



Demelza
Hospice Care for Children

Quality Accounts 2020/2021

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Lavinia Jarrett
Acting Chief Executive Officer

Part 1: Statement of quality by the Acting CEO

In the midst of a global pandemic, it is with great pleasure that I present Demelza Hospice Care for Children's Quality Account. I am proud to say that our clinical services' COVID-19 infection outbreak record is zero. We will continue to navigate our way with the same levels of clinical safety at all times whilst offering high quality care for our children, young people and families.

This year has been a year like no other – children and families have remained at the centre of our decision making along with the safety of all colleagues and volunteers involved in the direct and ancillary care.

During the pandemic, we have adapted our services to continue to offer a virtual lifeline to the vulnerable, who were severely impacted by spending months isolated and shielding. We developed a weekly timetable of virtual sessions to appeal to a wide range of children, young people and families and some were targeted at specific family members. One-to-one and group virtual sessions were set up with therapy and family support liaison colleagues. Our volunteers also supported by delivering therapy bags, Easter eggs, and Christmas presents; they also continued to support travel to hospital and other essential appointments.

We were able to offer access to our wonderful facilities, so generously funded by our donors, so that individual families could enjoy a session in their 'bubble' in the hydro pool, the sensory room, the playground, the garden or the cinema room. For many, it was the first venture into the outside world for many months.

I am extremely proud to report that Demelza was able to support the national efforts of the NHS and other colleagues during the pandemic by offering step-down care to several children, as well as a young person not on our caseload, to relieve the pressures on London hospital resources. Demelza supported a specialist

nurse to return to an adult ITU in the local general hospital and provided additional resource to local adult palliative care services. In return, we received the valued help and support of local children's nurses from other NHS Trusts and from a recently retired Demelza Registered Nurse who immediately returned to regular duty.

Throughout the pandemic, Demelza implemented rigorous infection prevention and control policies, procedures and training, and secured the essential equipment that enabled safe clinical care to continue for all emergency admissions including end of life care, social care placements and symptom management. Demelza rolled out rigorous testing regimes for all staff and volunteers who could not carry out work from home as early as possible to ensure we could safely restart our offer of respite care to children and families.

These accounts have been prepared by our Director of Clinical Services and her team, with the full support of Demelza's Board of Trustees.

Thank you

Lavinia Jarrett
Acting Chief Executive Officer

Part 2: Review of quality performance 2020/21



2.1 What we achieved in 2020/2021?

When setting out our strategy for 2020/2021, no-one could have predicted that we would be experiencing an ongoing global pandemic. We took quick action to suspend non-essential face-to-face services to protect vulnerable people from the spread of infection and maintain capacity for end of life and other urgent care and adapted our services to enable us to virtually support hundreds of families.

Despite the uncertain times we have made progress against our 2016-2021 strategy that was superseded in October 2021 with our 18 month Reset and Recovery Plan that is tailored to the more unpredictable landscape resulting from the pandemic.

Prioritising those in greatest need:

Since the start of the pandemic, we have focused on capacity for urgent care, to support the NHS, and to help those children and families with the greatest need. We have checked on the welfare of the families we support and identified alternative support that could be offered. Additionally, we have adapted our services to better utilise technology and digital platforms to enable us to support more families.

Throughout the pandemic the following clinical services were provided:

Nursing and care:

- End of life care in the Kent and South East London hospices.
- East Sussex worked together with Children's Community Nursing and Chestnut Tree House Children's Hospice on a shared rota to support end of life care at home.

- Step-down care for children on long term ventilation referred from Evelina London Children's Hospital.
- Bereavement care and use of bereavement suites.
- Residential stays for children who were unable to be safely cared for at home, and for those being treated in tertiary NHS hospitals to free up beds, and reduce infection risk for those children
- Urgent short breaks where capacity allowed.
- Supported training within the hospice for external provider staff to become competent in an individual child's ventilation needs to support the child and family to return home.
- Regular welfare calls to families and video contact with families and professionals.
- 'Little Dots' play sessions for younger children were moved from hospice-based to online 'virtual' sessions enabling more families to join.
- Provision of activity bags to families whose short breaks were cancelled (South East London).
- Practical support for families such as delivering shopping and medication, and delivering 'essentials' boxes which were donated by the Jack Jeffreys Superhero Trust (East Sussex).
- Supported children to attend essential hospital appointments.
- Provided 20 hours per week of commissioned care to one family throughout lockdown (East Sussex).
- Offered families access to the sensory room in East Sussex and hydro pool and cinema spaces at Kent, when Government guidance allowed.



2.1 What we achieved in 2020/2021?

Family liaison:

- Individual sibling support sessions.
- Weekly support groups for siblings aged 5 – 11 years old.
- Recorded series of videos on resilience, emotions and pre-recorded activity sessions for parents and siblings.
- Support helpline for parents and carers 10am – 4pm every weekday.
- Individual follow-up welfare calls and telephone support for parents.
- Weekly question and answer sessions involving problem solving and peer support for parents between 10am – 11am on Fridays.
- Volunteers phoning grandparents for welfare calls.

Therapies:

- Art and music therapy sessions for children and families onsite in Kent and SEL.
- Virtual art therapy sessions for families via zoom six times a week.
- Music therapy sessions for families in homes.
- Virtual individual family one-off music therapy sessions via Zoom.
- Saturday morning music therapy.
- Tuesday play specialism individual family sessions



I am writing to express my sincere gratitude with all my heart for looking after my beautiful granddaughter. Thank you for being so caring, considerate, compassionate and comforting during the sad loss of our baby. You were also very accommodating allowing me to be with my family at Demelza, especially during these current times of the coronavirus pandemic lockdown restrictions. You listened to us during our times of tears, anger, laughter, play and conversations. You were there for us in our time of need.

Feedback from a grandmother





2.2 Looking back - Patient safety 2020/2021

Infection Prevention and Control (IPC)

Successes include:

- Identified and defined an IPC Lead Nurse role, this enabled us to continuously review and implement changes in line with the national guidance in a timely manner. Including:
 - COVID-19 Infection Prevention and Control Clinical Guidelines, providing clear policy and procedures for clinical teams. These were approved by an external IPC specialist.
 - Infection Prevention and Control Board Assurance Framework, benchmarking Demelza against local NHS Trust Policy.
- All hospice sites have remained open and able to safely deliver direct care to children. This included: end-of-life care in hospices and at home; step-down care; emergency short breaks in hospices and at home.
- Training and support delivered for all care staff on safe usage of personal protective equipment (PPE).
- We have supported children whose parents have tested positive for COVID-19 and were unable to care for them at home.
- There have been zero clinical outbreaks of COVID-19.

Safeguarding children and adults

Successes include:

- Safeguarding Lead Nurse identified with defined role and responsibilities. This has enabled us to review our safeguarding policy and practice with considerable improvements:
 - Safeguarding training matrix review and implementation, including integration of safeguarding adults and review of our e-learning for levels 1 and 2.
 - Launch of new Safeguarding Assurance Committee, meeting quarterly as a multi-professional group to review

safeguarding across the breadth of the organisation, embedding the 'safeguarding is everyone's business' message. Chaired by the Clinical Safeguarding Trustee.

- Regular safeguarding supervision for staff, with both internal and external facilitation.
- Sourced external training for levels 3, 4 and 5.
- Monthly face-to-face safeguarding sessions for levels 2 and 3.
- Increased profile of our six Designated Safeguarding and PREVENT Leads across the organisation including a safeguarding section in our monthly staff newsletter.

Clinical safety improvements

Successes include:

- Clinical Safety Lead Nurse identified with defined role and responsibilities. This has given us the opportunity to drive the following improvements:
 - Reflective statement template updated.
 - Significant event audit training attended by all senior nursing and family liaison and support colleagues.
 - Consideration for second victim potential and measures put in place to mitigate this.
- Weekly clinical safety meetings chaired by the Deputy Director of Nursing and Care and attended by Lead Nurses from each site, and Director of Clinical Services as required, allowing discussion and future planning of clinical requirements and have strengthened quality and safety.



2.3 Looking back - clinical effectiveness 2020/21

Clinical education programme

Successes include:

- Based on staff feedback prior to the pandemic, changes were planned for our clinical training programme to be responsive to our teams identified needs and mandatory expectations.
- A virtual training programme was instigated. This included all clinical staff access to eLearning for health platform, as well as Demelza bespoke courses.

Clinical services development

Successes include:

- Virtual meetings of the Parent Carer Forum took place and their recommendations for improvement were actioned. For example, we made improvements to how we communicate to parents via email.
- The Parent Carer Forum voted for and nominated one of their members to become a trustee, to offer a parent voice on the trustee board.
- Surveys were sent to seek feedback from families regarding their experience of our services and these were responded to where appropriate, for example, by referring families to the practical support team if they had requested this.
- Families were offered the option to register to be contacted about short notice short breaks. Responses were registered on our database, enabling nursing and care staff to contact families to offer short breaks when the hospices had availability.



2.4 Looking back - Patient experience 2020/21

Mohammed Yahya's story

At Demelza, we care for children of all ages, from older teenagers all the way down to the tiniest babies. For each child our goal is the same; to give them the best quality of life we can – to give them moments of happiness and fun that will become their parents most precious memories for the rest of their lives.

Mohammed Yahya's care was challenging, his needs were complex and required a lot of clinical expertise to interpret. His apnoea's (when he would stop breathing, happened a few times a day) and his reflux meant we had to be constantly vigilant of his situation. Reflux is a burning feeling caused by stomach acid travelling up towards the throat. He had a feeding tube, which we would test to check it was in the right place before feeds. We found it was often easiest to keep an eye on him if we just held him all the time.

We got the family to a point where they were able to manage his care and felt confident enough to take him home for the first time, this was a massive milestone for them as a family. We continued to support them and when needed they would come back to stay at the hospice, they did this on four occasions.

Abdul, Mohammed Yahya's Dad said: "In our time there what quickly became clear was that the Demelza team weren't just lovely, caring people; they also clearly had the most exceptional medical knowledge and experience of caring for babies like Mohammed Yahya. They knew exactly how to care for him, and they trained us too.

"Thanks to Demelza, we were confident enough to be able to bring Mohammed Yahya home, for the first time, three weeks later. We knew it would only be for a short few days or weeks – but Demelza's team gave us Demelza's phone numbers so we knew they were only a call away."

In the end, he just died very quickly. He did not appear to be in any discomfort, he just stopped breathing. I was holding him, as I'd promised his parents. They came down and I gave their baby back to them – and comforted them as best I could as they held him. Our journey with Mohammed Yahya's parents won't stop there – we always keep in touch with our families and offer them bereavement support.

Sarah Jesson, Registered Nurse

“

In our time there what quickly became clear was that the Demelza team weren't just lovely, caring people; they also clearly had the most exceptional medical knowledge and experience of caring for babies like Mohammed Yahya. They knew exactly how to care for him, and they trained us too.

Abdul, Mohammed Yahya's Dad

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2.4 Looking back - Patient experience 2020/21

Virtual family support and therapies

Our family support teams' family-centric approach saw them introduce reading sessions during school closures, organise activities to combat isolation, such as virtual parties and create online age specific sibling groups, alongside an engaging weekly support programme.

Family support also created a designated weekday helpline and called over 100 families for Time to Talk Day. This resulted in an improved overview of caseloads and contact with families. We also did regular updates on our Demelza families group on Facebook and weekly emails were sent to families.

We created a new booking system for families looking to access our hydro pool, cinema space, sensory room and gardens, when government guidance allowed.

Changes to our bereavement support services

Our new bereavement service model was agreed and the new bereavement volunteer team were recruited and training was delivered in partnership with Holding on Letting Go, enabling the team to be ready for the opening of new services as part of our new bereavement model.

We have launched new Facebook groups to support families; including: a bereavement group, a dad's group and a grandparents' group. We have further groups planned for 2021/2022.

Family engagement

The family events lead role was identified and recruited, enabling us to offer families virtual events, including a programme of winter and festive themed events in December 2020. We also ran an inclusive dance workshop and sensory story craft parties.

We organised two milestone events for bereaved families, called the Candlelight and Snowdrop events. Our Snowdrop event saw us deliver bespoke event boxes to families which included an art therapy craft activity.



Beautiful. Such thought and care. Knowing that Demelza were thinking of me and my boy. Really liked that it was delivered by someone from Demelza. So very kind. Great idea to have everything you needed to make the snowdrop, even the glue! The tile is very special and already framed. The heart keepsake is simple and beautiful. I will always know that it is for my boy, without necessarily having his name on it and others asking who it is for.

Feedback from the Snowdrop event



Part 3: Priorities for improvement



3.1 Key priorities for improvement 2021/2022

The below key priorities will enable us to continue to be focused on providing a high quality, safe, effective and sustainable palliative and end of life care for the children and families who need us.

As COVID-19 uncertainty continues, we will continue to be flexible and responsive of the situation, which will be underpinned by our Reset and Recovery Plan. This plan was developed in partnership with families, staff, volunteers and supporters.

3.2 Future planning – patient safety

Priority 1: Focus on medicines management

This will be achieved by:

- The focus for 2021/2022 will be medicines management, recognising the inherent risks of nurses transcribing and maximising the provision we have with a highly specialised pharmacist, as well as a pharmacist clinical trustee. In 2021/2022 we will:
 - Commence quarterly Medicines Management Assurance Committee meetings. The committee will: share current best practice and medicines management updates; explore all clinical medicine management incidents and near misses, identify themes; make suggestions for improved practice; and monitor progress.
 - Review and update all policies and procedures in relation to medicines management.
 - Launch electronic drug charts at residential hospice sites.
 - Explore the potential to support two senior registered nurses to obtain non-medical prescribing status.

Priority 2: Safeguarding

This will be achieved by the following:

- We will continue to raise the profile of safeguarding within the organisation and continue to improve our working practices and embed safeguarding across the whole organisation.
- Demelza will be working to establish and incorporate ‘the voice of the child’ into future work and will be seeking external advice on this.
- We will continue to develop the Safeguarding Assurance Committee meeting to improve outcomes and increase safety across the organisation.

3.3 Future planning – clinical effectiveness

Priority 1: Reach and equity of service provision

This will be achieved by:

- Review of our caseload:
 - Utilising data available to us identify gaps between estimated prevalence of children and young people with life-limiting conditions across the areas we serve, and our current caseloads.
 - Outcomes from the above will drive focussed work to reach the additional children and families eligible to access our services.
 - In addition, we will review our discharge process to ensure that caseloads accurately represent children and families eligible and wishing to access our services.
- Short break booking system review:
 - Exploring a new long-term solution for booking short breaks that will protect our ability to be responsive to the core service provisions of end of life care, symptom control and bereavement support, whilst maintaining the vital short break provision that our families rely on.
- Transition working party:
 - The transition steering group is currently defining our transition offer, which will be finalised in line with the 2022 strategy.

- We want to equip and empower families to access all necessary information and be in contact with relevant agencies that can support them through the many aspects of transition. This will therefore form the foundation of decisions regarding support to be offered by Demelza once young people reach 18 years.

• Equality, Diversity and Inclusion (EDI):

- We are striving to continually improve our approach to EDI, in collaboration with another children’s hospice. The EDI work stream started with a workshop in March 2021. We want to ensure that:
 - > all people feel welcome and comfortable when receiving care or support from Demelza;
 - > that we have a diverse staff and volunteer workforce that benefits from the innovation and richness that diversity brings;
 - > that we play our part in making a fairer society by tackling prejudice and privilege.
- We will develop knowledge, skills and awareness of diversity, including considering how care and support can be improved for people from all cultures, those with faiths, beliefs and religions and those without. Demelza proactively seeks to identify and remove prejudice and discriminatory practices relating to race, ethnicity, culture, sexuality, gender, disability, age, marriage or partnership status, and social class.
- Demelza are seeking to build a network of stakeholders who can further engage with people we are less successful in reaching. Plans will be published within the 2022 strategy.

Priority 2: Digital transformation

An overarching digital transformation strategy is being developed which sets the tone, scope and direction for this work. For the success of this project, this cannot be a standalone piece of work and must form an integral element of all other strategies and projects across Demelza. This will be achieved by:

- Becoming a partner organisation with the Kent and Medway Care Record, which supports sharing of information

between service providers in health and social care. We will look for opportunities to collaborate with health and social care organisations across all of the areas where we provide services to ensure that Demelza is linked to external organisations to achieve the best outcome for the child.

- Family Support will continue to develop a hybrid approach of online and in-person support. Online sessions are delivered via Zoom and continually extend reach to families via the Demelza Families and Demelza Bereaved Families Facebook closed groups. Further to the weekly email updates with details of all online events or sessions and online systems for surveys and event bookings, a series of ‘Dem Talks’, similar to Ted Talks, for bereaved families is planned.



3.4 Future planning – patient experience

Priority 1: Expanding and embedding the voice of the child and family

This will be achieved by:

- Enhanced service user involvement:
 - Our new Service User Engagement Lead will be responsible for ensuring the design and delivery of Demelza’s services is informed by an evidence-based understanding of service user needs, wishes and feedback, maximising our impact on children, young people and their families.
 - We will develop and embed a culture of engagement with children, young people, parents, carers and other family members in designing, informing and influencing the services we provide.
 - We will develop and implement a service user engagement strategy, focused on providing opportunities for service user to participate at different levels to ensure their feedback is actioned.
 - We will offer a variety of ways for service users to engage with us and have their views heard and enable them to influence and co-produce services.
 - Family Events continue to be shaped and developed using feedback from families and the voice of the child.
- Review of key policies and processes to ensure the child’s voice is adequately represented:
 - Safeguarding policy review
 - Professional boundaries policy review
 - Consent policy review
- Dignity and respect policy review
- Datix incident reporting policy
- Website development project:
 - As part of a wider review of our website, consideration will be given to increasing accessibility of information for all ages, developmental stages and communication preferences.

Priority 2: Flexibility and responsiveness for place of care and support

This will be achieved by:

- We will continue to balance on-site, face-to-face sessions and therapeutic experiences for Demelza families with a continued and expanded virtual presence.
- We will monitor the services offered and update and develop them to ensure that they remain current and supportive of our family’s needs and wishes.
- This flexible approach, underpinned by a clear service model is informed by national service standards and shared good practice within the children’s hospice sector, alongside direct feedback and review by families.
- Expansion of Care at Home service:
 - We will seek to expand these services to include end of life nursing support in the community to allow children and families greater choice and control over place of death.
- Managed clinical networks:
 - We will work collaboratively with the Kent and Medway Managed Clinical Network (MCN) to maximise available workforce and resources to allow children and families greater choice about place of care.
 - We will learn from the successful working relationships with local children’s community nursing teams and Chestnut Tree House Children’s Hospice and develop a similar approach for South East London.
 - We will ensure we are represented and contributing to The London Children’s Palliative Care Network.

Part 4: The board of trustees commitment to quality



Part 4: The board of trustees commitment to quality

We are committed to our staff, volunteers, families and children to help those who may not live a long life to live life to the full.

We take our governance responsibilities very seriously and ensure that all trustees are briefed at every board meeting by the Chair of the Clinical Governance Committee on progress in clinical developments as well as highlighting challenges and concerns. A patient story is told at each meeting to ensure that trustees appreciate what children, families and staff are dealing with.

The Clinical Governance Committee has representatives from the clinical services leadership team, four clinical trustees, including a community paediatrician, a pharmacist, senior nurse and lead clinician from the Health Ombudsman's office. We've recently appointed a parent trustee who has brought a rich level of observation and scrutiny from a parent's perspective.

Demelza's established clinical governance structure ensures that trustees are confident in their role as a 'critical friend' but also comfortable in undertaking robust challenging conversations with the nursing, care and family support team. We have prioritised safeguarding to ensure that 'safeguarding is everyone business' across the organisation and all trustees have completed safeguarding training. We have robust safeguarding processes in place.

Each Clinical Governance Committee meeting reviews the clinical governance and quality progress and incident reports which are discussed in detail.

Key performance indicators, family and service user feedback and the clinical risk register is considered in detail at each meeting.

The clinical services team have been strongly involved in developing and delivering our reset and recovery plan.

We are confident that the treatment and care provided by Demelza is of the highest quality detailing a continuous improvement whilst ensuring it is cost effective and efficient.

There is no formula, everyone's journey is unique.

Part 5: Statements of assurance



Part 5: Statements of assurance

These statements are ones set out within Quality Accounts Regulations that all providers must include.

Review of services

Demelza worked closely with partners, including NHS Tertiary Centres, other hospitals, local adult hospices, community nursing teams, NHS England, CCGs and local authorities to collaborate and focus support where it would be most beneficial.

Collaborating with other providers

As mentioned, in this report we have collaborated with other providers and supported the NHS during the pandemic.

Participation in national audits

In 2020/2021 there were no audits or enquiries relating specifically to specialist children's palliative care.

Local clinical audits

We have a programme of internal clinical audits ensuring quality and performance are measured and monitored, meeting our statutory and regulatory requirements, as well as for informing risk management.

Audit tools are based upon Healthcare Quality Improvement Partnership best practice guidance. Whilst the clinical governance team plan and instigate clinical audits, a whole team approach to completing them is adopted. This ensures understanding and ownership of findings and recommendations.

Audit findings are presented quarterly to the clinical governance committee meeting, as well as being shared across our internal communication channels.

Infection prevention and control (IPC)

Infection prevention and control has been fundamental to safe service provision throughout 2020/21. More details on this can be found in Part 2 of the quality account.

In April 2021, Demelza hosted the NHS Deep Cleaning and Advisory Service in order to benchmark housekeeping and cleaning within the Kent hospice and received positive feedback available on page 27.

Our reset and recovery plan clearly outlines how Demelza can safely emerge from the current COVID-19 restrictions, whilst maintaining the safety of staff, volunteers and families.

The IPC Lead Nurse is responsible for continual review and updating of the infection prevention and control Policies and Procedures and for alerting the Senior Leadership Team of any areas requiring attention.



Part 5: Statements of assurance

MHRA and patient safety alerts

There is a formal system in place for the receipt, review and actioning of all MHRA alerts. A designated nurse reviews all alerts. On identification of ones relevant to Demelza, these are shared via email with a very clear 'problem', 'risk rating' and 'action required' format. Any high-risk areas are also printed and shared on information boards and within clinical handover.

This year has seen a recall for remediation of McKinley T34 syringe drivers and this has been carefully and successfully managed. Additionally, there have been numerous new national guidelines published in response to the COVID-19 Pandemic. The IPC lead nurse, alongside the clinical governance team, have managed these and ensured timely implementation.

Research

We value and encourage research into children's palliative care. As such, all external research requests are considered on their merit and, if required, the Clinical Governance Committee will review papers and receive a presentation from the researcher to ascertain appropriateness of participation. A formalised process is planned for 2021.

Demelza supported the following external research requests in 2020/21:

- University of York SWICH survey.
- Masters student survey regarding the role of the pharmacist / pharmacy technician in paediatric palliative care.
- Children's Palliative Outcome Scale (C-POS) study from Kings College London.
- Children's Cancer Priority Setting Partnership survey.
- Birmingham University survey evaluating perinatal advance care plans.
- North Dakota State University exploring the lived experiences of bereavement support professionals at children's hospices in the UK.
- PhD student interview study examining parental and organisational perspectives into how parents of children with medical conditions seek and access support for themselves.

Part 6: What others say about us



Part 6: What others say about us

Care Quality Commission (CQC):

Demelza Kent, South East London and East Sussex are individually registered by the CQC under the Health and Social Care Act (2008). Demelza East Sussex was registered as a separate service in July 2020.

Demelza South East London was last inspected in 2017 and was rated "good" overall and "outstanding" in being responsive to the needs of the child, young person and their family. They found that staff often went beyond the scope of their duties to show that they cared.

Demelza Kent and East Sussex were registered as a combined service and were last inspected in 2016 and was rated as "outstanding". "There was an open and positive culture which focussed on children and how to enhance the quality of their life," says the report.

Demelza's current registration status is unconditional, with no enforcement actions or participation of special reviews or investigations throughout 2020/21.

Demelza participated with the CQC's transitional monitoring approach (TMA) in March 2021. The feedback from this was: "At this moment we are unable to provide any quality statements. We are however happy to recognise the collaboration with Demelza in regards to engagement and the TMA and COVID-19 assurance framework, which for the time being indicates no serious risks identified."

NHS deep cleaning and advisory service:

Following an invitation from Demelza to visit and review Demelza housekeeping and cleaning standards in light of increased requirements due to the COVID-19 Pandemic, the NHS deep cleaning and advisory service stated that:

"(Demelza Kent is) very well maintained to an exceptional high standard throughout. They have gone above and beyond in their protocols, procedures and risk assessments – the detail in the planning is absolutely incredible".

Data quality

In 2020/21 Demelza collected and submitted data in respect of the following:

- CQC for child death data and reports of significant events/ investigations.
- Quarterly clinical governance and quality reports to the Clinical Governance Committee.
- All relevant information to the quarterly board of trustee's meeting.
- Service mapping information submitted to Together for Short Lives.
- Finance data submitted to Hospice UK.
- Capacity tracker data continues to be recorded and submitted to NHS England daily, including weekends and bank holidays.
- Data provided to the Child Death Overview Panel.
- Data submitted to London Borough of Bexley and Greenwich Clinical Commissioning Group.
- Clinical coding error rate.
- Demelza are not eligible to submit to the summary hospital level mortality indicator and are not subject to the payment by results clinical coding audit.

Areas for further improvement

Despite no external quality visits during 2020/2021, we are committed to striving for continuous improvement and are currently reviewing our clinical governance and quality improvement plan to be implemented from October 2021.

Part 7: Service Data



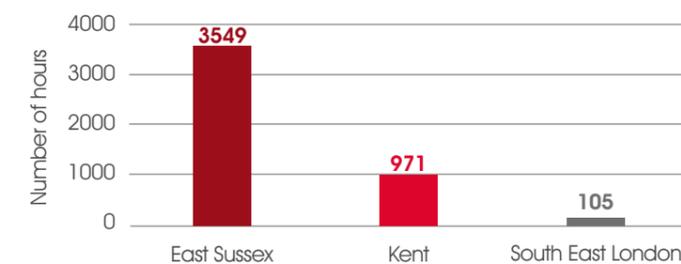
Part 7: Service data

Activity Report

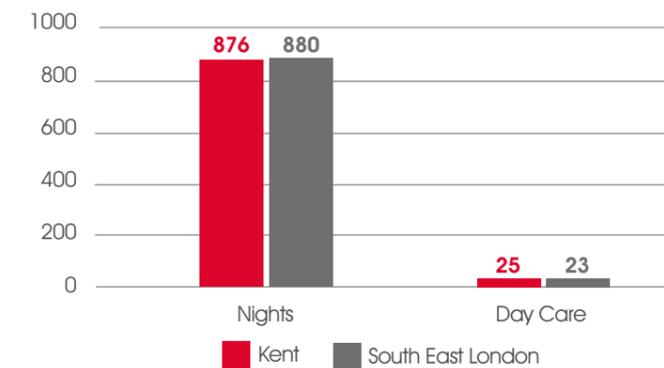
Demelza undertook a review of clinical key performance indicators in 2020/21. An important aspect of this is the number of unique children and families reached. This has allowed us to examine the equity of the service and ensures that we strive to reach the maximum possible number of different families. Data is provided to the Clinical Governance Committee quarterly outlining the following:

- Hospice overnight bed occupancy.
- Hospice day care.
- Care at home and community care sessions provided.
- External Hydro pool bookings.
- External Cinema room bookings.
- External sensory room bookings.
- Types of care delivered: emergency respite; symptom management; step down care from hospital; end of life care, offers of short breaks.
- Numbers of deaths and place of death.
- Bereavement suite usage.
- Family liaison contacts.
- Bereavement support and therapies sessions provided.
- Family events and virtual group session attendance.
- Training compliance figures.
- Activity levels from the reset and recovery milestones.

Care at Home hours 2020-2021



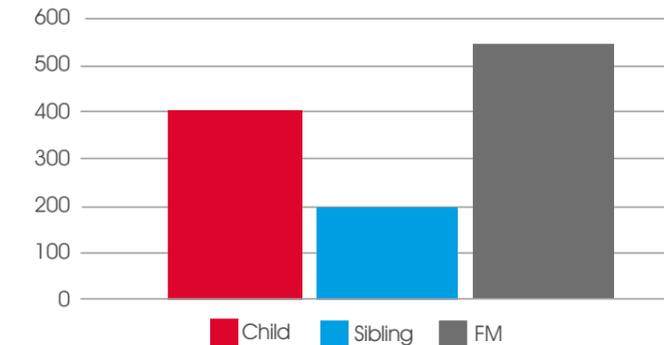
Hospice usage 2020-2021



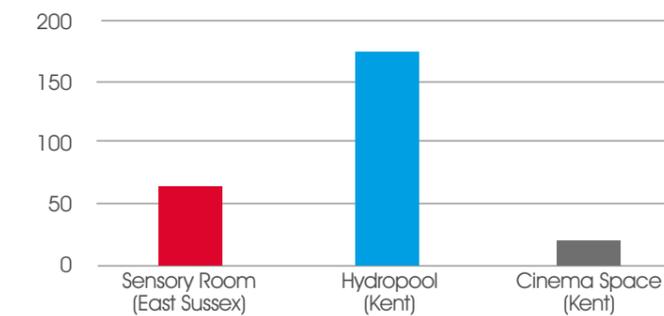
Family Support Department
Event & Group Attendance Figures (Jan to Mar 21)

Child	408
Sibling	201
FM	546
Total	1155

Event and Group Attendance Figures (Jan to March 2021)



Number of Family Led Bookings 2021-2021



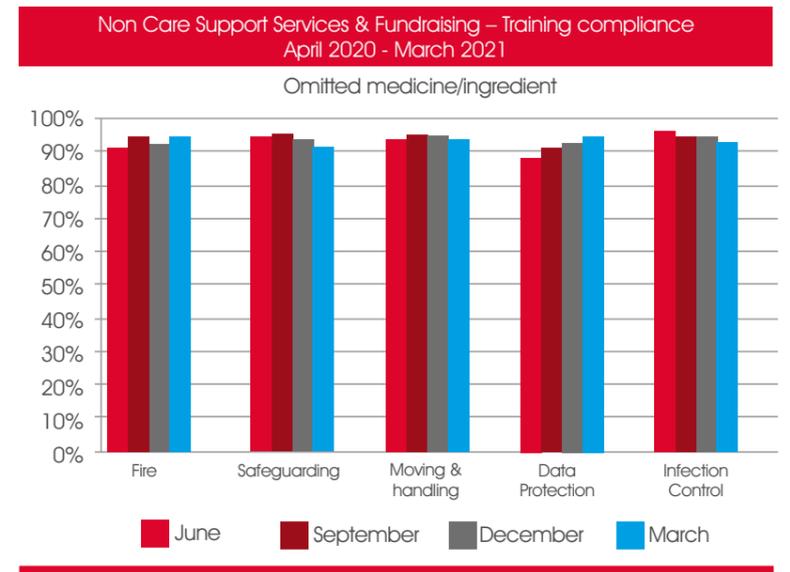
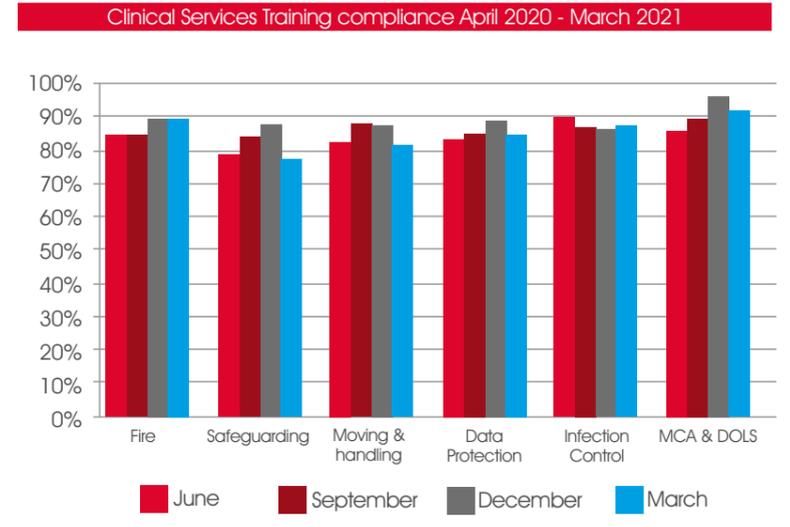
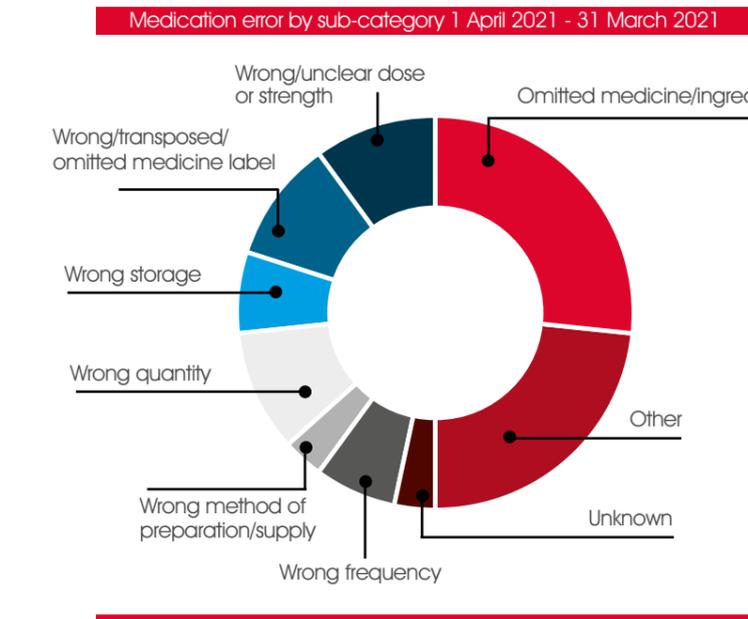
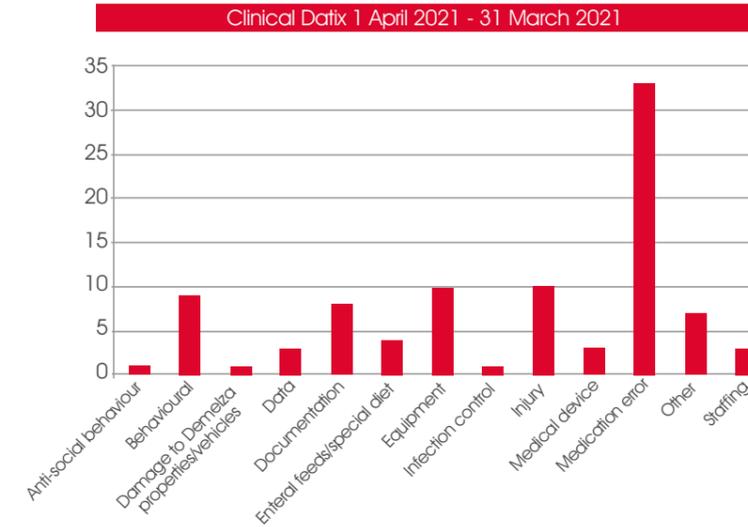


Part 7: Service data

Incidents, accidents, complaints and compliments

We utilise the Datix incident reporting system across the organisation. The data below demonstrates a positive culture of incident reporting within clinical services, further attention is planned to improve 'near-miss' reporting to build upon the figure of 22 reported near misses for 2020/21.

Throughout 2020/21 there has been encouragement for staff to also report compliments; this has been well received and is a constructive tool to encourage teams to recognise and applaud behaviours that align with Demelza values. Demelza clinical services received 1 complaint, 1 comment and 41 compliments within 2020/21.





Part 7: Service data

Finance and sustainability:

Demelza is in a strong financial position. We have made a surplus in four of the last five years. Our expenditure is well controlled, and has been increasing by an average of 10% per year over the last 10 years. Our main income streams usually have the following proportions:

Fundraising	28%
Retail	26%
Statutory Funding	15%
Lottery	15%
Legacies	12%
Dividends & Interest	2%
Others	2%

We have received two large legacies in 2018 and 2020 totalling £7.5m. Due to the legacies and careful financial management, Demelza has strong reserves. At 1 April 2020 we held £17m in free reserves, which is £4.3m more than our reserves policy. This allows us to weather the financial uncertainty brought by the COVID-19 pandemic, and to continue to plan for growth and sustainability. We expect to use these excess reserves over the next strategic period as we develop our care teams and invest in our main forms of income generation: fundraising, retail and lottery. We are committed to using our strong reserves to reach more children and families.

Duty of candour:

Demelza have followed all duty of candour processes for all incidents involving children and young people.

Equality, diversity and inclusion:

We understand that celebrating and embracing the unique differences people bring will engender a creative, forward thinking organisation.

Demelza is striving to continually improve its approach to equality, diversity and inclusion.

Demelza have identified a need to improve racial equality and have committed to addressing this problem. Whilst we are proud that the profiles of our service-users match the ethnic profiles of the communities in which we work, this is not the case for our workforce or leadership roles. We are formulating a plan, with support, to address this serious issue, for the benefit of the people and communities we serve and to improve our organisation. We welcome the advice and guidance of anyone who can help us achieve this aim.

Safeguarding:

A significant amount of progress has been made over the past year, including the review of our safeguarding policy and procedures, training matrix, training programme and providers, introduction of our 'Safeguarding Assurance Committee' and the implementation of regular safeguarding supervision for staff. We have strengthened our links with our local authorities and acute safeguarding leads in all 3 areas and established improved links with our local Child Death Review teams and processes.





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**Some photos featured in this document were taken pre COVID-19*

www.demelza.org.uk

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