Quality Account

2018/19

www.willen-hospice.org.uk

Willen Hospice
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Registered with FUNDRAISING REGULATOR
Registered charity number 270194

Willen Hospice
always there to care

Welcome to Willen Hospice Quality Account 2018/19

Chief Executive's Statement

Willen Hospice is proud to present this Quality Account describing our current service, and plans for future developments and improvement.

We remain committed to providing the highest standards of clinical care for our patients, throughout all areas of the service. Care is provided for all patients from the age of 18 upwards, 24 hours a day, at no cost to them (patient/recipient), and focuses on four key areas - specialist symptom control, emotional support, spiritual support, and care for carers.

Our vision is to the 'lasting and thriving provider of free specialist palliative care to our communities'. We do this in partnership with the local population, our supporters and wider stakeholders. One of our main aims is to open up the conversation around death and dying so that we ensure that we can support people appropriately to live their life's to the full and die with dignity in a place of their choice surrounded by their loved ones. We recognise that we need to support people and their families holistically and earlier on in their journey.

This is why our refreshed strategy focuses on the following:

1. **We aim to develop our services** to support more people with more diverse care needs and help harder to reach communities. We want to reach people sooner in their journey to enable them to live as well as possible.
2. **We will have a strategic focus on Quality and Building a Centre of Excellence** – We want to deliver the highest standards of care and education and work with our colleagues in the local health and social care economy share and leverage our expertise.
3. **We want to attract and retain high quality staff and volunteers** by increasing our staff and volunteer engagement, developing staff through a leadership and management development programme and increasing their skills and confidence to deliver.
4. **Drive growth in sustainable income** by differentiating our offering to different partners/ supporters, building sustainable relationships and developing an effective stewardship programme.
5. **Drive efficiency and reduce environmental impact through technology, resources, process and control** – we want to increase efficiency by utilising technology effectively, refining our processes and reducing our reliance on paper.

This is an exciting time for Willen Hospice as we build on and extend the excellent work done over so many years, to reach more people, support people with greater levels of acuity and keep people as well as possible for as long as possible.

Our aim over the life of our business plan is to:

- **Develop our services by**
  - Creating an integrated set of services and interventions across therapeutic and wellbeing services
  - Creating a service offering for hard to reach communities
  - Differentiating our offering to meet the needs of people with life limiting illnesses other than cancer
  - Developing our out of hospice services to increase access
- **Focus on excellence and effective outcomes by**
  - Implementing our quality improvement strategy
  - Delivering our audit plan and learning cycle
  - Developing and delivering our compliance structure and framework
  - Deploy our personalisation ethos and tools to ensure that everyone has a personalised care plan
- **Attracting and retaining high quality staff and volunteers by**
  - Delivering the key milestones in our OD and People management strategy
  - Embedding our values and implementing our competency framework
  - Deliver the volunteer strategy to increase volunteer engagement
- **Driving growth in sustainable income by,**
  - Increasing the number of donors and supporters
  - Increasing regular giving
  - Delivering our major donor strategy
  - Delivering our Legacy strategy
  - Increasing profit from our retail and fundraising activities
- **Driving Efficiency and reducing environmental impact**
  - Implementing our IM&T road map
  - Implementing the environmental strategy
  - Reviewing our procurement practices
  - Roll out our HR database to encompass 'self-service'

22% of our funding is received from Milton Keynes Commissioning Clinical Group (MKCCG), and the rest is raised from the local public. This means that our Business Development team is responsible for raising £5.5 million each year.

Corporate and clinical governance are taken very seriously at Willen Hospice. Information governance is also essential to support advances in the recording of care, and to share information with fellow professionals safely and securely.

Clinical governance enables us to monitor the service we provide, focusing on patient safety, clinical effectiveness and the patient experience. The experience of every patient and family is a reflection of the quality we provide.

I am responsible for the preparation of this report and its contents. To the best of my knowledge, the information reported in this Quality Account is accurate, and a fair representation of the quality of healthcare services provided by Willen Hospice.

Peta Wilkinson, Chief Executive May 2019

Section 1: **Key Performance Indicators**

The key performance indicators identified for 2019/20 are set out below and have been identified by the Senior Management Team.

Priorities for Improvement 2019/20

1 - Deliver a personalised outcome framework

How will this be achieved?

Our aim is to ensure that patients have more choice in the planning of their care.

Everyone should be able to choose the care that they want at the end of their lives.

We aim to improve the delivery of 'personalised care' within the Hospice to enable our patients to have choice and control over the way their care is planned and delivered on 'what matters' to them and their individual strengths and needs.

Whist the Hospice has introduced tools to explore what matters most to patient at the time they require hospice interventions; it is important that we expand the way in which we view personalised care for those nearing the end of life. Most importantly, our aim would include the implementation of a self-assessment tool to assist us to examine our services in relation to person-centred thinking.

Progress for Providers End of Life is a validated self-assessment tool for managers and teams who deliver end of life care. By introducing the tool to the Hospice clinical team, we will reflect on our existing practice and plan future approaches to deliver specific person-centred support.

We will undertake an audit as a baseline, the outcome of the audit will help us to plan for the future, implement new practices and re-educate clinical teams to achieve better outcomes for patients.

2 - Create an integrated set of services and interventions across Therapeutic and Wellbeing Services

How will this be achieved?

As part of the Willen organisational restructure a new Therapeutic and Wellbeing Service was established which brought together the following existing teams - Wellbeing Service, Physiotherapy, Patient and Family services, Psychology and Chaplaincy.

Consequently, work is required, supported by the Cranfield Trust to review and develop a more integrated Therapeutic and Wellbeing model of care to help support more users with new ways of working whilst also ensuring good governance.

Potentially this may result in a 2 to 3 year implementation plan.

3 - Develop and deliver a compliance structure and framework

How will this be achieved?

We recognise the need to have a robust compliance structure and framework in place to capture our incident, complaints, near miss and medication.

The Hospice has recently invested in data management software specifically designed for Hospices. This new way of incident reporting via an electronic system will help us to effectively safeguard patients, improve health and safety process and manage risks within the organisation.

Our plan to is systematically introduce staff to this way of recording vital data and will help us to

capture incident quickly whilst producing accurate data to measure improvements in practice.

The recent organisational restructure will now enable us to capture information, cross reference data and link important factors within one department, enabling the team to cascade and share data to the wider teams - internally and externally.

4 - Differentiate our service offering to meet the needs of people with life-limiting illness other than cancer

How will this be achieved?

Currently, the clinical teams are involved in the care of many non-cancer patients. These range from patients with neurological, respiratory, cardiac diagnoses. The Wellbeing service welcomes patients with a neurological diagnosis an opportunity to attend the facilities in the department monthly.

The Willen at Home Team Clinical Nurse Specialists have identified the need to increase their knowledge and skills in the management of care of these specialist groups of non-cancer patients. They have therefore chosen one particular group of patient diagnoses each to enhance their skills and improve care provision.

Our aim is to have 'champions' for each diagnoses including dementia and frailty in the elderly, renal, cardiac, respiratory and neurological patients.

The team will use System One to capture data to confirm our care provision interventions for patients with life-limiting illness other than cancer. The data will be shared with internal and external stakeholders to acknowledge the KPI which request the need to increase the number of people we support with life-limiting illnesses other than cancer by 10%.

5 - Implement leadership and core competencies

How will this be achieved?

During 2018, over 75% of the workforce took part in agreeing the four organisational values, which in turn has enabled us to develop a set of 'Core' and 'Leadership' Competencies. The core competencies describe the behaviours and skills we expect our teams to display in order to deliver their roles in line with our Values. Six further management/leadership competencies have also been prepared to describe the additional expectations of this population.

The next step is to fully embed the competencies and there a number of specific activities planned to achieve this:

- The simple graphic (page 8) developed to show the Values & Competencies is to be featured on all PC desktops to re-inforce the message, with the potential to extend its use and presence across the organisation.
- Introduce Core and Leadership competencies to all colleagues during the appraisal process in 2019 to start discussion on how their own skills and behaviours align. This will become a 'rated' element of the appraisal process in the future.
- A Management Development Programme to be rolled out to 30+ 'middle managers', specifically focussing on developing the Leadership Competencies and helping to confirm expected standards.

6 - Implement the revised appraisal process

How will this be achieved?

Over the next 18 months, the People Services Department will lead a complete overhaul of the current Appraisal Process moving away from assessing colleagues against the list of tasks

on a Job Description, to ultimately assessing performance in role against both Core/Leadership Competencies and Business Objectives.

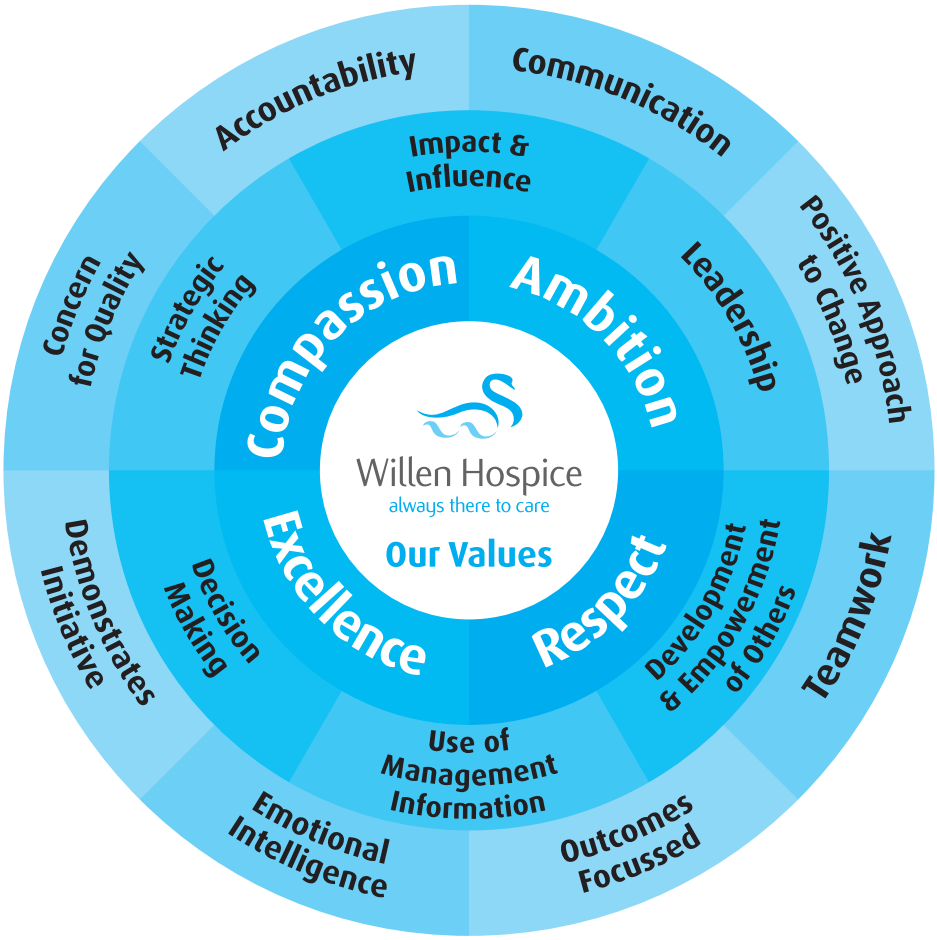
We have begun to introduce the new language to our teams; talking about competencies and the definitions behind them during the 2019 appraisal discussions, at this stage encouraging self-reflection on areas of strengths and development areas.

Next steps to deliver a new appraisal process include:

- Formation of a cross-functional project group to ensure any new 'process' meets the needs of all areas of the organisation
- Collation of feedback on the current system to capture learnings
- Consideration of alternative solutions including:
  - The use of 360 Degree feedback, particularly for those in management/leadership roles
  - A move away from annual appraisal to a more continuous assessment
  - Building the appraisal process into the new HR Database, PERCI, to completely alleviate the need for paper and enable easier identification of training needs
- Prepare a proposal for the revised process for approval by SMT and Trustees
- Undertake the development work for the new process in two key stages:
  - The content and style of appraisal (annual or on-going)
  - Commitment of the new process to an IT solution

It is envisaged that an interim solution will be available for Spring 2020, with the final package developed and trained into the organisation in readiness for December 2020.

Our Values:



Section 2: **Review of priorities for 2018/19**

Priority 1 - Increase patient satisfaction levels

How was this achieved?

We continued throughout the year to receive excellent feedback from patients utilising our services. We have not been able to increase the actual number of feedback questionnaires and therefore not achieved a measurable difference in patient satisfaction. We have reviewed the key performance indicators and identified the need to widen the questionnaire to gain a wider perspective of feedback related to our service provision.

A selection of positive, neutral and negative quotes are cited on page 14.

Priority 2 - Support more patients to die at home

How was this achieved?

We have reviewed and restructured our community services. In doing so, the integrated Willen at Home (WAH) team can now offer a responsive service to patients within our catchment areas. The team are able to prioritise care and respond directly to patients needs during a crucial period of time.

Priority 2 has been achieved, we have supported 201 patients to die in their usual place of abode (home or care home). Despite operating with vacancies of >2 WTE staff during quarter 4 we have maintained our standards and remained efficient in providing care to patients who choose to remain at home.

Priority 3 – IPOS questionnaire completed by 70% of new patients

How was this achieved?

The Integrated Positive Outcome Scale (IPOS) is an integral part of our holistic assessment for the patient under the care of the Hospice. IPOS can provide evidence of overall positive impact despite a patients deteriorating health and it helps the team to recognise and address the patients' main concerns.

Staff have achieved this KPI through audit activity during 2018. The overall aim of the audit undertaken was to explore if the IPOS questionnaire was completed and if staff were assessing patients using the tool.

Various members of staff were asked questions relating to the IPOS questionnaire. The auditors examined IPOS documentation in detail to explore if the document was being reviewed and completed on admission and discharge.

Compliance for completing the IPOS on admission was identified as 77%.

Whilst the overall compliance for the audit reached 69%, we were satisfied with the progress made since the introduction of the IPOS tool. We will aim to increase the overall compliance during the next audit cycle.

Priority 4 - Support 20% more patients to use the Community Hub

How was this achieved?

The Community Hub area of the Hospice provides opportunities for many activities for patients and carers, therefore we have been successful in achieving Priority 4.

Walking Group

The walking group has been established a year now and to mark the occasion and to remember walkers who have sadly died, the group planted some bulbs by the paddock gates.

The walking group meets every Thursday. We now have a variety of volunteers who take on the roles of co-ordinator, walk leader (10 trained leaders in total) and walk assistants.

The walking group hosted a walk as part of 'MK walking festival' in May, working in partnership with The Parks Trust it was one of 25 walks held over Milton Keynes at the weekend.

Due to the success of the walking group, the concept has also been directly duplicated at another local hospice (Katharine House in Banbury).

We also have bereavement support workers who join the walk every other week should their skills be needed.

We have had an average of 9 walkers on each walk in the past 6 weeks (in addition to walk assistants and walk leaders).

Wellbeing

The Wellbeing Team introduced evening Yoga sessions for patient and carers as a pilot project during a 4-month period. The uptake from patient and carers was poor. Feedback from patients highlighted that their preference is to attend day time activities.

Lymphoedema

Currently, our Lymphoedema team continue to deliver the Helping Overcome Problems Effectively (HOPE) course for people living with cancer. The course runs over a 6 week period and gives people the chance to refocus their inner strength and regain their confidence. The team ran 2 courses over the past year with a total of 20 attendees.

Some of the comments received from the attendees are:

"This course has made me confront my emotions that I had been expressing to protect my children. But were causing me to have sleep problems, mood swings, etc. By having a 'safe' environment to be honest without fear of looking stupid."

"I would recommend the course. I want to share how much I have been helped & encouraged."

"Definitely attend. Learning what you think are silly thoughts are shared by others. Helps to gain confidence. Helps make the transition back to a normal life possible."

"Very worthwhile. You are not alone and very helpful in setting achievable goals."

"The venue was calming & comfortable, the support from group facilitators & members was supreme. Out of sessions kept focus - heightened mood & confidence every session."

The Lymphoedema team work in collaboration with the MKUH Breast Cancer Nurses to deliver Breast Education and Lymphoedema Session (BLES). This is an opportunity for Breast Cancer patients to learn more about the impact of breast and Lymphoedema related issues. Sessions are delivered monthly dependent on referral numbers.

Priority 5 - Achieve discharge on agreed date for 50% of patients on IPU

How was this achieved?

We have achieved this by introducing weekly ward Multi-Disciplinary Team (MDT) meetings as part of our normal practice.

Individual care plans are now reviewed by the MDT and estimated dates for discharge are discussed. All plans for discharge dates are recorded on System One.

Where possible, an IPU nurse is rostered to take the lead on discharges. In addition, to this we have relocated the Social Worker to the IPU office, with an aim to improve the discharge process and look at ways to support patients and carers throughout the discharge process.

Priority 6 - Extend use of the Distress Thermometer

How was this achieved?

A proportion of the clinical team have undertaken a Level 2 psychological training programme with the clinical psychologist based at the Hospice.

The aim of the course was to enhance the clinical team knowledge and skills in the assessment of the emotional wellbeing of the patient.

Members of the team were introduced to the Distress Thermometer screening tool and have since continued to utilise the tool as part of their holistic assessment of patients. We have achieved this by investing in our staff. We will continue to deliver training to enable all staff to utilise the Distress Thermometer.

Priority 7 - Support 10% more patients by the Patient & Family Services Team

How will this be achieved?

The retirement of the Patient & Family Service Team Lead enabled the Hospice to review this Service. There has been an organisation restructure in Q3 with the appointment of an Associate Director (AD) of Therapeutic and Wellbeing Services.

The restructure of this service has enabled us to redefine supervision for the volunteers with a view to improving efficiency and becoming more effective for patients and other service users.

Future plans for this service will be driven by a 3-year strategy (Psychology & Wellbeing Therapy). This document when devised will create the vision for the service and assist in the delivery of improved services to patients and carers.

Section 3: **Other Quality Improvements 2018/19**

Patient Satisfaction responses

The in-patient unit (IPU) patient, family and friends survey is an optional questionnaire to be completed by those who wish to share and/or comment on their experience of their admission at Willen Hospice.

This questionnaire is not distributed on a compulsory basis, thus the response rate is affected by bed occupancy, willingness to participate, patient condition and appropriateness of encouraging those who are grieving or bereaved.

Positive Comments

"Help for personal care given expertly by staff."

"Privacy was given."

"Staff were very helpful and communicated well."

"I have been coming to Willen for some time and have got to know the Chaplain really well."

"Every member of staff I spoke to were very informative, easy to talk to and courteous."

"Pain was sorted in a fast fashion."

"Looked after very well, thanks to all the staff."

"Clean and tidy."

"Nothing is any trouble; all requests are met with a happy manner. You are never made to feel that you are a nuisance. Very caring."

"This was the second stay in the hospice to help adjust my medication in order not to be in pain. I really appreciate everything that the hospice staff have done for me. Thank you all very much."

Neutral Comments

"Not much appetite for food, my wife fed me mostly."

"Did not require any spiritual care, have not shared feelings with the staff."

"I was offered a lot of help but didn't always accept it as I am stubborn and independent."

Negative Comments

"Due to my length of stay, I felt that the food choices were a bit samey."

"I wasn't offered to see the Chaplain."

"You just don't eat that sort of stuff such as curry, pasta, strong herbs. I eat basic food like mash, veg and fish."

Actions

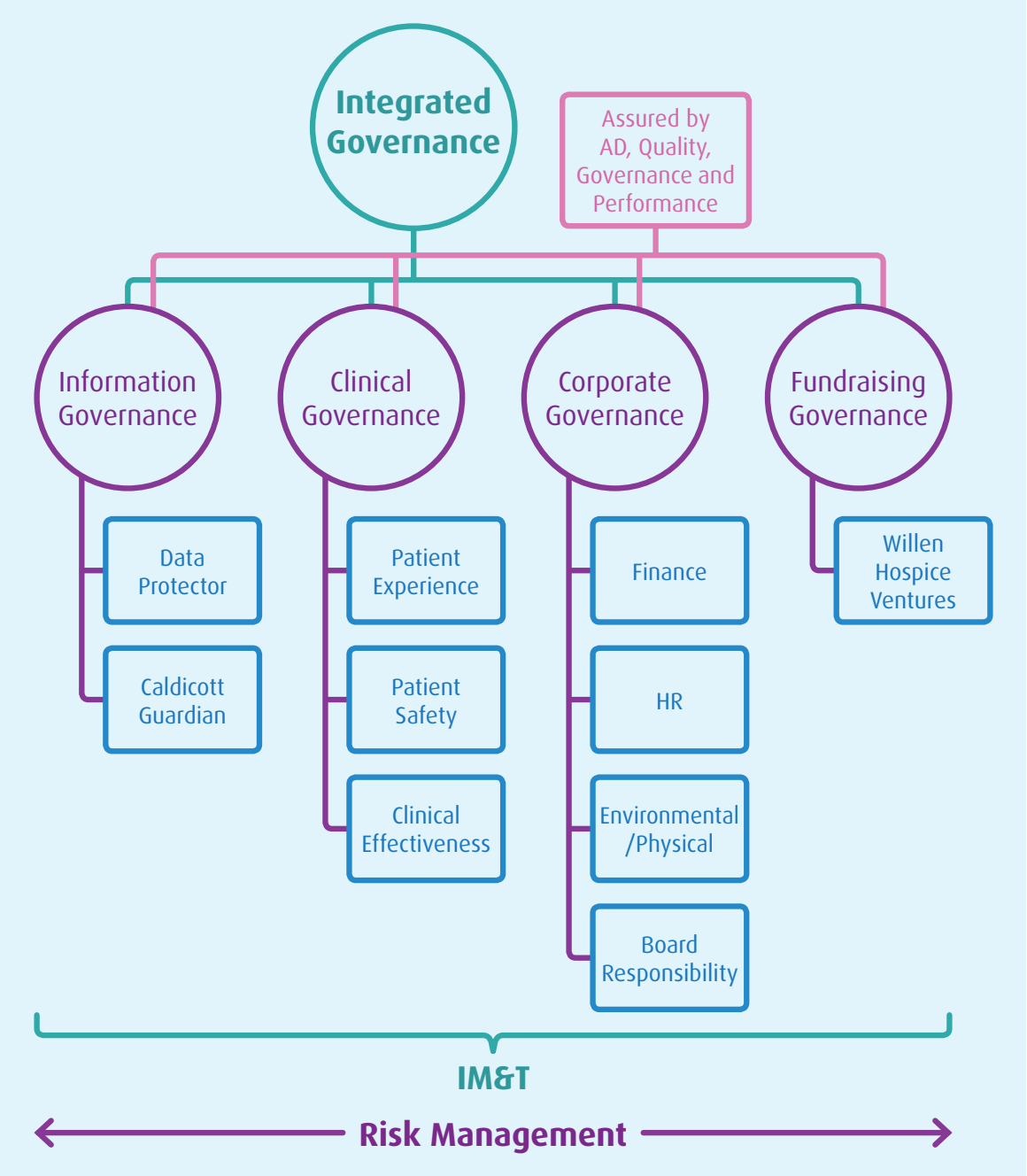
The Catering Manager has reviewed and revised the menus in light of the feedback from patients. New menus are now in circulation as from April.

Audit Activity	During this year the Hospice undertook 35 audit reaching a compliance level of 62%. Some of the audit activity included infection control, Mental Capacity and DOLS, Medicines and many other policies were audited.
GDPR compliance/ Data Protection	In March 2018, following a GDPR-readiness audit, we embarked upon a comprehensive data protection compliance project. Since then, across all departments, we have mapped all personal data flows and documented all personal data processing (including the lawful basis for processing, data subjects' rights and security methods). We created action plans to close any compliance gaps, as well as ensuring GDPR-compliant contracts with our third party processors. Information Asset Owners have been established for all databases where personal data is processed. New procedures for the management of data breaches, data subject access requests and data protection impact assessments have been written and deployed. Privacy Notices have been published for all stakeholder groups. We have also appointed a Data Protection Officer. Most recently we submitted a compliant response to the NHS's Data Security and Protection Toolkit.
CQC	The Hospice continues to have quarterly meetings with the Relationship Owner inspector from the CQC.
CHKS	The CHKS accreditation for the Hospice remains active. A monitoring visit undertaken in December 2018 confirmed that the standards continue to be achieved.
Quality Improvement Strategy	Since the restructure, the Quality Team has now produced a Quality Improvement Strategy which outlines the quality improvement initiatives plans for the organisation. This document enables the team to remain focused on the tasks that are outlined in the KPIs and the Strategic Plan.
Competencies	End of Life Care competencies for clinical staff have been introduced this year. These will be used as an opportunity for staff to demonstrate competence through evidence based practice and reflection.

Integrated Governance

Willen Hospice's approach to governance across the organisation brings together clinical, information governance, corporate and fundraising governance. During the past year, the Senior Management Team and Trustees have worked alongside managers to improve the foundation of Integrated Governance.

We have now produced a diagram to demonstrate the flow and structure:



Risk Management is a major part of the structure and continuously feeds into the organisation's operation and practice.

Information Management and Technology a key component to the Hospice as it enables us to organise the technology related process to maintain the everyday function of the environment.

The areas we define as being part of integrated governance are the systems, processes and behaviours by which we lead, manage and deliver our services and support. The outcome of managing integrated governance well, is the provision of safe, effective, quality and well managed services and support.

Section 4: **Statutory Information and Statement of Assurances from the Board**

Statutory Information

Willen Hospice is a company limited by guarantee (Company No 1231909) and a registered charity (Charity No 270194), governed by its Memorandum and Articles of Association. Willen Hospice submits and Annual Return to the Charity Commission and files its Audited Accounts at Companies House. From the income generated from the contracting of services to the NHS in 2018-19, 100% of this has been spent by Willen Hospice in providing those NHS services.

Services provided by Willen Hospice are funded through a combination of Voluntary income, fundraising, events, lottery and retail shops from the communities we serve. A partial contribution of our funding 22% is received from NHS local commissioning agreements.

Willen Hospice actively engages in constructive dialogue with all our commissioners about quality of care, models of care, sustainability of services and added value of service provision. Increasingly our services are being used to support more complex cases, and support hospital avoidance or early discharge. As a Hospice, we rely greatly on the generosity of the local community to help us raise the additional £5.5 million we need to ensure we are always there to provide our vital services to patients and their loved ones.

Review of Services 2018/19

During 2018/19, Willen Hospice provided the following services:

- In-patient beds
- Community Services – integrated CNS and Hospice at Home team to form WAH team
- Wellbeing Centre
- Physiotherapy
- Lymphoedema
- Patient and Family Services
- Chaplaincy
- Education, Learning and Development for staff

Research

During 2018/19 Willen Hospice continued to co-fund with the Open University a PHD student who is undertaking a research project based on end of life care.

As part of her research, the student has presented several aspects of her research at local and national conferences, including the Hospice UK annual conference and the Palliative care congress. Her work provided an insight into the demographics of Milton Keynes in relation to end of life care and the drivers required to undertake research project. A report prepared by the student is attached as Appendix 1 which details the demographics of Milton Keynes.

What others say about us:

Care Quality Commission

Willen Hospice is required to register with the Care Quality Commission.

The Hospice current registration is for the following activities:

- Treatment of disease, disorder or injury

The Hospice is subject to periodic reviews by the Care Quality Commission, although there was not an unannounced inspection during 2018/19.

In their last inspection in March 2015, the Care Quality Commission found that the Hospice had an overall rating of GOOD.

Ratings	Outcome
Is the service safe?	**Good**
Is the service caring?	**Good**
Is the service well-led?	**Good**
Is the service effective?	**Good**
Is the service responsive?	**Good**

Section 5 - **Quality overview**

Review of Quality performance

Willen Hospice remains committed to continuous quality improvement.

As a team we ensure quality is maintained by undertaking the following the quality initiatives:

- Comprehensive Audit Schedule and audit activity
- Service User feedback
- Complaints and responding proactively
- Providing evidence to the MKCCG via the NHS Quality Standard measure & CQUIN which form part of the community contract
- CHKS
- Key Performance Indicators
- Review of our Services for equitable care provision

Annual Complaints Summary April 2017 - March 2018

Complaints received	**8 in total**

We have shared our complaints policy and procedure with our commissioners to ensure the policy reflect changes to practice.

As part of the Quality Schedule with MKCCG we have provided detailed information outlining the nature of the complaint, our actions, feedback and lessons learnt.

One of the main themes from the complaints received is communication. We have worked in partnership with one complainant to address this by providing a bespoke communication training programme for our staff. The programme involves the use of actors to highlights the main issues related to the complaint. The scenarios will be filmed and used as a teaching tool for our staff. Our plan is to deliver the training before autumn 2019.

What our Regulator says

Willen Hospice is registered with the Care Quality Commission and as such is subject to regular review in the form of unannounced inspections. No inspections took place during the period of this Quality Account.

As mentioned earlier, regular meetings with the Relationship Owner CQC inspector are held with the newly appointed Registered Manager. The CQC Inspector has sight of all our website and hospice related information.

The Board of Trustees' commitment to Quality

The Board of Trustees of Willen Hospice is fully committed to prioritising the quality of patient and family care. All Trustees participate and take the opportunity to familiarise themselves first hand with the workings of the Hospice and to hear the views of patients, families, staff and volunteers. The organisation has a robust Quality Assurance framework with Trustees taking an active role in ensuring that the Hospice provides the best possible evidence based care and fulfils its Statement of Purpose.

Appendix 1 - **Health and Society Demographics of Milton Keynes**

Willen Hospice
always there to care

The Open University

Page No

The Impact of Deprivation

The recent health profile of Milton Keynes published by Public Health England (2017) stated that there is a great variance in health resulting in a significant inequality in life expectancy across the city. The profile evidenced there was over 7 years difference in life expectancy between the most deprived and least deprived wards in Milton Keynes. This shows that deprivation is having an impact on health in poorer areas of the city and therefore it will be a factor in end of life care provision as there is an increased rate of early deaths (i.e. under 75 years of age) in deprived areas. A recent report by Milton Keynes Council in 2015 concurred with Public Health England in highlighting the links between deprivation and specific health conditions locally, notably cardiovascular diseases, respiratory diseases, cancer and infant mortality (Public Health England, 2017; NEOLCIN, 2012). Milton Keynes experienced significantly higher levels than the national average in these conditions due to increased rates in its most deprived areas (Scott, 2015). These links with deprivation indicate that work needs to be undertaken to help understand and reduce the inequalities for the most deprived communities in Milton Keynes, as well as ensuring equity of access to end of life care and support for residents and their families.

Milton Keynes is currently within the top 20% most deprived populations of the UK, with nine wards showing in the top 10% of most deprived areas (Public Health England, 2017) who are less

likely to access health services than more affluent areas (Scott, 2015). Therefore 'tackling housing supply and neighbourhood conditions will help to resolve the social inequalities in health' (Scott, 2015, p.53) which has to include end of life health care, particularly as research suggests working directly with more. Interestingly this wide variance in areas of deprivation and affluence has Milton Keynes as being 'a tale of two cities' (MK Community Foundation, 2016, p14). This is due to their being two markedly different populations and economies with higher than average wages in the IT, information and business sectors creating an imbalance with the lower paid service, public and community sectors.

This has been a persistent concern in Milton Keynes with continued geographic inequalities shown as certain wards having high numbers of people who have never worked or are long-term unemployed (Milton Keynes Futures 2050, 2016). Looking at health inequity broadly as this illustrates, whilst may not appear to be directly linked to end of life care, it is important to remember that end of life care is indeed part of any health care need, and if we are more aware of the inequities for the deprived areas and communities Milton Keynes, who, as we have seen, are far more likely to experience health issues, then maybe we can also address their end of life care needs more effectively. Initiatives like the "Open Up Hospice Care" campaign by Hospice UK are aimed at raising awareness in communities such as those living in deprived areas who may not be as knowledgeable about the options for end of life care.

Learning Disabilities and End of Life Care

Recorded numbers of people with learning disabilities is growing nationally, due to population increase and increased life expectancy due to an improvement in care and treatment of certain conditions. In the UK it is estimated there are over 1 million people with learning disabilities in 2015, however records of people with learning disabilities on health and welfare systems was shown as just over 250,000 (PHE, 2016). Whilst it is recognised that life expectancy has increased, people with learning disabilities do still die at a younger age than the general population – recorded as up to 20 years younger for men, and 26 years younger for women with the most common causes of death being circulatory diseases, respiratory diseases and cancer (PHE, 2016). The larger numbers of older people with learning disabilities though will impact on end of life care, as by 2030 there will be a 14% increase in adults aged 50+ years with learning disabilities using social care services, and an increase in 164% for those aged 80+ years (Emerson and Hatton, 2011).

The increase in population will therefore mean an increase in need for support and services for people with learning disabilities including end of life care. Annual growth of people with learning disabilities is estimated to be 3.2% annually between now and 2030 (Emerson and Hatton, 2011). It is also estimated that 25% of new people identified as having learning disabilities will be from minority ethnic communities, 33% will be from homes where children are eligible for free school meals, and most concerning is that by 2030 adults aged 70+ (Emerson and Hatton, 2011). It is also expected that support needs may increase due to the changing family and cultural circumstances such as higher numbers of lone parent families, the expectations of the right to independent living, and increasing numbers of frail and disabled older people who may require support from their adult children (Emerson and Hatton, 2011). This creates a very diverse population of people with complex medical, social and cultural needs, indicating a changing and growing diverse minority population within Milton Keynes.

Recent analysis of national and local data estimated that there were just over 4600 adults registered with a learning disability living locally (Milton Keynes Council, 2017) however as some people consider 2.5% of the whole population have some form of learning disability (Tuffrey-Wijne, 2018) this would then give an estimated current population within Milton Keynes of 6725. This high statistic means palliative care providers have to consider the needs of this demographic:

'You cannot choose to exclude 2.5% of your patients simply because you do not know how to adjust your care to include them' (Tuffrey-Wijne, 2018).

Learning disability can be a complex condition, often comorbid with other conditions such as autism, mental health conditions, challenging behaviour or profound and multiple disabilities (PMLD) (Milton Keynes Council, 2017). This needs to be considered when looking at the needs of end of life care in Milton Keynes, as it highlights the importance of multidisciplinary working with support, training and advice for any practitioner supporting our local population in this field.

Research suggests that ways to improve end of life care for people with learning disabilities can be achieved through building relationships between practitioners and professional communities i.e. those working within learning disabilities teams and palliative care providers (Arrey et al, 2018: Dunkley and ales, 2014) which could then help to tackle potential issues around care such as poor funding, lack of autonomy and poor access (Arrey et al, 2018) and ties in with the Department of Health initiatives (DoH, 2015). More importantly though, it has been acknowledged that in order to truly know how to meet the needs of people with learning disabilities their voice needs to be included and the views of their carers (Dunkley and Sales, 2014). This could then possibly be incorporated into strategies and interventions which are working successfully in others areas, for example establishing a collaborative training programme between hospice and learning disability nursing staff (Kent NHS), or establishing an equalities steering group for involvement and representation within local community groups, charities and organisations (Woking Hospice).

The Ongoing Concern of Homelessness in Milton Keynes

Another key demographic that is concerning within Milton Keynes is that of homelessness. Homelessness became an issue as Milton Keynes was being developed and expanded, especially during the 1980's with the increase in house prices and change in planning for more privately own properties than rental accommodation, and the Government scheme for tenants to buy council properties (Bendixon and Platt, 1992). This trend is still being seen as between 2005 and 2015 house prices grew by 52% (Mk Community Foundation, 2016). Recent government statistics stated that in 2017 there were 227 registered rough sleepers in Milton Keynes, and 6.5 homeless households per 100 households, markedly more than the UK average of 2.4 households per 100 households (HM Government, 2017). This is an exceptionally high figure when compared to the rest of the UK; indeed only 5 other areas have higher populations of registered homeless, comprising four London boroughs and Manchester(HM Government, 2017). This is even more concerning when it is understood that the registered homeless is considered to only be a percentage of the true figure as many do not get recognised such as those sleeping on floors in people's houses etc.

Therefore this is an issue which should be a priority for the Local Authority, the Health Service and the local communities. Access to good health provision has to be a key component of that including when required, end of life care. That is a difficult task, with such a complex population with multiple needs and difficulties it is clear there will be many barriers for homeless people to access the right care they need including end of life care. The chaotic lifestyle which can be affected by social exclusion, mental health issues, substance misuse, negative experiences of death and negative experiences of professional interventions will need careful and considerate multi-agency working as it would be considered beyond the skills of hospice staff to support people with multiple issues without guidance (Hudson et al, 2016).

Staff would also need significant support and training in order to deliver that service with potential changes required in services, systems and processes in order to enable access to care for the homeless population locally (ibid).

Other hospices have engaged in effective outreach programmes to engage more with their local

homeless populations. Some hospices such as St Luke's in Cheshire and St Leonard's in York St Luke's Hospice have set up education and outreach initiatives locally to teach staff and volunteers about palliative care, raise awareness of support and other services and organisations locally, to create more collaborative and informed practice.

Black and Minority Ethnic Groups (BAME)

In order to understand the health and society demographics for minority ethnic populations it is considered more important to focus on specific details locally such as local politics, settlement patterns, employment and personal attributes such as sense of belonging and identity as statistics can only present a partial picture of communities (Garner and Bhattacharyya, 2011). That said, the statistical breakdown locally demonstrates some points of interest for beginning to understand these sections of our local population:

- Higher minority population (26.1%) compared to national average of 20.2% (Milton Keynes Council, 2013)
- Significant Somalian population (International Organisation for Migration, 2006) creating highest proportion of BAME
- 18.5% of Milton Keynes population were born outside of UK, compared to national average of 13.8% (Milton Keynes Futures 2050, 2016)
- Highest proportion of multiple resident minorities compared to national average of 1-2 minority groups within a geographical area (Garner and Bhattacharyya, 2011)
- Large recent increase in minority population (Milton Keynes Council, 2013)
- Expected continued rapid growth as 35% of local population of young people are from minority ethnic backgrounds (Mk Community Foundation, 2016).

This means several factors need to be acknowledged and addressed when trying to create a more inclusive, diverse and accessible end of life care system. The numbers of minority ethnic populations in Milton Keynes are large and growing rapidly. Milton Keynes have a much wider range of minority groups than other areas, meaning greater variance in need, and consideration of diverse cultural and religious preferences within that need. Particular support may be required for our largest community of Somalian background.

Strategies that are working in other areas include twinning with a hospital in another country to share expertise, cultural understanding and resources (LOROS, Leicestershire), arranging a consultation event with local BAME groups to improve mutual awareness and understanding (Ellenor Hospice, Kent) and creating detailed needs assessments of local need by engaging and listening to local communities at outreach and education activities (St Helena Hospice, Colchester).

Our Local Prison Population

Prisons are changing due to an increasingly ageing prison population, which means care for prisoners at the end of life is a growing responsibility; prisoners aged 60+ have increased by 142% within 10 years (Prisons and Probation Ombudsman, 2013) and account for 16% of the prison population (Prison and Reform Trust, 2017). During a recent review it was found that palliative care varied considerably between prisons (Prisons and Probation Ombudsman, 2013), and prisoners are disproportionately disadvantaged with over quarter from black and minority ethnic groups, high rates of mental illness and poorer literacy (Turner et al, 2018).

Milton Keynes has a significant prison population of potentially 800 men at HMP Woodhill. The prison has been experiencing substantial difficulties in recently, most notably staff shortages, high staff turnover, extremely high instances of suicide, and high rates of violence creating an unsafe environment (HMIP, 2018). This may impact on end of life care provision as staff shortages

and the stressful culture within the prison may impact on prisoners and staff providing that care. This would need to be taken into account by anyone working either directly within, or supporting staff working within the prison. There are significant challenges for health professionals within the prison system, notably prioritising the criminal justice system impacting on how, and what care, can be delivered (Lillie et al, 2018). It is a concern that in a survey conducted as part of an unannounced inspection of HMP Woodhill, less than half of prisoners felt they could access a doctor easily, and of those who had a disability, only 20% felt they were getting the support they needed (HMIP, 2018).

The need for end of life care provision in prisons is highlighted in the 2018 National Palliative and End of Life Care Partnership Dying Well in Custody Charter (DWICC) and self-assessment tool to help prison services improve their provision in line with the national Ambitions Framework. HMP Woodhill, alongside partners locally such as MKUH and Willen Hospice could work collaboratively to complete the tool and charter. Some prisons and local palliative care providers have made other changes to improve care for prisoners at end of life, for example building palliative care cells or units (HMP Isle of Wight) or developing links with a local hospice to enable care outside of prison (Prisons and Probation Ombudsman, 2013).

References

Arrey, S., Kirshbaum, M. and Finn, V. (2018) 'In Search of Care Strategies for Distressed People with Communication Difficulties and a Learning Disability in Palliative Care Settings: The Lived experiences of Registered Learning Disability Nurses and Palliative Care Professionals' *Journal of Research in Nursing* pp1-15

Bendixon, T. and Platt, J. (1992) *Milton Keynes: Image and Reality* Granta, Cambridge

Dunkley, S. and Sales, R. (2014) 'The Challenges of Providing Palliative Care for People with Intellectual Disabilities: A Literature Review' *International Journal of Nursing* 20:6 pp 279-284

Department of Health (2015) *Once Chance to Get it Right: One Year On Report* London Department of Health

Emerson, E. and Hatton, C. (2011) *Estimating Future Need for Social Care Among Adults with Learning Disabilities in England: An Update* Department of Health [Online] accessed 11th December 2018 at https://webarchive.nationalarchives.gov.uk/20160704171420/http://www.improvinghealthandlives.org.uk/publications/1029/Estimating_Future_Need_for_Social_Care_among_Adults_with_Learning_Disabilities_in_England:_An_Update

Garner, S. and Bhattacharya, G. (2011) *Poverty, Ethnicity and Place* Joseph Rowntree Foundation accessed online 26th January 2018 at https://www.jrf.org.uk/sites/default/files/jrf/migrated/files/poverty-ethnicity-place-full.pdf

HM Government (2017) *Detailed Local Authority Level Homelessness Figures: July to September 2017* accessed online 26th January 2018 at https://www.gov.uk/government/statistical-data-sets/live-tables-on-homelessness#homelessness-summary-local-authority-level-tables

HMIP (2018) *Report of the Unannounced Inspection of HMP Woodhill Prison* HMIP London accessed online 11th December 2018 at https://www.justiceinspectorates.gov.uk/hmiprisons/wp-content/uploads/sites/4/2018/06/Woodhill-Web-2018.pdf

Hudson, B., Flemming, K., Shulman, C. and Candy, B. (2016) 'Challenges to Access and Provision of Palliative care for people who are Homeless: A Systematic Review of Qualitative Research' *BMC Palliative Care* 15:96

International Organisation for Migration (2006) *Somalian Regions Mapping Regions* IOM, London accessed online January 2018 at http://www.iomuk.org/sites/default/files/doc/mapping/IOM_SOMALI_MR.pdf

Lillie, K., Corcoran, M., Hunt, K., Wrigley, A., and Read, S. (2018) 'Encountering Offenders in Community Palliative Care Settings: Challenges for Care Provision' *International Journal of Palliative Nursing* 24:8 pp 368-375

Milton Keynes Community Foundation (2016) *Vital Signs: Milton Keynes 2016* [Online] accessed 20th June 2017 at http://www.mkcommunityfoundation.co.uk/files/4914/7819/4217/MKCF_VitalSigns_lores_003_1.pdf

Milton Keynes Council (2013) *2011 Census Borough Level Results* [Online] accessed January 2018 at http://mkinsight.org/2011-census-borough-level-results/

Milton Keynes Council (2017) *2016/2017 JNSA Adults with Learning Disability* [Online] accessed 11th December 2018 at https://www.milton-keynes.gov.uk/social-care-and-health/2016-2017-joint-strategic-needs-assessment/2016-2017-jsna-adults/2016-2017-jsna-adults-vulnerable-groups/2016-17-jsna-adults-with-learning-disability

Milton Keynes Futures 2050 (2016) *Commission Working Paper 2: Milton Keynes Today Where we are Now* [Online] accessed 26th January 2018 at http://www.mkfutures2050.com/read-our-report

NEOLCIN (2017) *National End of Life Care Profiles for Local Authorities Milton Keynes* [Online] accessed June 2017 at www.endoflifecare-intelligence.org.uk/view?rid=599

Prison and Probation Ombudsman (2013) *Learning from PPO Investigations: Older Prisoners* [Online] accessed 8th July 2017 at http://www.ppo.gov.uk/wp-content/uploads/2017/06/6-3460_PPO_Older-Prisoners_WEB.pdf#view=FitH

Prison Reform Trust (2017) *Bromley Briefings Prison Fact File Autumn 2017* Prison Reform Trust London accessed online 11th December 2018 at http://www.prisonreformtrust.org.uk/Portals/0/Documents/Bromley%20Briefings/Autumn%202017%20factfile.pdf

Public Health England (2016) *Learning Disabilities Observatory: People with Learning Disabilities in England 2015: Main Report* Public Health England [Online] accessed 11th December 2018 at https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/613182/PWLDIE_2015_main_report_NB090517.pdf

Public Health England (2017) *Milton Keynes Public Health Profile* [Online] accessed September 2017 at http://fingertipsreports.phe.org.uk/health-profiles/2017/e06000042.pdf

Scott, M. (2015) *Health Inequalities in Milton Keynes* Milton Keynes Council, Milton Keynes accessed 28th May 2017 at http://www.parliament.uk/documents/fair-society-healthy-lives-full-report.pdf

Tuffrey-Wijne, I. (2018) 'Do you Provide Equal Healthcare to People with Learning Disabilities?' *Nursing Times* 106:31

Turner, M., Peacock, M., Payne, S., Fletcher, A. and Froggat, K. (2018) 'Ageing and Dying in the Contemporary Neoliberal Prison System: Exploring the 'Double Burden' for Older Prisoners' *Social Science and Medicine* 212 pp 161-167