Quality Account 2017-18

Lily-Mae making stars with Mum at Helen House

Helen & Douglas House
hospice care for children and young adults

Contents

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.

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, in 2017-18, provided specialist palliative and supportive care to young people 0-35 years of age: babies, infants, children, teenagers and young adults. We have also supported the families and carers of these young people through their shortened life, through their death, and in bereavement. In-patient care has been 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. Family support is provided at the hospice, at people's homes and in other community settings.

Helen & Douglas House is a registered charity based in Oxford and has been providing palliative care for 36 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 people – seeking to improve practice, structural delivery and funding of services to this population.

Meeting the Challenges of Service Sustainability

The long-term financial sustainability of hospice services for children and young people in England is a challenge that has been recognised for more than a decade – through local and national studies. The funding challenge, of not only sustaining services but also continuing to develop in response to emerging need, has been met in large part through substantial charitable initiatives and public generosity.

Helen & Douglas House has not been immune to the pressures of financial sustainability. Despite taking active steps over the years both to manage our costs and to seek to increase our income, we have repeatedly needed to rely on accumulated reserves in order to cover shortfalls. In this last year it became evident that the future viability of the organisation as a whole would be in jeopardy if we did not make fundamental changes to our cost-base. In January 2018 the Trustee Board made the difficult, but necessary, decision that regrettably our young adult service – Douglas House – would cease to operate by the end of July this year. It is our aspiration to be able to provide a service for young adults in the future, however this is dependent on us seeing an increase in our income to a level at which this can be sustained. We do not underestimate the impact of this loss of service to the young adults and their families who are affected, from across the south of the country, and we are actively working with them to signpost to alternative provisions where available. The impact on staff across the organisation is also significant, having worked with and for these young adults for many years. A number of staff are also affected by the loss of their own jobs where redeployment has not been possible.

These changes are necessary in order to secure services for future generations of beneficiaries. Helen & Douglas House will concentrate on providing specialist palliative care to children and young people up to the age of 18 years, within a re-focused model of care that can be reliably sustained and developed in line with realistic funding expectations and partnership working.

Our priorities within the second half of 2017-18 were dictated by the planning, preparation and implementation of this organisational change. Our commitment throughout has remained the provision of the highest quality, individualised care and support to our patients and families.

Amidst such challenges, I am proud of staff and volunteers across the organisation in their commitment to enhance the lives of all the young people in our care, and to support their families during the person's life and after their death.

We can only provide this care in active partnership with local healthcare providers in hospital and community teams, and with the support of NHS England and local commissioners. I am pleased that local commissioning relationships have progressed over the last 12 months. We have had positive re-engagement and a funding contribution from Buckinghamshire CCG (formerly Aylesbury Vale & Chiltern CCGs) for children's palliative care in 2017-18, and work is in process to secure an on-going agreement. In addition, we are hopeful that Oxfordshire CCG will formally recognise our contribution to the local NHS healthcare economy through their forthcoming Commissioning Plan for End-of-life Care, which now incorporates children and includes reference to Helen & Douglas House.

Despite the challenges of this last year to patients and families, staff and volunteers, I am confident that the actions we have taken place us in a strong position to move forwards and to grow our service from a secure and sustainable platform. We will be working ever more closely with our partners in the statutory and voluntary sectors, and with our charitable funders and supporters, without whom we could not achieve our goals for the benefit of the children and families who we are privileged to serve.

The Quality Account

This is the organisation's fifth 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 Director of Quality, Compliance and Commissioning, 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 2018

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

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.

Priorities for Improvement

Review of 2017-18 Priorities

Four priority areas for improvement were identified in the 2016-17 Quality Account for the following year. Whilst these have remained key drivers during 2017-18, they have been impacted by organisational change. A progress summary against each of the 2017-18 priorities is provided below.

1. *Patient Safety and Clinical Effectiveness*: review of **Patient Referral and Admission Procedures**

   These processes are currently being reviewed. The start of this project was purposefully delayed when the need for wide-scale organisational change became apparent during 2017-18. With the closing of our young adult service in June 2018, significant changes to these processes will be required – in addition to changes previously foreseen. Progress has been made in the review of the referral processes but this will remain a focus at least for the first half of 2018-19.

2. *Clinical Effectiveness*: **Service Delivery Model and Partnership Working**

   Our service delivery model has undergone significant review during the year. It has focused on maximising effectiveness within our financial means, and on our integrated roles within a wider system of care. Whilst the major implementation of change is not taking place until 2018-19, significant review, planning and communication occurred during the second half of 2017-18.

   Work with external stakeholders and potential partners has continued through 2017-18.

   - We have had encouraging conversations with both Oxford University Hospitals Foundation NHS Trust (OUHFT) and Oxford Health Foundation Trust around collaborative working and mutual support. We are now in receipt of Responsible Officer services from the OUHFT in support of medical revalidation. Our Paediatric Palliative Care Consultant had a successful interview at the OUHFT to secure an honorary consultancy post; it is hoped that this will further develop our relationship with our local hospital trust and also support our wider working in the region.
   - Through our work with the Quality and Safeguarding Team at Oxfordshire Clinical Commissioning Group (OCCG) in the past few years, we have established a further secondment for our Nurse Consultant into the CCG's Safeguarding Team. This integrated working has proved extremely valuable in ensuring we are fully informed, as an organisation, of any safeguarding developments and changes, as well as providing support to the OCCG Team.
   - We continued to work closely with Rennie Grove Hospice Care through a service level agreement to provide medical support to their nursing team. The secondment of a Community Outreach Nurse to Rennie Grove continued until its planned end-date in November 2017.
   - Work has continued with Oxford Brookes University to provide and assure training and professional opportunities for members of the care teams, and to plan training support for clinicians moving from adults' care to children's care.

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

   The Competency Framework has been reviewed but further work will be required following organisational change to ensure that the specialist needs of teams are reflected in the competencies.

   The nurse self-assessment tool that was developed in-house in 2016-17 is being widely used for all new starters, and will be used for on-going benchmark assessments for all nursing staff. At the end of 2016-17 outputs from the initial round of self-assessments identified areas for further workforce training and development. In 2017-18 a rolling training programme was initiated using the areas identified within the self-assessment process; this programme will be consolidated in the coming year.

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

   Care planning in Helen & Douglas House has continued to be reviewed and revised. Whilst the two hospice houses have different care plan frameworks, they are similar in their approach and in particular in the detail that they require.

   We have continued to operate regular audit and review of care plans, which have consistently demonstrated high quality care planning and detail, alongside focused learning. Given the quality assurance in 2017-18, care plan reviews will be conducted less frequently in the coming financial year. However, they will remain a focus to ensure that care plans are accurate and up to date, and provide an excellent guide for colleagues to follow when caring for the complex patients using our services.

Priorities for Improvement 2018-19

The clinical priorities for quality improvement in 2018-19 build on those of the previous financial year. Following the disruptions of organisational change in 2017-18, further focus on those priorities is needed to ensure they are suitable for our future service model for children and their families, and that they become firmly established.

1. *Patient Safety and Clinical Effectiveness*: review of **Patient Referral and Admission Procedures**

   This remains a priority as we develop and adapt our service model at Helen House in 2018-19. It is essential that referral and admission procedures complement the revised service model and work well for our families. Work has started with some families around the service model changes.

2. *Patient Safety and Clinical Effectiveness*: **Service Delivery Model and Partnership Working**

   A new service model is planned in Helen House, following the withdrawal of our young adult provision. The changes will be discreet and include the reduction of respite availability from 7 nights per week to 6, with the exclusion of Sunday nights which have historically not been well utilised due to patients' schooling on Monday mornings. In addition to in-patient care, children will continue to be cared for and supported via our outreach nursing and medical teams in the child's community or local hospital – as has been the case for many years.

   Service changes also include the introduction of a Youth and Transition Worker to support children and their families in seeking appropriate onward care for them post 18 years of age. (This was previously achieved through our own young adult service at Douglas House.) Building on expertise previously developed at Douglas House, the role will also aim to work closely with the older children in our care by encouraging and enabling them to set and to reach their personal goals, whatever they maybe.

   To fulfil the new service model there will be a continual need for us to recruit staff, particularly nurses. As a small organisation based in Oxford, this is a challenge for Helen & Douglas House since competition for nurses and costs of living are both high. We will continue to work creatively with the roles we need, and how they may be recruited to, and will investigate partnerships with other care providers which may assist in that aim.

   Partnership working remains a key focus in support of integrated models of delivery. Projected developments for 2018-19 include:

   - A new partnership with Oxford Brookes University for the provision of a children's nursing basic course for those nurses transferring to Helen House who have previously been working with young adults at Douglas House. This will provide a credible and solid training for these staff, and will benefit the patients and their families as we develop into the future.
   - Continued close working relationships with Oxfordshire CCG Quality and Safeguarding Team through the secondment of a senior member of the hospice clinical team, plus project working with other major stakeholders around patient pathways. Regular meetings continue between the Director of Clinical Services and the OCCG Safeguarding Lead.
   - Material engagement with Oxfordshire CCG, alongside Buckinghamshire CCG, on their new Commissioning Plan for end-of-life care, which now includes consideration of children as well as adults. It is anticipated that this will enhance partnerships between providers (statutory and voluntary sector) as well as relationships with the CCGs.
   - Consolidation and progression of Specialised Paediatric Palliative Care working with the Oxford University Hospitals NHS Foundation Trust and wider working across the central southern region.

- Core participation from our senior clinicians in the Oxford AHSN Patient Safety Collaborative, including work on their *Paediatric Safety Programme - Long Term Ventilation Project*. The Collaborative is working with the Thames Valley Children's Palliative Care Network (et al.) to develop and implement a regional pathway for children and young adults who are cared for at home and dependent on long term invasive ventilation via a tracheostomy.

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

   It is essential that training remains a priority in 2018-19 through a period of significant organisational change, in addition to the natural turnover of staff experienced in any workplace. Focus will include consolidation of the rolling competency training programme (initiated in 2017-18) alongside essential and mandatory training.

   Formal training provision will be enhanced though the partnership with Oxford Brookes University (above). We will also be looking at the possible re-introduction of student nurses in the new academic year.

4. *Patient Experience*: review of **Patient Feedback Initiatives**

   The service changes planned for Helen House will require a programme of feedback from patients, families and staff. The systematic capturing of patient feedback will be a focus for one of the new roles that will be initiated from August 2018, and will include a range of approaches. This will include opportunity for real-time feedback opportunities through tablet technology, and the engagement of trained volunteers working in the clinical setting to gain feedback from families. We also hope to establish a family focus group in the coming year to enhance our open engagement with families on matters of mutual importance.

5. *Patient Safety and Clinical Effectiveness*: **Infection Prevention and Control**

   A new and overarching framework for Infection Prevention and Control (IPC) was developed in 2017-18 by our in-coming IPC Lead, and is in the process of being embedded across the organisation. This work will continue as a priority for 2018-19, ensuring that fundamental standards and best practice are upheld, and supported through staff training and education.

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 2017-18 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 has included consultants in palliative medicine (paediatric and adult) alongside registered nurses, care workers, clinical psychologist, social worker, teacher, and counsellors. Specialist trained volunteers have 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 have been 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 to patients "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.

Children's services have been provided in recognition of the NICE Guideline on *End of life care for infants, children and young people with life-limiting conditions* (December 2016) and have this year been evaluated against the accompanying NICE Quality Standard (September 2017).

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 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).
- 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).

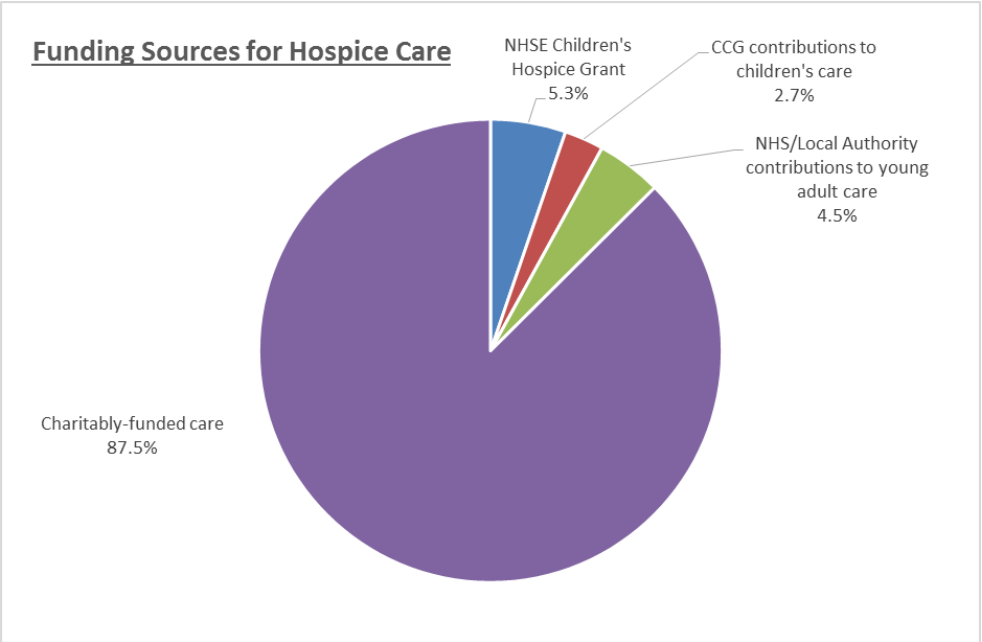
Helen & Douglas House has reviewed all the data available to us on the quality of care in these services.

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 relevant 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/statutory 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 2017-18 public sector contributions to care represented just 12.5% of the hospice's total expenditure on care services (patient care, family and bereavement support).



There is wide variation in engagement, approach to and levels of funding, between different commissioners across the more than 40 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 directly to us by the NHS/statutory services) and contributes significantly to the challenges of financial sustainability for the hospice. Such challenges were brought into stark relief this year when we announced the forthcoming closure of our young adult service (in June 2018) due to on-going funding shortfalls.

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 11% expenditure on children's hospice services and just over 5% of the hospice's total expenditure on all care services.

Public sector income source	**% Public sector contribution to total hospice expenditure on:**			
	Children's hospice care (Helen House)	**Young adults' hospice care** (Douglas House)	**Family support & bereavement services**	**All care services** (charitable activities)
NHSE Children's Hospice Grant	11%	-	-	5.3%
CCG contracts & grants for children	5.8%	-	-	2.7%
CCG & local authority contributions for young adults	-	9.6%	-	4.5%
Total	**16.8%**	**9.6%**	**0%**	**12.5%**

Through NHS contracts and grant agreements local Clinical Commissioning Groups together contributed just less than 6% to the cost of providing children's palliative care in 2017-18 (2.7% total expenditure on all care services). This included a one-off grant from Buckinghamshire (Aylesbury Vale and Chiltern CCGs), as well as continued contributions from Wiltshire, Swindon, Milton Keynes, Nene and Corby. We are pleased that there is provisional agreement for funding to continue from Buckinghamshire, and are hopeful that renewed engagement with Oxfordshire CCG might yield scheduled funding for the first time within their forthcoming Commissioning Plan.

At present we receive no NHS funding for *specialised* medical care for children (Level 4 palliative medicine), despite there being no local provision via the NHS. This has been repeatedly raised to NHS England, including via *Together for Short Lives*; it is hoped that this will be subject to active review in 2018-19.

We receive no Short Break funding from local authorities.

Funding for young adults is negotiated on a case-by-case basis from NHS and local authorities – an uncertain and time-consuming process. In 2017-18, statutory contributions accounted for less than 10% cost of care at Douglas House (4.5% total expenditure on all care services).

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 2017-18 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 clinical skills framework is used to inform our training needs analysis and staff development programme, which supports 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* is in post to promote and support existing practice and processes.

The assessment of clinical quality is driven through the audit programme managed by the Director of Quality, Compliance and Commissioning, with the Director of Clinical Services, in support of legislative and regulatory requirements, and clinical best practice. In 2017-18 a new Infection Prevention and Control framework has been initiated to consolidate, enhance and evidence good practice across the organisation. 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 and grant agreements, 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 associated feedback. 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

All 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, and specific projects.

Clinical teams have the opportunity to attend weekly case-based discussion sessions led by our Consultant in Paediatric Palliative Care, to enable staff to explore and reflect on topical clinical issues and research findings.

New in-house clinical skills frameworks promote evidence-based evaluation of competency, plus learning and development opportunities. Development resources are provided for Registered Nurses to enable clinical skills to be embedded in the context of their professional practice.

The number of patients receiving services (funded by the NHS) provided or sub-contracted by Helen & Douglas House in 2017-18 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 2017-18 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) and its current registration status is unconditional. The Care Quality Commission has not taken enforcement action against Helen & Douglas House during 2017-18.

Helen & Douglas House has not participated in any special reviews or investigations by the CQC during the reporting period.

Inspection Findings

The summary report from the latest CQC inspection (6 June 2017) is provided in Part 3 of the Quality Account. The service was rated "Good" overall.

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 2017-18 reflect items identified in the 2016-17 Quality Account and, in turn, inform priorities for the forthcoming year (2018-19).

Priority	Action & Progress in 2017-18	Plan for 2018-19
Activity data: Extension of the standardised reporting of performance data across additional areas of hospice activity.	Family Support Team caseload and activity reports consolidated. Progression of activity reporting to the Quality of Care trustee Sub-Committee via quarterly dashboard.	Streamlining of data capture and reporting in line with organisational restructure, including through revised referral and booking processes.
Information Governance: Continued implementation of the Information Governance Improvement Plan.	Achievement of Level 2 (minimum) against all requirements of the IG Toolkit. Development of approaches to comply with the General	Consolidation of GDPR implementation.

	Data Protection Regulation (GDPR).	
User Experience and Outcomes: Review and development of feedback mechanisms to capture user experience, evaluate and demonstrate outcomes, and inform on-going improvement.	Review of existing feedback capture forms. Initial meetings with parent representative to identify projects for co-design. (Development projects originally planned for 2017-18 have been deferred in light of organisational change priorities.)	Project for systematic capture of user experience and outcomes through a range of approaches (including tablet technology and the training of selected volunteers to engage with families). Establishment of a parent/family focus group.
Monitoring and Management of Staff & Volunteer Data: Consolidation of administrative data function to improve monitoring and management of workforce data.	Successful extension of HR information system to support efficient management of staff data, including sickness absence. Streamlined management reporting on mandatory training compliance.	Extend use of HR information system to manage data about the volunteer workforce.

NHS Number and General Medical Practice Code Validity

Helen & Douglas House did not submit records during 2017 -18 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 2017-18 by the Audit Commission.

Part 3: Review of Quality Performance

CQC Inspection Report

The service was inspected by the CQC in June 2017, as follow-up from the December 2016 inspection. The inspection report summary is provided in the inset below.

We inspected this service on 6 June 2017.

Helen and Douglas House is a hospice charity based in Oxford providing palliative, respite, end of life and bereavement care to life limited children, young adults and their families. Helen House can accommodate up to eight children and Douglas House up to seven young adults. At the time of our inspection there were four children in Helen House and three young adults in Douglas House.

The service provides complete care including counselling and bereavement support for children, young adults and their families. The hospice had a multi-professional team consisting of medical and nursing staff, spiritual care, family support workers and therapists. The hospice was also supported by volunteers.

There was a registered manager in post. A registered manager is a person who has registered with the Care Quality Commission to manage the service. Like registered providers, they are 'registered persons'. Registered persons have legal responsibility for meeting the requirements in the Health and Social Care Act 2008 and associated Regulations about how the service is run. The registered manager worked closely with the director of clinical services and a deputy manager.

At the last inspection on 6 December 2016, the inspection was prompted in part by a notification of a significant incident. On that focused inspection the service was rated inadequate in safe and requiring improvement in well led. Two breaches of the Health and Social Care Act 2008 (Regulated Activities) 2014 were identified. Following the inspection, we received regular action plans which set out what actions were being taken to ensure children and young adults were safe.

We undertook this inspection on 6 June 2017 in line with our inspection guidance to see if improvements had been made. At this inspection we found considerable improvements in the service. We saw that action had been taken to improve children's and young adults' safety and the provider's quality assurance systems were effective.

Children and young adults had a range of individualised risk assessments in place to keep them safe and to help them maintain their independence. Where risks to children and young adults had been identified, risk assessments were in place and action had been taken to manage the risks. Staff were aware of children's and young adults' needs and followed guidance to keep them safe.

Children and young adults received care that was personalised to meet their needs. Care plans were current and reflected changes in care.

The provider had effective quality assurance systems in place which identified areas of improvement and allowed learning across the board.

Children and young adults who were supported by the service felt safe. Staff had a clear understanding on how to safeguard them and protect their health and well-being. Children and young adults received their medicines as prescribed.

There were enough suitably qualified and experienced staff to meet children's and young adults' needs. The service had robust recruitment procedures and conducted background checks to ensure staff were suitable for their roles.

Staff received adequate training and support to carry out their roles effectively. Children and young adults felt supported by competent staff that benefitted from regular supervision (one to one meetings with their line manager) to help them meet the needs of the children and young adults they cared for. Nurses were supported through the revalidation process.

Children's and young adults' nutritional needs were met. They were given choices and were supported to have their meals when they needed them. Staff treated children and young adults with kindness, compassion and respect and promoted their independence and right to privacy.

Children and young adults were supported to maintain their health and were referred for specialist advice as required. Staff knew how to support children, young adults and their families through the bereavement process.

Staff knew the children and young adults they cared for and what was important to them. Staff supported and encouraged them to engage with a variety of social activities of their choice. Children and young adults were encouraged to develop friendships during their stays at Helen and Douglas House.

The service looked for ways to continually improve the quality of the service. Feedback was sought from children, young adults and their families and used to improve the care. Children, young adults and families knew how to make a complaint and complaints were managed in accordance with the provider's complaints policy.

Leadership within the service was open and transparent. Young adults, their families and staff were complimentary about the management team and how the service was run.

The registered manager informed us of all notifiable incidents. The registered manager had a clear plan to develop and further improve the service. Staff spoke positively about the management support and leadership they received from the management team.

Despite the significant improvements we found on this inspection, we could not improve the rating for safe from inadequate to good because to do so requires consistent good practice over time. We will check this during our next planned comprehensive inspection.

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, however an indication of the scope of measures for 2017-18 is provided in Appendix 2. Quality is assured through written and verbal reports, and through face-to-face contract review and performance meetings. We encourage an open and transparent dialogue with our commissioners.

NICE Guidance

The new NICE Quality Standard for End of life care for infants, children and young people was published in September 2017. Two members of Helen & Douglas House clinical team were on the NICE panel that developed the Guidance; and one staff member on the NICE team developing the associated Quality

Standard. We have made an initial draft assessment against the new Quality Standard, which is under internal review.

Our initial baseline self-assessment on putting this NICE guidance into practice concluded the following:

- All 135 areas identified in the baseline assessment tool are applicable to our service.
- There was 'current activity evidence' on some level for areas (100%).
- The recommendations were considered to be 'met' in 122 (90%) of cases.

We have identified and prioritised gaps, and initial actions against each area. Some of the action areas are system-wide (e.g. collaboration regarding rapid transfer, identification of lead healthcare professional); others are for more local implementation (e.g. provision of additional written information to support discussions with patients, parents and carers).

We are looking within the Thames Valley Children's Palliative Care Network to work with other services to ensure gaps can be minimised across the region (complementarity and partnership of services).

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. This is led and managed through the clinical governance framework and structures at Helen & Douglas House. Key points from the organisation's clinical governance reporting are summarised below, as demonstration of our quality of care and continuous improvement.

Clinical Incidents

In 2017-18 there was a total of 163 clinical incidents (excluding medication related incidents); 105 reported in Helen House and 55 in Douglas House. 3 were external to the houses. The total number of incidents is slightly reduced from last year (195).

The two most frequently reported categories of incidents were *Challenging behaviour* (16.5%) and *Communications* (15%). There were no trends observed in the reporting other than repeated challenging behaviour incidents which generally related to one or two patients or family members. These appeared as peaks in reporting associated with particular stays at the hospice; with learning from the incidents appropriate measures have been put in place for subsequent stays and a reduction in such incidents has resulted.

Following the serious incident of May 2016, the Coroner highlighted the need for learning from near miss incidents. The number of near miss incidents reported has seen an encouraging increase over the past year and we continue focus on the dissemination of learning from such reports within a 'no blame' culture.

Medication Incidents

There was a total of 75 drug incidents reported in the year: 52 in Helen House and 23 in Douglas House. The number in Douglas House has reduced significantly this year reflective of a reduction in the number of patients it has been possible to accommodate due to a shortage of nurses. Helen House continues to have steady reporting but their drug usage and complexity tends to be higher than in Douglas House.

57 of the 75 incidents were rated as low risk and only one as high risk. No trends were identified; however the number of prescription errors were noted. None of the prescription errors led to an actual drug error, as all were picked up through the nursing staff before medication was administered.

Clinical Risk Management

Following the inquest in July 2017 into the unexpected death of a young woman in May 2016, a decision was made to stop accepting patients requiring invasive ventilation for care at Helen & Douglas House. It was considered to be a significant clinical risk to continue to do so. Senior clinicians continue to input experience and learning from the serious incident to wider audiences to help avoid possible occurrence elsewhere.

The Lead Doctor and Nurse Consultant are part of the *Oxford AHSN Patient Safety Collaborative* which is initiating a project on Long Term Ventilation. They are also contributing to a project considering gastrostomy feeding as part of the same *Patient Safety* group.

Care planning has remained a core focus across the clinical teams in 2017-18. Regular audits demonstrate sustained improvements with consistently high quality care planning and improved written communication. More detailed planning has necessitated an extended planning process for families and staff, but with evident benefits for subsequent care.

During 2017-18 the Trustees of Helen & Douglas House prioritised a review of clinical risk and safety through a 'safety' sub-committee. Assurance was provided to the sub-committee through a presentation of the framework of measures that are in place to minimise/mitigate risk and protect the safety of patients and staff.

The Clinical Risk Register has been restructured and streamlined to emphasise four overarching risks, any of which might compromise the quality of care and could contribute to patient harm.

1. Inadequate recruitment and retention of clinical staff.
2. Staff are inadequately trained and experienced to care for the patients in house.
3. Breach of clinical regulations / non-compliance with contractual standards.
4. Staffing risk – due to acute emotional pressures, staff are unable to care for their patients.

Infection Prevention and Control

A new Infection Prevention and Control (IPC) Lead Nurse with a very strong NHS IPC background took up post in November, working one day a month. Initial work has included a review of IPC processes at the hospice and development of a comprehensive IPC Framework, from which an action plan will be created to monitor development and improvement.

Clinical Audits

A summary of key findings from the programme of clinical audits is presented below.

Audit	**Key findings**
Accountable Officer	Good compliance. Future focus on the continued monitoring of the prescribing practices of controlled drugs in the hospice, as this is a new process.
Controlled Drugs Prescriptions Monitoring	Any new controlled drug prescriptions are reviewed at bi-monthly Medicines Management Meetings. Prescription numbers have been very low and there have been no trends noted.
Management of General Medicines	Compliance was slightly increased from last year, which is encouraging as a new pharmacy service has been in place since the start of the financial year. The one area of concern related to the signed receipt of stock

	medications under the new contract; this has since been reviewed and revised.
Management of Controlled Drugs	Six out of seven sub-topics in the audit tool demonstrated 100% compliance. The remaining sub-topic achieved 97%. Non-compliance concerned the controlled drug record not indicating the name and address of the supplying pharmacy, although this is on the order form which is retained.
Care planning	House Managers conducted care planning audits at regular intervals throughout the year to ensure that standards were maintained and to note any areas for further improvement. The care planning audits have demonstrated evidence of strong, effective care planning. The care plans were initially renewed for each stay, now they are renewed every 4 months or if there are significant changes in the care to be delivered within the 4 month period. One area for continued focus concerns identification labels being present on each sheet on both sides. For 2018-19 the frequency of care plan audits will be reduced – reflective of the sustained improvements made in 2017-18.
Record keeping	The record keeping audit was incorporated into December's care planning audit. Areas for focus included: • Legibility of signatures, printed name and designation. • Signatures required on each sheet of notes. • Identification labels to be present on each side of each sheet. These will continue to be monitored.
End-of-life care discussions with patient/family	The NICE end-of-life care quality standard for children indicates that all patients should have had opportunity to discuss their wishes for emergency/end-of-life situations. This includes, but is not restricted to, development of Advance Care Plans. The full complement of children's patient notes (146) was audited on a specific date. 100% of notes had a documented discussion, although a small minority (3) were not recorded on the specified stationery. Future work will audit the focus of discussions, including preferred place of care and resuscitation wishes.
Nutrition and hydration	Nutrition and hydration form an essential part of our care planning for all patients. As part of the auditing of care plans during the year, nutrition and hydration plans were explicitly included. 100% of care plans audited included nutrition and hydration.

	Advance Care Plans were checked for inclusion of nutrition and hydration plans as part of the end-of-life care discussions audit. 100% had a documented record of wishes about nutrition and hydration.
Hand hygiene	Audits have yield results of over 90% on a regular basis. Hand hygiene is to be incorporated into the wider IPC Framework and auditing in future.
Mattress	This annual review identified one mattress with a small tear (investigating repair) and two mattresses which were taken out of use, along with one wooden cot.
Medical Gases	In four of the eight sub-topics, over 95% compliance was achieved. The remaining sub-topics achieved at least 82% compliance (noting that failure in just one category can significantly affect the percentage where the categories are few in number). In one of the sub-topics, decontamination and discharge, all of the categories were not applicable as none of the patients were discharged home requiring oxygen at the time of the audit and none required decontamination. Future developments, as part of organisational restructure, will extend the organisation's capacity to manage/change medical gas cylinders by reducing dependence on individual members of staff.
Data Protection	The audit focused on data consistency across electronic and paper records, including the list of professional contacts per patient. Results indicate areas for improvement in both process and system utilisation. Audit outputs are informing the GDPR programme and associated working practices (all are low and managed risks re data protection/security).
Information Governance	All requirements of the IG Toolkit have been evaluated and the self-assessment updated with relevant evidence of compliance. Achievement of a minimum Level 2 compliance across the board. Future focus on GDPR and on the revised Toolkit.
Complaints	Three complaints were received in 2017-18. All were received in Helen House, two in November and one in December. There was no theme to the nature of the complaints, although all included issues of communication. All were investigated by an appropriate investigator and were resolved satisfactorily. A low number of formal complaints, with little evidence of commonality, is consistent with previous years. Auditing proved challenging this year against the current tool, as none of the complaints were received in a standard way. We plan to review the tool prior to the next audit.

Safe Staffing

Safe levels and skill-mix are ensured at Helen & Douglas House by tailoring the numbers of beds available to which patients may be admitted according to staffing. This is planned shift-by-shift and reviewed on a dynamic basis, according to well-developed practice and guidelines. Nurse recruitment is a significant challenge, both locally and nationally; availability of palliative care nursing staff is a key factor in planning and staffing care shifts.

Visibility of staffing levels, and impact on capacity, is raised not only at operational and Executive levels, but also with Board Trustees via a Quality of Care Sub-Committee and also at Full Board meetings.

The scale of safe care that Helen & Douglas House can provide consistently has been central to strategic dialogue this year, as the overall care model has been reviewed and organisational change initiated on the basis of financial and care sustainability.

Patient Safety Alerts

Patient safety alerts are received by the Chief Executive Officer and then disseminated to the appropriate Director. These are then assessed for their relevance and shared if required. Three alerts were of direct relevance.

- One related to a ventilator battery which required replacing. The ventilator battery alert led to an extra check being made at the weekly inter-disciplinary team meeting in Douglas House; Helen House identified that these were not ventilators used by any of their patients.
- Another related to the fact that patients had been harmed through a lack of ability of carers and nurses to operate oxygen cylinders correctly. Checks were made with staff that they were able to operate the oxygen cylinders effectively.
- The third concerned interrupted infusions. Infusion pumps were all checked and adjusted, as required.

A majority of other alerts that were shared related to medications which have been found to cause unexpected side effects or that have been inappropriately labelled.

Clinical Staff Training and Skills Competency

Mandatory training levels for clinical staff are reported monthly and have been consistently over 90%.

During the year the safeguarding training approach has been developed to enhance training to Level 3 (or above) for all clinical staff who care for children. New Level 3 face-to-face training has been developed in discussion with, and approved by, the Oxfordshire Safeguarding Children's Board. The face-to-face training is being rolled out during the first half of the 2018 calendar year, and has been well received and evaluated.

In the last year and a half, Helen & Douglas House has been developing a Clinical Skills Competency Framework for carers/nursery nurses, and a Nurse Self-Assessment tool. The implementation of these tools is supported by Practice Development staff members and includes reflection on both competence and confidence.

- From a Nurse perspective – key focus areas from a baseline Training Needs Analysis (January-March 2017) included tracheostomy and suction, ventilation, syringe drivers and seizure management. The clinical skills training programme that was created for 2017-18 reflected these priorities.
- For carers, the Clinical Skills Competency Framework was reviewed in August 2017 and individuals' training is recorded and monitored by the Practice Development Nurse who also works with the team to continually develop and quality assure competencies. The Framework helps to ensure appropriate skill-mix to support particular patients' needs on each shift, alongside the nursing staff.

Duty of Candour

NHS England requires providers to 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 recently been evidenced through our openness with commissioners and their Quality Teams regarding our continued quality improvements following a Serious Incident in May 2016.

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 *Freedom to Speak Up Guardian*, as well as through their line management.

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 – with such active partnerships enabling the high degree of individualised support that is provided.

Helen & Douglas House provides a variety of methods 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 for written comment.
- Specific surveys with structured questions on focused areas of review (as required).
- In-depth case studies with patients and families.

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 below.

Individual and ad hoc Feedback

Ad hoc family feedback during the year illustrates an acknowledgement and appreciation of both clinical care and the wider support provided and enabled through our specialist hospice staff and environment. Examples include:

- Reference to Helen & Douglas House as a "life line", without which a family may have "sunk a long time ago".
- The value expressed by families of the quality of medical and care staff, and support received both whilst at Helen House and remotely (at home/hospital).

- The sensitive and considered manner of engagement by staff with families.
- Ensuring a family were able to have the best family Christmas that they were able to.
- The quality of, and attention to, high quality catering.
- Being able to be "mum" to a dying child who was being cared for by the team at Helen House. (Parents being able to be "parents", without the full burden of care at critical life stages.)

Case Studies

During the year we have compiled a number of case studies and examples, and have also invited families to share their experiences publicly via our annual Radiothon which took place in March 2018, run by JACKfm and hosted within Helen & Douglas House. Such personal stories are very powerful in being able to illustrate the personal nature of each situation, the individualised care provided, and the breadth of support that different people have needed and valued.

Examples of feedback about Helen House (children's service) through family stories:

- *"Helen House is my daughter's special place, to be safe, smile and be happy. A place for me to be mummy and to take 'the carer' role away. Life is precious and here we can make memories to treasure forever".* (Mother of child age 5.)
- *"It's the only place I will leave [our son]. The care he receives at Helen House, both physically and mentally, is brilliant."* (Mother of child with Prader-Willi Syndrome.)
- *"We're incredible proud of Helen House and the care they give us and the other families that visit. It's an inspirational place where we've brought friends and family to see first-hand how amazing it is. The building and facilities are great but it's the people that make Helen House, without their professional, caring, fun faces it wouldn't be the same. Both physically and emotionally the team at Helen House have lifted us as parents off the floor, helping us to recover from what life has thrown at us. The care for [our son] is second to none but the real impact is on us. Four years on we've adjusted to our life and thanks to the support of Helen House are doing all we can for [our son] at home, both working part-time, have a social life and have the energy to try and help others. We would not be where we are if it wasn't for Helen House and the team that bring it to life. The support we get enables us to be better parents to our little boy and have the energy to keep fighting the effects of his devastating illness."* (Parents of child aged 4, referred to Helen House when he was 9 months old.)
- *"We got to do some lovely things with [our daughter] that we could not have done in hospital, nothing was too much trouble. [She] got to have one last bath with her Daddy, and to paint a picture with Mummy and create some hand prints. These are such precious memories for us that help us through the bad days…. Helen & Douglas House have been so supportive to us since [our daughter] passed away. I have regular counselling to help me survive and get through the tough days. We also get to join a parents bereavement group which help us to realise we are not alone, and we can talk to others who are feeling the same as us and just understand how we feel. [Dad] attends a regular dads' group which is a great way for him to talk to other dads who often find it hard to talk to counsellors. Without this support I am not sure we would have got through the first year on our own, there is nowhere else that offers this support and we would be totally lost*

without it." (Parents of child who came to Helen House when it was discovered that their child had just days to live.)

- *"…for me Helen House is the only place I switch off. I can just relax. I have this constant guilt that I am not playing or interacting with [our daughter] enough. Now, when I am here I don't have that guilt because I am not trying to also clean the house and work out how to get to the shops...*
  When [our daughter] was diagnosed we were advised to enjoy every day that we had with her. They indicated that she wouldn't make it through her toddler years, but we don't really know. But I do think when you come here it gives you hope. Knowing that we have the support of Helen & Douglas House takes some of the fear out of our situation, knowing there will be people to talk to and to help us if the worst happens." (Mother of child aged 4, with a life-shortening neurological condition.)

Examples of feedback for Douglas House (young adult service):

- A new "Social Saturday" initiative for our young adult patients generated significant positive response from participants. This included meeting friends, the activities and visiting animals that were arranged, t-shirt making, and barbecue.
- *"Douglas House provided much needed support to my son Harry during the last year of his life. Harry loved staying at Douglas House and for me it made an almost unbearable situation survivable."* (Mother who is raising money for the charity in memory of her son who died at Douglas House.)
- Identification by a patient of Douglas House as their "*second home*".
- A bereaved family's recognition of the care and kindness shown to their child, and to them as a family, a number of years into bereavement.
- Parent and patient thanks to Douglas House staff for looking after them so well and for the quality of people involved in the care.

Professional Commendations

These are often received by email in response to particular episodes of joint-working, or as feedback this year to the hospice's role in local NHS care pathways.

- Exceptional patient interaction, care and general atmosphere. (DoLS assessor.)
- Thanks from hospital consultants and oncology outreach nurses for the support provided to specific patients during the year, and joint-working across organisations.
- Acknowledgement from senior clinicians at the Oxford University Hospitals NHS Foundation Trust of the essential and invaluable services provided to them by Helen House, of the upward trend of demand for groups of patients on the palliative pathway, of the expert support provided by the hospice to transition patients from hospital to home, and of the close partnership working between the organisations.

Complaints

Helen & Douglas House received 3 complaints in the year 2017-18. There were no themes within these complaints and all were resolved in a timely and acceptable manner.

Comments from Local Scrutineers

It is an NHS requirement that Quality Accounts be shared, in draft, with the local Healthwatch and with the local Overview and Scrutiny Committee. Any comments need to be included in the final Quality Account.

Helen & Douglas House has shared a draft of this Quality Account with **Healthwatch Oxfordshire** and with the **Oxfordshire Joint Health Overview & Scrutiny Committee**.

The following comment has been received.

Oxfordshire Joint Health Overview & Scrutiny Committee

Thank you for sharing the Helen & Douglas House draft Quality Account with the Joint Health Overview and Scrutiny Committee (HOSC) for comment. This document is a valuable tool in helping the public to understand the Trust's performance and priorities for improving the quality of local services.

We recognise the very valuable and unique services you provide to the residents of Oxfordshire; made clear from the feedback and case studies you report on from patients and their families. The financial challenges you have faced which have led to the changes in services are regrettable but we note the brave decisions you have taken to ensure you can continue providing services to children up to the age of 18.

The Committee is pleased to note the improvements made in a number of areas. They are particularly pleased to see the focus on partnership working which has been such a key priority for many across the health and care system in Oxfordshire.

The Committee recognises the learning taking place around incidents and near misses and encourages you to continue making improvements to the organisation's process and management to reduce the likelihood of such incidents in future.

Yours Sincerely

Cllr Arash Fatemian

Chairman Oxfordshire Joint Health Overview & Scrutiny Committee

Appendix 1 – Hospice Caseload and Patient Activity

Patient Caseload

Patient Caseload	Helen House	Douglas House	Total
Total Patients on Caseload over the Year	**198**	**99**	**297**
New referrals	74	20	94
Referrals accepted	45	0	45
Deaths of patients on caseload	21	7	28
Cases closed during the year (not deaths)	20	10	30
Patients on caseload in any one month (range)	148-158	82-99	239-250

In-Patient Activity

In-patient activity: Overnight care	Helen House	Douglas House	Total
Admissions for overnight care (stays)	**459**	**280**	**739**
Emergency & end-of-life	*24*	*2*	*26*
Planned	*435*	*278*	*713*
Bed-nights of care	**1242**	**1231**	**2473**
Emergency & end-of-life	*170*	*5*	*175*
Planned	*1072*	*1226*	*2298*
Patients in receipt of overnight care	**144**	**84**	**228**

In-patient activity: Daycare & Assessments	Helen House	Douglas House	Total
Episodes of care	**48**	**2**	**50**
Patients in receipt of daycare/assessments	**27**	**2**	**29**

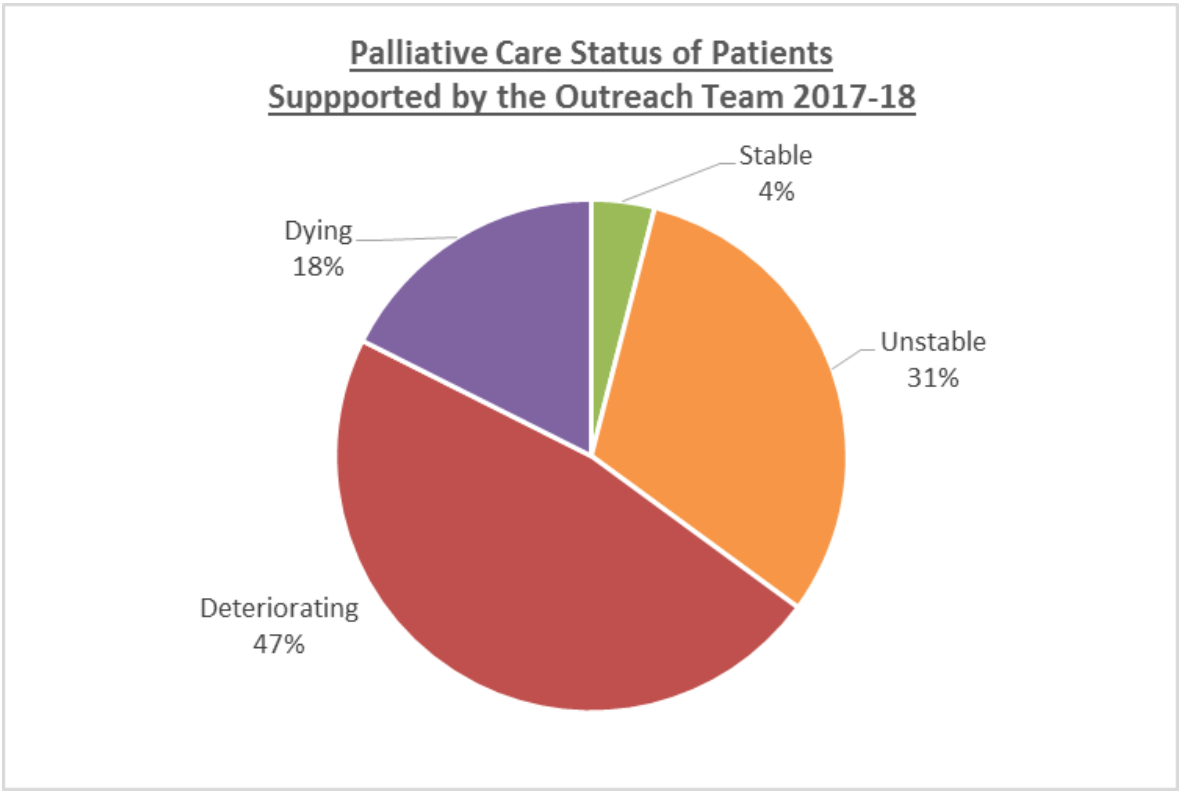
In-patient activity: Care post-death	Helen House	Douglas House	Total
Bed-nights (chilled room)	**17**	**0**	**17**
Patients cared for in-house post-death	**4**	**0**	**4**

Whilst caseload numbers have remained similar year-on-year for Helen House, including significant natural turnover in this population, activity levels have been restricted by staffing numbers – particularly Registered Nurses. Staffing pressures have also limited activity in Douglas House; here the patient population is relatively static, but caseload has reduced towards the end of the financial year following the decision that the service for young adults will close by the end of July 2018.

Outreach Activity

Outreach Care	Total
Number of patients supported	**116**
Episodes of face-to-face care with patients	**204**
At home	*73*
At hospital	*16*
At hospice (Helen & Douglas House)	*115*
Episodes of contact with carers or healthcare professionals (direct or by phone)	**915**
Total hours of direct contact with patients, carers or healthcare professionals (excludes preparation and follow-up)	**528**

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. 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.



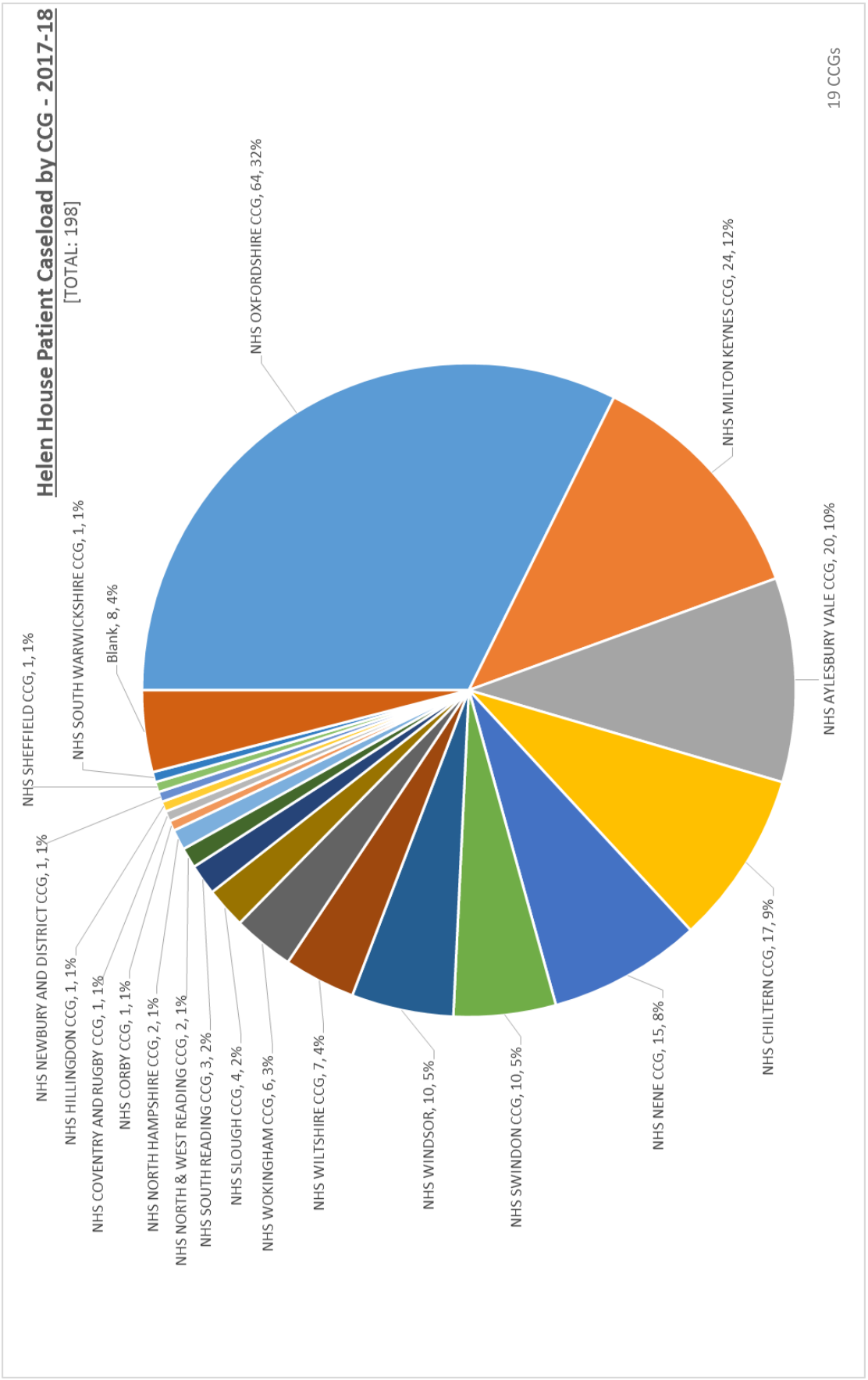
The complexity and vulnerability of patients supported by the outreach team is illustrated by the assessed palliative care status of those patients: the majority being *unstable* or *deteriorating*, with a significant additional proportion *dying*.

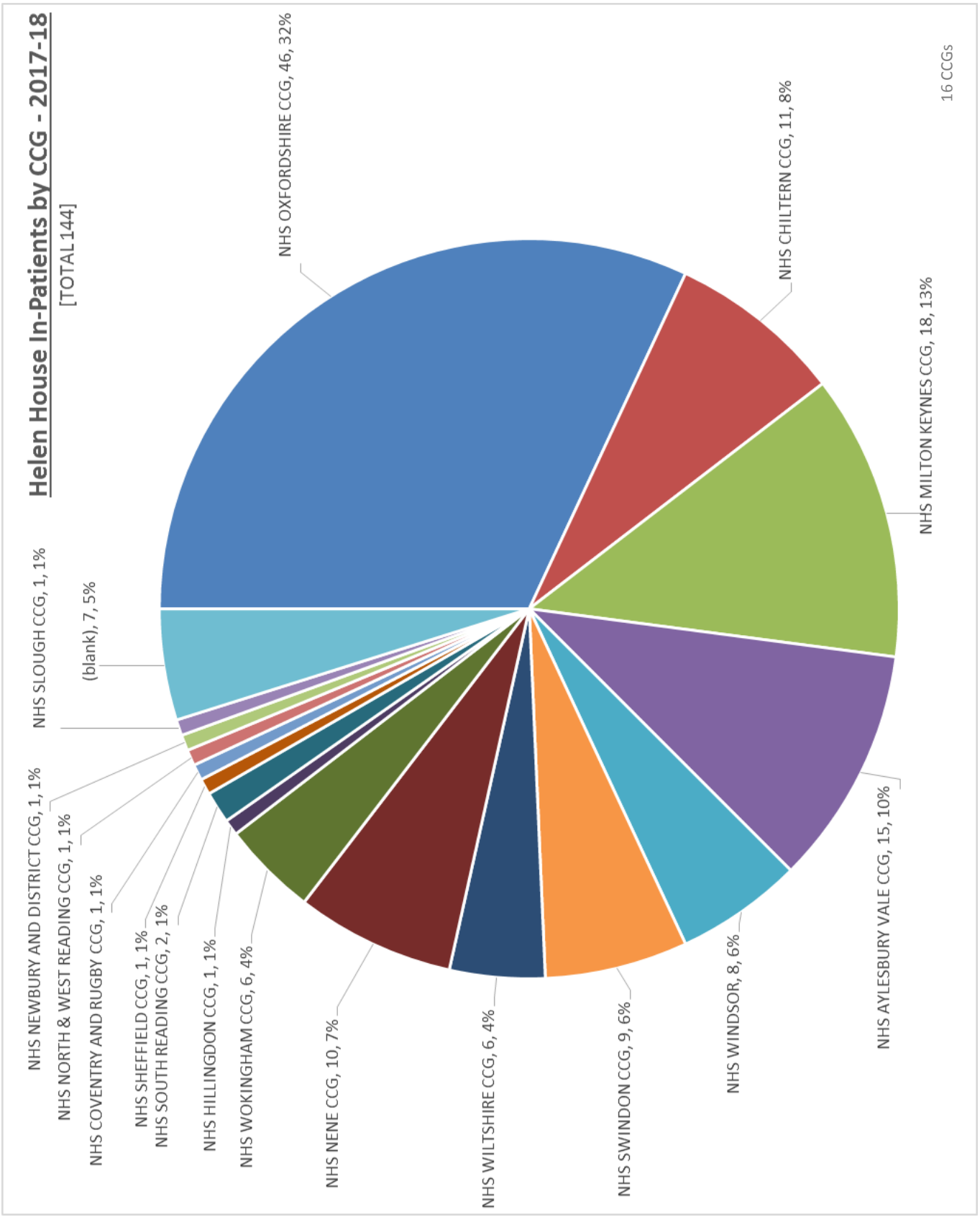
Family and Bereavement Support

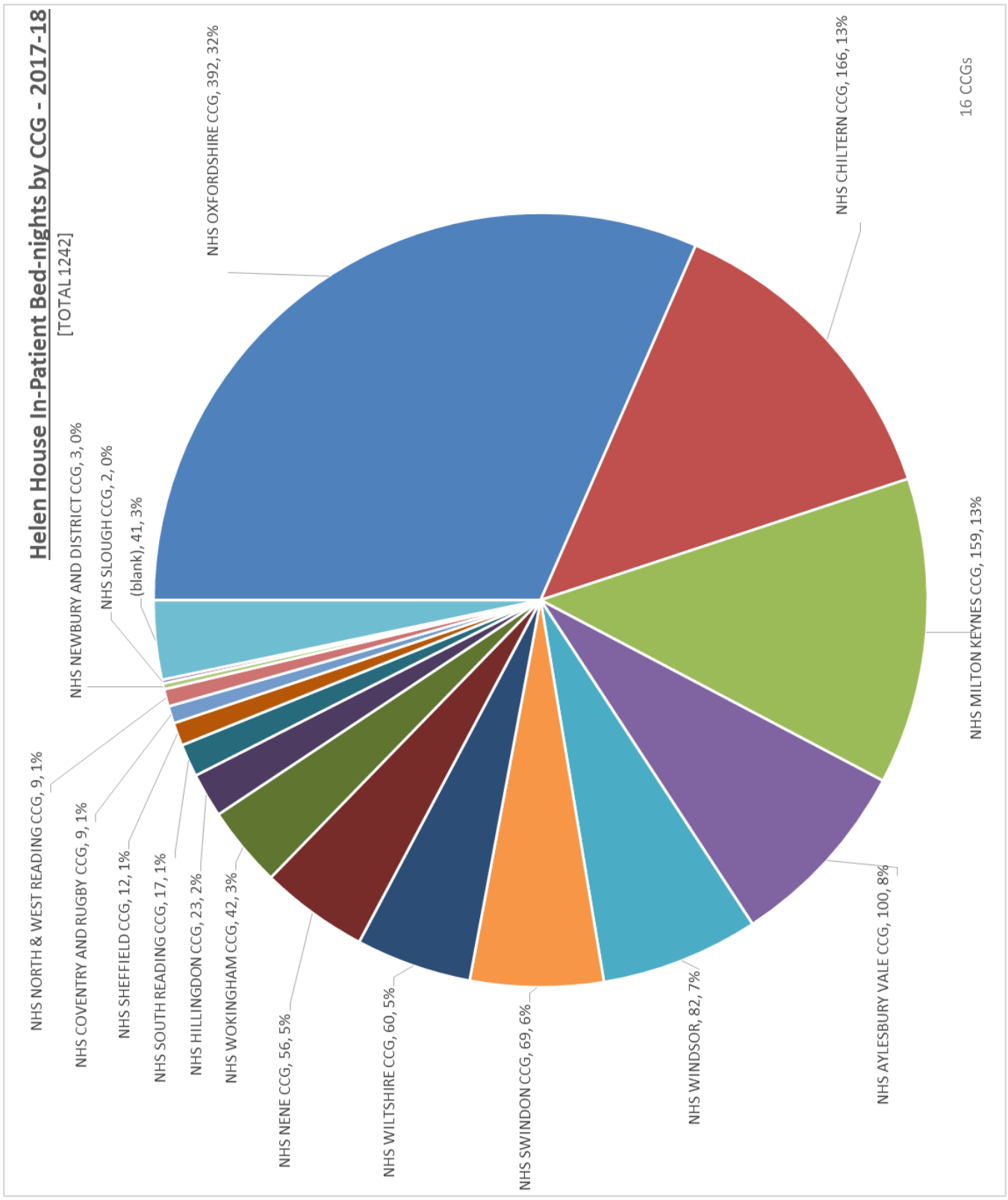
Family and Bereavement Support	Total
Counselling: individuals supported 1:1 (patients, family members, carers)	**57**
Counselling: couples supported	**9**
Clinical Psychology: individuals supported	**5**
Sibling support: individuals supported 1:1	**27**
Sibling support: individuals supported in groups	**11**
Social Work support: individuals supported	**32**
Social Work support: families supported	**6**

There have been significant changes within the structure and composition of the Family Support and Bereavement Team over the year, leading to reductions in capacity for counselling (adult and sibling) and in clinical psychology. The portfolio of family support remains a key part of the service offering and will be further integrated within our service model following organisational restructure in 2018-19.

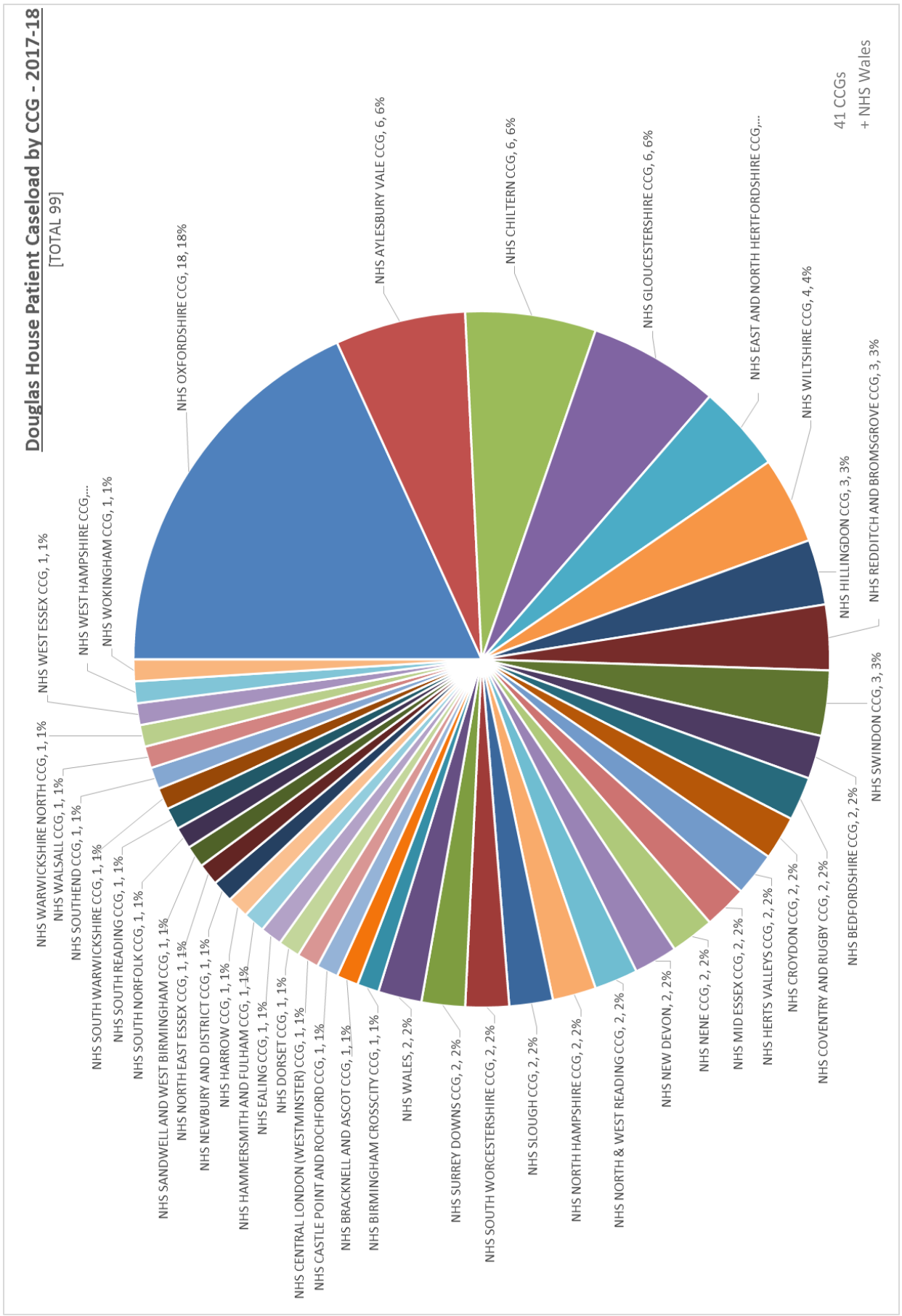
Caseload and Activity by CCG: Helen House

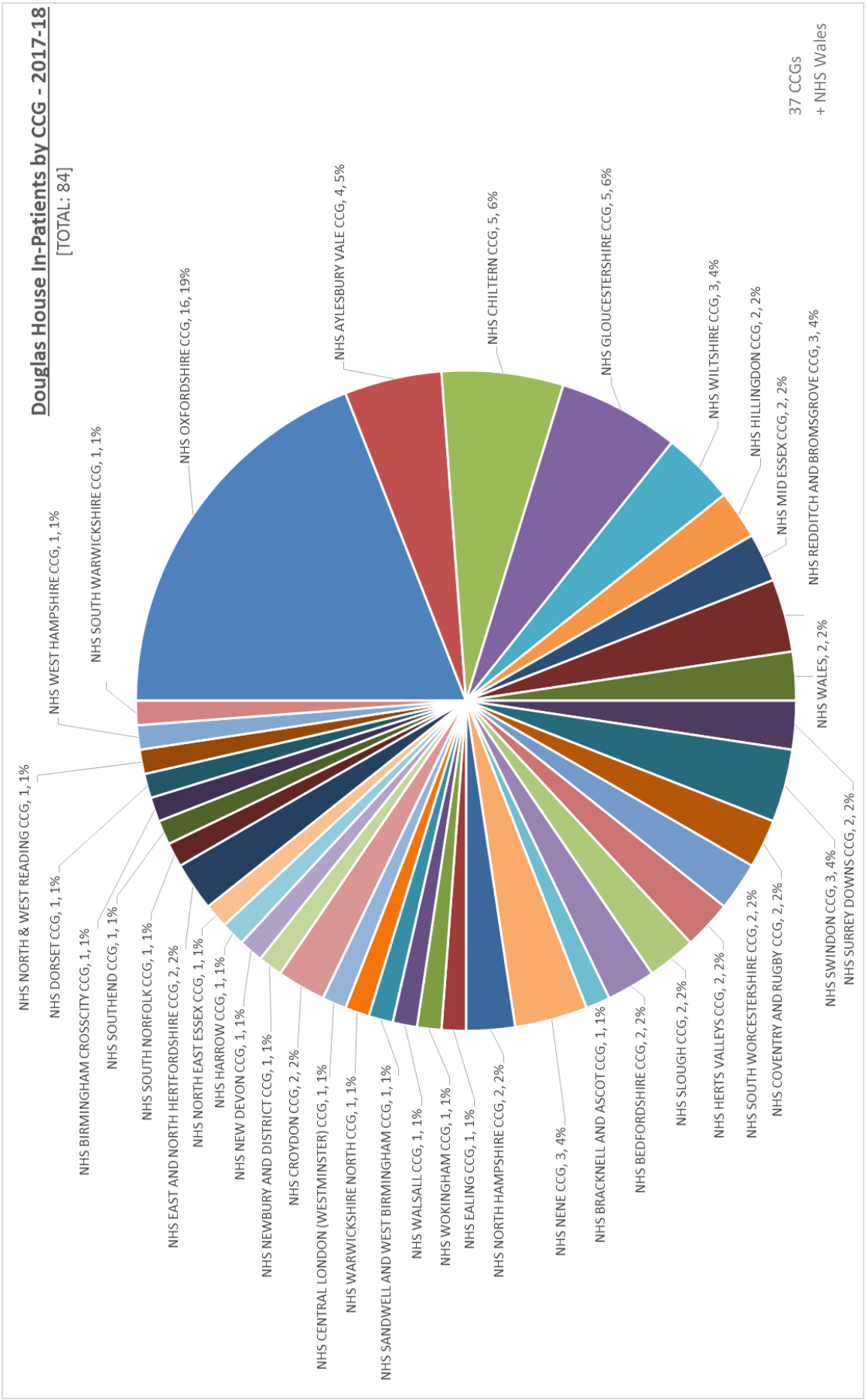


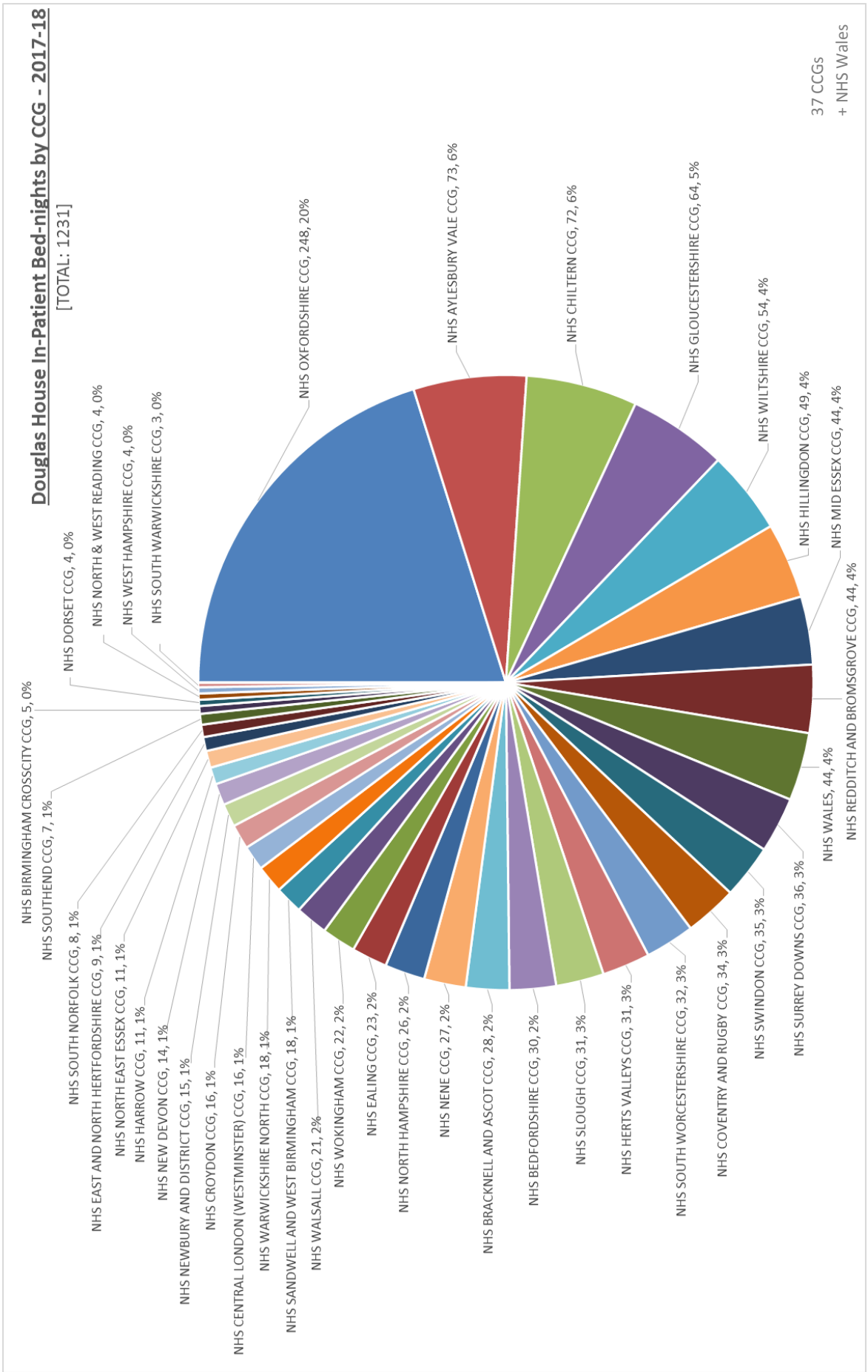

Helen House In-Patients by CCG - 2017-18
[TOTAL 144]
NHS OXFORDSHIRE CCG, 46, 32%
NHS CHILTERN CCG, 11, 8%
NHS MILTON KEYNES CCG, 18, 13%
NHS AYLESBURY VALE CCG, 15, 10%
NHS WINDSOR, 8, 6%
NHS SWINDON CCG, 9, 6%
NHS WILTSHIRE CCG, 6, 4%
NHS NENE CCG, 10, 7%
NHS WOKINGHAM CCG, 6, 4%
NHS HILLINGDON CCG, 1, 1%
NHS SOUTH READING CCG, 2, 1%
NHS SHEFFIELD CCG, 1, 1%
NHS COVENTRY AND RUGBY CCG, 1, 1%
NHS NORTH & WEST READING CCG, 1, 1%
NHS NEWBURY AND DISTRICT CCG, 1, 1%
NHS SLOUGH CCG, 1, 1%
(blank), 7, 5%
16 CCGs


Helen House In-Patient Bed-nights by CCG - 2017-18
[TOTAL 1242]
NHS OXFORDSHIRE CCG, 392, 32%
NHS CHILTERN CCG, 166, 13%
16 CCGs
NHS MILTON KEYNES CCG, 159, 13%
NHS AYLESBURY VALE CCG, 100, 8%
NHS WINDSOR, 82, 7%
NHS SWINDON CCG, 69, 6%
NHS WILTSHIRE CCG, 60, 5%
NHS NENE CCG, 56, 5%
NHS WOKINGHAM CCG, 42, 3%
NHS HILLINGDON CCG, 23, 2%
NHS SOUTH READING CCG, 17, 1%
NHS SHEFFIELD CCG, 12, 1%
NHS COVENTRY AND RUGBY CCG, 9, 1%
NHS NORTH & WEST READING CCG, 9, 1%
NHS NEWBURY AND DISTRICT CCG, 3, 0%
NHS SLOUGH CCG, 2, 0%
(blank), 41, 3%

Caseload and Activity by CCG: Douglas House




Douglas House In-Patients by CCG - 2017-18
[TOTAL: 84]
NHS OXFORDSHIRE CCG, 16, 19%
NHS AYLESBURY VALE CCG, 4, 5%
NHS CHILTERN CCG, 5, 6%
NHS GLOUCESTERSHIRE CCG, 5, 6%
NHS WILTSHIRE CCG, 3, 4%
NHS HILLINGDON CCG, 2, 2%
NHS MID ESSEX CCG, 2, 2%
NHS REDDITCH AND BROMSGROVE CCG, 3, 4%
NHS WALES, 2, 2%
NHS SWINDON CCG, 3, 4%
NHS SURREY DOWNS CCG, 2, 2%
NHS COVENTRY AND RUGBY CCG, 2, 2%
NHS SOUTH WORCESTERSHIRE CCG, 2, 2%
NHS HERTS VALLEYS CCG, 2, 2%
NHS SLOUGH CCG, 2, 2%
NHS BEDFORDSHIRE CCG, 2, 2%
NHS BRACKNELL AND ASCOT CCG, 1, 1%
NHS NENE CCG, 3, 4%
NHS NORTH HAMPSHIRE CCG, 2, 2%
NHS EALING CCG, 1, 1%
NHS WOKINGHAM CCG, 1, 1%
NHS WALSALL CCG, 1, 1%
NHS SANDWELL AND WEST BIRMINGHAM CCG, 1, 1%
NHS WARWICKSHIRE NORTH CCG, 1, 1%
NHS CENTRAL LONDON (WESTMINSTER) CCG, 1, 1%
NHS CROYDON CCG, 2, 2%
NHS NEWBURY AND DISTRICT CCG, 1, 1%
NHS NEW DEVON CCG, 1, 1%
NHS HARROW CCG, 1, 1%
NHS NORTH EAST ESSEX CCG, 1, 1%
NHS EAST AND NORTH HERTFORDSHIRE CCG, 2, 2%
NHS SOUTH NORFOLK CCG, 1, 1%
NHS SOUTHEND CCG, 1, 1%
NHS BIRMINGHAM CROSSCITY CCG, 1, 1%
NHS DORSET CCG, 1, 1%
NHS NORTH & WEST READING CCG, 1, 1%
NHS WEST HAMPSHIRE CCG, 1, 1%
NHS SOUTH WARWICKSHIRE CCG, 1, 1%
37 CCGs
+ NHS Wales


Douglas House In-Patient Bed-nights by CCG - 2017-18
[TOTAL: 1231]
NHS OXFORDSHIRE CCG, 248, 20%
NHS AYLESBURY VALE CCG, 73, 6%
NHS CHILTERN CCG, 72, 6%
NHS GLOUCESTERSHIRE CCG, 64, 5%
NHS WILTSHIRE CCG, 54, 4%
NHS HILLINGDON CCG, 49, 4%
NHS MID ESSEX CCG, 44, 4%
NHS REDDITCH AND BROMSGROVE CCG, 44, 4%
NHS WALES, 44, 4%
NHS SURREY DOWNS CCG, 36, 3%
NHS SWINDON CCG, 35, 3%
NHS COVENTRY AND RUGBY CCG, 34, 3%
NHS SOUTH WORCESTERSHIRE CCG, 32, 3%
NHS HERTS VALLEYS CCG, 31, 3%
NHS SLOUGH CCG, 31, 3%
NHS BEDFORDSHIRE CCG, 30, 2%
NHS BRACKNELL AND ASCOT CCG, 28, 2%
NHS NENE CCG, 27, 2%
NHS NORTH HAMPSHIRE CCG, 26, 2%
NHS EALING CCG, 23, 2%
NHS WOKINGHAM CCG, 22, 2%
NHS WALSALL CCG, 21, 2%
NHS SANDWELL AND WEST BIRMINGHAM CCG, 18, 1%
NHS WARWICKSHIRE NORTH CCG, 18, 1%
NHS CENTRAL LONDON (WESTMINSTER) CCG, 16, 1%
NHS CROYDON CCG, 16, 1%
NHS NEWBURY AND DISTRICT CCG, 15, 1%
NHS NEW DEVON CCG, 14, 1%
NHS HARROW CCG, 11, 1%
NHS NORTH EAST ESSEX CCG, 11, 1%
NHS EAST AND NORTH HERTFORDSHIRE CCG, 9, 1%
NHS SOUTH NORFOLK CCG, 8, 1%
NHS SOUTHEND CCG, 7, 1%
NHS BIRMINGHAM CROSSCITY CCG, 5, 0%
NHS DORSET CCG, 4, 0%
NHS NORTH & WEST READING CCG, 4, 0%
NHS WEST HAMPSHIRE CCG, 4, 0%
NHS SOUTH WARWICKSHIRE CCG, 3, 0%
37 CCGs
+ NHS Wales

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

CCG implementation of the NHS Standard Contract and of Grant agreements includes quality monitoring and assurance in the following areas:

• Serious Incidents Requiring Investigation	• Infection prevention and control	• Training needs analysis (clinical)
• Safeguarding (children & vulnerable adults), including training levels	• Medicines management	• Mandatory and competence-based training compliance
• Safety Alerts	• Medication incident review	• Staff appraisal and clinical supervision
• Regulatory compliance	• Clinical incident review	• Timely discharge summaries for patients
• NICE guidance implementation	• Care plan audit	• Equality / equity of access
• Patient safety	• Patient nutrition and hydration	• Support for patients with Learning Disabilities
• Safe staffing	• Patient/user experience and feedback	• Progress against local clinical priorities
• Clinical audit	• Complaints review	

Monthly performance statistics have also been submitted to CCGs (as per local agreements) relating to the following measures:

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

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hospice care for children and young adults