



Demelza

Hospice Care for Children



Quality Accounts
2021/2022

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Part 1: Statement of quality by the CEO

I am delighted to present Demelza Hospice Care for Children's Quality Accounts for 2021-2022. Over the past two years we have transformed our service offer to be less based in our care buildings and to offer a wider breadth of services in a choice of locations that better meet the needs of children and families.



We have provided more day care and more care at home services, more virtual support for groups and individuals than ever before, more utilisation of our building facilities driven by families than ever before and more events to bring people together and build peer support networks.

This year we have taken the opportunity to increase the leadership available to our Clinical Services Teams and the wider Leadership of the organisation by 50%, ensuring our decision making remains focussed on the needs of children, young people and families. Demelza has supported a pilot training programme for two Nursing Associates and has provided leadership training to line managers and those who wish to develop their skill base into line management.

We have been preparing for the April 2022 launch of Demelza's new strategy, consulting with children and families, staff and volunteers more than we have been able to do before. We will build on this consultation to drive forward true co-production of all services.

With an estimated national shortage of 40,000 Registered Nurses in the UK, Demelza has carefully considered our plans. Our 2022-2027 strategy will address potential nursing shortages with opportunities for Registered Nurse training, Nursing Associate training, providing a palliative care career pathway and increasing retention and attraction benefits. We will continue to

extend the breadth and reach of services provided in addition to our nursing and care provision to support children's palliative care in creative therapies, family liaison, transition support, bereavement support and family event opportunities.

You can read Demelza's new strategy here www.demelza.org.uk/strategy.

I am inspired by the children and families we meet in our roles, but I would also like to pay tribute to an amazing team of staff and volunteers. Their genuine commitment to provide safe, high quality care to the whole family drives us to continually improve standards. We are supported by a forward thinking and supportive group of Trustees and an incredible, generous and dedicated supporter base.

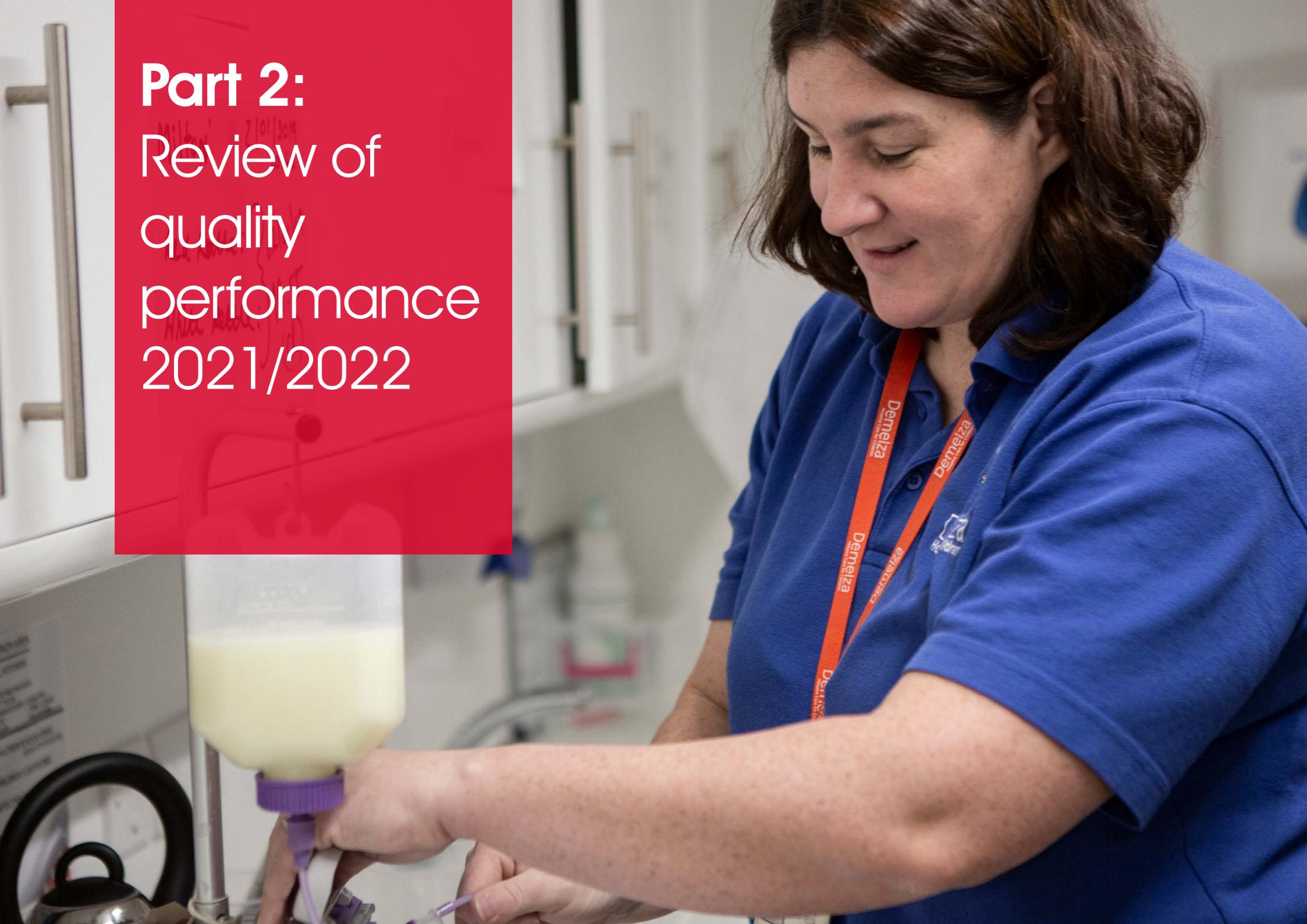
These accounts have been prepared by our Director of Quality Improvement and Clinical Governance and the team, with the full support of Demelza's supportive and proactive Board of Trustees.

Thank you,

Lavinia Jarrett

Lavinia Jarrett
Chief Executive Officer

Part 2: Review of quality performance 2021/2022



2.1 What we achieved in 2021/2022

Demelza has emerged from the COVID-19 pandemic more agile and responsive in how and where we offer services and choice. Our teams have constantly reviewed and adapted services to adhere to government infection prevention and control guidance and ensure we have been able to be responsive to meet the needs of the children and families on Demelza's caseload. We have focussed on being responsive and prioritising symptom management and end of life care along with supporting those in greatest need and adapted services accordingly. We have further developed our agile responses in Family Support via digital means and how we support differently with events for peer support and social interaction.

Achievements 2021/2022

2.2 Looking back – patient safety 2021/2022

Priority 1: Focus on medicines management

Medicines management was a focus in 2021/2022, recognising the inherent risks of Nurses transcribing and maximising the expertise we have from our highly specialised pharmacist and pharmacist clinical Trustee.

Successes include:

Quarterly Medicines Management Assurance meetings are now embedded to share current best practice and medicines management updates, exploring all clinical medicine management incidents and near misses, identifying themes, making suggestions for improved practice and monitoring progress.

This year work has focused on:

- Devising and implementing a new electronic drug chart at the residential hospice sites. Initial evidence demonstrates a reduction in medication incidents.
- An in-depth review of all medicines management policies and procedures. All have since been collated into one document making it easier for staff to navigate and find the information they are looking for.
- Considering the level of potential harm in medicines-related incidents.
- Developing an error workbook supporting reflection on errors.
- Registered Nurse link workers have been identified to feed information into the committee and cascade learning to the teams.
- Regular mandatory medicines training.
- Learnings shared wider through the Inter-Hospice Medicines Meetings.

Priority 2: Safeguarding children and adults

Demelza takes its safeguarding responsibilities very seriously and recognises everyone has a responsibility to make sure children are safeguarded and protected from harm. We have continued to raise the profile of safeguarding internally and improve practices to embed safeguarding across the whole organisation.

Successes include:

- Designated safeguarding leads coming together to share experiences and learnings through The Safeguarding Assurance Committee, which reports to the Clinical Governance Committee and Trustee Board.
- All staff and volunteers who support and work with children and families have received the training and support they need to recognise, respond, refer, record and review any safeguarding concerns.
- We have strengthened the 'voice of the child' in all of our areas of work, ensuring their thoughts, feelings and views are considered.
- We have been working with families on safe usage of technology and how we can improve communication with families and carers on these important issues.



Priority 3: Infection prevention and control

Infection prevention and control procedures have been constantly reviewed and updated in line with the latest government guidance on managing the COVID-19 pandemic and all changes communicated to staff, volunteers and children and families.

Successes include:

- No clinical outbreaks of COVID-19.
- All staff completed mandatory infection prevention and control e-learning and clinical staff completed annual face-to-face or virtual training.
- Clinical staff completed training on donning (putting on) and doffing (taking off) of Personal Protective Equipment (PPE)
- FFP3 mask fit tests were carried out for staff delivering Aerosol Generating Procedures (AGPs)
- Water safety issues, pseudomonas and legionella, at Kent and South East London (SEL) hospice sites managed and relevant works completed.
- Regular audits completed on hand hygiene and mattresses.
- COVID-19 information on family area of Demelza website and updates by email.

Priority 4: Clinical safety improvements

Successes include:

- Monthly risk management meetings have been implemented within Clinical Services to ensure robust and active management of risk.
- Medicines management assurance.

2.3 Looking back – clinical effectiveness 2021/2022

Priority 1: Reach and equity of services provision

Demelza strives to provide services that best needs the needs of children and families and ensure they are accessible to all. We know that advances in medical science are enabling babies and children to survive with increasingly complex needs. That is why we have been determined this year to extend our reach.

Successes include:

- Short break booking system reviewed and new system implemented to offer more families the opportunity to access short breaks.
- Online referral form implemented on Demelza website.
- Family focus groups set up to support families with grants and other measures.
- Art and music therapy sessions available in a number of settings including hospice sites, family homes, hospital, educational settings and virtually.
- Themed music groups hosted virtually after school and at weekends.
- Bereavement training delivered to over 60 staff across the organisation to increase understanding of grief and bereavement alongside gaining knowledge of how Demelza's bereavement model is actioned.
- Residential trip for siblings transitioning into secondary school - described as an 'opportunity of a lifetime' by a child who attended and 'an opportunity to meet other children that could really understand what it's like living in a family like ours,' by a parent.
- A sibling support group that had met virtually through lockdown met together in person in summer 2021.
- A transition framework developed to support young people and their families through transition from children's to adult services.
- Virtual and face to face bereavement remembrance events.



Priority 2: Digital transformation

Underpinning all of our work is an ongoing digital transformation strategy that will help Demelza build capacity to deliver more services to children and families.

Successes include:

- Review of the electronic clinical records management system, The Care Database, to ensure effective use and suitability going forward.
- Manual process put in place to mitigate audibility limitations and create an audit trail on data.
- Risk Management Policy and Procedure updated leading to the introduction of new risk registers and training for leadership team.
- Care at home teams provided with new technology to support remote working.
- Wi-Fi across all sites upgraded to ensure stability of connection for access to clinical data and records.
- Improved safety measures introduced for tablet devices used by children, including content filtering, group management of devices and upgraded wireless accounts.
- Further improvements planned for 2022-23.

Priority 3: Clinical education programme

Demelza is committed to continually updating training to ensure our Clinical Teams have the skills and knowledge to meet the ever-changing needs of the children using Demelza services.

Successes include:

- Paediatric Immediate Life Support (PILS) training implemented for all Registered Nurses.
- Development of bespoke behaviour management training package for all clinical staff.
- Effective Moving and Handling link programme embedded with moving and handling links on all three sites.
- 'You said, we listened' to our Flexi Bank and Lead Nurses resulting in a bespoke mandatory training programme twice a year within school holidays and at weekends to enable our bank staff, some of whom are school nurses, to attend.
- Successful qualification of two Nursing Associates (Kent and East Sussex) with preceptorship programme in place.

Priority 4: Clinical services development

Successes include:

Nursing and Care

- Implementation of electronic care plans.
- Enhanced roles for Health Care Assistants, with a key focus on bereavement and leading on play and leisure activities.
- Two members of Nursing and Care staff at each site were trained in memory making through life casting. This bespoke service was offered to families at Demelza hospices or in their own homes.
- Contracts with local hospital established to place experienced Registered Nurses there one day a week to increase awareness and understanding of what Demelza can offer to professionals, children and families.
- Pathway to enable agency nurses to continue caring for the children they care for at home, when they come into the hospices to enhance the child's experience and safety.
- Practice Development Nurses on all three sites.

Family Liaison

- The new Family Liaison practitioner role has improved the referral process and increased referrals to Demelza.
- A professionals day was held to demonstrate that Demelza is not just about end of life care, showcasing the range of Demelza services to the medical team.

Transition

- Transition Masterclass with Rett UK and Batten Disease Family Association (BDFA) bringing families together and offering advice.
- Contact with all service users aged between 17-19 years old, offering listening/ emotional support and gain the experience of families in order to inform future transition provision.
- Transition steering group developed, consisting of parent member and team members across clinical services.

Bereavement

- A new recording and communicating process for post death support was trialled and progressed.
- Post death huddle meetings were introduced along with family contact call.
- Befriending training for volunteers was set up and completed.

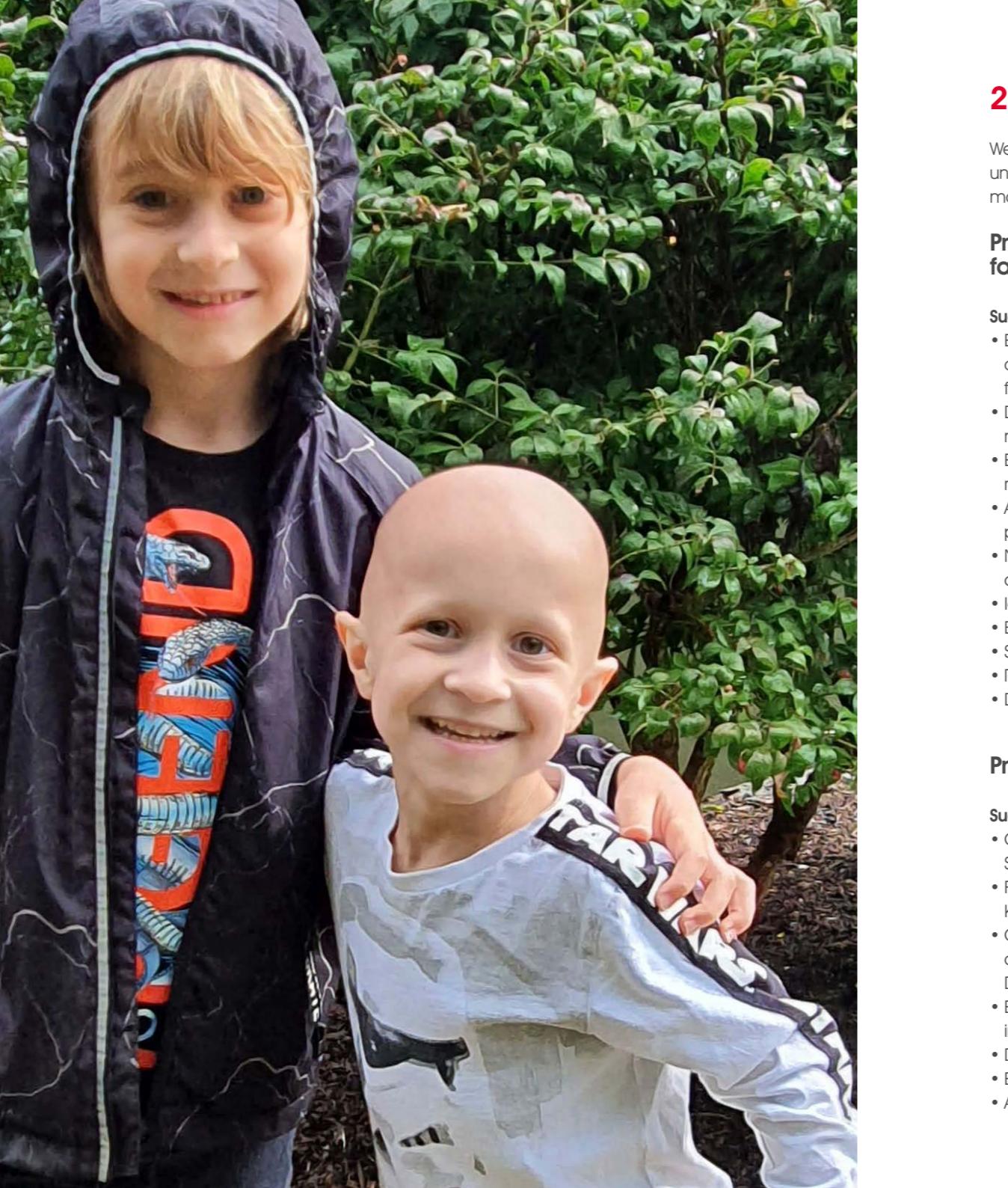


Zak's story

"Our darling Zak died at home on a Wednesday. Not long after he passed, the Demelza team arrived and took control and we felt an enormous sense of relief when they removed all of the medical paraphernalia from the living room. We needed to have Zak free from the equipment and medications that had consumed his short life for so long. We feel grateful that the team had also arranged for Zak to have a hand cast done with his brother a few days before - a memory Tom can treasure forever.

Arrangements could've been made to keep Zak in the house but we didn't want his death to affect our memories of Zak at home with his brothers. So, we decided the best thing was for him to go to Demelza. Zak laid at rest in the Hop Garden bereavement suite surrounded by all the things he loved and his brother Tom came to see him. We wouldn't have wanted an eight-year-old to visit a funeral parlour. But the Demelza setting was perfect – nurse Sacha made sure all the thoughtful touches were in place and it was so calm and serene. The team also helped with funeral arrangements and information on support grants - all things that took an enormous weight off our shoulders. Demelza has since offered bereavement support for our family, including a siblings group for Tom with other children who have lost a brother or sister."

Caroline, mum to Zak and Tom



2.4 Looking back – patient experience 2021/2022

We want to provide services that best meets need. Listening to children and families is key in understanding the areas in which we work and we strive to involve service users in decision making.

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

Successes include:

- Established and recruited a new post, Service User Engagement Lead, to seek involvement of and feedback from children, young people and their families, including review sessions following an activity.
- Demelza's first series of Whose Shoes consultation workshops to help develop the organisation's new five-year strategy was attended by trustees, staff, volunteers and families.
- Enhanced service user involvement. Children and families on interview panels including recent recruitment for the CEO and Director of Clinical Services.
- A new creative writing group began with an aim to explore feelings, share experiences and to promote collaboration and support amongst families.
- Nursing and Care teams completed sign language courses, furthering opportunities to gather and respond to the voice of the child.
- Identified the need for a designated lead for family communications.
- Bereaved families Facebook group established.
- Support groups, including bereavement café, dad's group and grandparents group set up.
- Review of key policies and processes to ensure the child's voice is adequately represented.
- Dedicated area for families on new Demelza website; launched in summer 2021.

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

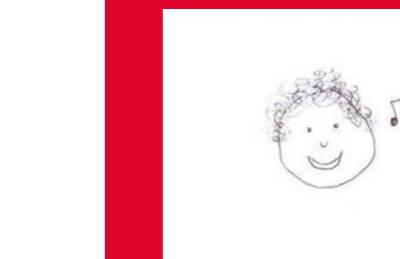
Successes include:

- Care at home services have been expanded across all three sites. Care at home launched in South East London, with plans to grow this considerably in 2022-23.
- Facilities for non-resident children and families increased, including hydro pool and cinema in Kent and the sensory room in East Sussex.
- Carefully managed overnight hospice closures and utilised staff flexibly to meet the needs when demands on the service were higher in response to the shortage of Registered Nurses, ensuring Demelza was able to respond to urgent or emergency care requests at all times.
- Expansion of Demelza Dots activity group to reach more children across catchment areas, including face to face sessions in Dover, East Sussex and Tunbridge Wells.
- Development of the East Sussex community team hub garden to offer more experiences.
- External professionals paediatric palliative care study day held at the Kent hospice.
- Active partners within Managed Clinical Networks across the south east.

"Really open discussions! Everyone had a voice."
Feedback on Who's Shoes

"A Demelza volunteer took my son and I to his appointment yesterday in a nice new minibus. This was really helpful as we only had to focus on the appointment and not the stressful drive and the worry of finding parking."
Feedback from parent/carer

"The first thing I will tell my family - I made new friends."
Sibling feedback



Child feedback from a sensory story online session with Demelza music therapist

"Demelza continues to work hard to engage with families and children in shaping the services that we offer to them. As a Parent Carer Trustee, I attend the Clinical Governance Committee and Safeguarding Committee meetings to offer the perspective of families and children to ensure Demelza tailors policies and procedures with their experiences in mind. Alongside our Service User Engagement Lead we've had families and children actively involved in the interview process of Senior Leadership appointments and organisation-wide strategy planning this year."

Charlotte Parry-Jones, Parent Carer Trustee



Case study – Offering families choice

At Demelza, family choice is vital in delivering our expert care; whether a child is expected to access our services for many years, or just for a few important days. A child was transferred to Demelza's hospice in Kent for withdrawal of ventilation and end of life care, after being born at full-term with catastrophic brain damage. This was his family's first time at Demelza, at a time when they needed support the most.

Following his admission, his parents were offered a choice of where the ventilation was withdrawn; either the child's bedroom, or the secret garden – a beautiful, private outdoor space. After a brief tour, his parents felt most comfortable in the garden. The child's mother was cuddling him, with his father and grandmother by her side, as the Neonatal Intensive Care team withdrew ventilation; a Demelza Registered Nurse and Healthcare Assistant were also present. Once the procedure was complete, clinical care was kept to an agreed minimum to allow his family the time and space to process their emotions in private.

Following a quiet hour in the secret garden, the child and his family were moved to his bedroom where he would spend the night. That evening the team started memory making with the family and made tiles and clay finger prints, creating tangible memories with the child while he was still alive that they'll have for years to come. The child's family stayed in his room with him throughout the night; care staff remained on-hand to help with feeds and suction as needed.

Early the next morning, the child died peacefully in his mother's arms with his family around him. He stayed in the bereavement suite for the next five days, allowing the family to say their goodbyes in their own time.

The team at Demelza continued to support the family following the child's death; offering bereavement support, assisting with funeral arrangements, as well as liaising with the GP, Coroner and Paediatric Palliative Care team to ease the burden as much as possible.



"Families' and children's choices are empowering and vital in the provision of end of life care, and facilitating those choices can aid the bereavement process. The secret garden is a beautiful and very private space and we were able to offer it, as well as a bedroom, to this family for the withdrawal of their baby's ventilation and subsequent end of life care. It was a warm sunny day and baby was in mum's arms, with his father and grandmother around him, when the tube was removed."

I was really moved by the experience. It's an immense privilege to be able to support a family as their child dies, and particularly in such a beautiful space. I felt really proud to be part of such an incredible service."

**Danni Kerri, Team Leader –
Palliative Care & Symptom Management.**

Part 3: Priorities for improvement 2022/2023



3.1 Key priorities for improvement 2022/2023

The need for a hospice service for children has increased and will continue to do so – our five-year strategy (2022/2027), which launched in April 2022, will therefore play a critical role in helping us to reach every family who requires our services.

The strategy focusses more than ever before on Demelza's history of actively seeking the views and feedback from those who are the real experts; the children, young people and their families. Demelza will strive to involve those who use or might need to use Demelza's services in our decision making and how we develop our services and ensure they are accessible to all those that need support - particularly those from diverse and minority backgrounds.

3.2 Future planning – patient safety 2022/2023

Priority 1: Embed and maximise opportunities created through enhanced quality and safety measures commenced in 2021/22:

- A new Director of Quality Improvement and Clinical Governance role will work closely with the Director of Clinical Services to enhance clinical services and provide increased capacity and oversight at senior leadership level.
- Clinical services risk management meetings to continue to develop with associated risk assessment and escalation processes.
- Focus on just culture within incident reporting and management.
- New Physiotherapist role working collaboratively with the Nursing and Care team and Occupational Therapist to enhance the care provided.

Priority 2: Workforce strategy

We couldn't do the work we do, or have the impact on the lives of children and young people like we do; without our people. That is why we are committed to provide professional development, growth and enhanced wellbeing for all staff and volunteers

To increase our impact, we must have an appropriately trained, highly skilled, diverse and motivated workforce. It is, therefore, essential that we invest in our workforce strategy to attract, retain and develop every individual, who all make a significant impact directly on our service users, in whatever role they carry out. We will create an agile workforce and become an employer of choice and recognised organisation for a positive volunteering experience.

This will be achieved by:

- Developing clinical career pathways that invest in our valued staff, developing their skills and creating career opportunities, supporting retention and subsequently safe and effective care.
- Attracting the highest quality team by being an employer of choice.
- Further development of the wellbeing strategy, helping the clinical team to feel and perform at their best and deliver safe and effective care.
- Developing our own Health Care Assistants by furthering opportunities for Nursing Associates and Nurse Degree Apprenticeships, to support recruitment and development.



3.3 Future planning – clinical effectiveness 2022/2023

We will offer a range of services that continually evolve and are responsive to the ever-changing needs of children and families.

Priority 1: Grow collaborative partnerships

This will be achieved by:

- Working across the south east with all partners to support planning and management of children on shared caseloads so that we can work together to increase choice of place of care and support.
- Family liaison and Registered Nursing in-reach into local hospital settings. Aiming to raise awareness of Demelza's service and offering our acute care colleagues' opportunities to seek support and training with children's palliative care expertise.
- Leading on the creation of a Clinical Governance framework by working closely with the Kent and Medway Managed Clinical Network to establish a means of working together across organisational boundaries to provide clinical care to children at the end of life in their own homes.
- Reaching out into acute trusts to place Demelza Registered Nurses within the acute areas with honorary contracts to provide clinical expertise and increase referrals. Create opportunities to mirror existing honorary contracts for Demelza staff to work in other primary, secondary and tertiary hospital environments, allowing staff from both organisations to learn and retain skills and knowledge and provide continuity of care to children across settings.
- Commitment to lead within the Kent & Medway Managed Clinical Network (MCN) to establish a governance and training framework across the area that will lead to greater collaborative working across teams and increase those trained and available to support children and families if they wish to be cared for at home for end of life care. Reducing postcode lottery and navigation of multiple services for families.
- Working collaboratively across London, the south east and East Sussex as active partners of clinical networking initiatives.

Priority 2: Embed and strengthen the transition model; bereavement model and creative therapies available

Demelza will focus on developing services to support the range of needs of children and families on the caseload and will look at a multi-disciplinary approach to enhancing care.

This will be achieved by:

- The implementation of the Transition Framework, which sets out what support can be accessed, initially focussing on ages from 16 – 25 years.
- Nursing care provided up until young person's 18th Birthday.
- Social model of support up until 25th birthday.
- Recruiting into the transition team to implement framework and development of service.
- Ensuring families are equipped with the right information at the right time using a pathway to guide involvement and connecting families with professionals/ services.
- Further understanding of accurate data needed.
- Working with adult hospices across the catchment area.
- Growth of bereavement team to ensure the bereavement model can be implemented and reach more families.
- Growth of creative therapies teams to ensure we can provide these services to more children and families.



3.4 Future planning – patient experience 2022/2023

Priority 1: Involve service users in decision making

Children and families will mould services in this strategy and beyond, through further consultation opportunities. A focus this year will be the in-depth review of the short breaks service offer to remain accessible for families and deliverable for Demelza with current challenges considered.

We will achieve this by:

- Embedding the engagement and involvement strategy and the new Demelza strategy through every engagement with families and children young people.
- Developing a children, young people and family advisory group and the further development of the parent carer forum membership.
- Continuing to develop feedback methods and reach with families and especially children and young people. Ongoing development of the child's voice at every recruitment level including a bank of questions and tasks set by children and families at Demelza to ensure their voice is heard at all levels but without a time impact where in person attendance is not possible.
- Recruitment of a Communications Officer to improve the information provided to families about services available and how to access these, including a new Guide to Services.
- Events planning and management to grow communities of support.

Priority 2: Digital Transformation

We will increase the use of digital to deliver services and provide efficiencies in process and resource to enable us to 'do more' and 'extend our reach'.

We will continue to seek out and embed how digital means can support Demelza to be effective and responsive to those who may need children's palliative care services now and in the future.

We will achieve this by:

- Engagement of workforce, listening to feedback and acting on it.
- Phone upgrades for team members onto latest models to ensure security of data and information.
- Tendering for a new clinical database to ensure that we are able to effectively manage our clinical data and caseload.
- Review of Quality Management System (QMS) procedure and systems.
- Current Incident Management system to be reviewed and updated to ensure that incidents and complaints are effectively managed.

Priority 3: Equality, Diversity and Inclusion

We aim to extend our reach by defining who we are not reaching, particularly those from diverse and minority backgrounds, and why, and plan to fill this gap.

We aim to grow the diversity of our workforce and volunteers, particularly in the representation of ethnic minorities, celebrating the positive impact of difference.

We will achieve this by:

- Undertaking an analysis of the areas in which we work; the geography, diversity, deprivation, economics and all other factors.
- Determining the spectrum of need on our caseloads and their families, for example, family dynamics, trigger points, crisis triggers and different services used.
- Continually evaluate the effectiveness of each service by analysing who accesses them and the outcomes achieved.

Part 4: The Board of Trustees commitment to quality

Charlotte Parry-Jones, Parent Carer Trustee



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.

Demelza's Trustees continue to provide scrutiny and professional challenge and take their governance responsibilities seriously. Demelza's Clinical Governance Committee is attended by representatives from the clinical leadership team, is chaired by a former lead clinician from the Health Service Ombudsman office and supported by a parent carer Trustee and three clinical Trustees, including a paediatrician, a pharmacist and senior nurse. The parent carer trustee has been invaluable in providing the team with a new dimension and viewpoint from a parent/carer perspective. All Trustees are briefed on clinical priorities and challenges at every board meeting by the Chair of the Clinical Governance Committee. The Trustee board meeting opens with a patient story to set the context for the meeting to remind everyone about the focus of the work we do.

Safeguarding continues to be a high priority and is embedding in practice across the organisation to ensure that safeguarding is everyone's business and that the voice of the child is heard.

The new medicines management assurance committee ensures that we reflect on current practice, learn from medication incidents and near misses, identify current themes and learning to ensure safe practice, encouraging an open and transparent learning culture.

The clinical services teams have responded well to the COVID-19 pandemic ensuring that services have been responsive to meet the needs of children and their families and continued to be provided in a safe and effective way.

The clinical capacity at Director level has been increased and a new role, the Director of Quality Improvement and Clinical Governance, has been established to support and work closely with the Director of Clinical Services to ensure clinical services continue to develop in a safe effective way.

Trustees were actively involved and participated in the 'Whose shoes' consultation workshops to ensure that service users were able to be involved in developing the next five year strategy. Trustees look forward to the implementation of the business plans supporting the strategy, in particular the workforce strategy which will ensure that Demelza has appropriately trained staff to provide responsive palliative care services to children and families on the caseload as well as ensuring we are able to reach more children and families.

We are confident that the clinical services provided by Demelza are of the highest quality, detailing continuous improvement whilst ensuring that services are responsive, cost effective and sustainable.

Part 5: Statements of assurance



Part 5: Statements of assurance

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

Review of services

Demelza continues to work closely with partners, including NHS Tertiary Centres, District General Hospitals, local adult hospices, community nursing and therapy teams, NHS England, CCGs and local authorities to collaborate and focus support where it would be most beneficial.

Collaborating with other providers

Demelza works collaboratively with other providers to ensure that palliative care can be delivered to children and their families.

Participation in national audits

In 2021/2022 there were no national audits or enquiries relating specifically to specialist children's palliative care.

Local clinical audits

There is an annual audit plan in place which is updated to review and monitor any changes to new or updated policies and procedures. Audit results are disseminated to the Nursing and Care Team at team meetings, reported in the quarterly Clinical Governance newsletter and reported to the quarterly Clinical Governance Committee. The newly appointed Practice Development Nurses on all three sites are instrumental in the roll out of these plans and support of the audits taking place.

Infection prevention and control (IPC)

- New policy on managing respiratory conditions, including COVID-19 to be written for ongoing guidance of all respiratory conditions.
- Review all policies/procedures and streamline into one document.
- Training on donning and doffing of Personal Protective Equipment (PPE) added to yearly update.
- Link Infection Prevention and Control roles identified across all three sites.
- Clinical mandatory training to be carried out face to face.

Medicines and Health Care products Regulatory Agency (MHRA) and patient safety alerts

The Clinical Governance team subscribe to the MHRA and patient safety alerts, keeping an accurate spreadsheet of those affecting the children and families and the organisation. Out of 100 alerts, 21 were shared with teams and actioned where necessary within Demelza to ensure safe practice for children and families using our service.

In 2021/2022 Demelza supported the following external research requests:

- NIHR Research: End of Life care of babies, children and young people.
- PhD Research: Quality of Life, Bristol.
- Perinatal Palliative Care Research.
- University of Korea student looking at palliative care in the United Kingdom as a place of excellence.
- Representation at Joint Research Group, Together for Short Lives.
- Attendance at webinar held by Martin House and Together for Short Lives.
- Research into MARS charts by Martin House MSc student.

Part 6: What others say about us



Part 6: What others say about us

Care Quality Commission (CQC):

The Care Quality Commission carry out monthly reviews of the data available to them about Demelza in Kent and South East London. They report that they have not found evidence that they need to carry out an inspection or reassess our rating at this stage. This could change at any time if we receive new information. We will continue to monitor data about this service. Demelza, East Sussex is due to be inspected imminently.

Referrers

"Demelza offers support to many of our patients. This can take the form of short breaks, support with symptom management, family support and therapies and end of life care both in the hospice and in children's homes across the region. This offers families meaningful and supported choice at challenging moments of their children's lives which families regularly tell us is extremely important to them. Our team and the families we care for recognise the importance of this service and the skills and dedication of the team that work hard to provide it."

Consultant in Paediatric Palliative Medicine

Data quality

In 2021/2022 Demelza collected and submitted data in respect of the following:

- Care Quality Commission for child death data and reports of significant events/investigations.
- Quarterly Clinical Governance and Quality reports to the Clinical Governance Committee.
- Quarterly Safeguarding Assurance reports to the Safeguarding Assurance Committee.
- All relevant information to the quarterly Board of Trustee's meeting.
- Annual data and accounts information to Together for Short Lives.
- Data provided to the Child Death Overview Panel.

Areas for further improvement

Despite no external quality visits during 2021/2022, we are committed to striving for continuous learning and improvement.

Part 7: Service Data



Part 7: Service data

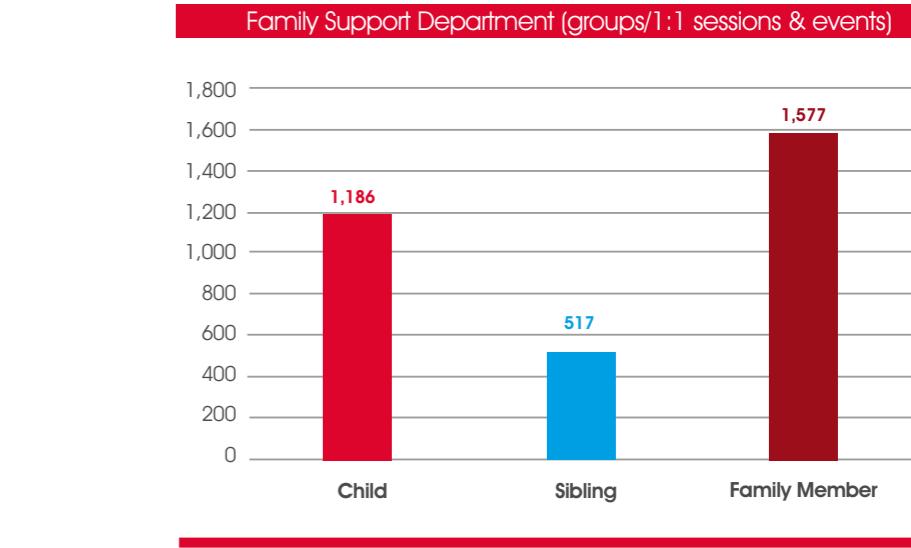
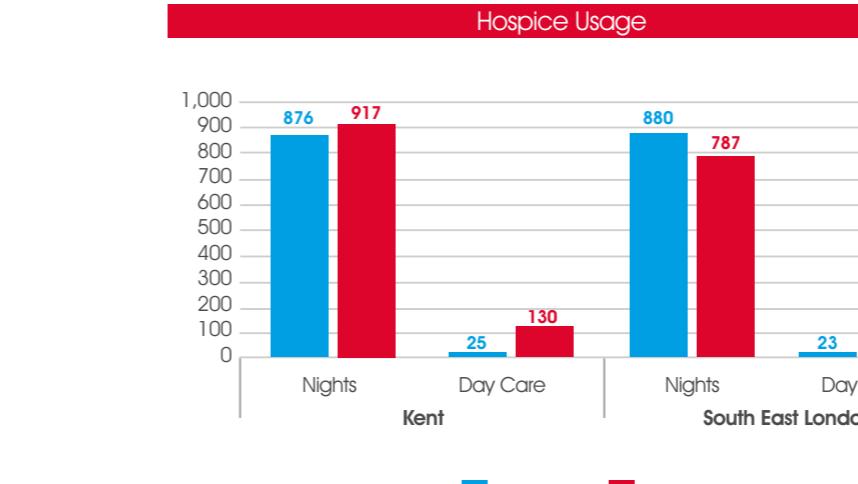
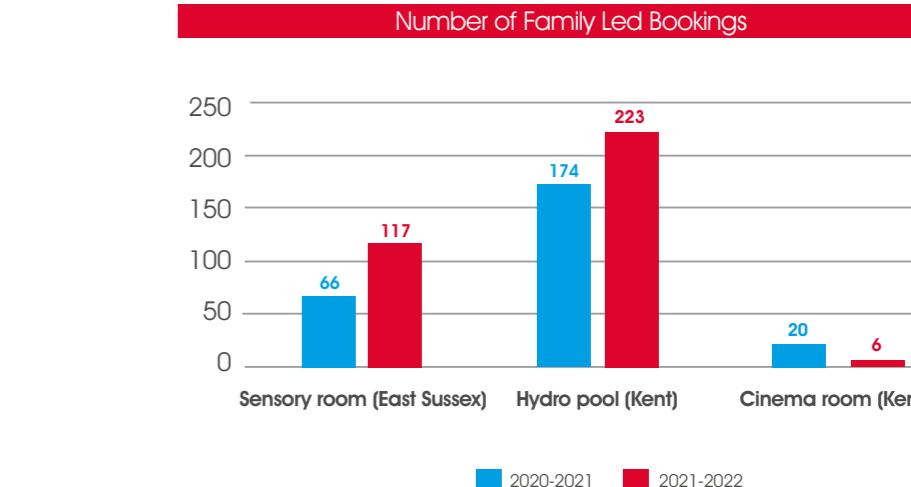
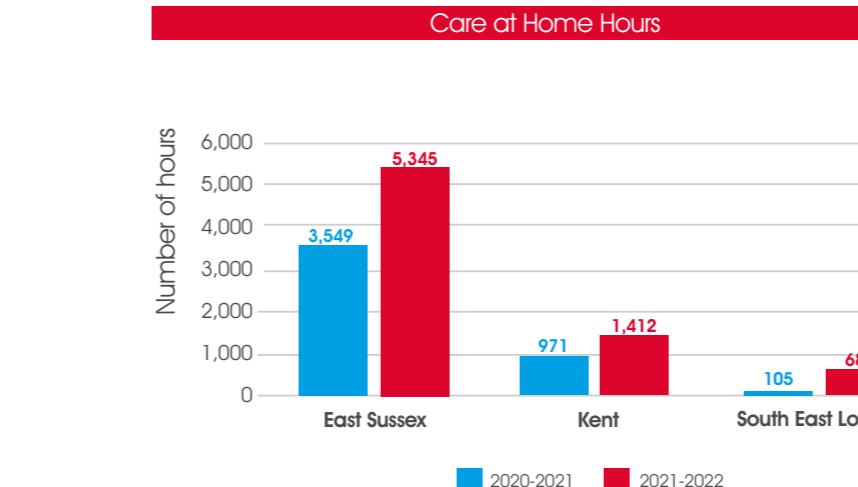
Activity Report

Clinical key performance indicators are reported to the Clinical Governance Committee quarterly outlining the following data:

- 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.
- CQC death notifications.
- Bereavement suite usage.
- Family liaison contacts.
- Bereavement support and therapies sessions provided.
- Family events and virtual group session attendance.
- Training compliance figures.

An important aspect of this data is the number of unique children and families reached. This enables us to examine the equity of the service and ensures that we strive to reach the maximum possible number of different children and families.

The comparisons of data from 2020/2021 to 2021/2022 shows an increase in hospice residential and day care and care at home across all areas except overnight hospice stays in the South East London hospice and cinema bookings at the Kent hospice. The reasons for the decreases are that in the South East London Hospice there was a child on a long term residential placement who was discharged and the cinema bookings decreased as lockdown restrictions eased in the community.

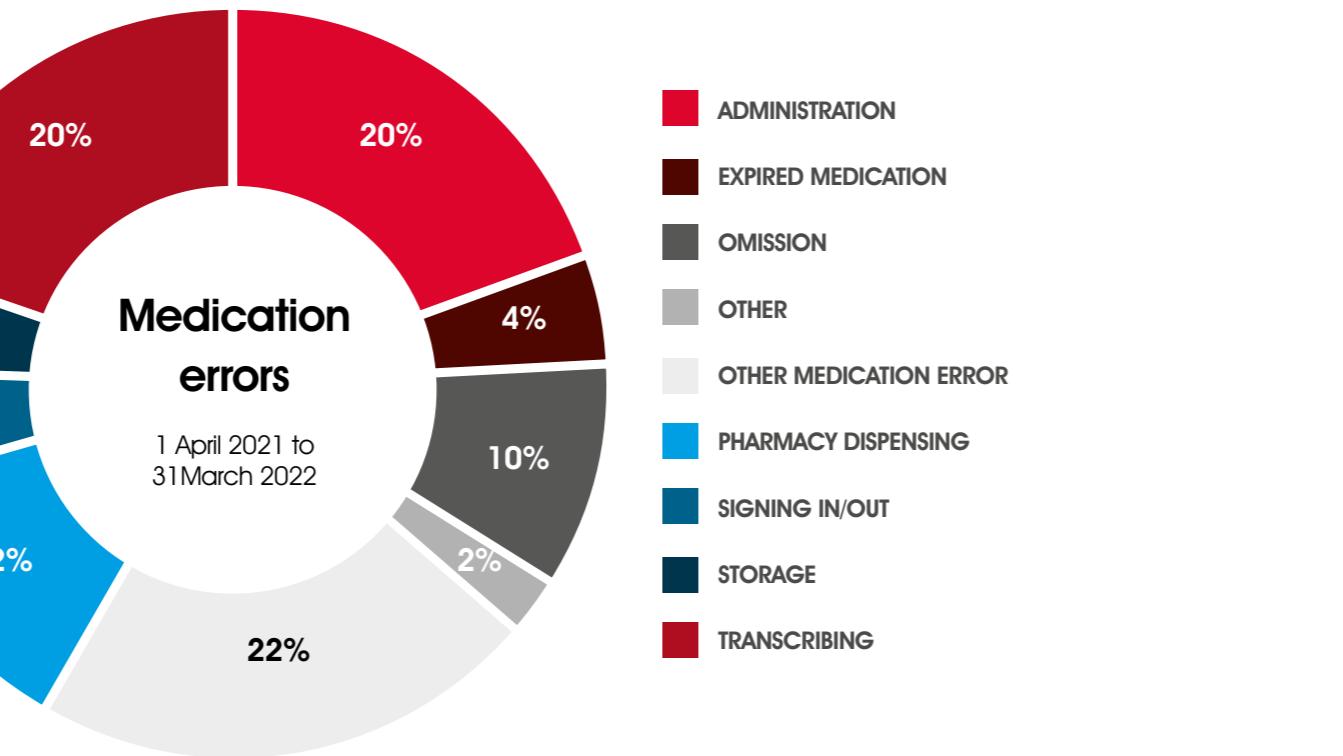


Incidents, accidents, complaints and compliments
Incidents affecting clinical areas are monitored and managed by the Clinical Governance team with clear pathways to upload onto the risk register if required and targeted work aiming to achieve the 31-day turnaround benchmark for incident approval.

Medicine incidents have reduced, coinciding with the implementation of the new electronic drug chart and focused education programme. Injury related incidents are often associated with behaviour and therefore a new bespoke behaviour management study day is being delivered by one of our Learning Disabilities Registered nurses to empower staff to effectively support children and manage behaviour. Collaborative multidisciplinary team (MDT) discussions are held to plan ahead for future admissions.

Compliments received from children, families and external stakeholders including local authorities and health care professionals, are recorded on Datix and personal feedback given to individuals or teams complimented.

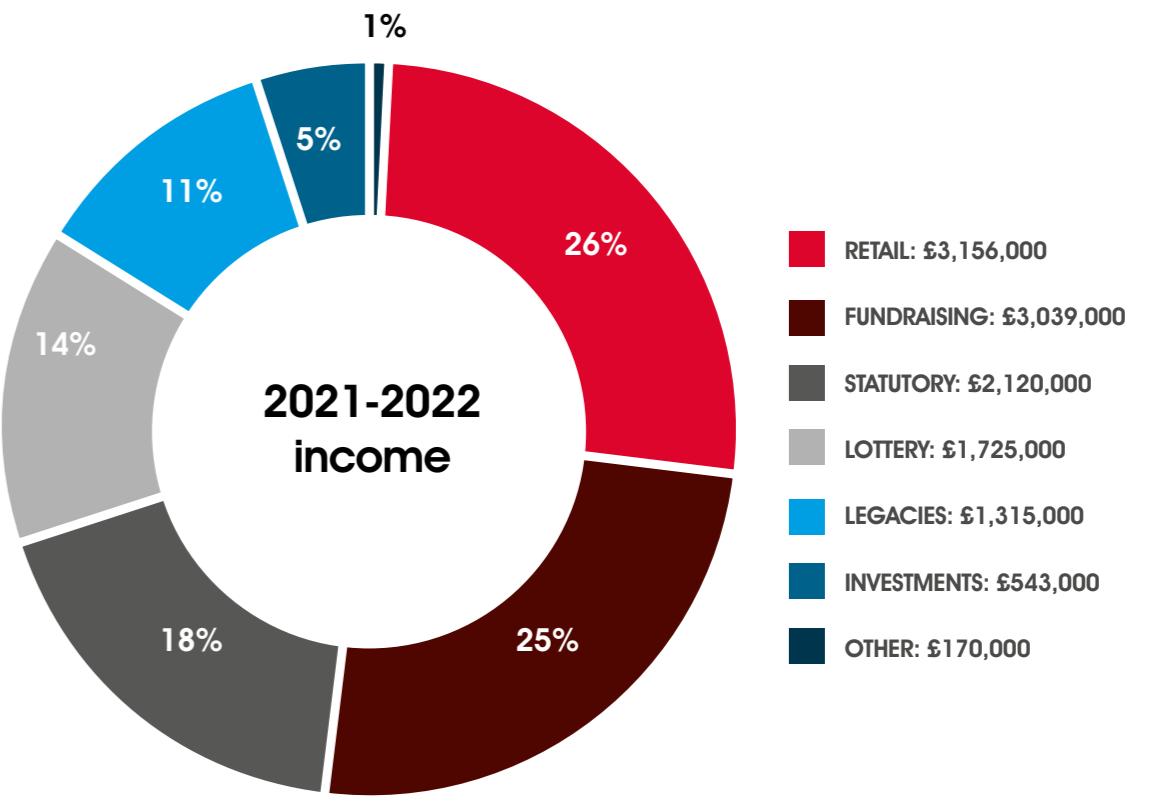
Duty of Candour
Demelza continue to follow duty of candour processes for all incidents involving children, young people and family members.



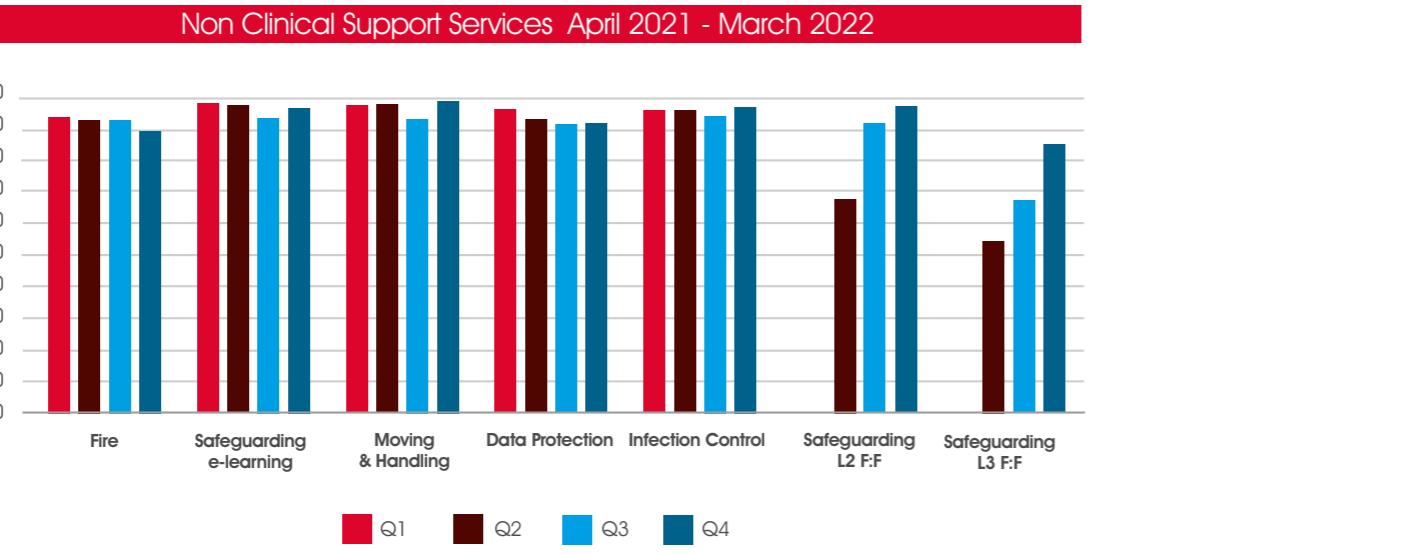
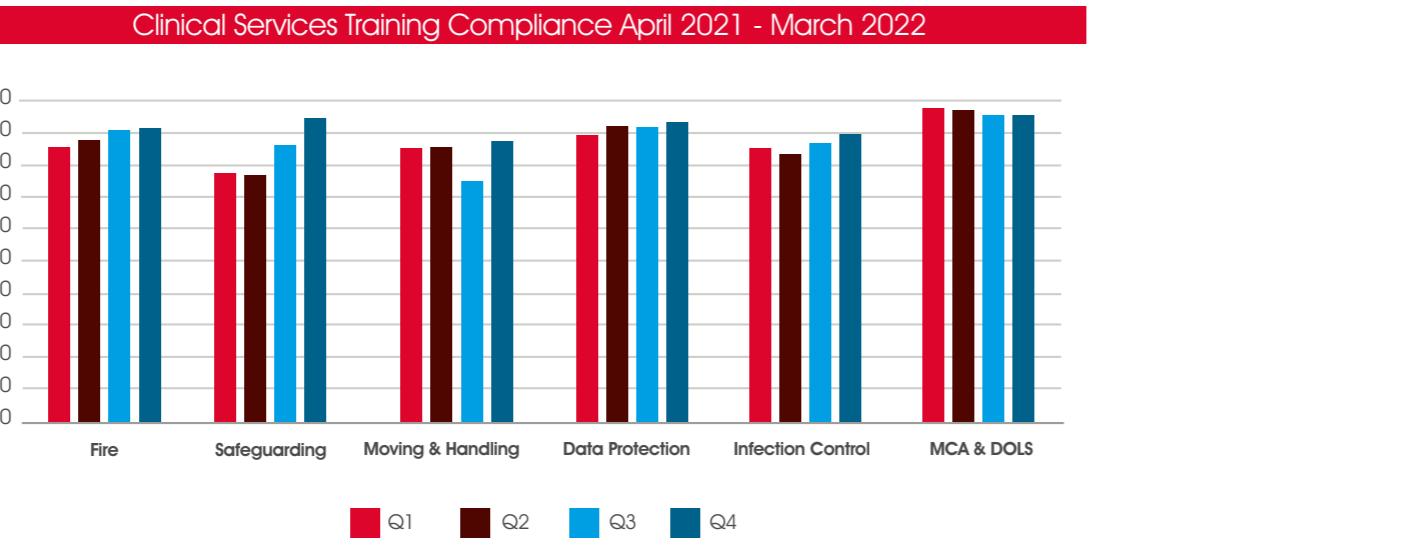
Finance and sustainability
Demelza Hospice Care for Children is in a strong financial position. We received two large legacies over the last five years totalling £7.5m which have contributed to free reserves of £15.3m while the annual running costs were £12.3m. Our policy is to hold 12 months of running costs in reserve, so at March 2022, we held an additional three months in free reserves above our policy. Over the five year strategy we plan to use these additional reserves to strengthen and develop our services. Meanwhile we plan to build capacity to our support services.

Our income is well diversified. In 21-22 we received 94% of our income from five main areas as shown. We plan to develop each of these forms of fundraising in order to fund the increased services and to achieve break-even budgets by the end of the five year strategy.

The Trustees are aware of the volatility in the UK and world economy at the start of 2022. They are committed to the five year strategy, but will review quarterly financial results carefully. If necessary, we will adapt plans to ensure the financial sustainability of the charity.



Training compliance



Equality, diversity and inclusion

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

Everyone at Demelza is of equal value and we strive to continually improve our approach to diversity, inclusion and equality of opportunity to ensure that:

- Our care and support can be improved for people from all cultures, those with faiths, beliefs and religions and those without.
- All people feel welcome and comfortable when receiving care or support from Demelza.
- We have a diverse employee and volunteer team that benefits from the innovation and richness of diversity.
- We are contributing to making a fairer society by tackling prejudice and privilege.

We will proactively seek to identify and remove prejudice and discriminatory practices. Our aim is that we will treat each other with respect and no one will be disadvantaged by conditions, requirements or practices that cannot be shown to be just and fair. Anyone who feels that Demelza's services, recruitment, employment or volunteering practices do not uphold this statement has a responsibility to raise the matter with the relevant department director.

Safeguarding:

We have continued to strengthen our safeguarding policies, procedures and training and we are maintaining positive and effective links with our external partners. The quarterly Safeguarding Assurance Committee meeting is well established and has positive engagement from all departments across Demelza. We have, and will continue to improve the measures we already have in place to provide further assurances that children's safety is our priority.







Demelza

Hospice Care for Children

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

Registered Charity Number: 1039651