

Quality Account 2016-17



Structure and Contents of the Quality Account

The Quality Account has a structure prescribed by NHS England: Parts 1 and 2 comprise elements that meet *national* regulations, and include statements *common* to all providers. Part 3 is for *local* determination and comprises a review of quality performance in relation to the *specific* organisation and its operating context.

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Part 1: Statement of Assurance from the Chief Executive on behalf of the Board

Who we are and who we serve

Helen & Douglas House is a hospice service which provides specialist palliative and supportive care to young people 0-35 years of age: babies, infants, children, teenagers and young adults. We also support the families and carers of these young people through their shortened life, through their death, and in bereavement. In-patient care is provided in two hospice houses on a joint site in east Oxford: Helen House (children's services 0-18 years); Douglas House (young adult care 16-35 years). Paediatric outreach care is provided within Oxfordshire and surrounding counties, in partnership with hospital and community teams.

Helen & Douglas House is a registered charity based in Oxford and has been providing palliative care for 35 years. We serve a wide geographical area centred on the Thames Valley but extend care to patients from many counties and Clinical Commissioning Groups in response to the needs of the population, and reflective of our level of expertise and experience. We work in close partnership with professionals in hospital and community settings to provide coordinated care, alongside the public sector and other voluntary services.

Whilst our primary focus is on the direct delivery of care, Helen & Douglas House has an active profile in regional and national forums relevant to palliative and supportive care for children and young adults – seeking to improve practice, structural delivery and funding of services to this population.

Our Commitment to Service Quality and to Continual Improvement

Quality of individualised care has always been at the heart of what Helen & Douglas House is about. For many years we have delivered, and played a leading role in the development of, excellent care for the people we serve.

Over time the complexity of care needs for many patients has increased, in line with medical and technological advances. We have continually striven to respond to evolving clinical needs and to develop our services accordingly, whilst maintaining an ethos of person-centred care that is provided within an enabling culture and environment. The value of this approach is affirmed by our service users, many of whom have long-term contact with the organisation.

Very sadly, in May 2016, a young adult who had been cared for at Douglas House, died unexpectedly. We fully acknowledge the tragedy for the family involved, and continue to do all we can to support associated investigations, learning and improvements to understanding and practice. As well as working with statutory bodies and scrutinising our own practice to enhance the robustness of our clinical practice, we have also been open in sharing our experiences and learnings with other providers in our sector, who may equally be exposed to similar risks.

This Serious Incident, and subsequent CQC inspection, have necessarily informed and influenced our quality agenda. We have made solid progress in securing required improvements and have worked with the support of the Designated Nurse and Safeguarding Lead from Oxfordshire Clinical Commissioning Group in the fulfilment of our CQC action plan.

Service users have expressed an overwhelming desire and commitment to continue accessing our services following notification of the incident and of the CQC findings, reflective of their experience of high quality care at Helen & Douglas House. We have supported a similar number of people to last year (2015-16), across the breadth of our service areas.

As part of our drive for continual improvement, an on-going programme is in place to enhance patient safety, clinical effectiveness and user experience. In order to effect some of the necessary changes in 2016-17, our in-patient respite bed capacity was temporarily reduced to allow workforce capacity to implement improvements to practice. Workforce capacity has also been constrained by recruitment challenges, particularly for registered nurses, reflective of both the local and national situations.

We have continued to move forward in line with the priorities of our new organisational strategy which was launched to staff in June 2016. Our aims for the five-year period support the continual development of high quality, effective services, including at a Specialist level:

- To deliver high quality of care and continue to develop as a Specialist level provider.
- To provide care and support to more people.
- To improve efficiency.
- To enhance impact, develop and demonstrate the difference we make.
- To achieve financial sustainability.
- To enhance organisational accountability and governance.

Priority in 2016-17 has been on quality, financial sustainability, and enhancing organisational governance frameworks. Funding – through voluntary donation, retail, and commissioning contribution – remains a significant and persistent challenge, necessitating a review of frontline and supporting services in the coming year. At the same time, as both a healthcare provider and a fundraising charity, the overheads associated with increases in sector regulation and scrutiny present on-going challenges.

Amidst such challenges, I am proud of the commitment and resolve demonstrated by staff and volunteers across the organisation to continually review and enhance the quality of our care. Such commitment is echoed across our clinical and non-clinical teams as together we seek to enable and promote the specialist, individualised care that our patients and families need and value.

The Quality Account

This is the organisation's fourth published Quality Account. The Quality Account is a means by which we are able to share information publicly about the quality of care we provide, in a format common to other providers of services to the NHS. It is an assessment of the quality of our healthcare services in the form of an annual report, demonstrating evidence of our achievements in the past year and our commitment to excellence through our quality improvement priorities.

This report has been prepared jointly by the Director of Clinical Services and the Associate Director - Strategy, and is endorsed by the Board.

To the best of my knowledge the information reported in this Quality Account is an accurate and fair representation of the quality of healthcare services provided by Helen & Douglas House.



Clare Periton
Chief Executive Officer
June 2017

Part 2: Priorities for Improvement and Statements of Assurance from the Board

Priorities for Improvement

Evaluation of 2016-17 Priorities

At the start of 2016-17, seven areas for improvement were identified. During the year our priorities were re-evaluated in light of a Serious Incident and associated recommendations. Progress is described below within both of these contexts, and as a background to the setting of our priorities for 2017-18.

Evaluation of Progress made against the 2016-17 Priorities

The NHS considers the three key domains of *Patient Safety*, *Clinical Effectiveness* and *Patient Experience* when describing the quality of care. Priorities are described in line with these domains.

Patient Safety: Infection Prevention and Control – continued focus.

The prevention and control of infections is necessarily an on-going priority. Whilst no provider-acquired infections have been identified during 2016-17, continuous good practice is a pre-requisite for good quality care and this will remain on our agenda for sustained focus.

Patient Safety: Mental Capacity Assessments and Deprivation of Liberty Safeguards (DoLS) – staff awareness and understanding.

This has become an established part of Safeguarding training. The processes around identification, evaluation and submissions of DoLS assessments are in place and being incorporated into working practice. The initial work to raise awareness and establish processes has been completed; this is no longer a priority for improvement as DoLS becomes part of “business as usual”.

Clinical Effectiveness: Mandatory Training – additional courses, streamlined processes, and enhanced staff access.

Significant work was undertaken at the start of 2016-17 to redesign the training framework in order to improve access for staff and enable more effective monitoring and management of compliance. As a result of this focus, compliance rates have shown sustained improvement and systems are in place to enable effective on-going review. This priority was successfully achieved in 2016-17.

Clinical Effectiveness: Information Governance (IG) – improvement throughout the organisation.

The organisation has continued to make progress against its IG Improvement Plan, and awareness of IG issues amongst staff continues to grow – as evidenced through the reporting of IG incidents (actual/potential).

There are two IG requirements against which we are not rated at Level 2 compliance at the end of 2016-17. One is a new IG requirement (14-322) introduced within the year against which work is in progress; the other (14-325) concerns the security of an older IT server – however, the risk the organisation is assessed as very low and is being actively managed.

Clinical Effectiveness & Patient Experience: Outcomes Measures – for children’s and young people’s hospice care.

Helen & Douglas House has taken a leading role within a working group of children’s hospices considering approaches and frameworks for the assessment of patient outcomes. Through this process it was recognised that *patient-defined* outcomes are rarely captured and reviewed systematically – there being opportunity to utilise this information to enhance quality of care and local service delivery, and to inform priorities. Helen & Douglas House is developing revised care planning documentation and processes within which self-defined outcomes can be captured and evaluated.

*Patient Experience: **Enablement Project*** for young people.

This project reflects our on-going approach to respite care, particularly with young adults at Douglas House. Staff changes and priorities during 2016-17 have meant that project work has not made the anticipated progress during the year. However, enablement remains a key dimension in our approach to care – as reflected strategically in our organisational vision (“*Every life a full life; every death a dignified death*”) and operationally in the on-going review and development of enhanced care planning processes.

*Patient Experience: **Real-time, continuous feedback*** via interactive, electronic tool.

The aim of this project is to enhance the range of tools available for patients and families to be able to feed back on their experiences. The piloting of this project has not progressed during 2016-17 due to emerging priorities during the year. Existing feedback mechanisms have remained in place for service users and this is reported on later in the Quality Account.

Serious Incident

In May 2016 there was a Serious Incident concerning the unexpected death of a young adult who was ventilated via a tracheostomy. Due to the nature of the incident there has been a Police investigation and reference to the Coroner to determine the cause of death. The Coroner’s verdict remains outstanding at the time of publication of this report. Helen & Douglas House has cooperated throughout with statutory bodies including the local adult Safeguarding Board.

In June 2016 Helen & Douglas House commissioned an independent Root Cause Analysis (RCA) into the Serious Incident; the RCA commenced following the conclusion of the initial Police investigation. Recommendations from the RCA have been incorporated into an on-going development programme within the hospice. Externally, key findings/learnings from the RCA have been shared with commissioners, and within the wider hospice sector.

In December 2016 the CQC undertook a focused inspection of the hospice with reference to the Serious Incident. The subsequent CQC report found shortcomings with regard to patient safety and a warning notice was issued in January 2017. The inspection pointed to improvements in two key areas (i) care planning and risk assessments, and (ii) maintaining an organisational overview of the training matrix for clinical staff to ensure safe rostering, reflective of patient needs. An immediate action plan was established and associated changes were implemented during the following days and weeks. Full implementation of the CQC action plan has been overseen and supported by the Designated Nurse and Safeguarding Lead at Oxfordshire Clinical Commissioning Group.

In addition to the immediate items actioned following the CQC findings, Helen & Douglas House has established a longer-term programme to embed learning and improved practices with staff, and to review processes around patient referral and admission. This programme extends in to 2017-18.

In regard to both the Serious Incident and the CQC inspection findings, Helen & Douglas House actively notified patients and families, relevant care professionals, commissioners and other stakeholders – with reference to the Duty of Candour, the NHS England Serious Incident Framework, and requirements of local commissioning agreements.

Priorities for Improvement 2017-18

Our priorities for clinical quality improvement in the coming financial year build on experiences from 2016-17. The number of priorities is reduced from previous years but their scope is enlarged (in extent and/or duration).

*Patient Safety and Clinical Effectiveness: review of **Patient Referral and Admissions Processes.***

This review aims to ensure that the extent of each patient's care needs can be safely and effectively met by the staff skill-mix at Helen & Douglas house (or in partnership with external carers). This is anticipated to be a large part of the workload in 2017-18 to ensure the processes are appropriate for both the service users and the professionals involved.

*Clinical Effectiveness: review of **Service Delivery Models and Partnership Working.***

Service models are continually under review to ensure their effectiveness in response to emerging needs, changing care landscapes, and affordability. Organisational restructure in early 2017-18 is necessitating a more thorough review of care models to ensure efficiency and effectiveness – particularly around family support and clinical administration. Consideration and development of partnership working is an essential element of such review to ensure services are sustainable, appropriate and of high quality, and to enable organisations to play to their respective key strengths. Partnership working, in support of more integrated and effective care, is a key strand of our organisational strategy (2016-21).

*Clinical Effectiveness: review of **Frameworks for Clinical Competency and Workforce Training.***

The assessment framework for nurse competency has been identified as a specific improvement project during 2016-17. Initial work has included a comprehensive nurse self-assessment and review programme in the final quarter of 2016-17. This is informing an on-going training needs analysis and associated training plan. Progress will be monitored through annual competency assessment processes.

*Patient Experience: review effectiveness of **Revised Care Planning Approach.***

As procedures are developed in 2017-18 to enhance care planning and refine the referral and admissions processes, it is important to understand the impact of changes on our service users. In addition to continuous feedback and review with patients and families, a user survey is planned for 2017-18 as a more formal opportunity to capture patient experiences in response to specific developments made.

All of these priorities are related and aim to improve the overall quality of our care – particularly around patient safety, care planning and competence. This needs to be achieved under a sustainable model of care, with appropriate integration of services around patients and families.

Statements of Assurance from the Board

This section includes statements that all providers must include as part of their Quality Account. Some statements are less applicable to providers of specialist palliative care, such as Helen & Douglas House; where this is the case a brief explanation is included.

Review of Services

Services Provided

During 2016-17 Helen & Douglas House provided specialist palliative care services to children and young adults (0-35 years), and supportive care to their families – in line with its charitable objects and service agreements with the NHS. The organisational mission is:

- To enable young people (0-35 years) with life-shortening conditions to live as well and as fully as possible to the end of their lives, and to support their needs and wishes at the time of their death.
- To provide palliative care at a specialist level for young people, through medical and nursing expertise, emotional and practical support.
- To support the families and carers of young people through their shortened life, through their death, and into bereavement.
- To be a regional centre of excellence in palliative care, based in Oxford, working closely with professionals in hospitals and in the community, to plan and provide local support tailored to individual needs.

In delivery of the mission, Helen & Douglas House has provided specialist palliative and supportive care via an interdisciplinary team that includes consultants in palliative medicine (paediatric and adult) alongside registered nurses, care workers, specialist therapists (physiotherapy, occupational, music, complementary), clinical psychologist, social worker, teacher, chaplain and counsellors. Specialist trained volunteers have increasingly supported the holistic care of patients and families as a complement to contracted staff, enabling the achievement of a higher quality and more responsive experience for service users beyond their clinical needs.

In-patient services are provided at the two hospice houses (Helen House (0-18 years) and Douglas House (16-35 years)). These are age-appropriate environments equipped to a high standard in support of patients' and families' holistic needs.

Specialist clinical care is also delivered "out of house" in local communities and hospital settings, to support families and professionals in their provision of more complex palliative care in those environments. Psychological and practical support is offered to families through one-to-one and group interactions that take place at the hospice, in families' local settings, and at external venues.

Services provided include:

- Symptom management (routine and complex).
- Medically-supported short-break respite (at the hospice).
- Stepped-discharge from hospital to the hospice to manage patients' return home (reducing avoidable hospital stays).
- Emergency care (for medical or social emergencies, or for lack of capacity and expertise in public sector provision).
- Day care (in-house) and home visits.

- End-of-life care.
- 24-hour telephone support for patients, families and professionals for symptom management and end-of-life care.
- Specialist medical and clinical advice to NHS hospital and community teams, and to other hospice care providers.
- Care coordination and planning (including Advance Care Planning).
- Physiotherapy, occupational, music and complementary therapies to support individuals' development, enable greater independence, and improve quality of life.
- Psychological, spiritual and bereavement support for patients and families/carers, including siblings.
- Advocacy for service users (patients and families).
- Practical help for families (via a supported volunteer service run by the hospice).
- Strategic contributions to the development of paediatric and young adult palliative care.

In December 2016, NICE published its Guideline on *End of life care for infants, children and young people with life-limiting conditions*. The development team for this NICE Guideline included two members of staff from Helen & Douglas House (a medical and a nurse consultant).

Helen & Douglas House has reviewed all the data available to us on the quality of care in these services.

Commissioning of Services

The requirement for non-NHS organisations to produce a Quality Account is based on their delivery of services under NHS contract. It is therefore pertinent to outline the nature and extent of commissioning agreements in place, and the level of funding received to support quality service delivery and development.

For those who need to be cared for or supported by Helen & Douglas House, services are provided free of charge to the beneficiary.

Our services are funded through a combination of fundraised income/voluntary donation, shops and lottery, and negotiated contributions from public sector bodies (health and social care). Where a public sector contribution is made, this is only ever a partial contribution to the cost of an individual's care at the hospice. For the year 2016-17 public sector contributions to care represented less than 12% of the hospice's total expenditure on care services (patient care, family and bereavement support).

There are wide variations in engagement, approach to and levels of funding, between different commissioners across the c. 50 NHS health commissioning bodies represented by our patient caseload. The commissioning landscape is complex and relatively few CCGs and Local Authorities have formal commissioning arrangements with us. This leaves us with a lack of any direct funding for a significant portion of our work (including cases referred to us by the NHS/statutory services) and contributes significantly to the challenges of financial sustainability for the hospice.

Like other children's hospice services in England, Helen & Douglas House is in receipt of a central NHS England Children's Hospice Grant. In our case, the grant is equivalent to just over 5% of the hospice's total expenditure on patient care services for children and young adults (2016-17).

At present we receive no NHS funding for *Specialised* medical care (Level 4 palliative medicine), despite there being no local provision via the NHS.

We receive no Short Break funding from Local Authorities.

Aside from the funding contributions received for direct patient care, Helen & Douglas House receives no public sector funding for the supportive care provided to family members and carers – during a patient’s life and in bereavement.

Participation in Clinical Audits

National Clinical Audits

During 2016-17 Helen & Douglas House did not participate in any national clinical audits or national confidential enquiries as there were none that related to specialist palliative care.

Local and In-House Clinical Audits – Frameworks for the Assessment of the Quality of Care

Within Helen & Douglas House, quality of care is monitored throughout the year via a governance framework which includes regular Executive Team meetings, monthly Clinical Governance meetings, Quality of Care Trustee Sub-Committee meetings that feed in to the main Trustee Board, and an annual schedule of clinical audits. Organisational and clinical risk registers facilitate the identification, assessment and management of key corporate risks. Risk assessments are also conducted in relation to procedures, equipment and activities, and as part of care planning procedures with each patient. A review of clinical skills has been carried out with all of our registered nurses to inform a training needs analysis and subsequent development programme, which will support the safe rostering of staff in line with known patient needs.

Staff and service users are encouraged to report any concerns, incidents or exceptional practice (good or bad) within a supportive and open management culture. *A Freedom to Speak Up Guardian* has been appointed during the year to promote and support existing practice and processes.

The assessment of clinical quality is driven through a comprehensive audit programme managed by the Clinical Governance Lead/Director of Clinical Services in support of legislative and regulatory requirements, and clinical best practice. High quality clinical practice is supported by a suite of organisational policies and guidelines which are reviewed regularly to reflect changing requirements. National and local quality requirements are also defined within NHS Standard Contracts, which provide a framework for external reporting. (See Appendix 2.)

User experience feedback is encouraged on a continuous informal basis through our model of individualised care and through feedback postcards. More structured surveys and consultations are also initiated on a periodic basis and according to need. Key outcomes from user experience evaluations are outlined in Part 3 of the Quality Account.

Commitment to Research as a Driver for Improving the Quality of Care and Patient Experience

Helen & Douglas House continues to demonstrate a high level of commitment to research, as a key way to continually improve the care services offered. All members of staff are encouraged and supported to be involved in research at a level appropriate to their role and experience – through daily practice, in-house training and forums, specific projects and university-based courses. This is particularly true of the clinical teams.

Fortnightly research forum sessions are open to all staff to explore pertinent issues through discussion and reflection. Topics have included compassion, resilience, and emotion/hope in the hospice setting; other sessions have focused on practical skills such as critical thinking and planning your own learning.

This year, research projects carried out at Helen & Douglas House included:

- A qualitative evaluation of the support offered by the Family Support and Bereavement Team. (A summary of findings is presented in Part 3 of this Quality Account, under Patient Experience.)
- An exploration of the experience of young adults with life-limiting conditions in finding employment.
- Evaluating the value of a tool (Voicing My CHOICES) in end of life conversations with young men with Duchenne Muscular Dystrophy.

Research proposals involving Helen & Douglas House staff, patients, and families require consideration by an internal Ethics Committee. In 2016-17, one external project and one internal research project were approved by the committee.

Staff at Helen & Douglas House have also had work accepted for publication (3), and shared their innovative work through presentations (1) and posters (5) at national/international conferences, workshops and study days. In addition, we have externally offered specialist teaching on bespoke days, and within other courses.

The number of patients receiving services (funded by the NHS) provided or sub-contracted by Helen & Douglas House in 2016-17 that were recruited during that period to participate in research approved by a research ethics committee was zero. This statement refers to research approved by a research ethics committee within the National Research Ethics Service; Helen & Douglas House is not aware of any of its patients that were involved in any such research.

Goals Agreed with Commissioners

Use of CQUIN Payment Framework

Helen & Douglas House income in 2016-17 was not conditional on achieving quality improvement and innovation goals through the Commissioning for Quality and Innovation payment framework. NHS funding is only ever a contribution towards cost of care and, ultimately, commissioners did not consider it appropriate to include in NHS Standard Contracts.

What Others Say about Us

Care Quality Commission

Registration and Actions

Helen & Douglas House is required to register with the Care Quality Commission (CQC). The CQC imposed a condition on our registration for the regulated activity of Nursing Care, following a focused inspection on 6th December 2016. The condition remained in place as at 31 March 2017.

Pursuant to Section 12(5) (b) of the Health and Social Care Act 2008 the following condition on registration was imposed:

- The registered provider must undertake an audit of the care plans which will include risk assessments of residents at Helen and Douglas House 14A Magdalene Road, Oxford, Oxfordshire, OX4 1RW and send to the Care Quality Commission a copy of written report of the result of the audit and any action taken or to be taken as a result of the audit by 03 February 2016 and thereafter such reports to be sent on the last Friday of each calendar month a report on the actions taken or to be taken as a result of care plan audits.

The CQC has taken the following enforcement actions against Helen & Douglas House during 2016-17, consequent to the inspection of 6th December 2016:

Regulation 12 HSCA RA Regulations 2014 Safe care and treatment [Regulation 12 (2) (a) (c)].

- People did not always have risk assessments and risk management plans in place.
- People's care plan records were not always up to date.
- The provider had no clear process of ensuring staff were familiar with different breathing equipment.

Enforcement action: *Warning notice.*

Regulation 17 HSCA RA Regulations 2014 Good governance [Regulation 17 (1)].

- The provider's quality assurance systems were not always effective at identifying risks and driving improvements.

Enforcement action: *Positive condition. Service to send regular audits.*

Inspection Findings

In December 2015 the CQC conducted a full inspection of Helen & Douglas House. The service was rated "Good" in all five domains, with no recommendations for improvement.

On 6th December 2016 we received an unannounced focused inspection by the CQC looking at the *safe* and *well led* domains, in connection with the Serious Incident of the previous May. As stated in the CQC report (published 8th February 2017):

"This inspection was prompted in part by a notification of a significant incident. The information shared with CQC about the incident indicated potential concerns about the management of risks in relation to medical equipment. This inspection examined those risks and reported on the findings in the safe and well led domains."

Ratings were issued for the two inspected domains (below), but no overall rating for the service was made on this inspection.

The following table summarises the inspection findings, extracted from the CQC report.

<p>Is the service safe?</p> <p>The service was not always safe.</p> <p>Risks to people were not always managed and assessments were not always in place to manage the risks and keep people safe.</p> <p>People's care plans were not always current and did not always reflect changes.</p> <p>People were protected from the risk of abuse as staff had a good understanding of safeguarding procedures. Safeguarding was embedded into everyday practice.</p>	<p>Inadequate ●</p>
<p>Is the service well-led?</p> <p>The service was not as well led as it should be.</p> <p>The provider had quality assurance systems in place. However, these were not always effective at identifying risks and driving improvements.</p> <p>Accidents and incidents were managed safely and learning was shared across the board.</p> <p>Transitioning of care between services was effective and ensured consistency.</p> <p>There was a clear leadership structure.</p>	<p>Requires Improvement ●</p>

Two breaches of the Health and Social Care Act 2008 (Regulated Activity) Regulation 2014 were identified by the CQC, as detailed at the beginning of this section.

Full details of this and the previous inspection report can be found on the CQC website (<http://www.cqc.org.uk/location/1-1731744597/reports>).

Helen & Douglas House has cooperated fully with the CQC in addressing their concerns and in complying with the condition imposed. All actions agreed with the CQC have been completed. The CQC has made a subsequent full inspection of the hospice (6 June 2017), from which the formal report is outstanding at the time of publication of this Quality Account.

Data Quality

Statement and Actions to Improve Data Quality

Helen & Douglas House acknowledges the importance of good quality information in supporting the effective delivery of patient care and improvements to services. Actions during 2016-17 include items identified in the 2015-16 Quality Account and, in turn, inform priorities for the forthcoming year (2017-18).

Priority	Action & Progress in 2016-17	Plan for 2017-18
<p>Activity data:</p> <p>Extension of the standardised reporting of performance data across additional areas of hospice activity.</p>	<p>Continued improvements achieved in data consistency, quality and timeliness.</p> <p>Data for non-in-patient activity (Outreach and Family Support) captured with greater consistency.</p> <p>Clinical activity dashboard extended.</p>	<p>Continued improvement to streamline processes and ensure consistency of data capture across all clinical functions.</p>
<p>Information Governance:</p> <p>Continued implementation of the Information Governance Improvement Plan (IGIP).</p>	<p>Incremental improvement against IG Toolkit standards. One item remains outstanding at Level 1 compliance – this has been assessed and managed as very low risk. One item is new this year on the Toolkit; work is in process to achieve compliance.</p> <p>Increased staff awareness of IG and reporting of incidents (actual & potential).</p>	<p>Continued implementation of IGIP and review against IG Toolkit standards.</p> <p>Achievement of minimum Level 2 compliance against all requirements.</p>
<p>User Experience and Outcomes:</p> <p>Review and development of feedback mechanisms to capture user experience, evaluate and demonstrate outcomes, and inform on-going improvement.</p>	<p>Continued use of existing feedback mechanisms.</p> <p>Implementation of a tablet-based tool for user engagement “on hold”.</p> <p>Draft outcomes framework/ considerations for children’s hospice care in development.</p>	<p>Evaluation of patient experience and outcomes as a result of new care planning procedures.</p> <p>Re-scheduling implementation of tablet-based tool for gathering feedback.</p> <p>Biannual user survey.</p>
<p>Monitoring and Management of Staff & Volunteer Data:</p> <p>Consolidation of administrative data function to improve monitoring and management of workforce data.</p>	<p>Successful implementation of Human Resources Information System (HRIS) and associated workforce data.</p> <p>Improved visibility and management of training compliance.</p>	<p>Extension of HRIS implementation and visibility of key data to managers to support timely and effective workforce & organisational performance management.</p>

NHS Number and General Medical Practice Code Validity

Helen & Douglas House did not submit records during 2016-17 to the Secondary Uses service for inclusion in the Hospital Episodes Statistics which are included in the latest published data. Helen & Douglas House is not eligible to participate in this scheme.

Clinical Coding Error Rate

Helen & Douglas House was not subject to the Payment by Results clinical coding audit during the 2016-17 by the Audit Commission.

Part 3: Review of Quality Performance

Hospice Caseload and Activity during 2016-17

Patient Caseload

Referrals to Helen & Douglas House can be made by anyone with the permission of the patient/family. Referrals may be made for urgent care (symptom management, end-of-life), for step-down care between hospital and home, for respite – or for a combination of these.

New referrals are assessed against well-established criteria to ascertain eligibility for hospice care. *Emergency* referrals can often be facilitated within 24 hours when needed. Where there is opportunity to assess patients for less urgent *planned* care, the assessment process includes liaison with the patient’s current practitioners, understanding of their medical history and records (with necessary consent). The assessment process is two-way, with both the individual and the hospice deciding whether they wish to proceed at this time. On occasion, it may be necessary to decline patients who, although they meet the criteria to access the hospice service, have care needs beyond the scope of the competence of the majority of the staff at Helen & Douglas House.

For some patients, acceptance will be followed by an urgent admission or by a programme of planned care of symptom management or respite. Other patients, typically with high fragility, may be accepted onto the caseload in anticipation of an urgent admission should their condition deteriorate and hospice care be appropriate at that time. The total “open” caseload therefore comprises a majority to whom direct care and support is provided, and a number for whom there is a watching brief and to whom varying degrees of support or advice may be given as part of their network of professional care.

Patients cease to be part of the caseload if their condition or symptoms improve to an extent that hospice care becomes less appropriate at this stage, if they die, or if they move out of the catchment, no longer wish to attend, or choose to access another hospice for inpatient respite care. Each patient is formally reviewed at least annually to assess their on-going needs and access to services. Any decision by the hospice to reduce or withdraw access to its service is made as part of a planned process in full discussion with the patient/family and associated professionals; where appropriate, alternative provisions will be signposted as part of this process.

Each year there is a small cohort of patients who will transition from Helen House to Douglas House as they reach their older ‘teens, resulting in movement between respective caseloads.

Patients on the open caseload may be seen in-house and/or as part of our outreach provision in hospital, home or community settings.

Patient Caseload	Helen House	Douglas House	Total
Total Patients on Caseload over the Year	206	119	325
New referrals	86	33	119
Referrals accepted	52	19	71
Deaths of patients on caseload	31	11	42
Cases closed during the year (not deaths)	19	11	30
Patients on caseload in any one month (range)	147-156	95-101	242-255

In-Patient Activity

During 2016-17 the following volumes of **in-patient** activity were recorded.

In-patient activity: Overnight care	Helen House	Douglas House	Total
Admissions for overnight care (stays)	432	343	775
<i>Emergency & end-of-life</i>	<i>21</i>	<i>9</i>	<i>30</i>
<i>Planned</i>	<i>411</i>	<i>334</i>	<i>745</i>
Bed-nights of care	1326	1469	2795
<i>Emergency & end-of-life</i>	<i>212</i>	<i>24</i>	<i>236</i>
<i>Planned</i>	<i>1114</i>	<i>1445</i>	<i>2559</i>
Patients in receipt of overnight care	151	105	256

In-patient activity: Daycare & Assessments	Helen House	Douglas House	Total
Episodes of care	61	9	70
Patients in receipt of daycare/assessments	44	8	52

In-patient activity: Care post-death	Helen House	Douglas House	Total
Bed-nights (chilled room)	45	2	47
Patients cared for in-house post-death	14	1	15

Totals	Helen House	Douglas House	Total
Admissions for overnight or daycare	507	353	860
Bed-nights of care (pre- and post-death)	1371	1471	2842
Daycare episodes	61	9	70
Patients in-house (overnight &/or daycare)	171	108	279

Outreach Activity

The Outreach nursing team supported a total caseload of 124 patients over the year, through direct and indirect support. Direct, face-to-face care was provided by this team to 91 patients – 67 of whom were seen outside the hospice through home and hospital visits (the remainder being supported in-house, in response to service demands). In addition to the direct face-to-face care provided by this team, patients may be supported through multidisciplinary and professionals' meetings and telephone advice, Advance Care Planning and care coordination.

The outreach service at Helen & Douglas House focuses on providing additional, specialist support for more complex cases, in partnership with patients, families and professionals (in community and hospital).

It includes symptom management and planning, plus the teaching of hospital-based and community teams to enable their support of patients requiring complex and end-of-life care.

Family and Bereavement Support

The Family Support and Bereavement Team actively supported the following numbers of individuals during 2016-17. The majority of care is provided to people in connection with patients cared for by Helen & Douglas House, however, the team also responded to a number of “external” referrals for bereavement support for people whose family member had not received care from the hospice.

The support provided by the team has continued to play a significant part within the service offering. The introduction to the team of a part time Clinical Psychologist (shared post with Oxford University Hospitals NHS Trust) has further developed this service. Workshops and other group sessions have been coordinated by the team through the year to meet the varying needs of as many people as possible. Sibling support continues to be

Family Support	Total
Individuals supported on a 1:1 basis (patients, family members, carers)	151
Individuals supported as couples	62 (31 couples)
Siblings supported by the ‘Elephant Club’	57
Families/individuals supported by Helen & Douglas House social worker	54

delivered on a one-to-one basis and also within the ‘Elephant Club’. As in previous years, two residential camps have been held involving a mixture of activities and therapeutic approaches, along with other focused activities during the year.

Comparison to Previous Year

The number of patients supported in 2016-17 was comparable to 2015-16, with a significant turnover of caseload each year due to the nature of this population. Whilst the number of patients supported has been upheld, the total number of in-patient bed-nights provided has decreased between the two years as a result of our decision to temporarily reduce bed capacity in each House due to staffing pressures. Nurse recruitment is a challenge locally and nationally; in response, Helen & Douglas House has chosen to flex its service capacity to ensure maintenance of safe staffing levels with suitably experienced practitioners (external agencies are not used).

Wherever possible we have sought to maintain the amount of respite care offered to individuals however, with reduced capacity, some respite allocations for in-patient care have needed to be reviewed to accommodate the volume of emergency care that we needed to provide. Reduced bed capacity has also resulted in a waiting list for new admissions for non-urgent respite care at Douglas House. Urgent care has remained available to all patients on our caseload throughout the year.

Family and Bereavement Support has also been provided to similar numbers of people this year compared to 2015-16 – with a slight reduction in the work provided to “couples”, and a slight increase in the number of people supported by the Helen & Douglas House social worker.

Quality Monitoring Requirements for NHS Commissioners

Helen & Douglas House is required to report to NHS Commissioners on the quality of its services via the NHS Standard Contract and NHS grant agreement. Individual CCGs are able to specify local variations to reporting requirements; an indication of the scope of measures for 2016-17 is provided in Appendix 2.

Duty of Candour

For this year's Quality Account, NHS England has requested that all providers indicate how they are implementing the Duty of Candour. The Duty relates to the culture as well as the practice of being open and transparent with people who use services, and other relevant stakeholders, regarding care and treatment. It includes specific requirements for providers when things go wrong. Our exercising of the Duty of Candour has been evidenced through our active and open communications following the Serious Incident and subsequent CQC findings.

The professional Duty of Candour relates to all healthcare professionals. Helen & Douglas House encourages a culture of openness and of actively reporting incidents (actual and potential). Policies and systems are in place to support this, and care practices enable dialogue between staff and other professionals, as well as with people using our services. Openness with patients and families is part of daily interaction within the hospice's model of individualised care, and any concerns or issues can be raised promptly with the people affected.

Staff are encouraged to speak up if they have concerns, and are supported in doing so through the likes of staff forums, incident reporting, whistleblowing policy and introduction of a *Freedom to Speak Up Guardian*, as well as through their line management.

Patient Safety and Clinical Effectiveness

The provision of high quality care includes the delivery of excellent, effective and safe care. It is developed through continual learning and improvement to practice – proactively and in response to identified issues.

In order to monitor and continuously improve patient safety and clinical effectiveness, a regular programme of audit and risk assessment/review is in place. These systems demonstrate that the organisation takes patient safety and clinical effectiveness seriously and develops systems to support continuous improvement in all aspects of service delivery. Results from the 2016-17 Clinical Audit Programme are summarised overleaf.

Drug-Related Incidents	
Audit Tool	In-house tool
Target	Continuous monitoring to identify and reduce risks
Result	106 incidents reported Previous: 106 incidents
Commentary	A total of 106 drug-related incidents were reported in the year 2016-17. 46 of these incidents were patient-related; none caused any harm to patients. The most prevalent type of incident was <i>omissions</i> (which had also been noted in 2014-15). Other identified themes related to <i>storage</i> and to <i>delivery</i> issues – it is anticipated that a new pharmacy contract will help in both of these areas.
Key Recommendations	The medicines management committee to focus again on <i>omissions</i> in an attempt to reduce the number of these incidents. In addition, reinforcement of staff guidance regarding classification of incidents to reduce the number defaulting to a category of “ <i>other</i> ”.

Accountable Offer	
Audit Tool	<i>Hospice UK</i> Self-Assessment Tool for the Accountable Officer
Target	100% compliance
Result	91% compliance 92% compliance
Commentary	At the time of the audit, planned processes to monitor controlled drug prescription activity had not yet been implemented, resulting in a slight reduction in overall compliance. These changes were identified through the previous audit and implementation remained on schedule for the end of the financial year. Implementation will ensure that the organisation maintains a systematic and safe approach to the management of controlled drugs.
Key Recommendations	Develop and implement a system to monitor controlled drug prescribing activity within the organisation. COMPLETED post audit.

Information Governance	
Audit Tool	Information Governance (IG) Self-Assessment Toolkit
Target	100% attainment of Level 2
Result	16/18 requirements achieved the targeted Level 2 Previous: 16/17 requirements achieved the targeted Level 2
Commentary	The development and implementation of the Information Governance Improvement Plan over the past year has had a positive impact on the overall result and will be updated and used to underpin the plans to reach the assigned targets for the next self-assessment in March 2018.
Key Recommendations	Achieve Level 2 in 14-322 (new IG requirement). Achieve level 2 in requirement 14-325 (“non-compliance” at Level 2 is understood, assessed and managed as very low risk). Achieve Level 3 in selected IG requirements, in line with the Information Governance Improvement Plan.

Management of General Medicines	
Audit Tool	Hospice UK General Medicines Audit Tool
Target	100%
Result	97% compliance Previous audit: 96% compliance
Commentary	<p>Overall there has been a slight increase in compliance year-on-year. There are two areas for focus which are continuing to have an impact on the organisation's compliance with all the elements of this audit. These relate to the documentation of evidence:</p> <ul style="list-style-type: none"> the lack of documented evidence that patients/families/carers are being given information about newly prescribed medication, and the lack of system or process to provide evidence that staff have read policies and procedures.
Key Recommendations	<p>Develop a system to show that patients who have <i>new</i> medicines prescribed whilst at Helen & Douglas House will have documented evidence that they had been given information about the relevant medication.</p> <p>Develop a system or process for staff to sign that they have read policies and procedures.</p>

Management of Controlled Drugs	
Audit Tool	Hospice UK Controlled Drugs Audit Tool
Target	≥95%
Result	99% compliance Previous audit: 98% compliance
Commentary	<p>There has been an increase in compliance in two sub-topics compared to the previous year:</p> <p><i>Prescribing of CDs</i> (from 95% to 96%), and <i>Examination of Stock Held</i> (from 88% to 100%).</p> <p>The only area of non-compliance in the audit was under <i>Prescribing of CDs</i> - a patient's (child) weight was not recorded on a drug chart where controlled drugs were prescribed.</p>
Key Recommendations	<p>Ensure all staff are aware of the need for an up to date weight on children's drug charts.</p> <p>Re-audit drug charts in 3 months (March 2017) to ensure all have the child's weight on them. COMPLETED</p>

Record Keeping Audit	
Audit Tool	In-house tool based on standards and guidelines from <i>Nursing and Midwifery Council, Royal College of Physicians Health Informatics Unit, Department of Health National Minimum Standards, and Health and Social Care Act (2008)</i> .
Target	100%
Result	92% Previous: 90%
Commentary	Overall compliance is steadily improving against previous years' internal audits, however an equal amount of criteria have improved and declined in compliance (24%) in this year's audit.
Key Recommendations	Record keeping update sessions to be kept in place for staff in January and September 2017 training days. Re-Audit to ensure all the above targets are met – June 2017.

Infection Prevention and Control	
Audit Tool	<i>Hospice UK</i> The Health and Social Care Act 2008 Code of Practice: Self-Assessment Audit Tool. This is an alternative audit tool to that used in the previous year, so results cannot be compared directly. Results of this year's audit to be used as a baseline to identify areas for further development and to shape the existing audit tool.
Target	≥90% compliance
Result	98% compliance overall Previous: 16/16 (100%) modules achieved >90% compliance
Commentary	Under the <i>Policies and Procedures</i> topic the audit identified some gaps in local procedures within the organisation. Whilst these procedures are not yet in place, policies and procedures pertaining to areas where our patients are most at risk (e.g. MRSA, Pseudomonas, CPE (draft)) are in place. The robust application of standard precautions in everyday practice minimises the risk of infection and cross infection.
Key Recommendations	Develop the following local procedures: Local Procedure for glycopeptide resistant enterococci (GRE). Local Procedure for viral haemorrhagic fevers (VHF's) Local Procedure for transmissible spongiform encephalitis. Re-audit using the same audit tool in January 2018.

Complaints	
Audit Tool	Tool developed by the <i>Clinical Audit Support Centre</i>
Target	100% compliance
Result	100% compliance Previous audit: 80% compliance
Commentary	There were 3 complaints in this financial year: all were dealt with in a timely and acceptable way.
Key Recommendations	Continued focus on the detail of the process around complaint management to ensure sustained compliance.

Mattress Audit			
Audit Tool	Mattress Audit Tool adapted from <i>North Yorkshire and York Community and Mental Health Services</i> , NHS, UK. (Adapted in response to the Care Quality Commission Practice Alert September 2009.)		
Target	≥90% compliance		
Result	<table border="1"> <tr> <td>Compliance: Mattresses: 87% (20/23 passed) Covers: 87% (20/23 passed)</td> <td>Previous: Mattresses: 90% (18/20) passed Covers: 95% (19/20) passed</td> </tr> </table>	Compliance: Mattresses: 87% (20/23 passed) Covers: 87% (20/23 passed)	Previous: Mattresses: 90% (18/20) passed Covers: 95% (19/20) passed
Compliance: Mattresses: 87% (20/23 passed) Covers: 87% (20/23 passed)	Previous: Mattresses: 90% (18/20) passed Covers: 95% (19/20) passed		
Commentary	The mattress audit was completed in two sections. 3 mattresses were decommissioned; 2 have been replaced along with 2 new mattress covers.		
Key Recommendations	Staff are consistently reminded not to place sharp objects on the mattresses at any time, particularly when they are not in use, as the covers puncture very easily. A new audit form is being considered for subsequent audits.		

Hand Hygiene Audits			
Audit Tool	In-house tool developed based on <i>World Health Organisation's 5 Moments of Hand Hygiene</i>		
Target	≥90% compliance		
Result	<table border="1"> <tr> <td>97% average compliance</td> <td>Previous audit: 93% compliance</td> </tr> </table>	97% average compliance	Previous audit: 93% compliance
97% average compliance	Previous audit: 93% compliance		
Commentary	Feedback from hand hygiene audits is disseminated to all staff to highlight areas for continual improvement.		
Key Recommendations	Practical hand hygiene will take priority during the Infection Prevention and Control training session with staff.		

Management of Medical Gases			
Audit Tool	<i>Hospice UK Medical Gases Audit Tool</i>		
Target	≥90% compliance		
Result	<table border="1"> <tr> <td>6/8 sub-topics achieved ≥ 90% compliance; overall compliance 89%</td> <td>Previous audit: 6/8 sub-topics achieved ≥ 90% compliance</td> </tr> </table>	6/8 sub-topics achieved ≥ 90% compliance; overall compliance 89%	Previous audit: 6/8 sub-topics achieved ≥ 90% compliance
6/8 sub-topics achieved ≥ 90% compliance; overall compliance 89%	Previous audit: 6/8 sub-topics achieved ≥ 90% compliance		
Commentary	Improved compliance from 2015-16: the risk assessments are now in place, along with a policy and procedure that includes the use of e-cigarettes. Areas requiring more work include: reporting of broken oxygen concentrators (annual service May 2017), clear prescribing and recording of administration of continuous oxygen therapy.		
Key Recommendations	A short audit of the minibus is required to ensure its compliance. Medical Gases Group to revisit areas deemed <i>not applicable</i> for the audit.		

The clinical audit framework used at Helen & Douglas House enables the monitoring of clinical performance and comparison year on year. The audits demonstrate high performance in all areas. Our aim is to match or exceed the previous year's achievements, and this is demonstrated in most of the audits noted above.

When audit results have been below expectation, decisions have been made to carry out re-audits – honing down on the areas of specific concern (for example looking at the recording of patients’ weights on drug charts in Helen House when considering controlled drug prescribing).

Since the CQC inspection in December 2016, monthly audits of care planning and of other clinical notes have been run, informing an internal action plan which has demonstrated month-on-month improvement.

Patient Experience

Helen & Douglas House offers a personalised model of care based on a rounded understanding of each individual patient. This necessitates a high level of engagement with patients and their families/carers to assess their needs and preferences, plan the care, and evaluate its outcomes. Within this process, there is acknowledgement of families as experts in the care of their own child – such active partnerships enabling the high degree of individualised support that is provided.

Helen & Douglas House provides a variety of routes through which patients and families can provide feedback. This ranges from informal, ad hoc conversations with a member of the care team to more formal gathering of comment through focused surveys and studies. We offer opportunity both for continual comment and for feedback on specific aspects of care. Mechanisms include:

- Face-to-face review of experience as a natural part of individualised care planning and evaluation.
- Feedback postcards/forms that are available throughout the houses for written comment.
- Specific surveys with structured questions on focused areas of review.
- In-depth case studies with patients and families.

In 2016-17 an internal evaluation of the Family Support and Bereavement service was published; this included valuable feedback via case examples and user survey.

Individuals may also raise concerns or make compliments verbally or in writing. Concerns and complaints are logged and managed via relevant in-house systems, with a fair and timely resolution sought.

Examples of feedback, including themes identified, are given in the inset boxes overleaf.

Feedback Postcards

Feedback cards are available to all users and visitors. There is also a mechanism for families to feedback on their experiences in the family accommodation. In 2016-17 the mean score for user experience was 8.7/10 (where rated on feedback postcards (19 submissions)). Comments from young adult patients at Douglas House included:

"I enjoy it here. It is nice to catch up with my friends"

"Good care, friendly, asked me how I am, I felt safe"

"Always have a good time".

When asked what difference Helen & Douglas House makes, specific feedback from Douglas House patients included:

"Treated like an adult. I get to make more choices"

"Not having to stick to a time limit"

"To be able to do what I want".

Feedback from a parent of one patient reflected the level of trust experienced:

"Overall it is the only place of respite for my son which I can trust"... "Fantastic staff, very compassionate and taking care of details. Very nice atmosphere around the unit. Good facilities unknown in our town."

Other positive comments reflected the quality of care, the welcome received from staff, the opportunities for interaction, activities and independence as part of the respite provision.

Feedback forms also seek suggestions for improvement. There were no evident themes; specific suggestions included the enhancement of family accommodation, opportunity for fuller pre-visit planning of activities, more extensive staff-patient communication regarding what can/can't be achieved during a respite stay.

Case Studies

Case studies seek to establish an in-depth picture of the impact of Helen & Douglas House for specific patients and their families. In response to questions about the difference that Helen & Douglas House makes, reflections included:

"It is a lifeline. It is the best care we have ever had. It is how we survive."

"I don't feel so alone during the sometimes exhausting and terrifying experiences of living with a child who has a poor prognosis."

"It makes you feel normal again and able to carry on with one of the hardest roles there is in life."

"Helen & Douglas House now provides our stability and tranquillity. We know that they will be there for us."

"We have to have an enormous amount of trust to hand over our precious son. We have that at Helen & Douglas House."

"They stepped in at our lowest moment to support us medically, practically and emotionally."

Professional Commendations

Other compliments and comments are captured by members of staff, often via email. Compliments are frequently sent by professional colleagues for assistance provided around the care of a patient. This could be for the inpatient units at Helen & Douglas House, the Doctors' Team or the Outreach Nursing Team. Recent feedback referenced "expert advice", "sensitivity and honesty", "consistent quality care", "sensitive and clear communication with the family in particular when dealing with difficult conversations", and a "collaborative approach".

Service Evaluation: Family Support & Bereavement

In July 2016, Helen & Douglas House published internally a research evaluation of its Family Support and Bereavement (FSBV) service, following a qualitative review over the previous 6 months. The core elements of the evaluation were individual interviews with the FSBV team, a survey of all those in touch with the service over the past two years, and group sessions with siblings aged 6-11 and 12-18.

Overall, the evaluation found that the support of the team has a significant and meaningful impact on the lives of the individuals and families they work with. The most important outcome for families was to help them to find their place in the world (whatever that may mean for them). In terms of tangible outcomes, finding your place in the world meant different things to different families, but was dependent on core elements, most notably understanding of losses, time and space to talk, comfort and connection, and coping with grief. The evaluation also found a strong congruence between what staff in the FSBV team are seeking to achieve and the feedback from families about the meaning and impact of that support.

The evaluation identified scope for improvement to the processes within the service – in particular regarding the consistency of the timeliness of engagement with families to identify and support their needs; also in connection with collection and utilisation of relevant data (a continued focus for improvement regarding our Data Quality).

In response to the survey, families reported extremely positively on their experiences of support from the FSBV team. They were asked to rate (overall) their contact with the team: 91% felt that their contact had been positive or extremely positive. Families were also asked to rate the impact of the service on their lives and experiences: overall, 89% felt that the impact had been positive or extremely positive. For siblings, having a safe space and time to talk was hugely significant for both age groups.

Complaints

Aside from the Serious Incident reported in May 2016, Helen & Douglas House received 3 complaints in the year 2016-17. There were no themes within these complaints and all were resolved in a timely and acceptable manner.

Statements from Clinical Commissioning Group and Local Scrutineers

There is no formal “lead commissioner” for Helen & Douglas House.

The highest caseload and greatest volume of care is provided to Oxfordshire CCG, however the CCG has no formal contractual relationship with the hospice. In 2016-17 Oxfordshire CCG has, however, actively supported Helen & Douglas House via its Quality Team, from whom a statement is provided below.

Statement from Oxfordshire CCG (OCCG)

Oxfordshire Clinical Commissioning Group (OCCG) has reviewed the Helen & Douglas House Quality Account and believes that the information it provides about their service is accurate. OCCG has no formal contractual relationship.

The Quality Account presents a description of the service provision at Helen & Douglas House Hospice. The report demonstrates the commitment of the team at the hospice to improving quality of care, patient safety, clinical effectiveness and risk management.

OCCG would like to congratulate the Hospice for the hard work and commitment of all Helen & Douglas House’s staff in proactively providing complex and specialist care that is valued and respected regionally and nationally.

Over the past year the Oxfordshire CCG has developed a closer relationship with Helen & Douglas House to provide external scrutiny and support their improvement plans following the incident and inspection described in the report. The team has worked with the CCG, appropriately using us as a critical friend to oversee action plans and improvements. Their responsiveness to learn from incidents and Inspection processes in a transparent manner is to be commended.

During 2016-17 Helen & Douglas House has actively welcomed scrutiny and feedback from all their commissioners and inspectors, showing a determination to understand how they can improve. It is clear from the priority plans that some of this determination will be reflected in embedded quality improvements over this coming year.

OCCG notes the range of research and innovation that the organisation is involved with and wishes to congratulate Helen & Douglas House for this work in improving healthcare. Their active involvement in the new NICE guidance is testament to the commitment and expertise in the field of end of life care.

Helen & Douglas House has shown how it is sharing its knowledge and expertise to support the challenges of developing a skills workforce through training and dissemination of good practice. Internal work to continually develop in line with medical advancement is fundamental to quality care. The introduction of competency assessment processes that inform training strategies will support the growth of a skilled workforce and may assist in retaining staff.

Patients’ feedback and experiences in this report are a powerful reflection on the quality of care they receive. It is a credit to Helen & Douglas House staff that they retain a personalised care package that is highly valued by the patients and their families.

OCCG would like to continue supporting Helen & Douglas House to ensure that the excellent care they offer can be sustained and their reputation maintained. We look forward to continuing to work with you to this end.

Sula Wiltshire

Alison Chapman

Director of Quality

Designated Nurse & Safeguarding Lead

A further CCG statement has been provided by Nene and Corby CCGs who do commission Helen & Douglas House for the provision of children's palliative care. The statement comprises input from three perspectives: the Quality Lead; the Commissioning Manager; and the Designated Nurse for Children's Safeguarding.

Statements from NHS Nene and Corby Clinical Commissioning Groups

Statement from the Children's Commissioning Manager

Nene and Corby CCGs has had a formal commissioning arrangement with Helen & Douglas House for the last three years with a plan to continue this arrangement through a formal Grant Agreement in the future. The Lead Children's Commissioner has provided the following statement regarding the quality of care that Helen & Douglas House provided for the children and young people of Northamptonshire:

The families of children who receive regular support from Helen and Douglas House have expressed that they feel the quality of care their children receive is of a high standard and the staff are always very friendly and supportive. They have reported that the environment is very child and family focussed with lots of activities that are available for their child to participate in. Families have stated that they feel they can leave their child with the staff and have a really good break.

As a Commissioner of specialist services I feel Helen and Douglas House offers a level of care and specialist advice and support that is really valued by our children and their families.

The commissioning relationship between Helen and Douglas House and the CCGs has always excellent communication has always been very transparent and open.

Statement from the Quality Lead for Children

During 2016-17, representatives from the CCGs have actively engaged with Helen & Douglas House in response to the CQC findings. The Quality Lead for Children has provided the following statement:

Helen & Douglas House annual quality account for 2016/17 has been reviewed. It is noted that the account was reviewed in draft format. Nene and Corby CCG are not the lead commissioners for this service.

Nationally mandated elements that are relevant to Helen & Douglas House have been included in the report.

Achievement against quality priorities is outlined in the account.

Information relating to key themes from complaints, patient and staff surveys has been provided within the account.

NHS Nene and Corby CCG support the 2017/18 quality priorities set by Helen and Douglas House in relation to making improvements in the domains of safe, caring, effective, responsive and well led.

The CCGs will continue to work closely with Helen & Douglas House to support ambitions to sustain high quality standards of care to people who use the services.

Statement from the Designated Nurse for Children's Safeguarding

In April 2017 the Designated Nurse for Children's Safeguarding for Nene and Corby CCGs visited Helen & Douglas House, alongside the Designated Nurse and Safeguarding Lead from Oxfordshire, to review progress made by the organisation against the CQC action plan and to seek assurances regarding patient care and safety. The following statement has been shared for inclusion in this Quality Account.

I have read the report.

When I made my visit I can confirm that they had taken the enforcement order very seriously and developed a comprehensive action plan which they shared with me.

There was clear evidence that they had reviewed their processes and paper work in response to the recommendations and had put them into practice.

They were very open and it was obvious they were keen to learn from the tragic death and the enforcement order from CQC.

They also acknowledged their limitations and the need to ensure that no child is admitted without the appropriate skill level available.

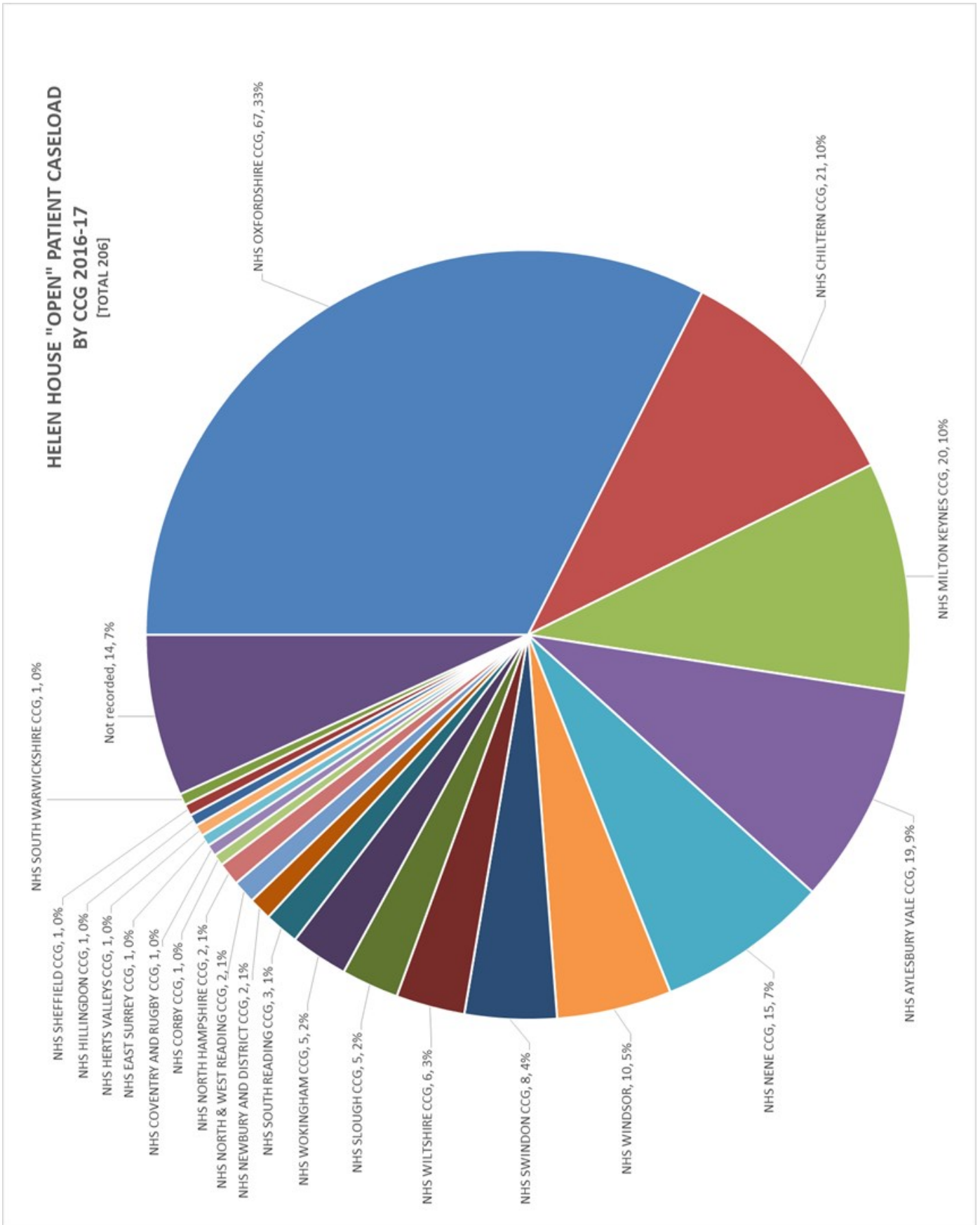
They all worked very closely with the Designated Nurse from Oxford but were also very receptive to my visit.

I made a point of talking to families alone who all gave an outstanding report of the care they had received.

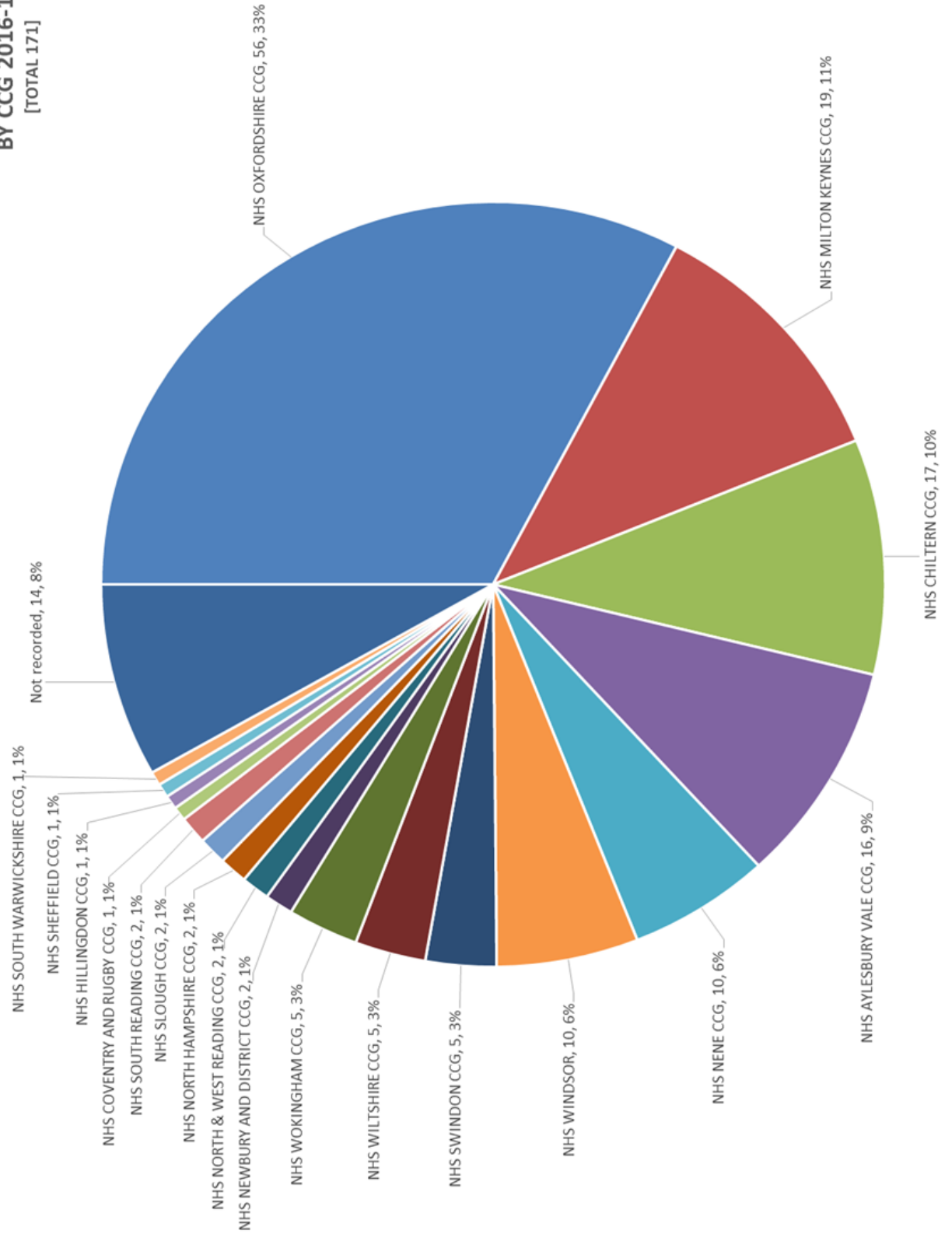
This Quality Account, in draft form, has also been shared with **Healthwatch Oxfordshire** and with the **Oxfordshire Joint Health Overview & Scrutiny Committee** offering opportunity to feedback and to provide a statement for inclusion in this section. At the time of publication, no response has been received from either organisation.

Appendix 1 – Hospice Caseload and Patient Activity

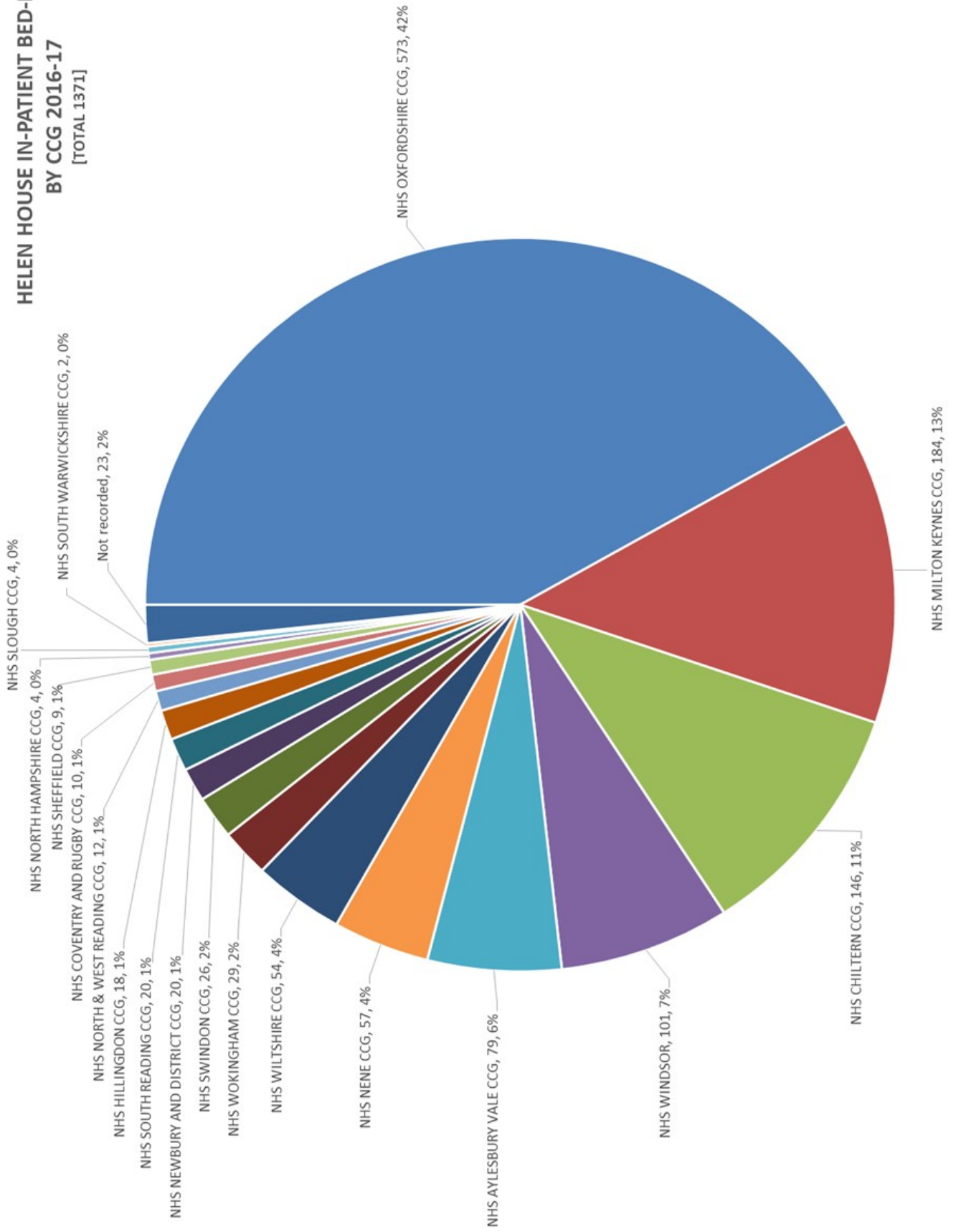
Helen House: Children’s Hospice Care



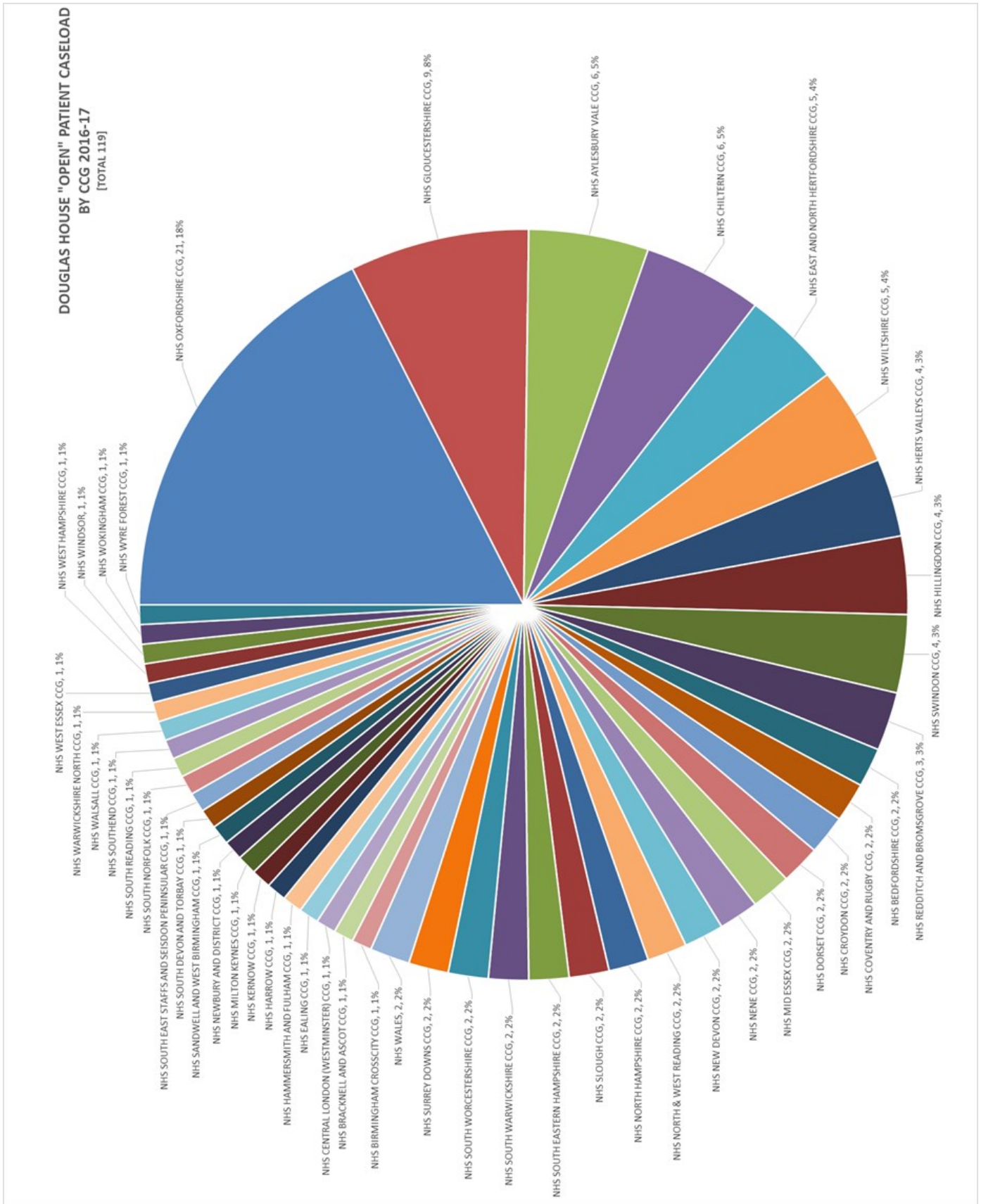
**HELEN HOUSE PATIENTS
IN RECEIPT OF IN-PATIENT CARE
BY CCG 2016-17
[TOTAL 171]**



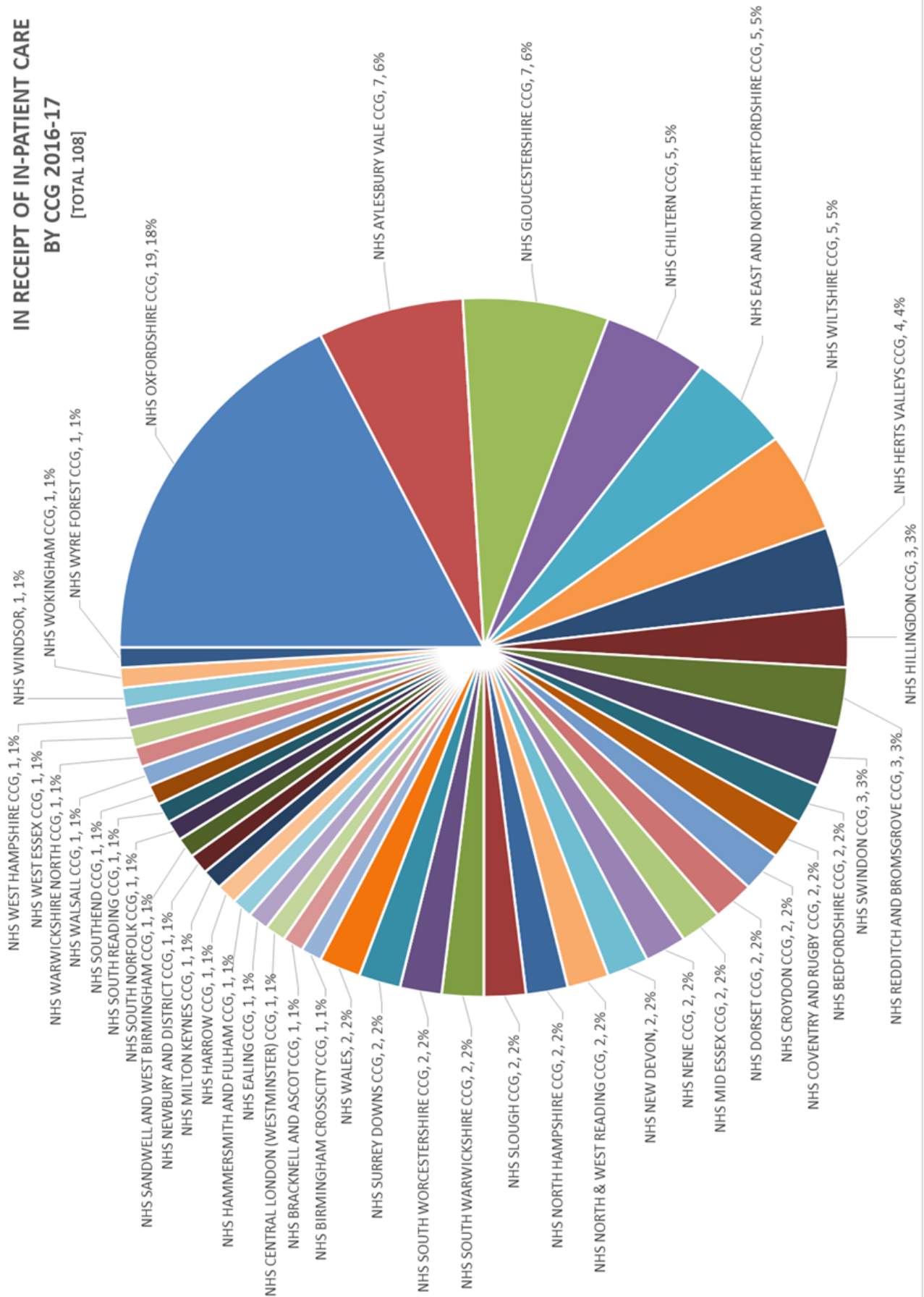
**HELEN HOUSE IN-PATIENT BED-NIGHTS
BY CCG 2016-17
[TOTAL 1371]**



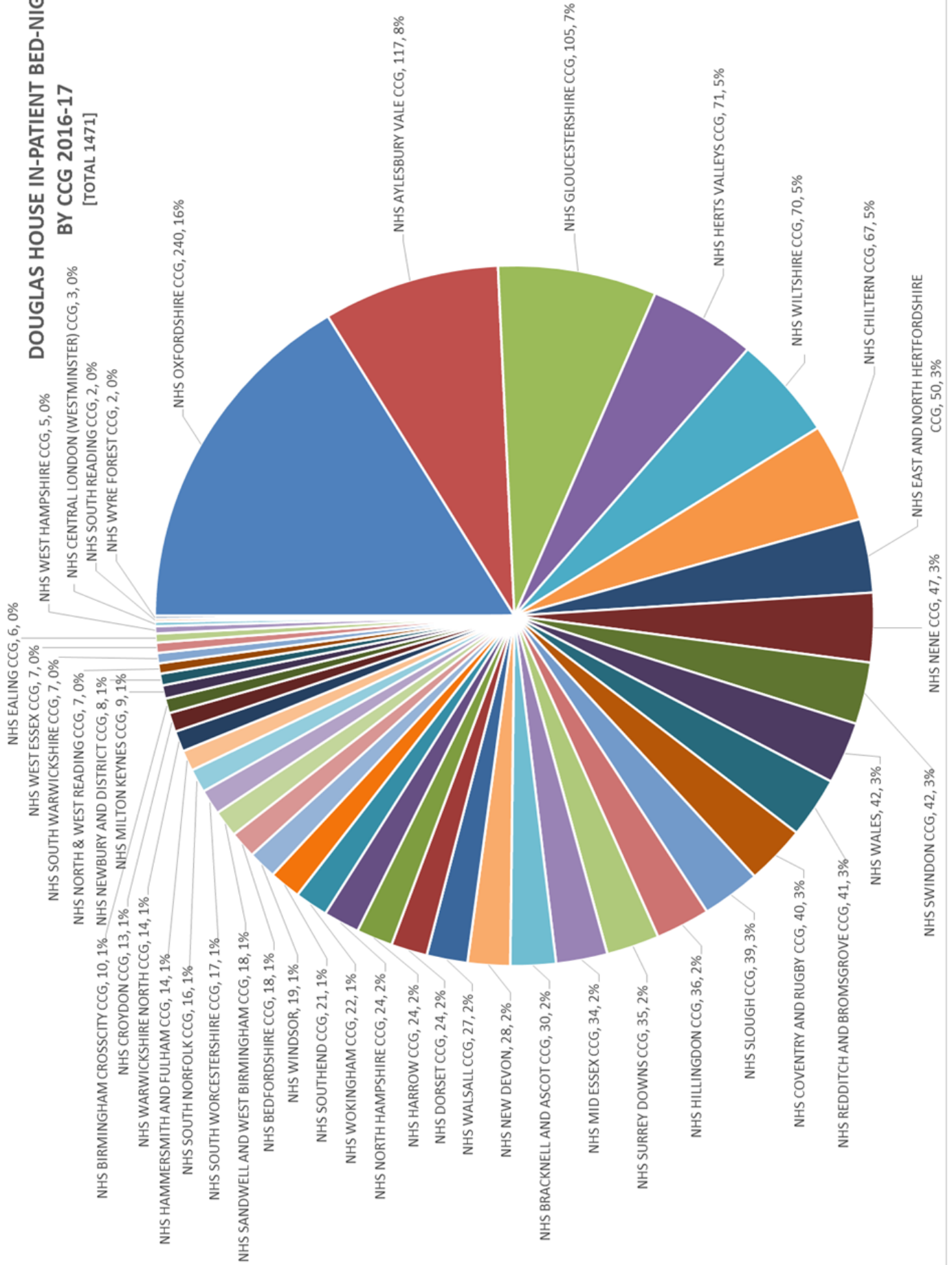
Douglas House: Young Adults' Hospice Care



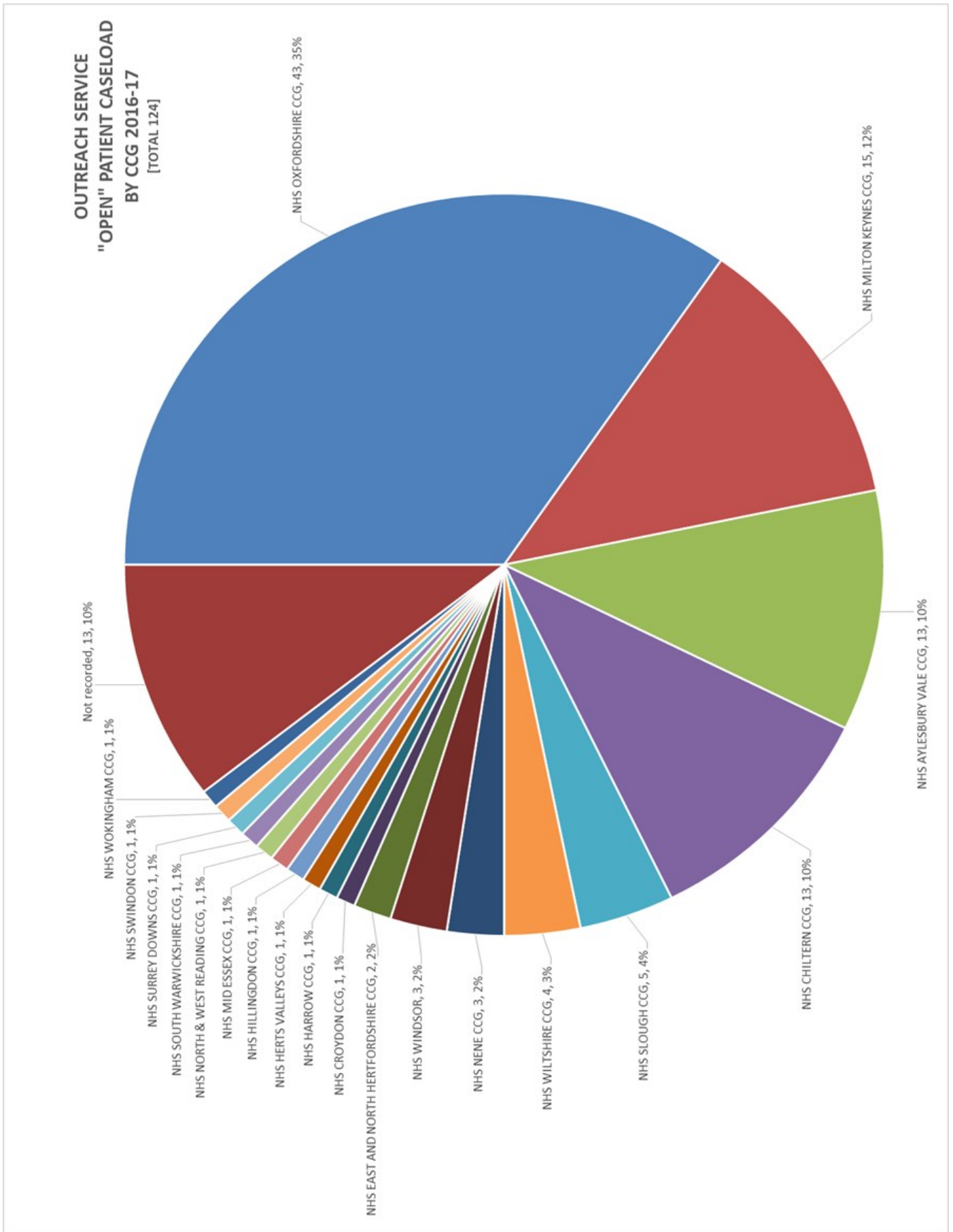
**DOUGLAS HOUSE PATIENTS
IN RECEIPT OF IN-PATIENT CARE
BY CCG 2016-17
[TOTAL 108]**



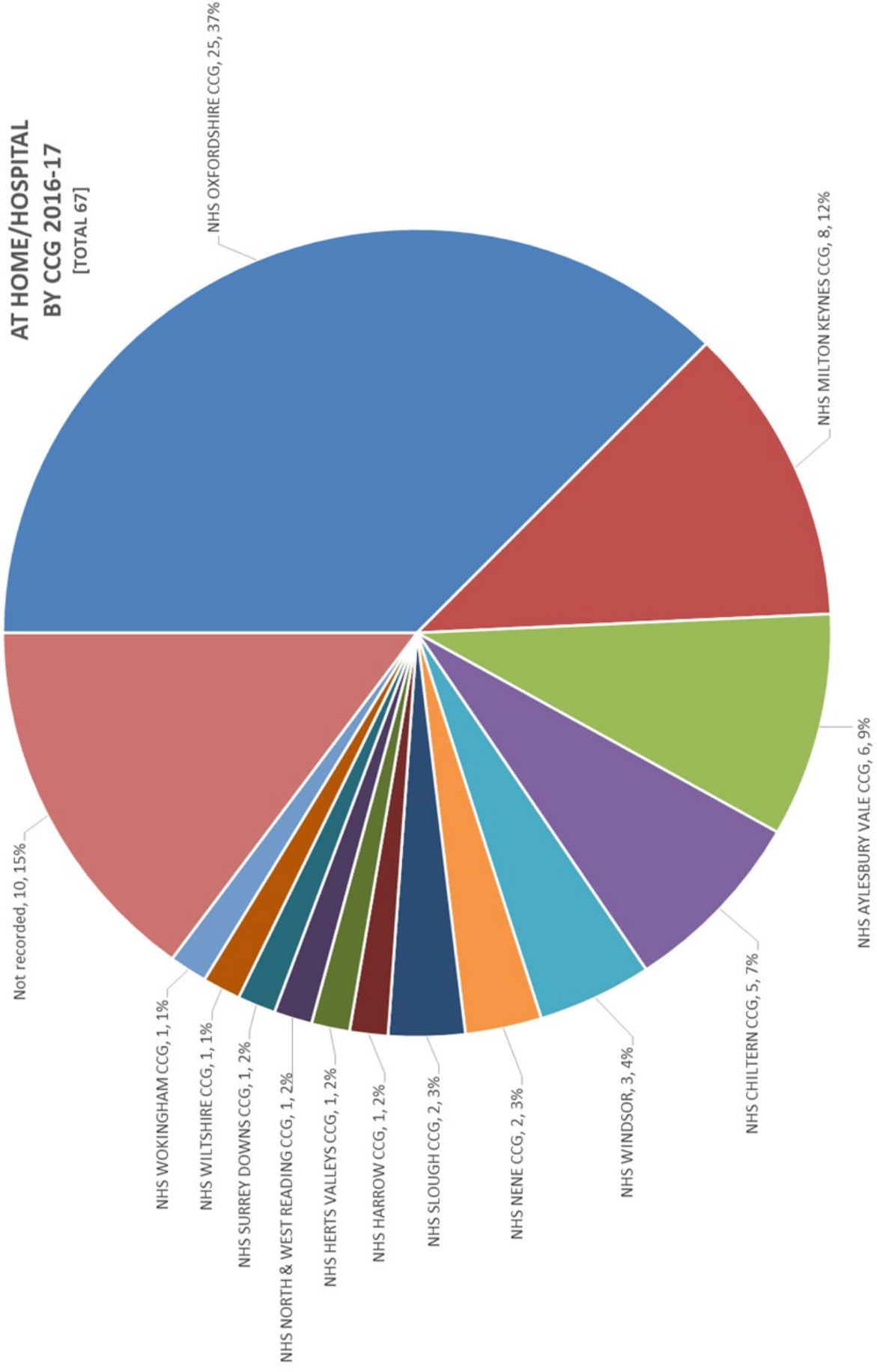
**DOUGLAS HOUSE IN-PATIENT BED-NIGHTS
BY CCG 2016-17**
[TOTAL 1471]



Patient Outreach Service



**OUTREACH SERVICE
PATIENTS RECEIVING DIRECT CARE
FROM HELEN & DOUGLAS HOUSE
AT HOME/HOSPITAL
BY CCG 2016-17
[TOTAL 67]**



Appendix 2 – NHS Standard Contract Reporting Compliance against National and Locally-Defined Quality Measures

As part of the *NHS South, Central and West Commissioning Support Unit's* implementation of the NHS Standard Contract for 2016-17, Helen & Douglas House has provided assurance in the following areas:

Safeguarding (children & vulnerable adults)	Patient experience and feedback	Case reviews and inquests by a Coroner
Compliance with relevant NICE guidance	Same sex accommodation	Response to CAS system alerts
Clinical audit	Workforce and training	Risk reporting
CQC registration (and any associated conditions)	Access to service for people with learning disabilities and/or autistic spectrum conditions	Response to relevant National Guidance and report (such as the Francis Report)
Implementation of local guidance for End of Life Care,	Outcomes and learning from user surveys	Equity of access
Patient nutrition and hydration	Infection Control	Lone Working
Timely discharge summaries for patients	Serious Incidents Requiring Investigation	
Patient participation in decisions regarding their own	Patient safety and quality (including incidents reported)	

Quarterly dashboards of monthly performance statistics have also been submitted relating to the following measures, as required by the Commissioning Support Unit:

Complaints received	Clinical incidents (not SIs)	Staff turnover
Discharge summaries issued within 24 hours	Safeguarding referrals made (adult and children)	Vacancy rate
Provider-acquired infections	Provider-acquired catheter-associated UTI	Sickness
Never Events reported	Provider-acquired Venous Thromboembolism	Agency/Bank staff usage
Serious Incidents logged	Provider-acquired falls (with and without harm)	Staff compliant with statutory and mandatory training
Medication errors	Provider-acquired pressure ulcers (all grades)	



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Helen & Douglas House
hospice care for children and young adults