be a centre of excellence for children and young people's palliative care.

MISSION

To provide a quality palliative care service to children, young people and their families through effective partnership working aligned with our values.

Paediatric Palliative care is a complete approach to treating serious illness that focuses on the physical, psychological and spiritual needs of the child. Its goal is to achieve the best quality of life available to the child or young person by relieving suffering and controlling pain and symptoms

VALUES

Respect – we foster a culture of respect and maintain the environment of team work, growth and diversity

Excellence – we strive to be efficient, effective and innovative, giving our best with passion and consistency and continually searching for ways to do things better

Integrity – we are ethical, professional, honest and accountable in our approach to everything we do

Openness – we encourage an open and transparent culture which fosters trust, collaboration, continual learning and community spirit

Fairness – we endeavour to provide a balanced approach at all times which is equitable and non-discriminatory

Enablement – we support and empower our children, families, staff and volunteers to have a say in the way our services are delivered and to influence the future direction of the organisation.

**THE DONNA LOUISE TRUST – EXPECTED BEHAVIOURS AND
ATTITUDES**

In conjunction with the values of the organisation all staff working in the care department will.....

- Be willing to do things differently, try new things.
- Be solution focused, focusing on 'how we can' as opposed to 'why we cannot'
- Be proactive
- Show initiative
- Be challenging and comfortable being challenged
- Be willing to actively engage in personal development opportunities
- Be motivated to be the best you can be
- Take personal responsibility for actions.
- Have a positive attitude towards the team, the department and the trust. If at any time this is not the case, individuals will take personal responsibility for discussing this with their team leader, or a senior member of staff, in a solution focused manner.

Section 1: Priorities for Improvement and statements of Assurance from the Board

In November 2013, the hospice was inspected against the Essential Standards of Quality and Safety by the Care Quality Commission (CQC).

All the standards inspected against were found to have been met.

The CQC has categorised the hospice as a low risk organisation.

In developing the strategic plan for the hospice, particular attention was paid to the rapidly changing health and social care environment, the changing needs of the population and our drive to be fit for purpose and to continue to deliver excellence in these changing times. The Board looked at how the hospice could continue to improve its services and also extend its services to meet the needs of the local population, enabling people to receive care in the place of their choice.

Following consultation with the staff and using feedback from the Family Survey and the Parent Forum the DLCHT confirmed the top seven quality improvement priorities for 2014 to 2015 to be as follows:

Improvement area 1

To implement a care co-ordination service that will :

1. Improve and increase care co-ordination, family liaison and support through the use of a named individual to act as the family care co-ordinator.
2. Work with children and families to identify the outcomes that they would like from services
3. To support families to access services that will enable them
4. to meet their identified outcomes
5. Act as the single point of contact for families

This will be achieved through:

- The review, redesign and restructure of internal resources
- The development of promotional materials for families and professionals
- The development and implementation of a new outcomes based assessment tool

Improvement area 2.

To establish and implement a real time electronic patient documentation system that will enable patient records to be accessed and updated in any care setting, ensuring that care staff have access to the child's records in all places where the child and family are cared for.

This improvement project will address the following challenges and opportunities:

Challenges

1. The Trust is not yet using the functions and capability of the system to its full capacity
2. A strong reliance on the use of paper patient documentation.
3. Limited storage space and opportunities
4. Limited access to real time records and documentation in any setting
5. Lack of confidence in staff to adopt electronic ways of working

Opportunities

1. Full use of functions on Chase Database System
2. Reduce organisational risk around storage of personal information, information sharing / data protection
3. Reduce need for future storage to archive child and family records
4. Access to real time records and documentation in any setting
5. To engage all care team staff in adopting new more efficient ways of working

This will be achieved through:

- Review and re allocation of internal resources to identify a project lead
- The creation of a project brief, risk assessment and other project documentation
- Creation of a project group – with relevant representation from areas affected
- Staff training
- Development of standard operating procedures and training materials
- Review and investment in current IT infrastructure to ensure systems are fit for purpose

Improvement area 3

Implement an effective booking system to enable a more proactive approach to bed management and allocation of care.

This will be achieved through;

1. Review of current system, identifying the strengths and weaknesses of the current system.
2. Liaison with families in relation to preferred approaches to booking short breaks proactively
3. Review of systems used by other hospices and similar organisations
4. Design and development of the new DLT booking system
5. Implementation of the new system
6. Piloting of the new system
7. Informing families' of the new system

Improvement area 4

Implement and evaluate the role of Senior Care Worker Role, following feasibility study in 2013.

This will be achieved through:

- The development and implementation of a 6 month development programme with identified learning outcomes, competencies and objectives.
- Internal recruitment of 4 care support workers to undertake the development programme
- Evaluation of the programme in autumn 2014

Improvement area 5

To employ a sessional children' physiotherapist

Evidence from the Care Needs analysis and Training Needs analysis identified that between 95-98% of children and young people served by DLT have a range of physical care needs that would benefit from physiotherapy interventions. The contribution of specialist knowledge and skills of an experienced physiotherapist would improve the quality of care that we are able to provide and improve the outcomes for children and young people.

This will be achieved through;

- The development of a job description & person specification
- The establishment of a partnership with the local children's community physiotherapist department to develop a Service level agreement for the provision of a sessional physiotherapist

Improvement Area 6

To recruit a medical lead for the Trust

The Trust needs to consider the future medical support needs of the organisation in order to plan for future service delivery and for succession planning should our current Medical Officer step down.

The option DLCHT would like to proceed with is the development of a team of medical staff contributing through sessional work to provide appropriate cover and medical expertise.

The suggested make up of this team would be 2 GP's and 2 Paediatricians.

In order to proceed with this DLCHT are looking to work in partnership with local Trusts and GP's to identify:

- (a) potential for shared investment in recruitment and development of a paediatric palliative care consultant or a paediatrician with a special interest in paediatric palliative care.
- (b) Purchasing, through a service level agreement, an identified number of sessions of paediatric support
- (c) Potential GP's interested in developing skills and expertise in Children's Palliative Care

In order to achieve the above we will:

- Develop a Job description, person specification and work plan
- Meet and discuss possible opportunities for shared posts with UHNS and other potential partners
- Raise awareness of the opportunity at children's palliative care networks regionally and nationally

Improvement Area 7

To co-opt a current parent representative onto the Clinical Governance and Care Development Committee.

In order to improve service user engagement and participation in the work of the Trust, the Board of Trustees have agreed to support the addition of a Parent Trustee to the Clinical Governance and Care Development Committee.

This will be achieved through:

- Development of a Parent Trustee role profile
- Advertisement of the vacancy to all current families through use of social media, website, parent information boards, Parent Forum, and support groups.
- The pro-active work and support of the Director of Care in liaising with potential parents who are expressing an interest in the role

Progress against the improvement priorities identified in 2012-2013

Throughout 2012-2013, the hospice had a number of initiatives to enable it to offer a more comprehensive service to the population served, whilst remaining within the limitations of the financial constraints at that time. All plans for improvement were identified at the annual care development planning workshop. In identifying the areas for inclusion in the development programme for 2013- 2014 we considered the following:

1. What is working / has worked and what has not worked so well?
2. How do we want our families to experience our services?
3. How do we want our staff to be?
4. What areas for improvement can we identify
5. What service developments would you like to see? What service do we want to be offering?
6. Are we using our staff/ resources in the best possible way to provide the maximum service at an acceptable quality?
7. What do we want to have achieved as a department by end of 2013-14?

Inevitably, progress against the quality improvement priorities for 2012-2013 was influenced by financial constraints of the charity and changes to the external environment. Progress is discussed below.

Improvement Area 1

To improve the standard/ quality of care team documentation and record keeping.

The following key milestones have been achieved in this piece of work

1. Development and implementation of Record Keeping competency for all care staff to complete
2. Production of a guideline on completing and maintaining accurate care documentation
3. Production of a template/ exemplar set of care documents
4. Review of current care documentation in use to assess if it is fit for purpose
5. Audits undertaken of 2 documents contained within the care team documentation – (1) manual handling assessment and care plan and (2) care plans

There are ongoing documentation audits planned for 2014-15

Improvement area 2

Develop and implement a robust set of Nursing/ Care procedures and /or guidelines

There is now a robust set of care policies, procedures and guidelines in place with a Donna Louise template for policies, procedures and guidelines. This piece of work is ongoing as all care documents have to be reviewed and updated regularly to maintain the evidence based approach. However, there is now a system in place for the continuous monitoring and maintenance of these documents.

This was achieved through the following:

1. The current list of policies, procedures and guidelines was reviewed and updated
2. Each policy, procedure or guideline to be written or reviewed and updated has been allocated to a member of the care team.
3. Each new policy was ratified via Clinical Governance committee.
4. All new procedures and guidelines are checked and ratified by Director of Care
5. All completed documents are saved electronically in central resource and a paper copy of each will be kept on file in Care Team Office

Improvement area 3

Implement mechanisms to support effective transition of young people from our care at age of 19.

A framework including a policy and procedure for transition planning and discharge was developed, piloted and implemented, teaching to the care team on this process and the wider issues of transition was delivered in care team training programme.

Team leaders have objectives to be achieved around transition planning for those young people on their caseload.

Due to staffing issues this became a lower priority and has not yet been embedded as well as the team would like. Therefore, it continues to be on the care development improvement plan for 2014 -15.

The team have made progress in contacting and liaising with schools in relation to transition assessment and planning. The team awareness is much higher.

Improvement Area 4

Feasibility study onto the development of Senior Care Worker Role

This project received full support from the Clinical Governance and Care Development Committee and is currently live with 4 candidates selected internally to be the first to undertake the Senior Care Support Worker development programme.

During 2013 the following were undertaken;

1. An analysis of the skills currently available within the care department
2. Identification of any gaps in skills and experience
3. Identification of current or potential problems that would be solved through the development of a Senior Care Support Worker Role, or improvements that will be made.
4. A full analysis was made of all the above information to enable an informed decision to be made.
5. A report summarising above, with recommendations was provided to Clinical Governance in order to inform the decision to progress or not.

Improvement Area 5

Refurbishment and update of the environment

As a result of securing funding from the Department of Health Capital Appeals Bid we were able to embark upon an extensive building refurbishment and modernisation programme. The aim of the project was to make the building fit for purpose for the next decade, improve the sensory facilities; improve the child/ family friendly focus of the building; improve the therapeutic benefits of the building through improved use of lighting.

This was a large two phase project which absorbed a lot of the Chief Executive and the Director of Care's time during 2013 and which required a huge amount of teamwork and flexibility by everybody concerned, especially as we remained open to care throughout the refurbishment.

The result is a brighter more modern house which has been upgraded and is fit for purpose for the next decade, enabling the trust to focus its funds on the delivery and improvement and expansion of services as opposed to building development and maintenance.

In addition to those improvements listed above we also:

- Developed and Implemented an Integrated Care Team
- Improved staff knowledge, skills and competence around audit
- Reviewed, redesigned, implemented and evaluated a Clinical Supervision model
- Reviewed, redesigned and improved Mandatory training for the Care team
- Explored the possibility of employing a sessional children' physiotherapist and built the business case
- Designed a medical support model that will meet the needs of the hospice in the next 5 years

Statements of Assurance from the Board:

The following are statements that all providers must include in their Quality Account. Many of these statements are not directly applicable to specialist palliative care providers, and therefore explanations of what these statements mean are also given

Review of services

During 2013- 2014 the hospice provided the following services to NHS patients :

- In- patient services
- Day care services
- Community services
- Counselling and psychological support services

The hospice has reviewed all the data available to us on the quality of care in these services.

The DLCHT Clinical Governance and Care Development Committee receive regular reports, which enable them to review both the quality and quantity of care provided by all clinical services. A report on all clinical incidents, including medication errors and accidents is provided annually.

All services delivered by the Hospice are funded through a combination of fundraising activity and contracts with NHS. The NHS contracts mean that all services delivered by the hospice are part funded by the NHS. Where NHS funding is secured this only partially contributes to the costs of clinical care of children. The cost of provision of a holistic family focused service are borne by the charity through fundraising activity, for example, counselling and emotional support, Play and recreational Services, Music specialist; Family accommodation; hospitality, bereavement care; on-going supplies and provisions; costs of maintaining the house and gardens are all reliant upon fundraising/ charitable income.

Participation in National audits

During 2013 the hospice was ineligible to participate in the national clinical audit and national confidential enquiries. This is because there were no audits or enquiries relating specifically to specialist palliative care in 2013/14

Research

The number of patients receiving NHS services provided or subcontracted by the hospice in 2012 that were recruited during that period to participate in research approved by research this committee was **0**.

Quality improvement and innovation goals agreed with our commissioners

A proportion of hospice income in 2013 was conditional on achieving quality improvement and innovation goals (CQUIN) agreed between the hospice and any person or body they entered into a contract, agreement or arrangement with for the provision of NHS services, through Commissioning for Quality and Innovation payment framework. Only one CCG included a CQUIN in their 2013 contract.

The goals and indicators for the hospice identified by the CQUIN were as follows:

How likely is it that you would recommend this service to someone with a similar need?

We sought feedback from families/ parents through our family feedback survey for 2013 when we received the CQUIN. We received feedback from 40 families out of a caseload of 173 and got 100% extremely likely response.

What others say about us:

The hospice is required to register with the Care Quality Commission (CQC) and its current registration status is unconditional. The hospice has no conditions on registration. The CQC has not taken any enforcement action against the hospice during 2013- 14.

The hospice has no actions to take and no points were made in the CQC's assessment. The hospice was fully compliant and rated as low risk.

The hospice has not participated in any special reviews or investigations by the CQC during 2012.

Data Quality

The hospice did not submit records during 2013 to the Secondary Users Service for inclusion in the hospital episode statistics which are included in the latest published data. This is because the hospice is not eligible to participate in this scheme.

DLCHT collects and submits the following data:

- Internal activity/ performance data
- Submits annual data to Together for Short Lives
- Submits annual data to the National Child Health Mapping Project
- Child death data to Child Death Overview Panel

Clinical Coding Error Rate

The hospice was not subject to the Payment by Results clinical coding audit during 2013-14 by the Audit Commission.

Part 3: Review of Quality Performance

Total number of current open cases	198
Total Cases Open during 12- 13	173
No of families actually supported	133
Number of new patients	29
Number of referrals made – % accepted, % declined	Referrals received 41 Accepted - 29 (71%) Declined – 6 (15%) 1 child died before panel Outstanding – 5 (12%)
No of Bed nights Available (based on 5 beds)	1572
No of Bed Nights Taken	1417 (90%)
Number discharged from care	15
Number in transition (aged 16- 19)	10
Number of day care episodes	341

No of youth group support sessions delivered	58 episodes of youth support via 10 youth group meetings
No of siblings supported through sibling group	23 via 3 sibling group sessions
No of families attending stay and play sessions	35
Number of episodes of care in community	90
Number of episodes of end of life care	1
Number of nights provided	22
Number of complaints requiring further investigation and response	1
Garden Room Number of Nights/Cases	20 (3 Cases - 2 known to DLT 1 not previously known)

Local quality measures

In addition the national dataset for palliative care, the following measures reflect our performance.

Referrals

There has been a slight decrease of 8.6% in referrals during 2013- 2014 on 2012-2013

Our participation in clinical audits

To ensure that the hospice is providing a consistently high quality service, we undertake our own clinical audits, using national audit tools, where available, developed specifically for hospices, which have been peer reviewed and quality assessed. This allows us to monitor the quality of care being provided in a systematic way and creates a framework by which we can review this information and make improvements where needed.

Each year the Clinical Governance Committee approves the audit schedule for the coming year. Priorities are selected in accordance with what is required by our regulators and any areas where a formal audit would inform the risk management processes within the hospice.

Through the Clinical Governance report, the Board of Trustees is kept fully informed about the audit results and any identified shortfalls. Through this process, the Board has received an assurance of the quality of the services provided.

The following audits were completed between 1st April 2013 and 31st March 2014.

Clinical Audit	Outcome
Annual audit of clinical Incidents	<i>No actions required</i>
Twice yearly audit of Medication errors	<p><i>Medicines Management policy and procedures reviewed and re-written to reflect the outcome of the audit.</i></p> <p><i>Annual drugs calculation test for all Nurses introduced</i></p> <p><i>Reflective logs introduced for those nurses involved in medication errors</i></p> <p><i>Medicine Administration chart to be reviewed in 2014</i></p>
Infection control: Code of Practice	<i>Minor areas of shortfall identified. Action plan implemented to remedy any areas not meeting required standard</i>
Staff attendance at mandatory training	<i>Some areas identified to be addressed specifically, these are completion of annual safeguarding and basic life support training. These are currently being addressed/ have now been addressed.</i>
Record Keeping Audit	<i>Some areas of improvement identified. Action Plan developed to be implemented during 2013 in response and will be re-audited in 2014</i>
Mobility assessment form audit	<p><i>Some areas of the form not completed</i></p> <p><i>Some areas of improvement identified. Action Plan developed to be implemented during 2013 in response and re-audited in 2014</i></p>

Quality Metrics/ Quality Markers we have chosen to measure

Patient Safety

<p>Number of incidents/accidents, including medication, clinical and health and safety (patient safety) related incidents</p>	<p>Total number of accidents recorded = 12 Total number of incidents, both clinical and non-clinical = 44 Total clinical incidents = 19 4 Red rated incident- safeguarding, care 23 Amber rated incidents 13 Green rated incidents Total medication related incidents = 26 Total non-clinical incidents =25</p>
<p>Number of reportable (to local safeguarding services) safeguarding incidents occurring in the organisation</p>	<p>1</p>
<p>Infection Prevention and Control rates:</p> <ul style="list-style-type: none"> ➤ Total number of children admitted with known infection ➤ Total number of children developing infection at hospice 	<p>0 0</p>

Clinical Effectiveness

Please see section on local audits.

Patient Experience

An annual Family survey is undertaken to secure feedback on the quality and range of services provided by the hospice. A summary of last year's results can be found in appendix A. In 2013 the annual survey was offered to families as an on-line survey using Survey Monkey or as a booked telephone interview using the same questionnaire as the on-line version over the telephone. We recruit and train volunteers to undertake the telephone survey in order to maintain the independence and the integrity of the survey as best we can. An example of the type of questions asked is below:

How satisfied are you with the support you and your family receive from the following

Extract from Family Survey via Survey Monkey -2013

	<i>Very satisfied</i>	<i>Satisfied</i>	<i>Dissatisfied</i>	<i>Not applicable</i>	<i>Total respondents</i>
In house stays	84%	10.3%	5%	2.5%	39
Day care	79%	15%	0%	39%	40
Home Support	78%	10%	0%	55%	40
Counselling and emotional support	77%	14%	0%	42.1%	38
Activities and groups	69%	18.5%	2.6%	32%	38

In addition to the annual survey we are keen to secure on-going feedback from children, young people and families. To enable this we have put up a number of feedback/comment boxes with comment cards to encourage all family members and visitors to let us know what they think of our services and what changes they would like to see. Between July 2013 and end of March 2014 we received 10 completed comments cards with a range of suggestions including suggestions to invest in family bedroom improvements and specific pieces of equipment to make children's stays better including seating and specific games for visually impaired children.

In order to involve children and families in the proposed Playground improvement plan we created a display for children to vote on their favourite pieces of playground equipment using stickers. We encouraged all families to engage with this when they were visiting or staying and the staff encouraged the children they were caring for to vote. The results of this voting by stickers engagement will be used to inform the design and development of the playground in 2014.

"I really don't know where we would be without the love and support we receive from the hospice.

Our journey has been a struggle, but now we have the hospice to give us new ways of coping and to help put us back on track when things go wrong."

Mum of child aged 11.

"Thank you all very much for last weekend. J, S, T and I enjoyed ourselves very much. It was so kind of the chef to bake a cake for T's birthday and we look forward to coming to Donna Louise again very soon if dates become available. All the nurses seem to know J now very well and we feel very comfortable and relaxed. A big thank-you again to you all for making the family welcome."

Mum of a recently referred family.

"We find the support invaluable and never thought we'd be so confident letting others care for our child."

Staff information and experience

As of 01.04.13 we had 68 members of staff (excluding bank staff)

By end of 31.03.14 we had 77 members of staff giving a staff turnover or separation rate of 12.4%, this is a reduction on the previous year (comparison with other children's hospices identified turnover rates between 7.2% and 25%)

In addition to the data above we collate and evaluate information from exit interviews when staff leave the organisation. No themes requiring actions to be taken by the Trust were identified through the exit interviews in 2012-13.

In 2012-13 there has been significant investment in the development and implementation of a new Individual Performance Appraisal and development system across the Trust.

The Donna Louise Trust Expected Behaviours and Attitudes was developed, discussed and shared with all staff. The first version did not have staff engagement in its development, however, staff

involvement is planned for the review and future development of this tool as this tool becomes embedded into the IPR system in 2014.