

QUALITY ACCOUNT EXECUTIVE SUMMARY

The past year at **ellenor** has been a positive one in which we have continued to work through our current strategy, while achieving and exceeding many of our goals.

As ever, patient and family experience remains key to us and every comment, however informal, has been followed up. We are proud of the many positive comments we receive from patients and family members – including ‘thank you’ cards. We have backed these up by collecting feedback from families. 86% of those that responded to a one of our recent surveys stated they are ‘satisfied’ with the support that they are currently receiving, with the remaining being mostly satisfied. Some positive comments included:

*“My life would be very difficult if I didn't have the **ellenor** team. They are always there for me either face to face or a phone call away. The **ellenor** nurses are very caring and supportive they are fantastic.”*

We are constantly working to improve the service we provide and, over the past 12 months, we have enhanced our ability to reach more people in our local community who need our support. We are also connecting with more people in different ways – including establishing outreach clinics in Swanley, Dartford and Bluewater.

We have also increased the education and training we offer to support other providers – including giving pioneering training to local ambulance crews on recognising patients at the end-of-life and training staff at local care homes to ensure better palliative care in residential homes.

*“**ellenor** have been a lifeline to us. A constant support helping fight our corner, liaising with medical professionals and*

helping with pain management. Couldn't be without you. Thank you."

We have continued to improve the care we offer to our children and young people – including our children's hospice care respite provision. We recently completed the children's service family consultation and, on the back of this, are currently piloting usage of the respite framework.

"We have nothing but wonderful things to say about the staff in the Childrens Team. They're all wonderful, caring, people who really helped us through the hardest time of our lives. So, for that, they will hold a place in our hearts forever. "

A key part of our work over the past year has been in expanding the support which we offer to carers – not just of our own patients, but of carers in our local community as a whole. This work – which has included launching both a Carers' Course and Carers' Cuppa drop-ins – is now award-winning.

Our priorities for the year ahead will see us continuing to develop our wellbeing offering – emphasising that struggling with a life threatening illness isn't all about the medical care we can provide – to developing our outreach work into our local community and providing continued support for carers.

"To the lovely nurses who came to our house and helped my mum in her final days. Thank you for supporting us and my mum. Thank you for helping us when we just didn't know what to do. You all do an amazing job."

INTRODUCTION



MISSION - To lead and coordinate the best personalised care for all ages, sharing our expertise to ensure that all families facing terminal illness get the right support in the best place possible, enabling them to make the most of the time they have.

ellenor cares 24 hours a day, 365 days a year.

ellenor cares for people of all ages – babies, children and adults.

ellenor cares for families in their place of choice.

ellenor cares for the whole family.

ellenor cares about reducing the fear and anxiety a diagnosis brings.

ellenor cares for families and is free at the point of use.

ellenor cares about life and making the most of every second.

ellenor cares for very sick children and adults at home.



1. Part 1- Quality Statement from Chief Executive

Statement

A quality account is produced to inform the public about the quality of services that are delivered. The aim of this report is to demonstrate organisational accountability, including how we review our services, demonstrate our improvement plans, and provide data on the quality of care provided.

The organisation places quality and safety of care as of the utmost importance. We have a robust and open Clinical and Corporate Governance framework in place. The Board of Trustees have ultimate responsibility for ensuring that the highest standards of care are provided. Governance is managed through a structure of sub-committees, each chaired by a Trustee, and reporting directly to the Board. This includes a Clinical Governance committee which oversees the quality and safety of all aspects of patient care. A Governance and Risk committee meets quarterly and reviews the Risk Register for increasing or high-level risks. The Trustees are provided with the information they require to carry out their responsibilities, including regular reports from the Executive Team, a Dashboard of Key Performance Indicators, and ad hoc reporting as required. The Executive Team are in attendance at the Board and Sub Committee meetings and there is regular contact between the CEO and Chair of Trustees.

All complaints and incidents are investigated thoroughly. Policy and practice are amended as required as an outcome of learning, and performance is managed accordingly.

Patient and family experience is important to us, and every comment, however informal, is followed up. We strive to do the very best we can and are grateful to those who help us identify improvements in our care. We participate in the national hospice patient survey, as well as our own internal surveys, and have a suggestion box for comments. Over the past year a more robust approach has been taken to ensure that there is a clear framework for responding to feedback, both positive and negative.

Patient safety is ensured by a comprehensive programme of staff education and support. We work on a “no blame” culture and encourage staff to feel able to identify situations they are finding difficult. This is reflected in our policy and practices, which clearly demonstrate that staff are given training and support on the importance of raising concerns about poor practice. Where areas for improvement are identified, a training and support programme will be implemented with the individual staff member concerned. A robust safeguarding framework is in place, with a nominated Safeguarding Lead. The organisation achieved the Safe Networks Standards for safeguarding children in December 2013.

All health and safety guidance is observed, audited and a report is available at the Governance and Risk committee. A qualified Health and Safety Officer is in post and adds significant expertise to the organisation.

ellenor recognises its duty under the Health and Social Care Act 2008 Regulations 2014 to act in an open and transparent way where a service user is involved in a notifiable safety incident. A 'Duty of Candour' Policy is in place.

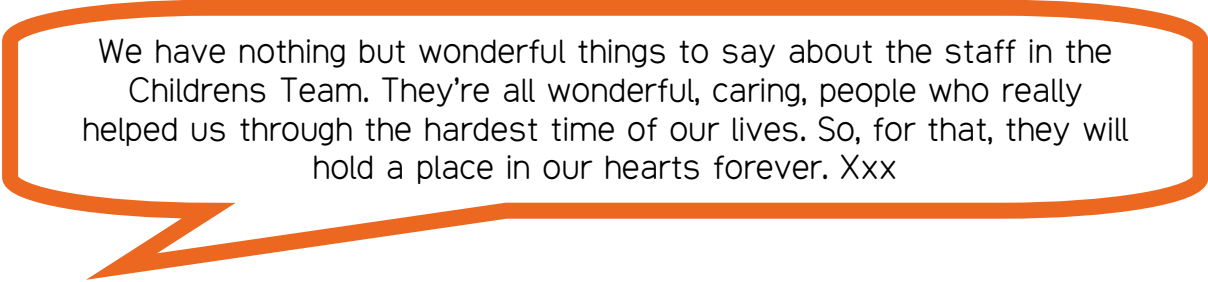
In the role of Senior Information Risk Owner, I take overall responsibility for all aspects of Information Governance. All staff and volunteers have training as part of their regular updates and there are clear policies and procedures in place to ensure high levels of data protection and confidentiality.

Clinical effectiveness is assured through the leadership of senior clinicians, including the Director of Patient Care and the Lead Consultant. National guidance and best practice are followed, and research and audit results are utilised in the continuous improvement of practice. Clinical staff have regular training and update sessions, and follow a competency based framework relevant to their role.

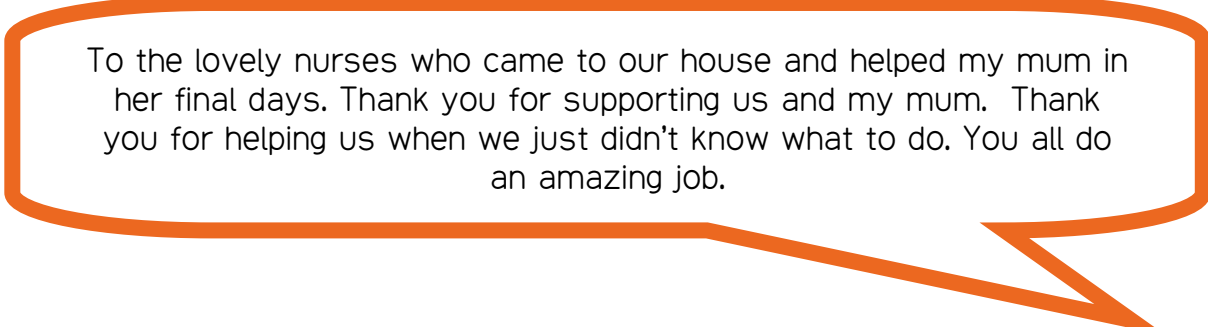
I have overseen the production of this Quality Account, in my role as Chief Executive. I commend it to you as an honest and open account of some key aspects of our work, to the best of my knowledge. An executive summary is being produced and will be available electronically for the public to access and will contain a précised version of this account.



Claire Cardy
Chief Executive
31 May 2016



We have nothing but wonderful things to say about the staff in the Childrens Team. They're all wonderful, caring, people who really helped us through the hardest time of our lives. So, for that, they will hold a place in our hearts forever. Xxx



To the lovely nurses who came to our house and helped my mum in her final days. Thank you for supporting us and my mum. Thank you for helping us when we just didn't know what to do. You all do an amazing job.

2. Part 2- Priorities for Improvement

I. Priorities from 2015-2016

We are nearing the latter part of our current strategy, which runs from 2013 to 2018, and our key aims are to enhance our ability to reach more people who need our support. We will continue to develop services for patients and families by using innovative approaches and new ways of working to ensure we respond to changing needs and can reach more people in different ways, e.g. by developing more volunteer-led initiatives, working with other organisations and increasing the education and training we offer to support other providers.

The following were the three improvement priorities for 2015/16 and related directly to our organisational strategy and strategic objectives. Priorities for this coming year are below these.

15/16 Priority 1- Reach more people in our area

We needed to continue to reach out to and ensure expert care was provided for anyone who needed it, in the place of their choice, when they need it, to ensure they were able to achieve their preferences of care. Our strategy recognised that we did not care for as many of our local population at the end of life as we could. Our services had previously been more specialist and local people were dying without the support they needed.

We were also advised by members of the public and other stakeholders that our messaging was confusing, as well as much confusion in how to access our services or their entitlement to access the services. Through our re-branding and clearer message, we are working on minimising confusion of the services and areas we cover. Our 'one point of referral' triage service that was piloted and implemented from early 2015 has assisted in a reduction of declined referrals and increased self referrals drastically. We are designing a number of services to meet the needs of patients with different conditions as well as targeting GPs to increase referrals, following our 'planning for change' pilot. We continue to operate our out of hour's advice line and this remains part of our priority in reaching more people.

UPDATE

Our new referrals into the organisation have officially increased by 3% however, attendance at drop-in sessions and carers cuppa has doubled. These users do not always register as new referrals, unless they access our other services, therefore, in real terms, the increase is around 10-15%.

Attendance at other drop in sessions and new services (For example, our therapeutic groups – low impact/ relaxation and breathlessness) has also increased. We are also continuing our partnership working with Carers First and Alzheimer's and Dementia Service.

Access to services is monitored via a KPI dashboard and from feedback received from other healthcare professionals

OUTSTANDING AREAS FOR 16/17
The need to develop our outreach has been included in the coming year's priorities.
15/16 Priority 2- Develop and deliver an accredited training model
As the Lead Provider for End of Life Care in our area, we share our expertise with other health and social care providers to improve the quality of care for everyone. We offer accredited training which is a level 3 award in end of life and dementia.
UPDATE
The programme is now running and we were the first hospice in Kent to offer accredited learning. We have supported 6 staff on the Level 3 apprenticeship in Health and Social care and have staff currently undertaking a Certificate in Assessing Vocational Achievement (CAVA) and the Quality End of Life Care for All Programme. This will further support ellenor's strategy of being the lead provider for end of life care in our area.
OUTSTANDING AREAS FOR 16/17
We are planning on training an internal quality assessor. We are running more accredited courses throughout the year.
15/16 Priority 3- Improve our children's hospice care respite provision
We needed to ensure equitable access to our respite provision across each of our areas with a clear concise framework of our offer.
UPDATE
We listened to feedback from families, and are currently reviewing our service delivery. We recognise that our respite care does not always offer an equitable service to all of the children on our caseload, and this is often affected by geographical location, age or other factors. The consultation results can be found within the Quality Account in section 3. We have commenced a pilot to review the respite referral process and discharge criteria. We are in contact with a number of families who have offered to provide feedback and consultation surrounding the implementation. The assessment tool is currently in use.
OUTSTANDING AREAS FOR 16/17
We recently completed the childrens service family consultation and are currently piloting usage of the respite framework. This work is ongoing and we will be liaising with parents that agreed to participate in this.

II. Priorities for the year ahead 16/17

16/17 Priority 1- Continued development of the wellbeing model of care
We need to continue to reach out to, and ensure expert care is provided for anyone who needs it, in the place of their choice, when they need it, to ensure they are able to achieve their preferences of care
<i>How was it identified</i>
Following a benchmarking exercise, we reviewed wellbeing models in other

hospices. This has to lead to the need to develop a wellbeing model of care for patients and their families.

How will it be achieved

A head of wellbeing has been appointed and we will be completing a comprehensive review of our existing day service provision, which will be accompanied by a caseload review of day therapy patients. As part of this review, we will be liaising with our users in day therapy and community which will feed into the development of the wellbeing model to ensure it meets the needs and wishes of patients and their families.

How will progress be monitored and reported?

We will report our progress to our care practice group, senior management team and to the board against our strategies to widen our access and increase our range of services. Progress will be monitored against a timetable of therapeutic groups and activities being in place and the successful implementation of groups and services as well as attendance to each of these.

16/17 Priority 2- Development of the community outreach work and support for carers

We need to provide our service in the place that people need it and support carers to provide care for their loved ones.

How was it identified

Following on from community engagement it became apparent that hard to reach groups preferred services near to home within their community. It was also identified that our carer support did not cater for carers of children or for young carers.

How will it be achieved

We have piloted 3 outreach groups in Swanley, Dartford and Bluewater providing specialist advice/ support and information for families and the local community. These have been positively evaluated by those attending. We will be looking at implementing regular clinics in multiple areas across our catchment where patients will be able to access these by using a booking system or through dropping in.

We are currently working with the Sikh community to develop a questionnaire on how we can best meet the needs of the local Sikh population and also looking at commencing a parent carers group and working with Carers First to provide support for young carers. We are working with the Alzheimer and Dementia support service to enable families to access end of life care and support from ellenor.

How will progress be monitored and reported?

This will be monitored through engagement with our GPs and Healthcare professionals as well as attendance at our drop in's and clinics. The number of outreach clinics and locations will increase producing an increase in numbers of those accessing these services. We will also be able to evaluate the questionnaire from the Sikh community. We will report our progress against this to our care practice group, senior management team and to the

board against our strategies.
16/17 Priority 3- Ensuring the quality and safety agenda are embedded throughout the organisation.
We need to use an evidence based approach to manage quality and safety across the organisation.
<i>How was it identified</i>
Further to external evaluation of our quality and safety markers (falls, pressure ulcers, complaints and infection), we identified that we needed to review the associated policies and processes.
<i>How will it be achieved</i>
Nominated individuals have been identified as leads for each of the quality makers. Working groups have been established across the organisation to ensure that changes to practice are embedded. We will also participate in further research and projects that promote awareness and interest in the palliative community.
<i>How will progress be monitored and reported?</i>
Audits will assist us in understanding our progress against this. We will also ask our commissioners to appraise our progress against the changes made. We will also be seeking further external audit and review.
We will also report our progress against this to our care practice group, senior management team and to the board against our strategies.

III. Statements of assurance from the board.

The following are a series of statements that all providers must include in their Quality Account. Many of these statements are not directly applicable to hospices.

A. Review of Services

During 1 April 2015 – 31 March 2016, **ellenor** provided specialist palliative care in a range of settings, available 24 hours a day and 7 days a week. The provision comprised the following services:

For adults living in Dartford, Gravesham and Swanley:

- x In-Patient Ward (ages 14+)
- x Day Therapy
- x Out Patients Clinics
- x Hospice at Home including:
 - o Specialist Palliative Care
 - o Palliative Care Support Team
 - o Care Home Support
 - o End of Life Care Crisis Support

For children and young people in Dartford, Gravesham and Swanley, West Kent and the London Borough of Bexley:

- x Hospice at Home including:
 - o Specialist Palliative Care
 - o Community oncology care
- x Respite and Short Breaks
- x Family Drop In sessions and Day Care Facilities
- x Transition services including Youth Groups

ellenor has reviewed all the data available to them in the quality of care in all of its services.

All these services are delivered by a multidisciplinary team, comprising nurses, doctors, allied health professionals, and psycho-social staff (including social workers, chaplains and counsellors). Patients and families under the care of the organisation receive regular assessment and review by an appropriate member of staff (or registered volunteer). Hospice at home services are provided 7 days a week with a 24 hour on call service staffed by Specialist Nurses and Doctors, and with access to other staff to visit and provide care as required.

B. Income Generated

The income generated by the NHS services reviewed in 2015/16 represents 100% of the total income generated from the provision of NHS services by **ellenor** for 2015/16.

The income generated from the NHS represented 24% (unaudited) of the overall cost of running these services.

The above mandatory statement confirms that all of the NHS income received by the Hospice is used towards the cost of providing patient services.

C. Participation in National Clinical Audits

During 2014/15, **ellenor** was not eligible to participate in any national clinical audits or national confidential enquiries.

D. Participation in Local Audits

We regularly undertake audits of our services against national or local standards. All the local audits are taken to check and to improve our current practice. In particular we are highlighting two significant audits here. First an audit completed by the medical team revisiting an audit on discharge letters, demonstrating a huge improvement in the quality and relevance of the

information sent out when a patient is discharged. Second is the Documentation of End of Life priorities paving the way for an improvement in the level of documentation through identified changes.

Audit	Results and actions																																																																
<p>Discharge letter to GP</p> <p><i>This audit aimed to evaluate the discharge summaries, mainly focusing on timeliness and quality of information.</i></p> <p><i>Information includes: Reason for admission, date of admission, investigations done, medications changed, reason for the medication change, location of discharge, any follow up plans, any follow up/action needed from GP, details of Do Not Attempt Resuscitation (DNAR), Preferred Place of Care (PPoC) / Preferred Place of Death (PPoD) (if discussed), details about appropriateness of hospital admission (if discussion)</i></p>	<p>Results (comparing previous results in 2014 and May – Oct 2015)</p> <p>(i) Each audit looked at 30 discharge letters from inpatient unit</p> <p>(ii) Significant improvement in documentation in following area: Medications changed (61% → 90%), Reasons for the medication change (58% → 89%), Location of discharge (79% → 97%), Follow up plans (24% → 77%), DNAR (18% → 100%), Date of discharge (43% → 90%), Information copied to consultant (64% → 89%) and district nurse (0% → 92%).</p> <table border="1" data-bbox="587 1077 1337 1733"> <thead> <tr> <th></th> <th>2014</th> <th>2015</th> <th>Improvement</th> </tr> </thead> <tbody> <tr> <td>reason for admission</td> <td>100%</td> <td>97%</td> <td>-3%</td> </tr> <tr> <td>date of admission</td> <td>93%</td> <td>97%</td> <td>4%</td> </tr> <tr> <td>investigation</td> <td>44%</td> <td>55%</td> <td>11%</td> </tr> <tr> <td>medications changed</td> <td>61%</td> <td>90%</td> <td>29%</td> </tr> <tr> <td>reasons change</td> <td>58%</td> <td>89%</td> <td>31%</td> </tr> <tr> <td>location of discharge</td> <td>79%</td> <td>97%</td> <td>17%</td> </tr> <tr> <td>follow up plans</td> <td>24%</td> <td>77%</td> <td>53%</td> </tr> <tr> <td>action from GP</td> <td>15%</td> <td>28%</td> <td>13%</td> </tr> <tr> <td>DNACPR</td> <td>18%</td> <td>100%</td> <td>82%</td> </tr> <tr> <td>PPC/PPD*</td> <td>18%</td> <td>47%</td> <td>29%</td> </tr> <tr> <td>hospital admission</td> <td>9%</td> <td>100%</td> <td>91%</td> </tr> <tr> <td>date of discharge</td> <td>43%</td> <td>90%</td> <td>47%</td> </tr> <tr> <td>letter sent < 36 hours</td> <td>75%</td> <td>87%</td> <td>12%</td> </tr> <tr> <td>copied to consultant</td> <td>64%</td> <td>89%</td> <td>25%</td> </tr> <tr> <td>district nurse</td> <td>0</td> <td>92%</td> <td>92%</td> </tr> </tbody> </table> <p>Future plans and recommendation:</p> <p>(i) A further need for clarity about PPoC and PPoD, follow up plans / requests and level of further treatment options (including hospital admission / investigations)</p>		2014	2015	Improvement	reason for admission	100%	97%	-3%	date of admission	93%	97%	4%	investigation	44%	55%	11%	medications changed	61%	90%	29%	reasons change	58%	89%	31%	location of discharge	79%	97%	17%	follow up plans	24%	77%	53%	action from GP	15%	28%	13%	DNACPR	18%	100%	82%	PPC/PPD*	18%	47%	29%	hospital admission	9%	100%	91%	date of discharge	43%	90%	47%	letter sent < 36 hours	75%	87%	12%	copied to consultant	64%	89%	25%	district nurse	0	92%	92%
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	<ul style="list-style-type: none"> (ii) Plan to modify the discharge letter template to accommodate the findings and to repeat this audit on yearly basis (iii) Plan a further survey of GPs and district nurses to get their views to improve the discharge letter, which in turn will help to improve the communication
<p>Audit of Documentation of End of Life Care Priorities in Patients under Local Hospice Services</p> <p><i>This audit completes an audit cycle presented in January 2015</i></p> <p><i>This retrospective audit reviewed the case notes of 15 patients from each of our three hospice services; inpatient unit (PU), home care team (HCT) and day therapy unit (DTU). These patients were referred before 20th November 2015 and had been seen by ellenor health care professionals a minimum of three times</i></p> <p><i>The audit was aimed to look at patient's documentations on preferred place of care (PPoC), preferred place of death (PPoD), resuscitation decisions and whether an advance care planning</i></p>	<p>The standards had been set in the previous audit and results of this audit were</p> <ul style="list-style-type: none"> (i) Excellent standard achieved in documenting resuscitation decisions across three units (100%) (ii) Satisfactory results in documenting the PPoC across three units (>=80% documented) and the PPoD in patients from inpatient unit (86%). Inpatient unit was the only unit that achieved the standard of documenting PPoC/PPoD (~90%) (iii) Underachieved in documenting PPoD in the homecare team (53%) and day therapy team (73%) when comparing against the standard (80%) (iv) Of those patients from home care team that died 66% did not die in their PPoD – 44% of them did not have a recorded preferred place of care (v) Results were presented to the teams to continue to improve the outcomes and documentation <p>Future plan and recommendation</p> <ul style="list-style-type: none"> (i) Ongoing progress in this area is required, particularly in having a record of the PPoD from patients of the home care team (ii) Future work can be pursued on initiating more advance care planning discussions with patients, and certainly having the advance care planning discussion scanned to Infoflex

(ACT) document had been discussed and then scanned onto the electronic case note system (Infoflex)

(iii) The audit to be repeated in 1 year

	Home Care Team	Day Therapy	Inpatient Ward
Preferred place of care (%)	100	80	93
Preferred place of care 2 (%)	0	20	0
Preferred place of death (%)	53	73	86
Preferred place of death 2 (%)	6	40	6
Standard of documenting PPOC/PPoD (%)	80	80	80
Total PPOC/PPoD documented (%)	76.5	76.5	89.5
Patients that died (%)	20	20	93
Patients did not die in the PPOD (%)	66	0	7
Standard of documenting resuscitation (%)	60	80	100
Total resuscitation documented (%)	100	100	100
Patients remained for CPR (%)	46	26	6
Advance care planning initiated (%)	46	86	46
Advance care planning scanned to Infoflex (%)	6	6	0

Assessment and of Nausea / Vomiting

This audit showed an overall need for improvement in documentation of assessment of patients admitted with nausea or vomiting to inpatient services.

<p><i>This audit was planned to check "How we assess & manage these symptoms" as palliative care inpatients management. This was mainly to document the baseline standards.</i></p>	<p>It is expected that patients admitted with nausea and vomiting should have a comprehensive assessment that includes the following: History, what treatments have been given, what the outcomes were, physical examination to assess hydration and if any further investigations were undertaken</p> <p>Inpatients from ellenor and another Kent hospice were audited and results were:</p> <p>1)More than half of the 30 patients (sample size) had their history, frequency, physical assessment and abdominal examination documented in relation to their nausea/vomiting events 2)Underachieved documentation across most assessments, including precipitating, reliving, worsening factors, amount of vomit, hydration, used assessment tool and per rectal examination Future plans and recommendations include</p> <ol style="list-style-type: none"> a. improved awareness in documentation of assessment of patients admitted with nausea or vomiting to inpatient service, b. agreement on an assessment tool so that the management/symptom could be reassessed, c. audit against local guidelines <p>ellenor to agree guideline and implementation. We will consider a research project.</p>
<p><i>Audit of Usage of Steroids in Inpatient</i></p> <p><i>Steroids are widely used in palliative care for a variety of indications. However, they are associated with significant side-effects and for this reason should be used with care. Their use should be reviewed on a frequent basis to ensure patients are receiving the minimum effective dose for the minimum required time.</i></p>	<p><i>This audit was a repeat of last year after a conclusion that those who have steroids started as inpatients have indication, review, and plans documented better than those admitted on steroids.</i></p> <p><i>We are currently working on data collection.</i></p>

E. Research

The organisation supports appropriate research in palliative care with the aims of enhancing the experiences of patients and families. There is a research governance committee which approves the participation in all research studies as appropriate, to ensure good governance. All research undertaken within the hospice setting has received appropriate ethics approval. We are also part of the Kent and Medway Research Group.

Hospices struggle to provide capacity to grow research due to competing demands on staff time and resources. **ellenor** collaborated with other Kent Adult Hospices to jointly appoint a Research Practitioner. This post was filled in September 2015 with the aim of building strategic governance and raising the profile of research within the group, paving the way to take an active role in portfolio studies.

After 5 months, we had prepared the ground for the 'Collaborative' to establish and develop a research system including a collaborative research strategy, established a research ready work force and expressed an interest in participating in several portfolio studies as appropriate (see below). Subsequently we successfully submitted a bid for continued funding for this role to the National Institute for Health Research (NIHR). The expectation is that the number of patients participating in research will increase across the Collaborative from 12 to over 100 patients in year 1.

Over the year we have encouraged staff to undertake research and audits where they can see a clinical need and to meet their own area of interest.

a. Prognosis Prediction by Palliative Prognostic Index (PPI): Multi-centre Prospective Study -2 with Two Calculations of PPI in UK Hospice Patients

Prognosis prediction by palliative prognostic index- involved 10 Hospices- Conducted by Dr Siva Subramaniam with University of Kent- This study was presented at European Palliative care conference at Copenhagen in May 2015 and Hospice UK conference at Liverpool in November 2015.

Conclusion: PPI score is more accurate if calculated twice and the rate of change of PPI is useful.

b. Ongoing data collection for the multi-centre research – OASis Trial- (An Observational study of the frequency of oral symptoms in patients with cancer)

This study was coordinated by Royal Surrey Hospital (RSH) Research team, to devise an assessment tool for oral symptom assessment for patients with advanced cancer. This involved data collection using a structured questionnaire. Dr Siva Subramaniam was the Principal Investigator for **ellenor**. We recruited 12 patients (our target was 10). The study was coordinated by Royal Surrey Hospital Research team. The study has now completed and **ellenor** are awaiting the final results from Royal Surrey Hospital (RSH.)

Conclusion: Oral symptoms are common in patients with advanced cancer and are significant cause of morbidity. The purpose of this multi-centre study is to determine the prevalence of range of oral symptoms in patients with advanced cancer and to use this information to develop and validate an oral assessment tool

c. Ethnicity, Gender, Sexual Orientation, Religion, Class and Other Social Markers in Palliative and End of Life Care

- x Research proposal submitted for international funding, waiting to hear the outcome. If funding becomes successful, this research project will be conducted in collaboration with University of Greenwich.
- x This project uses an intersectional approach to investigate how communication takes place in patients who are facing terminal illness or dying according to their ethnicity, gender, religion, disability, age, sexual orientation or social class.

d. Five Expression of Interest forms submitted for National Portfolio Studies. Chosen as a recruitment site for two studies due to start recruitment. They are:

- x PiPS2 (The Prognosis in Palliative Care Scales 2)
- x The aims of this study are to validate the PiPS prognostic scores in an independent cohort of patients with advanced incurable cancer and to compare its accuracy to clinician predictions of survival and to assess the accuracy of the Feliu Prognostic Nomogram
- x Patients that fulfil inclusion criteria will be invited to take part in the study and several measures will be collected from patients, such as patient's illness, severity of symptoms, pulse rate
- x The recruitment of this study is aimed to last for 18 months, starting in May 2016

e. Alcohol Study (An observational study investigating the prevalence and impact of alcohol-related problems in cancer patients and their non-professional caregivers)

- x The aim of this study is to assess the prevalence of alcohol use disorders and the relationships between alcohol use disorders, psychological/physical

problems and drug abuse in a large cohort of advanced cancer patients and their non- professional caregivers

- x Patients from IPU, DTU and home care team that fulfil inclusion criteria as well as their caregiver will be invited to take part in this study. Recruited participants will be filling out multiple questionnaires to complete the research study.
- x The recruitment of this study is aimed to last 1 year

F. CQUIN Payment Framework

ellenor income during 2015–2016 was not conditional on achieving quality improvement and innovation goals through the Commissioning for Quality and Innovation (CQUIN) payment framework.

G. What others say about us

ellenor is required to register with the Care Quality Commission (CQC) and it has current registration status. We have no conditions on our registration. We have not had an inspection during the year April 15 – March 16 and were asked to submit our Provider Information Return for Gravesend in October and for Dartford in April 2016. Both were successfully submitted on time. The Care Quality Commission has not taken any enforcement action against **ellenor** during 2015–16.

The inspection took place in May 2016 and results will be published as soon as it available. These were not available

Where no rating exists yet, we have set out our own views on the five key questions used by the Care Quality Commission in their inspections of services:

1. Are we safe?

Policies and procedures are in place providing guidance to staff alongside a robust governance structure. We hold a risk register and update it quarterly. Our recruitment processes are efficient and competent staff are trained to complete their role effectively. Robust disciplinary procedures are in place to manage performance issues. **ellenor** operate an open and transparent culture throughout the organisation, encouraging feedback from staff and enabling them to raise concerns.

2. Are we effective?

Care needs are reviewed regularly with MDT meetings held throughout the organisation for all patient groups. All patients are given packs containing information about the services they can access. Patients are consulted using surveys and questionnaires. All staff work to competency frameworks, are

annually appraised and development needs are identified. We provide disabled access throughout our buildings.

3. Are we caring?

Compassion, kindness and caring form the core of our mission and values. Upon recruitment we ensure staff have an understanding of principles and values of palliative care. Patients and families are treated with dignity, compassion and respect and regularly comment highly on the care they receive, by being treated as individuals and getting involved in their care.

4. Are we responsive to people's needs?

We have an open referral policy and accept direct referrals from patients and families, as well as professionals. All referrals are triaged and are allocated to the appropriate team.

We provide an out of hours on call service 24/7, which includes crisis support for patients at the end of life and their families. We also an advice line to professionals.

We have a complaints policy and actively seek to learn from all comments and complaints both positive and negative.

5. Are we well-led?

There is a governance structure in place which includes a governance policy and supports appropriate decision making at all levels of the organisation. The Board of Trustees meets quarterly and reviews and challenges practice and governance requirements. Sub- committees of the board meet regularly to review specific areas in more detail, including clinical governance and risk. We have a robust reporting framework.

Twice yearly all staff meetings are held to give updates on the strategy and to reinforce the vision and mission of ellenor. Staff engagement is encouraged through the staff communications group which provides an opportunity for two way communication between Management and staff representatives.

The strategy document, key performance indicators and quality markers are regularly reviewed by the Senior Management Team. Team away days and working groups are used to actively engage staff in service development. An open door policy at Director/CEO level provides staff with the opportunity to discuss issues and concerns, there are policies in place to support this.

Visits are made regularly to all services and standards of care monitored by unannounced 'walk rounds'. The Director of Patient Care and Head of Quality and Development undertake occasional clinical shifts. Trustees are encouraged to visit departments and engage with staff. Staff are encouraged to reflect on their own practice when involved in an incident and to report near misses.

External advice is actively sought to support the development of services and when appropriate the review of policies and procedures. Quality is monitored regularly and reviewed by the Care Practice Group and Clinical Commissioning Group quality team. Staff working out of hours are supported by a Senior Nurse Manager on call.

A Director of HR is in place to lead the development of the HR strategy development and implementation including managing sickness absence and any areas of poor performance. Staff are supported through 1:1 supervision, appraisals and clinical supervision. Mandatory and development training is provided, this includes specialist training, palliative care updates and Schwartz Rounds.

H. Data Quality

In accordance with the agreement with the Department of Health, **ellenor** submit a National Minimum Dataset (MDS) to the National Council for Palliative Care. We provide the MDS report and a copy of the quarterly activity report to the local commissioning organisations. A summary of the activity statistics can be found in Part 3.

ellenor did not submit records during 2015-16 to the Secondary Uses service for inclusion in the Hospital Episode Statistics which are included in the latest published data because we are not eligible to participate.

Information on the number of patient records held by an organisation which includes NHS number and General Medical Practice Code: 1053 out of 1078 current patients/clients (97%) have an NHS number recorded, 91% have a GP practice recorded which is an increase on last year.

Number of errors introduced into a patient's notes: there were 222 reported errors in our patient documentation during the year 2015-16 which is an increase of 39 last year. This is due to an increased reporting rate through improved checking systems and processes, and is not thought to represent an actual increase in errors.

ellenor continues to take the following actions to improve data quality:

- x A clinical administration team manager was appointed and now oversees and monitors the accuracy of data entry. There is subsequently a more robust process in place and we have seen a reduction in missing data overall.
- x A data quality project has been in place throughout the year to improve the accuracy and timeliness of clinical information reporting for both internal and external stakeholders. We are looking into how to improve this further in the coming year.

- x We are participating in a national pilot for the Palliative Care Funding Review which has meant improved clinical record keeping and an ability to record information remotely.
- x Our Information governance lead attends network meetings which act as a resource; sharing of information at a local and national level, sharing experiences and ideas surrounding health informatics within a hospice setting, including management/ development of electronic patient records and clinical data reporting, for the benefit of service improvement and supporting best practice.

I. Data Quality

ellenor's Information Governance Assessment Report score overall score for 2015–16 was 72% and was graded Satisfactory. This is an improvement on last year.

Assessment	Stage	Level 0	Level 1	Level 2	Level 3	Not Relevant	Total Req'ts	Overall Score	Self-assessed Grade ?	Reviewed Grade ?	Reason for Change of Grade ?
Version 13 (2015-2016)	Latest	0	0	22	5	2	29	72%	Satisfactory	n/a	n/a

Grade Key

Not Satisfactory	Not evidenced Attainment Level 2 or above on all requirements (Version 8 or after)
Satisfactory with Improvement Plan	Not evidenced Attainment Level 2 or above on all requirements but improvement actions provided (Version 8 or after)
Satisfactory	Evidenced Attainment Level 2 or above on all requirements (Version 8 or after)

J. Clinical Coding Error

ellenor was not subject to payment by results clinical coding audit during 2015–16 by the Audit Commission.

3. Part 3- Review of Quality Performance

A. Boards commitment to Quality

The Board of Trustees regularly review the performance measures and a Dashboard has been produced to enable clearer reports. Members of the Board undertake periodic visits to different parts of the organisation, to speak to patients, staff and volunteers to ensure they are kept fully apprised of what is happening. During visits, the Trustee visits different parts of the organisation and speaks to patients and staff. There is a Clinical Governance Sub-Committee chaired by a Trustee, focusing on care services. It thoroughly reviews varied information relating to the quality of care provided, including statistics relating to any staff shortages or concerns in clinical areas. Senior members of clinical staff attend this meeting to discuss current issues in an open and transparent environment. A report is sent to the Full Board meeting regularly. In this way, the Board has knowledge of the quality of the service provided, through regular reporting. The Board is confident that the treatment and care provided by the Hospice is of high quality and is cost effective.

B. Minimum Data Set Comparison

Activity statistics are submitted as part of the Minimum Data Set (MDS) and the figures below are in accordance with these figures. National figures (median) are based on the National MDS 2014-15 (latest report available).

IN PATIENT WARD	2015-16 No MDS comparison available	2014-2015	2013- 2014
Number of admissions (unique patients)	274	322	305
% of new patients (i.e. admitted for the first time) <i>S= 90.3</i>	78	91.1	91.8
% of patients admitted within 24 hours of referral	74	76	81
% of patients with a non-cancer diagnosis <i>S= 11%</i>	17.5	12	19
Average length of stay <i>S= national between 10-13 days</i>	9.7	10	10

We were classed as a small unit during the MDS year 2014-2015. I have provided the national comparison figures for small units as follows S=0. It should be noted that significant funding was not available in the 2015-16 year therefore bed numbers were reduced in line with staffing.

DAY THERAPY	2015-2016 No MDS comparison available	2014-2015	2013-2014
<i>Number of patients</i> <i>M= 144</i>	171	172	178
<i>% attendance</i> <i>M= 71.3%</i>	58	68	66.6
<i>Average length of care</i> <i>M= 154.8 days</i>	272	265	350
<i>% of patients with a non-cancer diagnosis</i> <i>M=25</i>	26	22	22

We were classed as a medium unit in 2014-15. Therefore, we have provided the national comparison figures for medium units.

We do note that our lengths of stay for patients appear to be double that of the national average. We also understand our attendance is much lower than the national average and this is due to dependency of patients.

HOSPICE AT HOME FOR ADULTS INCLUDES CARE HOME SUPPORT	2015-2016 No MDS comparison available	2014-2015	2013-2014
Number of new patients (national 596)	890	718	567
Total number of patients (national 832)	1238	970	839
% of patients with a non-cancer diagnosis (national 17)	41	31	24
Average length of care in days (national 87.9)	97	101	133

We are experiencing a significant increase in referrals from care homes (312% increase since 2011).

CHILDREN'S HOSPICE CARE	2015-2016	2014-2015	2013-2014
No MDS comparison available for children			
Number of new patients	52	44	51
Total number of patients	154	147	155
% of patients with a non-cancer diagnosis*	77	82	78

*To ensure consistency, we have adjusted the collection date to the last day of the financial year and for all continuing patients with our service.

C. Patient Safety

The following quality marker data is for our In Patient Ward only.

PRESSURE ULCERS

We changed our mechanism for recording this information in August and were able to retrospectively record for July. We have had 4 internally acquired pressure ulcers this year, and due to the nature of our services, it is often unavoidable due to the significant deterioration at the end of life. Work continues to minimise the effect that a pressure ulcer has on patients.

Pressure Ulcers (Grades)	Jul-15	Aug-15	Sep-15	Oct-15	Nov-15	Dec-15	Jan-16	Feb-16	Mar-16	YTD Total
Total Pressure Ulcers	1	0	0	5	0	0	1	3	1	11
Externally Acquired	0	0	0	4	0	0	1	1	1	7
Internally Acquired	1	0	0	1	0	0	0	2	0	4

FALLS

We have a falls assessments in place that we aim to complete within 24 hours of admission to our in-patient ward. We have also started a falls group to discuss falls that occur and how to prevent in future.

Falls	Apr-15	May-15	Jun-15	Jul-15	Aug-15	Sep-15	Oct-15	Nov-15	Dec-15	Jan-16	Feb-16	Mar-16	YTD Total
Total number of falls	4	3	1	0	1	5	0	2	3	2	1	3	25
No Harm	1	1	0	0	0	4	0	1	1	2	1	1	12
Low Harm	3	2	1	0	1	1	0	0	2	0	0	2	12
Moderate Harm	0	0	0	0	0	0	0	1	0	0	0	0	1
Severe harm	0	0	0	0	0	0	0	0	0	0	0	0	0
Death	0	0	0	0	0	0	0	0	0	0	0	0	0

INFECTIONS

Our infections for the year are as follows:

HCAI	Sep-15	Jan-16	YTD Total
MRSA (Hospital Only)	0	2	2
MRSA (Community Acquired)	0	0	0
MSSA	0	0	0
C.Diff	1	0	1
E Coli hospital acquired infections reported	0	0	0

Both MRSAs were externally acquired.

We have recognised the significant importance of the infection control lead role and have identified a full time Registered Nurse on the ward to receive extended training and to lead on this important area of work. We have also established an infection control working group who will monitor the quality and oversee the outcomes of this action plan plus future audit outcomes. WE have a comprehensive housekeeping schedule in place to support the infection control programme.

INCIDENTS

Our clinical incident learning for 2015-16 is as follows:

- x Ongoing training is in place for medicine incidents and syringe driver/ medicines charts have been reviewed and simplified. Calculations tests are in place and take place annually to maintain standards of competency.
- x The membership to the Infection Control and Prevention group has been reviewed and widened. Training has been revised.
- x Leads for the key quality roles, infection control, manual handling and falls prevention, wound care, safeguarding and nutrition were identified and in place. They will work to ensure the care delivered is evidenced based, this will continue throughout 2016.
- x Further training in relation to incident recording is being delivered together with training regarding incident investigation to ensure that root cause analysis is embedded in practice. This will form part of the annual training and development review plan. The way incidents, accidents and complaints are monitored and discussed and learning shared will be reviewed to ensure the organisation gains the maximum benefit from any learning.

- x Competency Frameworks for all nursing staff will be updated; this will include overarching values and knowledge, communication skills, assessment and care planning, symptom management, education and professional development.
- x Review planned of managing out of hours phone calls to ensure calls are not left on answer phones but are responded to in a timely manner. Review to be led by Director of Patient Care.
- x A review of the provision of support for patients in the community by reviewing skill mix and staffing levels in order to support patients to achieve their preferred place of care and death.
- x A review of the use of care plans and symptom management plans for inpatients and community patients.
- x Carers support services have been reviewed based on carers' feedback. We plan to develop and offer outreach support for carers in the community. This will involve engagement with our community partners.
- x We are looking to increase the number of volunteers in order to support more carers and increase the use of the Carer Support Needs Assessment Tool (CSNAT).
- x A working group will be reviewing the ward environment to maximise privacy and dignity.
- x We are reviewing the Hospice at Home for adult and children's staffing ratios and skill mix to ensure the team are staffed to respond to urgent changes in patients' conditions.
- x We have developed and are widening access to bereavement support groups by offering groups in the evening and at weekends.
- x We are in the process at reviewing how visitors are greeted prior to entering the inpatient ward.
- x We are undertaking a falls audit.

D. Clinical Effectiveness

COMPLAINTS

ellenor treats all complaints seriously and records all expressions of dissatisfaction, both verbal and written, as complaints. These are all reviewed by the Director of Patient Care for opportunities to learn and improve practice. A regular report is provided to the Board of Trustees and action plans are put into place.

We consider complaints essential to improve our services. We had a complaints audit completed by our local CCG and the conclusion was that there were no significant concerns identified from the complaints audit.

However, the overall categories prompt further exploration into the triangulation of complaints within the organisation and how learning is disseminated and embedded. The Quality and Safety Lead advised that she will follow up on the identified complaint with **Ellenor** to review quality and safety aspects and gain some further information and assurance; however, this is to be addressed separately to the complaints audit.

We are also developing our NHS Choices profile to enable reviews.

Number received	Number upheld	Trends noted
17	10	<p>These figures include both informal and formal complaints.</p> <p>Following a review by our Clinical Commissioning Group, the main themes identified were related to:</p> <ul style="list-style-type: none"> • Patient care/ Experience of care <p>Care planning is being reviewed and the competency framework has been updated and implemented. All nurses have been assigned a mentor to support and oversee their practice.</p> <ul style="list-style-type: none"> • Communication- lack of contact and delay in response time. <p>The clinical administration system has been thoroughly reviewed. All administrators are now line managed by an administration manager. A duty nurse has been allocated daily to take and respond to all incoming patient and family calls.</p>

EDUCATION

During the year training was delivered to over 20 external groups, reaching in excess of 440 staff, and evaluated as good or excellent by 100% of attendees. 97.5% of clinical staff are up to date with their statutory and mandatory training. We have continued to support the professional training placements for 17 student nurses and 7 GP trainees this year.

However this year we have focused on building our capacity to deliver and support accredited training, linking into the government apprenticeship approach. As such, we are the first hospice in Kent to deliver an accredited Level 3 Award in End of Life Care with Dementia at end of life. This training was developed in partnership with St Christopher's Hospice and has been instrumental in establishing **ellenor** as a recognised satellite training site. Partnership working has been key to supporting the development of the current workforce of Healthcare Assistants (HCA), working with Croydon College and the South London Hospice Education Collaborative (SLHEC). Six staff are due to complete their Level 3 Apprenticeship Award in Health and Social Care including care for Long Term Conditions and Frailty. Two of our staff were nominated by Croydon College for awards for their work on this programme.

Our staff have taken the lead role in steering the development of the Level 5 Higher Apprenticeship programme for Assistant Practitioners. This course offers a HCA an opportunity to progress their career, developing their clinical knowledge, critical thinking and teaching skills. With the recognised national shortfall of a trained workforce, the Assistant Practitioner courses are aimed at providing a bridging gap into Qualified Nurse training for some staff. It is hoped that this pathway will encourage more people into a career in Nursing. This course has completed year 1 of 2, and the programme is being externally evaluated. A Poster was presented at the Hospice UK 2015 conference.

Volunteers are an integral part of the workforce at **ellenor** providing essential hours in a number of departments including patient facing services, including drivers, companions, befrienders, reception and the ward areas. As such it is vital to have quality training to prepare individuals to support their care work. We have worked closely with colleagues in the SLHEC to develop patient facing training for new volunteers working with **ellenor**. This training has been evaluated and was the subject of a poster presented at the Hospice UK 2015 conference.

ellenor has developed its outreach to the 16–19 year olds in order to encourage more young people to take up a career in care. In June 2015 we ran a pilot programme offering three city and guilds qualifications. This was so successful that we have extended our programme in 2016, with the backing of funding from Health Education England, Kent, Sussex and Surrey (HEEKSS). We intend to run two courses along with two volunteer placement programmes of six months during which time the learners will gain experience and competence of the care certificate.

To support these vocational qualifications we have three staff that have completed or are working towards their Certificate in Assessing Vocational Achievement (CAVA).

Future plans for education include the development of an Internal Quality Assessor (IQA) for vocational achievements and the development of an accredited Palliative Care module for Registered Nurses.

We presented the following posters in 2015.

- x Patient facing Volunteer training, Hospice UK
- x Level 5 Assistant Practitioner, Hospice UK
- x South London Hospice Education Collaborative – Partnership working Poster, Hospice UK
- x Symptom Management Drug Charts, Kent Community Research Awards – Prize winner

PARTNERSHIP WORKING

We work with a number of partners including:

- x Macmillan- funded a financial and benefits post that assists patients and their families with decision making by signposting.
- x Carers First- have assisted in our Carers courses and cuppa's as well as ensuring we are able to meet the needs of our carers
- x South East Coast Ambulance Service- we have delivered training, and continue to do so, to a number of their staff to ensure that they are able to recognise dying and access the support they need to keep people out of hospital at the end of life.
- x Alzheimer's and Dementia Support Service- we are looking at ways to facilitate advanced care planning in those with Alzheimer's and Dementia. We are also planning on delivering end of life care training for their carers.

CLINICAL NETWORKS

Our lead consultant attends the south east coast strategic clinical networks palliative care and end of life care clinical advisory group which looks at end of life care across all the 4 strategic clinical networks, which are

The 4 networks are

1. Cardiovascular including heart, stroke, renal and diabetes,
2. cancer,
3. dementia, mental health and neurological conditions and
4. maternity, children and young persons.

The advisory group comprises of a wide membership from across the south east coast of providers, commissioners, patient, carer and third sector members. It provides a forum for bringing together and agreeing the end of life care strategic work programme. The groups aim to influence and advise on the commissioning of end of life care services which address the whole patient pathway and deliver the required patient outcomes.

Our lead consultant also attends the Kent and Medway Children and Young People Palliative Care Network meetings. This group brings together providers, commissioners and third sector members from across Kent and Medway to look at palliative care and end of life care provision. The group has been working on an end of life care pathway, advance care plans, symptom management and drug charts, mental capacity and looking at education gaps and the possible delivery of a yearly network education event.

The Director of Patient Care attends the 'Executive Clinical Leads in Hospice and Palliative Care (ECLiHP). This is a forum which shares good practice and discusses issues relevant to palliative care. They also attend the Controlled Drugs Local Intelligence Network (CDLIN) which discusses best practice and shares learning and knowledge.

The Childrens Hospices across London (CHAL) registered managers meeting is attended by the Director of Patient Care and Head of Childrens Service. This forum is used to develop best practice initiatives.

E. Patient Experience

Last year, we completed a number of surveys and feedback.

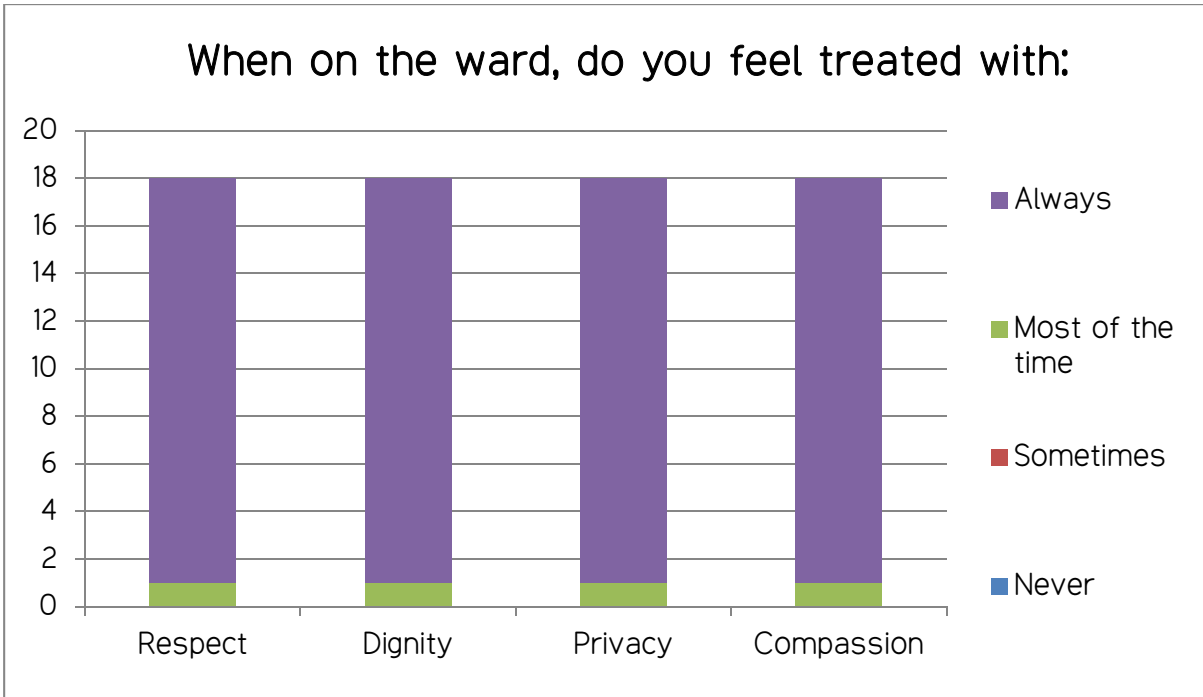
Rather than implementing a regular forum, we will be continuing to complete ad-hoc user involvement to ensure our feedback remains current. All services are encouraged to seek and use the views of the people who use them.

INPATIENT WARD SURVEY

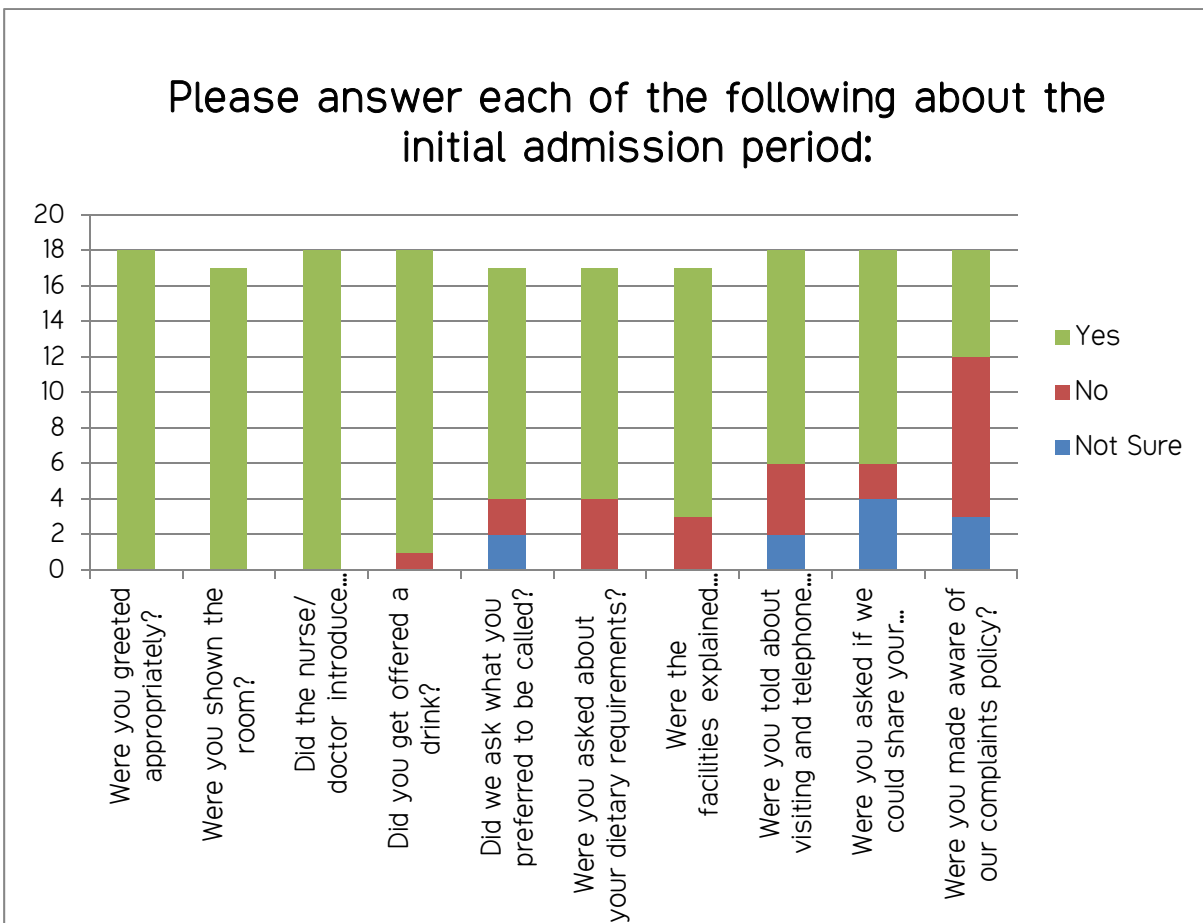
We completed this survey on those that came in for symptom management mostly due to many end of life being quite late stage.

We had 19 responses. 8 were completed by patients, 11 by their relatives. This was totally anonymous and returned in a sealed envelope advising that it would not affect their care.

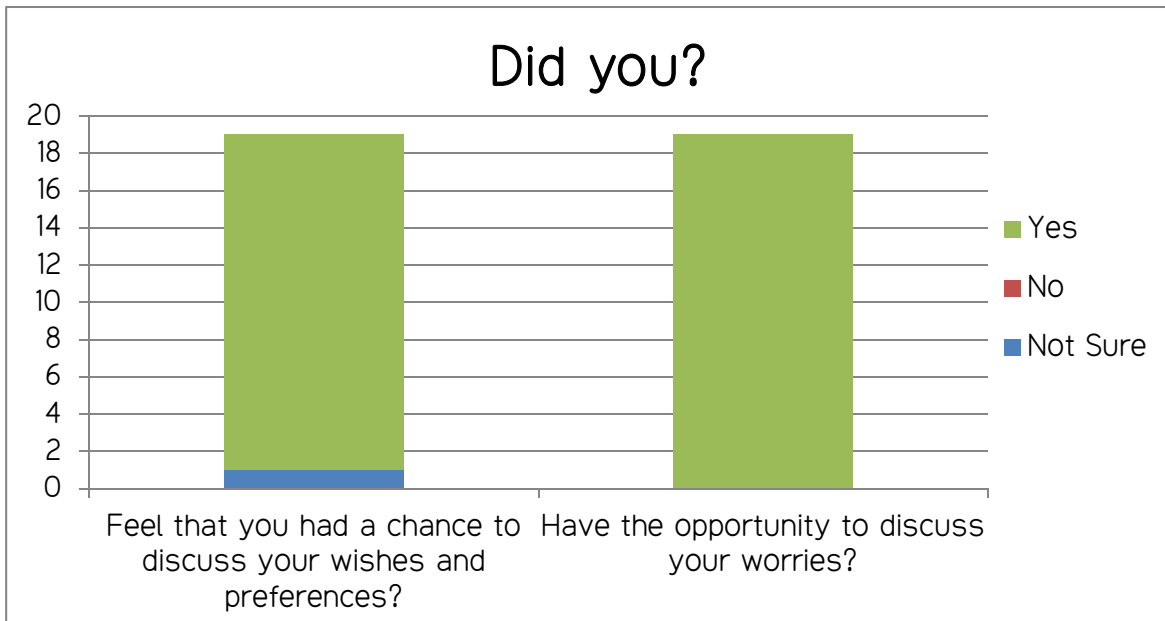
- x 100% advised that our admission process was smooth and well organised. A comment on difficulty with hospital transport was raised and we regularly raise any issues with the hospital directly.
- x Over a third of admissions advised that they were not given a patient pack and a further third were not sure. We are looking into how this can be made clearer.
- x Every person admitted understood the reasons for admission. However, some were not sure about what care would be provided. We are aware that this may have been if a relative was completing the survey and the patient hadn't wished to share the care plan with them.
- x We asked if our name badges could be read- a third advised they couldn't. We are looking into this.
- x 100% of those that responded would recommend us.
- x Proudly, everyone that responded felt treated with respect, dignity, privacy and compassion either always or most of the time.



The table below identifies some core items that we consider essential to a good admission. We are identifying ways to ensure that each of these items is considered when admitting and reviewing our admission process.



The table below demonstrates that the majority of those questioned felt that they had the opportunity to discuss their wishes, preferences and worries.

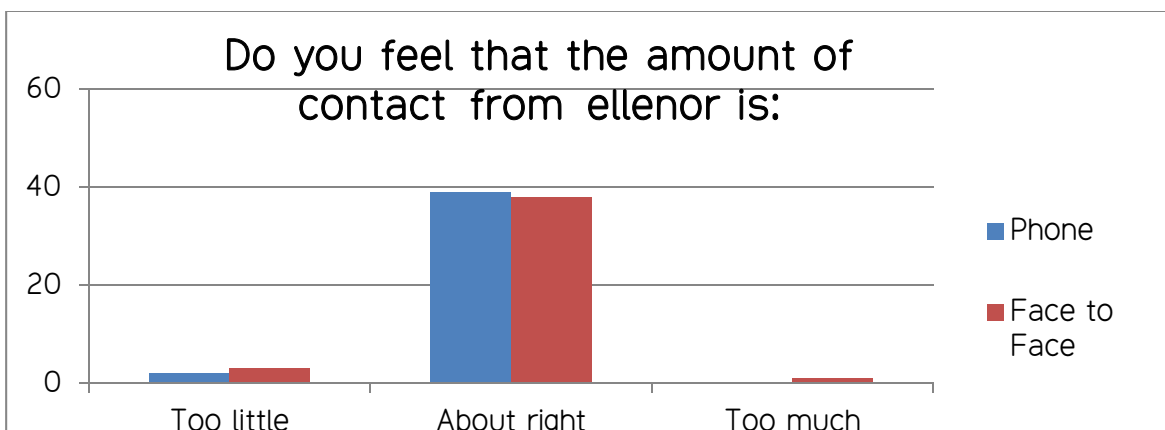


CHILDREN'S PROVISION CONSULTATION

We received 43 responses to this consultation. 60% of the respondents received our specialist nurse care and advice.

- x 64% of the respondents had used our out of hour's telephone service. All of those that had used it had found it helpful.
- x 30% of those that responded access our respite provision. Out of those that said they do not access it, two thirds advise that it would be something they would find useful.
- x We asked if they would be interested in attending a parent carers group and over 70% said yes or maybe dependant on times etc.

The table below identifies the feelings about the contact from our service to the families.



- x 86% of those that responded are satisfied with the support that they are currently receiving, with the remaining being mostly satisfied. Some positive comments are below:

My life would be very difficult if I didn't have the **ellenor** team. They are always there for me either face to face or a phone call away. The **ellenor** nurses are very caring and supportive they are fantastic.

ellenor have been a lifeline to us. A constant support helping fight our corner, liaising with medical professionals and helping with pain management. Couldn't be without you. Thank you.

All staff were very friendly, always on time and made you feel at ease.

Our **ellenor** nurse has always been available to help, assist or to put my mind at ease for any reason. She comes to the school to help with care plans and talks to the teachers about anything that would benefit my son with his transition back to school.

She is warm and caring, and always happy to see him, putting his mind at rest with any questions he might have, and include him with all she does with and for him. She lets him do things like make up his tray so he feels part of what is happening so it's better for him.

If she is unavailable at any time she always makes arrangements for someone else to come in her place, she tries to keep it to someone we know to keep the continuity of care.

She is lovely and made this al so much easier journey to be on. She is also helpful to me and encourages me to make sure I'm in the best frame of mind to take care of my son. She includes our other children too, and makes us feel like old friends.

ellenor are really helpful to me. Sometimes I don't know who to turn to when I have concerns with my son as I don't feel that everyone understands and the local hospital just don't seem like they want to know as they don't understand but **ellenor** are really supportive and help get things done and to get my son seen by the right people With their input the doctors listen more.

There is always someone at the end of the phone which is reassuring.

All the nurses are lovely and very caring towards the children; nothing is a problem you feel you can ask anything.

I couldn't do without the help from **ellenor**. The nurses are brilliant. Helpful, knowledgeable and always doing what they can to help.

The **ellenor** team visit is always inspiring, encouraging and comforting. I was also happy that they remember my baby's birthday even while in hospital and

she even sent her a birthday card right in the ward. I was very grateful about this.

I could not care for my child without the support of **ellenor**. My nurse is wonderful and gives me all the support & encouragement that I need to carry on. All the nurses in the team that I have met are very supportive and are always up to date on my child's care so there is always someone for me to talk to. I do not feel that any question I have to ask is considered silly and I am always treated respectfully.

I could not care for my child without the support of **ellenor**. My nurse is wonderful and gives me all the support & encouragement that I need to carry on.

The staff are very good at what they do. They seem very supportive and caring.

Cannot fault any of the services received from **ellenor**. Am always more than happy with the help and support provided by the team. So easy to talk to about absolutely anything and approachable. Always gets back to my calls/emails/questions so quickly. Has been a massive support to us recently with a situation with school. Am really pleased with the respite currently receiving too.

So friendly and didn't feel worried leaving my son with her at all. So happy to have **ellenor** to turn to whenever I need advice or support or just someone to talk to! Thank you all so much.

The staff are incredible and genuinely care about their patients/families!

The service we receive from **ellenor**, and in particular from our palliative care nurse is second to none. We don't know how we would cope without her!!

We as a family have relied upon the care and support from our **ellenor** nurses over the last 18 years. We have been very fortunate that our son has kept remarkably well for the most part of his life. Prognosis in the early stages was very grim but with the help and support of the **ellenor** team we are truly thankful for the 18 years we've had them on board.

Things will now have to change due to my child reaching adulthood, however I feel we would not be where we are today without the nurses love and dedication.

I am happy that I can always speak to someone any time of day or night if I am ever concerned about my child.

My daughters nurse is fantastic and makes us feel comfortable that if we ever

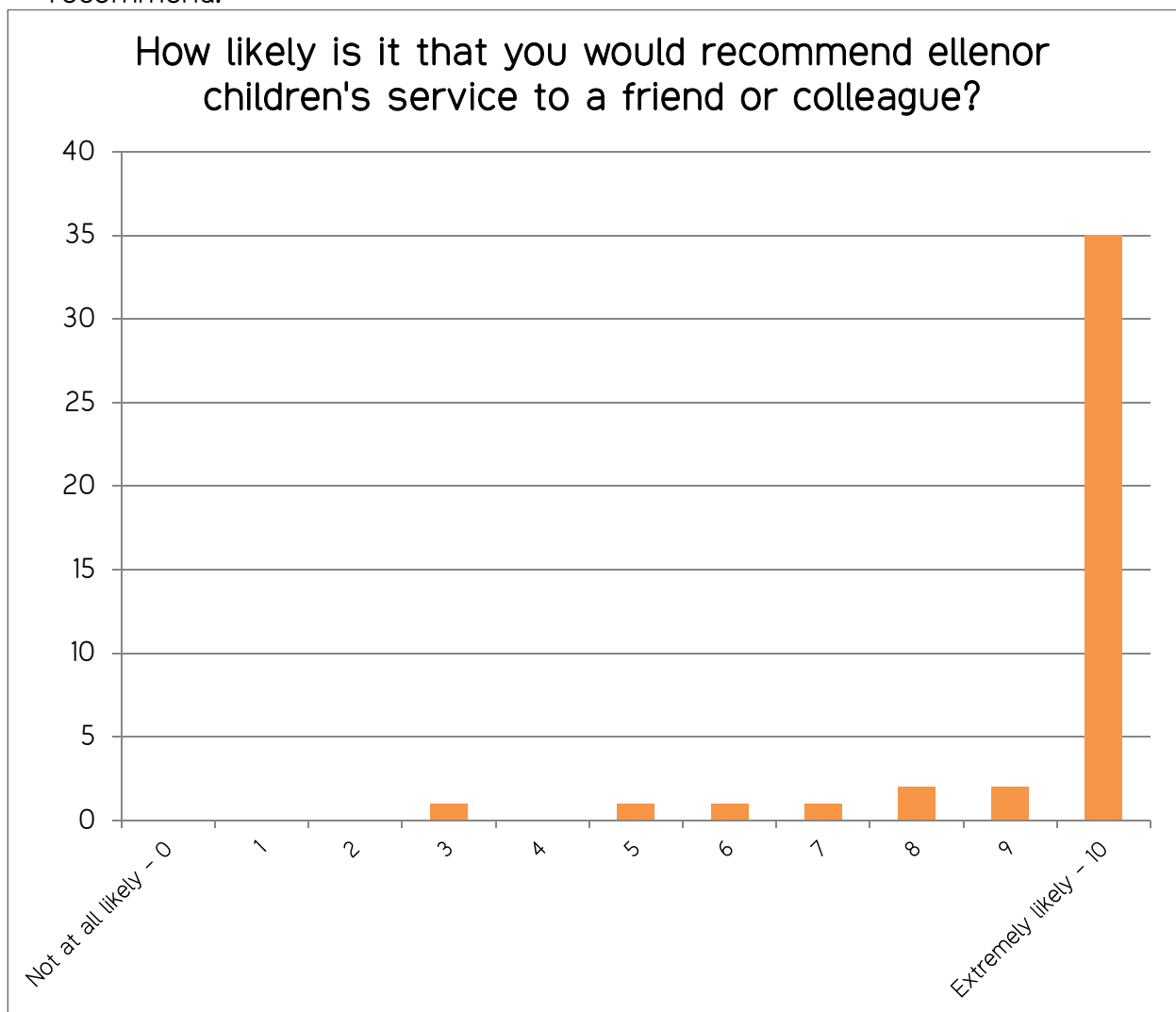
need her we can call any time. She has been a great support regarding visiting my daughters school to explain her illness and setting up some extra help with schooling.

It was a great comfort to have an **ellenor** nurse when your mind is full of questions and appointments and still having to carry on as a family.

Mainly have used **ellenor** nurses for my daughters blood tests at home, this has been a really useful service & the nurses are amazing & kind, not just for my daughter but for me to talk to somebody.

We have had so much support from **ellenor**. If I have a problem or don't understand what is going on I phone up and am able to speak to her nurse which has helped me a lot. It has helped us so much.

- x We asked our families to score us in a similar fashion to the "Friends and Family Test". 91% scored us at an 8-10 meaning very or extremely likely to recommend.



OUTREACH PROVISION

Throughout the year, we have been working hard to commence outreach clinics. We have a number of clinics including:

Swanley Link
Dartford Orchard
Blue water is commencing in May 2016

We are also liaising with the Sikh community and will be completing a questionnaire in conjunction with a leader in their community. This questionnaire is going to assist us in our understanding of what they would wish to access from **ellenor** and how we can help this part of our community.

CARERS SUPPORT & AWARD

ellenor recently had its pioneering work with carers recognised when it won an award from the NHS North Kent Clinical Commissioning Groups in the category of 'Empowering hard to reach groups'. The award was presented during a Patient Experience Shared Learning Event at the Hilton in Dartford.

The award particularly recognised the introduction by **ellenor** of its Carers' Cuppa initiative which was set up by the charity to provide support to carers, both caring for **ellenor** patients and others in the local community.



According to the Carers UK Manifesto, families are caring more than ever and many are finding it harder to get support – as the numbers able to access social care in England fall. Research has shown that full-time carers are more

than twice as likely to be in bad health as non-carers; half of carers say they have experienced depression after taking on a caring role; and 61% say they are at 'breaking point'.

Carers' Cuppa provides an opportunity for carers to come together in a safe and sociable environment where they can meet other carers, have a break and find out about accessing services which could provide further support to them in their role. **ellenor** work in partnership with Carers First and other local providers to ensure that people are signposted effectively.

There to collect the award was Terrie Marsh, who **ellenor** supported during her husband's illness, since his death and now runs some of the Carers' Cuppa groups. She put into words how **ellenor** has helped her.

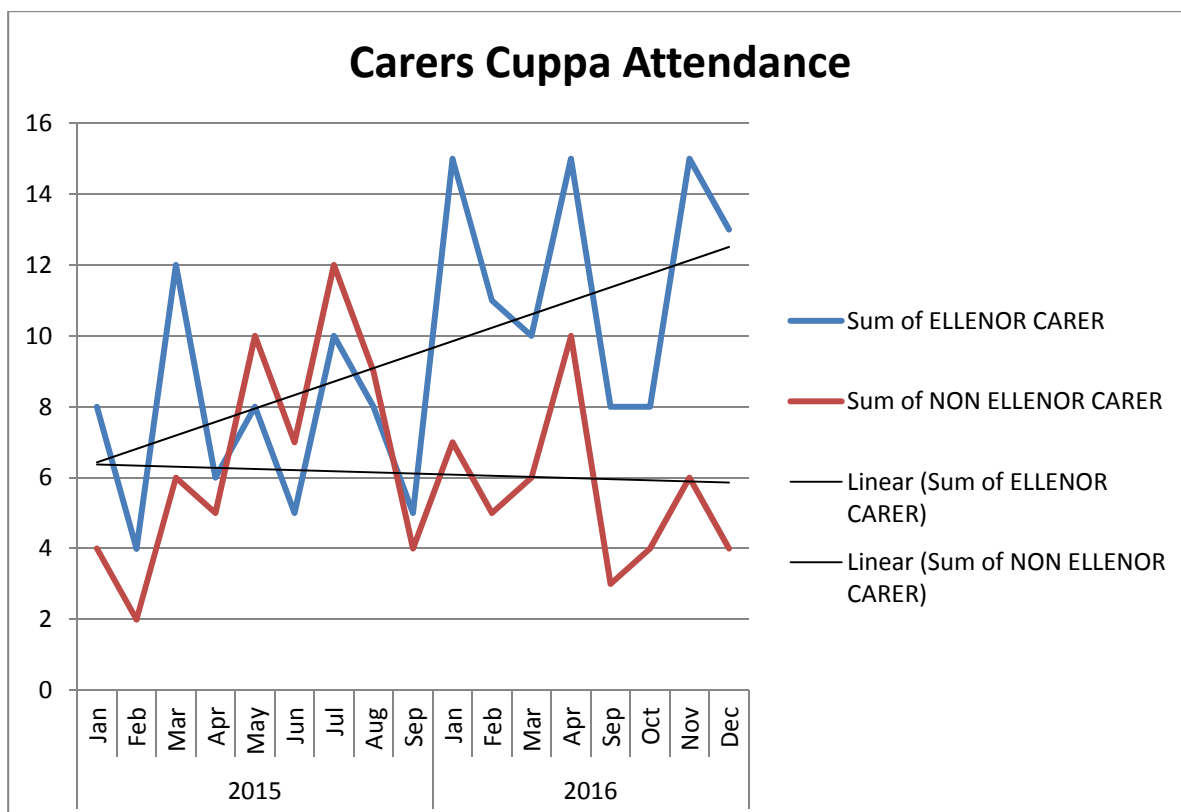
Words cannot express the feeling of absolute relief that we felt knowing that at last we were being supported and cared for by such a marvellous organisation. The knowledge gained during the 6 week carers course was shared with my husband and enabled us to talk openly about the challenges that lay ahead and the difficult decisions we were facing. The nurses helped and supported us through these very tearful days.

Carers Cuppa evolved after the course as all of us that had attended had voiced that it was an ideal opportunity for us to meet in a friendly secure environment, supported by the care team and each other. To be able to meet up gives us the chance to talk about our caring issues and fears with others that are in the same situation. Understanding the emotional rollercoaster that we are each travelling and the sometimes negative feelings that we have are not so unusual.

A few hours away from the home to relax a little is so important. I personally have made new friends and continue to gain knowledge support and advice from the other carer's and all the Hospice Staff. We are privileged to be able to have these meetings.

If I could sum up the Carers Cuppa it would be "A Cup Full of Care, Heaped up with Support"

Attendance at our carers cuppa drop in is increasing as identified in the table below. Non **ellenor** carer attendance remains static.



ellenor are about to launch a bereavement cuppa to support those past the death of their loved ones.

COMPLIMENTS AND THANK YOU'S

We receive a lot of compliments for our service, which all mean so much to the **ellenor** family. During the 2015–16 year, we received 137 compliments and over 70 Friends and Family cards. We value every comment received. Any negative comments are sent to the appropriate team manager and complaints follow the complaints process. We are also developing our NHS Choices profile to enable reviews.

It is hard to pick just a few for this, however:

The staff were so much more than just professional and caring. They have made a difficult time much easier for our loved one and all of us visiting. Thank you so much!

There are no adequate words to express my thanks to all the staff at the hospice for making mum's last few days peaceful and pain free. From the moment we spoke to you, the huge burden of seeing mum in so much pain and torment in the hospital was lifted, knowing she would now be looked after with the dignity she deserved. I feel blessed that she was taken into your care where she was treated the greatest respect. Also, a big thank you, for taking care of me, and my family. To have been able to stay with her day and night, right until the end was everything we wanted.

Just want to thank you for all your care for my sister and all the family. She was so comfortable there with you all, loved you all from the Dr/ nurses/ cook/ cleaners/ tea lady event the gardener who potted her rose. Nothing was too much trouble if she asked for anything it would be got! We have a very big hole in our family but knowing she passed away peacefully, being cared for so well is a great comfort. Thanks a million.

Thank you all for caring for her. You were always there for us, right up until mums last night when we really needed you. We are so grateful for all the care mum received from the nurses at such a difficult time.

We just wanted to express our heartfelt thanks for looking after our sister/ auntie both during her pain relief stay and during her final days with you. We are so grateful for the wonderful way in which she was cared for with loving kindness and also respect. You are all angels.

My entire family and I would like to extend our sincerest thanks for all of your love, care and the vast amount of support that you have given us during this difficult time of grief.

I'm so grateful for all your help and support as a service. I really would be lost without all the care and support. Also- everyone at **ellenor** is so much fun to be around. Truly wonderful caring people. Thank you!

I came along to the carer's course last year and started to come to the carer's cuppa group. We are made to feel so welcome and secure. I have made so many friends and we share our problems and experiences with each other. They have helped me to cope with some of the most difficult times of my life. It has made me become a person in my own right again.

Time has now passed since my husband's death. As a family, we want to express our thanks for the wonderful support and care you gave him over the last 18 months of his life. Each one of the team demonstrates outstanding empathy, kindness and care. We felt the Dr supported him in his final weeks on this earth, all those who visited our home and provided support via the phone- all helped to ease his emotional needs and that of family members. We have to say a special thank you to those who helped us through the final days- as well as those who worked so well with us as a family. It would be unfair not to mention the carer's course programme leaders, who prepared me so well for weeks and months ahead in the progression of his illness. Thank you to each and every one of you, we all hear of the wonderful work hospices deliver but it is not until it is experienced firsthand that one realises just how wonderful that is.

How can a simple card ever convey to you all the gratitude and love felt for all of you. He became part of your family for nearly two weeks before Christmas. For all the love and amazing support you gave us and all the family during this terrible time. You made us both feel safe in your care. Nothing was too much trouble. You truly are amazing people.

Our mum spent her last two days being cared for at the hospice. Thank you all so very much for making her stay so enjoyable- for her and us. Your kind words and calm presence in a difficult time were very much appreciated. From the lovely tea ladies, volunteers and nursing staff to the pastoral care. She was very scared at the idea of staying at the hospice but when she joined you, mum was relieved and glad that she was there. I'm sorry that I can't remember any names as much of the time went in a blur. Mum did remember you all however, and told us how caring and kind you were to her. She told us how a couple of carers had told her about her Catherine Tates 'Nanna' laugh. I'd already told her and showed her a video- she said she would calm it down! Thank you all again.

I am writing to thank all the very kind people who helped me through a very difficult time when my husband was very ill and wanted to stay at home. It was because of their wonderful help and also support from the carers that I was able to do this. It was very reassuring to have someone here to stay overnight so that I could get some sleep and I appreciated the many calls to check if I was alright. It really was first class support for me as well as my husband. I am enclosing a donation in the hope that it will help someone else who finds themselves in a similar situation.

I would like to thank you so very much for everything you have done for my mum. Not only have you looked after her every need and made her feel at ease, but you have given me time to stop being a carer and spend time with her as her daughter. This I cannot thank you enough for. You're amazing. Thank you.

Our **ellenor** nurse has always been available to help, assists or to put my mind at ease for any reason. She comes to the school to help with care plans and talks to the teachers about anything that would benefit my son with his transition back to school. She is warm and caring, and always happy to see him, putting his mind at rest with any questions he might have, and include him with all she does with and for him. She lets him do things like make up his tray so he feels part of what is happening so it's better for him. If she is unavailable at any time she always makes arrangements for someone else to come in her place, she tries to keep it to someone we know to keep the continuity of care. Our nurse is lovely and made this al so much easier journey to be on. She is also helpful to me and encourages me to make sure I'm in the best frame of mind to take care of my son. She includes our other children too, and makes us feel like old friends.

I could not care for my child without the support of **ellenor**. My nurse is wonderful and gives me all the support and encouragement that I need to carry on. All the nurses in the team that I have met are very supportive and are always up to date on my child's care so there is always someone for me to talk to. I do not feel that any question I have to ask is considered silly and I am always treated respectfully.

Thank you for all your help and support during my father's illness from the initial diagnosis to his passing in July. He loved his day-care visits and couldn't wait for Thursdays and when he was admitted he enjoyed the Jacuzzi. You really couldn't do enough to help both my father and myself. I really can't thank you enough for your compassion you all showed us as a family.

The whole atmosphere here is so supportive of family and friends.
Faultless!

FRIENDS AND FAMILY TEST

This was delivered and has been implemented at our Gravesend site. It is sporadic at Dartford. As you will see, though the responses are not in large quantities; those that we have received, have been mostly excellent. We are looking at how we can get more responses. We have introduced removal of non-care related cards (as the F&F card replaced comment cards) to ensure that this is only appropriately recorded for our care and support.

Friends & Family Test	Jan-16	Feb-16	Mar-16
FFT Responses	1	34	16
FFT % Excellent	100	91	94
FFT % Good	0	9	6
FFT % Average	0	0	0
FFT % Poor	0	0	0

F. Health Statements

As part of the requirements for the Quality Account, we are required to ask our commissioners and the local Healthwatch for a statement on our quality account.



**Dartford Gravesham and Swanley
Clinical Commissioning Group**

ELLENOR IS A PATIENT AND FAMILY CENTRED ORGANISATION WITH
PATIENT EXPERIENCE AND QUALITY AND SAFETY OF CARE BEING A
PRIORITY AND KEY FOCUS

NHS Dartford, Gravesham and Swanley (DGS) Clinical Commissioning Group (CCG) acknowledges the 2015/16 draft Quality Account submitted by **ellenor** and confirms that it has been reviewed against the Department of Health reporting requirements and as far as can be determined the commentary and data presented are an accurate and honest reflection of progress made in improved service delivery and patient outcomes. Below is the CCG statement in accordance with the National Health Service (Quality Accounts) Amendment Regulations 2012.

The Quality Account presents an overview of the quality priorities identified for improvement in their 2014/15 Quality Account; these being:

- Priority 1 – ‘reach more people in our area’ in which **ellenor** piloted and implemented their ‘one point of referral’ triage service which has assisted with a reduction in declined referrals and an increase in self-referrals.
- Priority 2 – ‘develop and deliver an accredited training model’ – **ellenor** are the first hospice in Kent to deliver an accredited Level 3 award in End of Life Care and Dementia training scheme for health and social care providers.
- Priority 3 – ‘improve our children’s hospice care respite provision’– following a period of consultation **ellenor** is piloting a revised respite referral framework to assist with offering an equitable service to all children on their caseload.

ellenor is a patient and family centred organisation with patient experience and quality and safety of care being a priority and key focus, this is evidenced in the results from national and internal patient experience surveys, together with their openness to learn and make changes resulting from both negative and positive feedback. In 2015/16 **ellenor** won an award at North Kent CCGs Patient Experience Shared Learning Event in the category ‘empowering hard to reach groups’ in recognition for the work they have done to support carers with the introduction of ‘Carers’ Cuppa’ initiative.

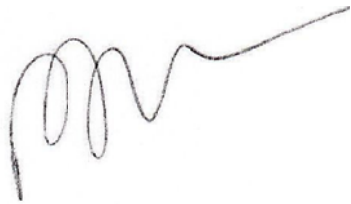
ellenor made improvements in many of the local clinical audits they undertook in 2015/16; in particular improving the quality and relevance of patient discharge information sent to GPs together with documenting patient’s end of life priorities. **ellenor** has identified the audit areas in which they wish to further improve; these include recording preferred place of care/death in patient records.

ellenor took part in research into palliative care in 2015/16 with the aims of enhancing the experience for patients and their families. **ellenor** are part of the Kent and Medway Research Group and have collaborated with other Kent adult hospices to jointly appoint a Research Practitioner. The collaborative group successfully won a bid with the National Institute for Health Research for continued funding of this role with the expectation the group will increase the number of patients participating in research from 12 to over 100 in year 1.

ellenor’s 2015/16 Quality Account outlines the key achievements and developments across the past year. The CCG are pleased to see **ellenor**’s progress in improving the quality of services they provide and the CCG supports the three priorities for service development and improvement for 2016/17, these being:

- Continued development of the wellbeing model of care;
- Development of the community outreach work and support for carers;
- Ensuring the quality and safety agenda are embedded throughout the organisation.

NHS DGS CCG look forward to continuing to work closely with **ellenor** to assure the quality of local services are maintained and to ensure the culture of continuous improvement is present throughout the organisation.



Patricia Davies
Accountable Officer
NHS Dartford, Gravesham & Swanley
and NHS Swale CCG



Gail Locock
Chief Nurse
NHS Dartford, Gravesham &
Swanley and NHS Swale CCG

NHS
Bexley
Clinical Commissioning Group

THE SERVICE IS OUTSTANDING. OF A HIGH QUALITY STANDARD AND GREAT VALUE FOR MONEY.

Bexley CCG commission one nurse from **ellenor** who delivers palliative care for children in the community with life limiting conditions. The service is outstanding, of a high quality standard and great value for money. Although Bexley CCG only funds one full time nurse **ellenor** provide from their funds an additional nurse; consultant support; equipment and any other costs associated to the child's care. **ellenor** provide the knowledge and skills for the care of the child at end of life, before death, at time of death and after death, and care of the family.

ellenor have evidenced to Bexley CCG that they have prevented the children in their care from being admitted into hospital through the interventions they have put in place in the home. The organisation gives full support to the families in the community and supports and trains them to a high standard to care for their children in the home. This empowers the family and gives them the reassurance and confidence to manage their child's condition, this means the child is not unsettled and the condition is not exasperated as they can remain in their own home and it reduces the need for them to access costly, high end services. **ellenor** collate satisfaction surveys and they always

achieve a good or outstanding standard for the care they provide. **ellenor** also support effective bereavement care, informed by a greater understanding of grief and loss.

The organisation supports the care and continuous professional development of all staff by advocating the importance of reflection and supervision and ensures they are up-skilled to develop a greater awareness of the regulatory and legal requirements after death with their teams. Finally **ellenor** do not work in isolation and work well in partnership they either refer or signpost to other services if they are unable to meet a particular need. They promote excellent communication between professionals and families and the wider sector, enabling the sharing of good local practice to the benefit of our families.

Jacqueline Skinner

Head of Children, Young People and Maternity Commissioning
London Borough of Bexley and Bexley Clinical Commissioning Group



FAMILIES DESCRIBE ELLENOR NURSES AS THEIR MAIN LIFELINE.

NHS West Kent Clinical Commissioning Group commissions Children's Community Services from **ellenor**. The service provides 24 hours support for children and their families and we receive excellent feedback on the services that our patients and families receive. Families describe **ellenor** nurses as their main lifeline. The nurses also provide a co-ordinating function to enable patient and their families to navigate around the healthcare system. The effectiveness of the 24 hour service is seen in a reduction in hospital admissions.

The **ellenor** Quality Account describes the commitment to patient and carers and the feedback included reflects this. The priorities for 2016/2017 will underpin **ellenor's** strive to continually improve the quality of their services.

Dr Steve Beaumont

Chief Nurse
NHS West Kent Clinical Commissioning Group

PATIENTS WHO TOOK PART IN THE SURVEY WERE EXTREMELY SATISFIED WITH THE CARE THEY RECEIVED

As the independent champion for the views of patients and social care users in Kent we have read the Quality Accounts with great interest.

Our role is to help patients and the public to get the best out of their local health and social care services and the Quality Account report is a key tool for enabling the public to understand how their services are being improved. With this in mind, we enlisted members of the public and Healthwatch staff and volunteers to read, digest and comment on your Quality Account to ensure we have a full and balanced commentary which represents the view of the public.

We are pleased that **ellenor** has listened to our input from last year and developed a summary for the Account, this should make it more accessible to people. There are some occasions when jargon is used which may confuse the reader (e.g. "Dashboard" and "KPI"). However, on the whole the document follows an improved structure from last year and is presented in a very readable way.

Progress on this year's priorities have been honestly reported with areas requiring further work and improvement clearly set out and influencing priorities for next year. Some of the successes include increased reach, work on a single point of referral and partnership with other organisations such as Carer's First.

It appears there has also been some good work undertaken to engage with hard to reach groups. Preferences about where these patients would like to access their care have been listened to.

We welcome how patient views have been sought about the inpatient care they have received. This has established some clear priorities for improvement including larger name badges and ensuring information for patients is being given out across the board. While the inpatient survey is largely positive, Healthwatch Kent would like to understand how **ellenor** plans to improve the way patients are made aware of the complaints policy. While it seems patients who took part in the survey were extremely satisfied with the care they received it is really important that they, and their family members, are aware of how to give feedback about their experiences, even if they don't want to make a complaint.

Finally, we would be interested to hear from **ellenor** about any issues around patient transport as this is one of our own priorities this year. We will shortly

be publishing our own report on End of Life Care which **ellenor** were involved with. The report will detail the experiences of patients and families and we would like to thank **ellenor** for their support in this work.

Healthwatch Kent June 2016

CHANGES POST STATEMENTS

Small grammatical changes were made following these statements which have made no material changes to the document. A summary document is available separately.

END OF QUALITY ACCOUNT