



demelza

Quality Account 2022/23



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Part 1 – Statement of quality by the CEO

I am very happy to report Demelza's Quality Account for the year 2022/23. This report was prepared by our director of quality improvement and clinical governance with input and support from across the organisation and has been read and approved as accurate by me and by our Board of Trustees.

We are one year into our five-year strategy and have made significant progress against our strategic objectives. Like most providers of clinical care, we have faced challenges pertaining to nurse shortages. To mitigate this, we have made efforts to grow our team of nurses without compromising the quality and expertise of our clinical team and those efforts continue into the coming year. We have also grown our provision of community nursing, which allows greater choice in where children can receive the care they need.

Our staff – clinical and non clinical – hold a great deal of experience and expertise. We have sought to share our knowledge in a way that demonstrates our proficiency and support development of existing and future health and social care professionals with a series of hosted Professionals' Study Days and seminars delivered to students of nursing and other associated student professionals.

Our caseload has grown significantly this year. Our referral data indicates that this is largely a direct result of our In-Reach programme. This is a dual model which dovetails our family liaison practitioners offering advice both to families and professionals in hospitals and palliative care nurses working shifts on paediatric wards alongside NHS nurses and other healthcare professionals.

We strive to provide extraordinary care to extraordinary children. We feel that alongside quantitative data, the best way to measure our success is by seeking

feedback directly from the families who use our services. We have included quotes, testimonials and case studies in this account to showcase the extraordinary care we provide.

Children are living longer with increasingly complex medical and social needs. We know that we could improve our provision of services by extending the breadth of our support to those already on our caseload. Last year we launched a Transition pathway and in the coming year, we will develop this service which prepares young people for adult services. We will collaborate with other experts and providers across the sector to best meet the needs identified by the young people themselves.

We will always look for new ways to support those who need our services and will endeavour to attract more people to join our greatest asset – the employees and volunteers at Demelza.

I believe that this Quality Account is an accurate synopsis of the quality of care provided by Demelza and am happy to be able to demonstrate how we, as a charity that also receives some limited statutory funding, delivers care that complements NHS services.

Lavinia Jarrett
Chief Executive Officer



Part 2

Review of quality performance in 2022/23



2.1 What we achieved

During this first year of our strategy, we extended our reach by increasing the number of referrals received and accepted, and thus our caseload grew month-on-month. We have incorporated the voice of children and their families in our decision-making to provide a quality service effectively. We were more responsive to the needs of the children and families we support and grew the provision of care in community settings. We increased the number of staff dedicated to engaging with families by developing and appointing roles in both the marketing and family liaison departments. We also made appointments in both the organisation's marketing and service development areas dedicated to collaborative working with Managed Clinical Networks, the Integrated Care Boards in our areas and other health and social care professionals.

The most significant change we made was to rebrand Demelza. Every element of the brand was open to discussion, including the name of the organisation, and an external agency was commissioned to engage with stakeholders including staff, volunteers, families, retail customers, health and social care professionals and the family who founded us 25 years ago in memory of Demelza Phillips. The objective was to provide Demelza with a stronger and more consistent visual presence – including digitally – that would help us to support more families, expand our service capacity, attract a higher number of care staff with the right qualifications and experience and sustain our income, all in line with our strategic objectives. The result, based on research data with these key stakeholders, was that we retained the name 'Demelza' but removed

the word 'hospice' from all of our branding in order to help us break down the misconceptions of children's hospice care that have prevented us from gaining more referrals and care staff in the past. A cleaner, digital-friendly branding alongside a new tone of voice will allow us to do this more efficiently and effectively as we advance.

During the final quarter of 2022/23 we commissioned a mock CQC inspection with the aim of ensuring that we maintain or increase our CQC rating to 'Outstanding'. The feedback report was extremely positive, citing multiple areas where Demelza operates 'above and beyond' expectations and includes numerous examples of excellent practice:



We saw many examples of outstanding service provision including an outstanding commitment to providing a caring and safe service, outstanding leadership and excellent responsive and effective services across all 3 locations (Kent, East Sussex and South East London)

2.2 Looking back – patient safety

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

As a priority, this objective was realised by investment in staff at the Director level. The newly-appointed director of clinical services works in collaboration with the newly-created director of clinical governance and quality role, who leads on all opportunities to develop quality in our care provision including patient safety.

Successes include:

- The implementation of monthly risk management meetings to discuss emerging risks, manage existing risks and work together on resolutions during and after incidents. There is good engagement with representatives from the nursing and care, family support, service development and clinical governance teams
- The presentation of quarterly Clinical Governance Committee papers includes a Clinical Risk Register summary analysis report
- The Mock CQC report stated that:
 - ‘There is a good risk register in place, that is notably better than many similar services, care risks are especially well captured, logged and monitored and there is a clearly documented process for staff to nominate new risks for addition to the register’
 - ‘The senior leadership team, chair and trustees demonstrated a detailed understanding of the current main risks to the organisation and their services’
 - ‘Staff reported that they felt the management team responded well to risks and safety concerns’

Priority 2: Workforce strategy:

At Demelza, we understand that we are our people. With the right people in our nursing and care teams, we will enable our organisation to be well-led in all respects. We will ensure we meet the ambitions and aspirations to support children and their families through our staff’s appointment, retention and development. We can only safely increase the number of children in our care by exponentially growing the number and expertise of, those at Demelza who deliver that care.

Successes include:

- Establishing a career pathway from healthcare assistant to nursing associate via an apprenticeship programme. Two nursing associates have completed this training and are now in post, one in Kent and one in East Sussex
- Signed off on a nurse degree apprenticeship programme, in collaboration with an acute trust and an educational provider, for delivery starting in January 2024
- Increase in student placements to increase knowledge around hospice care career pathways
- Development of nursing through masters’ pathways and NHS Leadership Programmes – such as the Mary Seacole award, achieved by two of our lead nurses
- Launched our Wellbeing Strategy which details how we will invest in our Wellbeing Programme to support and develop our workforce and embed our commitment to our people. The wellbeing of our care staff is critical to patient safety

2.3 Looking back – clinical effectiveness

Priority 1: Grow collaborative partnerships

We have committed to developing all of our services in line with the changing needs of the children and families for whom we care and have made progress over the last year.

Successes include:

- The pandemic paused the work of the Kent & Medway Managed Clinical Network, so we have helped to revive it during 2022/23, and our deputy director of nursing and care jointly chairs the group alongside the lead nurse from Kent Community Health Foundation Trust. We co-chair quarterly meetings, bringing together professionals from across primary, secondary and tertiary services to agree on joint working protocols that enhance choice and clinical safety for children requiring palliative care across Kent and Medway. In addition, the same deputy director of nursing and care is leading a shared clinical governance framework that will establish a means of working together across organisational boundaries to provide clinical care to children at the end of life in their own homes
- We have strengthened our collaborative efforts with the five other children’s hospices with whom we make up Children’s Hospices across London (ChAL) who work together in committees of Clinical, Service Development, Strategic Planning and CEO. During 2022/23 a subcommittee was formed in order to dedicate expertise to developing shared clinical competencies, thereby enhancing clinical governance oversight which reduces the workload for partners, allows transferrable skills for clinical staff to relocate and thus makes each ChAL member organisation more clinically effective. One of our Practice Development Nurses sits on this subcommittee.

- The South East Oversight Group utilises a co-design project team approach to deliver Palliative and End of Life Care (PEoLC) Services. The group utilises collaboration to deliver programmes including service development, education, and clinical care delivery, focusing on the national priorities – access, quality, and sustainability. Our deputy director of nursing and care was an active partner during 2022/23 and continues in this role.

- Demelza has worked collaboratively with Maidstone and Tunbridge Wells Hospitals and during the reporting period established an honorary contract for a Demelza nurse to work one day a week within the Trust. This post supports the identification of children who meet Demelza criteria for referral when they access acute services, supports existing service users throughout acute admissions and supports early discharge. Additionally, Demelza can educate and support acute staff on the care of children with complex health and palliative care needs to develop confidence and skills to improve experiences for children and their families.

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

During 2022/23, we adapted our family support services to facilitate greater choice in how and where they can engage with us. For transition, bereavement, physical therapy and creative therapy services, most families can engage either virtually or face-to-face, in a community setting or at one of our sites, individually or in a group and at organised events.

Transition:

- Counsellors and transition navigators have been recruited, with specialist skills in Welfare and Digital and a counselling space at the Kent hospice site has been established
- Established a transition caseload, with family support services available only from 18 years up to 25th birthday. The first dedicated transition event was launched accompanied by the new transition framework, which defines the transition offer

Bereavement:

- We amended our referral process to accommodate post-death referrals for those children who would have met our eligibility criteria
- We appreciate the value of peer-to-peer support for bereaved parents and hosted a bespoke Baby Loss Remembrance event

Creative Therapy:

- During 2022/23, we developed the service to include dance and movement therapy, reflexology, baby massage and choir
- We also expanded our location-based service by delivering creative therapies as a Hospital In-Reach offer

Physical Therapy:

- We embedded this service by incorporating referrals specifically for physical therapy into our care database, traditionally used solely for clinical referrals. This allows us to monitor and categorise the types of service users relative to the therapies received, thereby strengthening the model by offering insight with which we can make earlier interventions where this service could be of benefit to a child on our caseload.
- We launched an aquatic therapy service
- We submitted a successful business case, securing funding for a speech and language therapist to start this year



Jake is 15 years old, and he wants to be like any other teenager. However, when he was 10, he was diagnosed with Friedreich's ataxia – a degenerative and life-limiting muscle-wasting disease. He walked into Great Ormond Street Hospital to have corrective surgery for scoliosis, but due to the diagnosis of ataxia shortly after his surgery, it became clear that he would never walk properly again.

We first heard about Demelza's transition services at their transition event. This was for families like ours to meet with the Demelza team, as well as other charities and services in our local area, to help us understand what will support be available when Jake turns 16 and begins the transition to adult services. It was really helpful to chat with everyone and understand what our options will be.

Jake already has a good relationship with Paul, one of Demelza's Transition Navigators; Paul phones him once every two weeks for half an hour and that time is totally his. Jake can have a rant about

what's bothering him, or just a catch-up about what's going on, and Paul listens and gives him an outlet for whatever he might be feeling that he doesn't want to tell me or Craig, his dad.

Claire, another Demelza Transition Navigator, has also put our minds at ease about finances when Jake turns 18. It's a big relief that she'll be able to sit down and fill out the forms with us; it sounds silly but form-filling is really stressful and we want to make sure Jake gets everything he's entitled to. It would be wonderful to think Jake could go out and get a job as an adult but the reality is that it might not be possible for him to work, so having that assurance that he'll be financially supported whatever happens is really important to us.

It's just great to know we have that Demelza team to rely on going forward – you get used to people, and knowing that they'll still be there for us after Jake turns 18 and transitions out of Demelza's clinical care is a real comfort."

Sarah, mum to Jake

2.4 Looking back – patient experience

Priority 1: Involve service users in decision making

At Demelza, we commit to offering a service that is better, and reaches more families, than ever before. In order to develop our services, we involve a number of stakeholders in our decision making and engaging with the children and families who use our service means that we do not speak for them, they speak for themselves.

- Created and appointed a new role; children and young people engagement officer
- Created and appointed a new role; engagement coordinator
- Implemented ‘Super Saturday’ sessions at which we can gather children’s feedback on our offer in a fun and relaxed environment
- Ensure service users are present at ‘Extraordinary Conversations’ – these are round table stakeholder discussions that form the basis for insight-based decision making
- Continued ‘Families’ Voice’ parent carer forum with additional support to link this group with ‘Demelza’s Young Voices’ children’s forum and peer groups such as Demelza Dads



There is an outstanding family, children, and young people engagement service run by committed leads.

Some examples of how we involved service users in making important decisions during 2022/23:

- Transition service development roundtable
- Short breaks discussion roundtable
- 25th anniversary family events steering group
- ‘The Family App’ working group
- Hill Farm facility purpose scoping group
- ‘Moving bereavement services forward’ roundtable conversations
- Rebrand Advisory Group
- Recruitment panels for director and CEO roles
- Parent Carer Forum (The Families’ Voice) development



They (cupboards next to the bed) are filled with oxygen tubes and nappies. As a teen, I want somewhere to store my phone and personal items next to me

The clinical team now ensures that there is appropriate space for young people’s belongings during their short break stay to meet their requests.



Why do we get an email every time our child’s picture is used, we already said that we give permission, we get too many emails from Demelza

The marketing and communications team has amended the consent policy and forms to allow parents to choose the regularity of notifications for photos being used.

Priority 2: Digital transformation

During 2021/22 we identified that we would be better placed to make earlier interventions for children and their families to benefit from a broader range of services, if we were able to track their journeys more effectively. As a byproduct of digital transformation, we are increasingly able to demonstrate evidence of our quality.

- New document control process in place, replacing Quality Management System for all policies, procedures and supporting documents
- Steering group established to provide governance to the management of documents across the whole organisation
- New incident management system identified and procured with an implementation date of June 2023. The new system has the option to increase modules such as to manage risk, policies and procedures in the future
- Completed a full review and tender of the clinical/patient management database to ensure that we can effectively manage clinical data and caseload.

- Enhanced audit function within the clinical database to put in place safeguards and create an audit trail on data

- Full review of document control policies and systems – accessible system, supports staff training and information sharing and keeping information up to date

- Completed full review and tendering for new incident management system to ensure effective management of incidents and complaints

- New KPI management reporting and information to allow for data analysis across statistical processing controls

- Engagement of the workforce, listening to feedback and acting on it:
 - Migration to Cascade Payroll
 - Migration to a new electronic expenses system to support easier and more timely claiming and payment of expenses
 - Digital training for all staff with the recruitment of a new digital solutions trainer to upskill the clinical workforce and provide bespoke training support.
 - Introduction of a new Clinical Database Steering Group with representation from across Demelza to ensure system functionality is maximised and engagement and system knowledge increased.

- Review of individual systems applying single sign on where systems permit, to allow for ease of access and increased security.

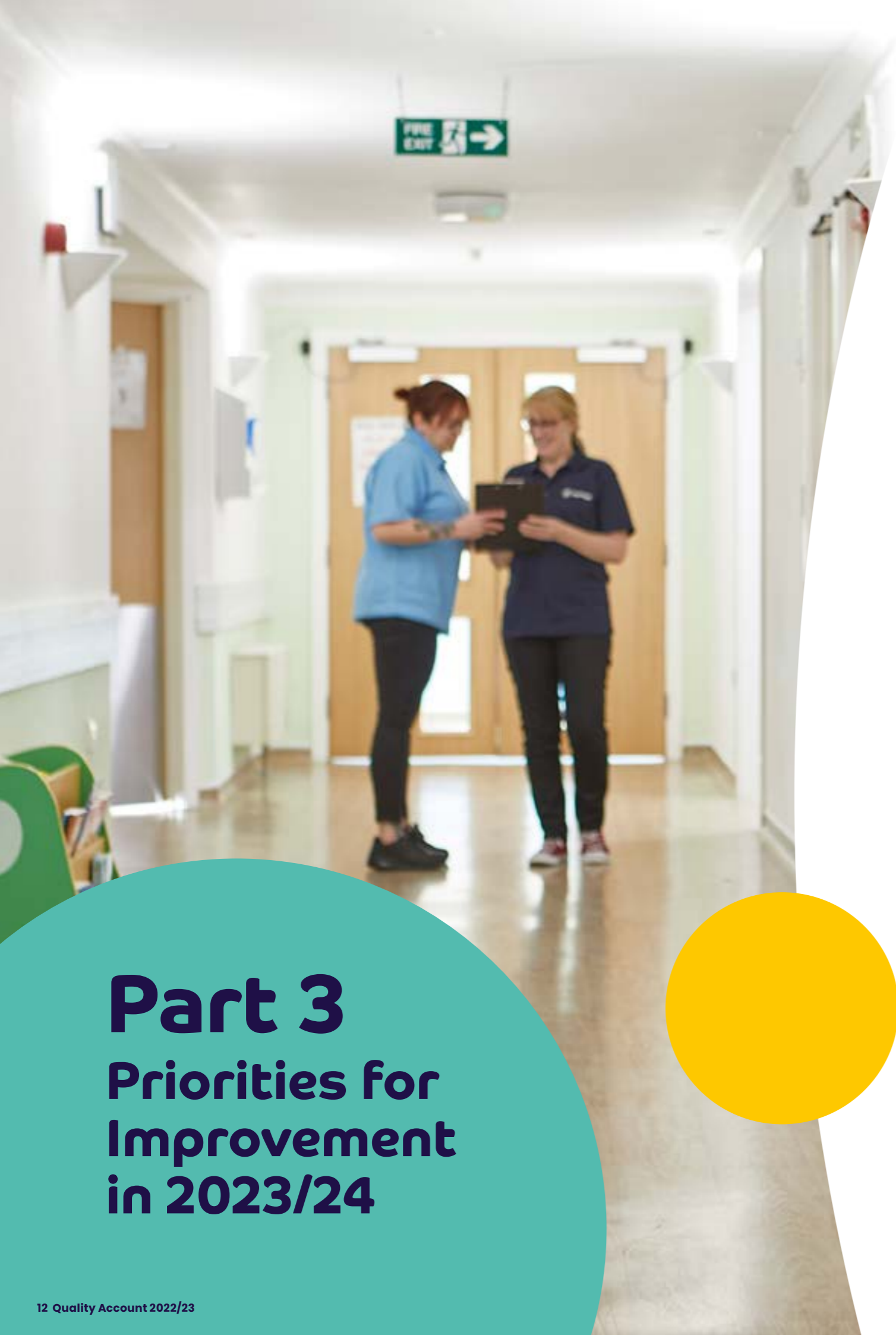
- New IT infrastructure rolled out across office sites, to allow for consistent user experience across devices and to enhance hybrid working.

Priority 3: Equality, Diversity and Inclusion

We have partnered with the National Centre for Diversity, working towards an objective to achieve Investors in Diversity accreditation. We have established a FREDIE steering group which adds Fairness, Respect and Engagement to Equality, Diversity and Inclusion.

- Captured feedback from service users, staff, volunteers and external stakeholders via FREDIE surveys to provide a baseline with which we identified areas for improvement

- Work continues into 2023/24 using the groundwork from last year to drive our planning and actions



Part 3

Priorities for Improvement in 2023/24

3.1 – Key priorities for improvement

- Lead the way for the creation of a South East London Managed Clinical Network. This will link health professionals and organisations from primary, secondary and tertiary care to ensure high quality, coordinated care focussing on choice and dissolving organisational and professional boundaries
- Replicate our successful Maidstone and Tunbridge Wells nursing In-reach model at other sites across South East London and East Sussex. This will increase awareness and understanding of our services, ensure that families who may be eligible for Demelza services are provided with timely and accurate information about what we can offer, enhance professional networking, and allow Demelza nurses and acute care colleagues to share clinical expertise
- Increase access to perinatal and neonatal multi-disciplinary team meetings across the areas Demelza covers to offer support and advice and to increase awareness of our services to gain a greater number of referrals earlier
- Further expand community teams in Kent and South East London, informed by the significant expertise already in place within our East Sussex community team. This will enhance our ability to be responsive to children and families' choice of place of care and death
- Review how short breaks are offered and booked to ensure that we are offering the most equitable and transparent service whilst protecting our ability to respond and prioritise end-of-life and urgent care
- Ensure nursing and care staff have a palliative care career pathway, with opportunity for appropriate progression aligned to their role that acknowledges and respects their expertise and commitment, whilst attracting high calibre new team members

- Demelza has invested time to train four professional nurse advocates in 2022/23. Through 2023/2034 we will embed these individuals within their roles and train an additional three professional nurse advocates to cover all our locations. Professional nurse advocacy is a supportive model of restorative supervision that reduces burnout, moral distress and compassionate fatigue. Through listening and understanding, professional nurse advocates can deliver quality improvement initiatives to improve staff wellbeing which will have a positive impact on the quality of services delivered

3.2 Future planning – patient safety

- Engagement with NHS to access clinical records across the geographical areas that Demelza supports to enhance and support patient records and timely access to key medical information for babies, children and young people
- Review of document management and security, to ensure safe ease of access and sharing of information
- Implementation and training of new Vantage Incident Management System
- Continued focus on our Clinical Database ensuring functionality and engagement is enhanced
- LFPSE (Learning from Patient Safety Events) and PSIRF (Patient Safety Incident Response Framework) which support the key principles of a patient safety culture, focusing on how incidents happen rather than apportioning blame; allowing for more effective learning, and ultimately safer care for patients. Action plan being devised. Collaborating with ICBs and hospices to implement a framework. Investigator training for key staff

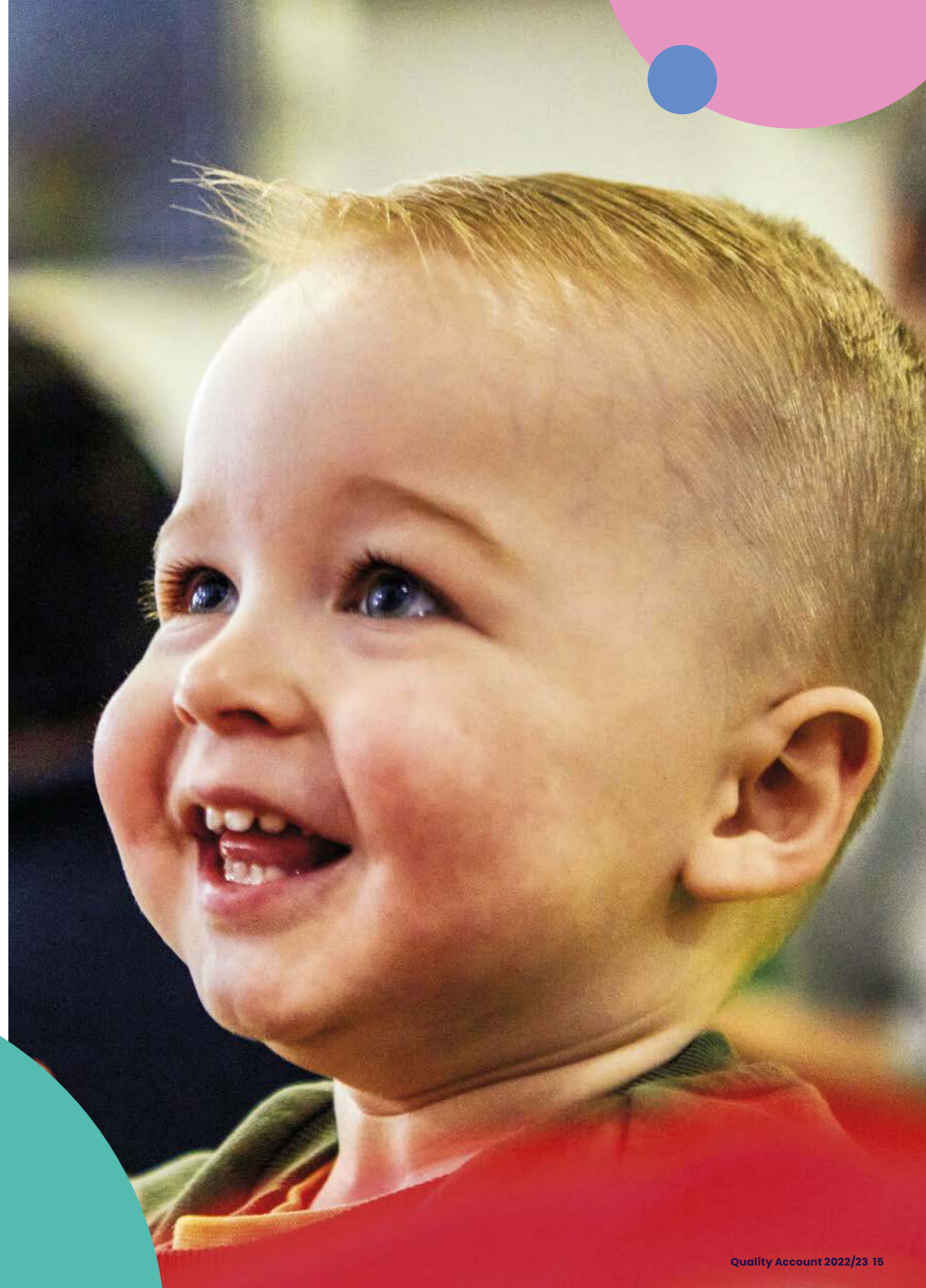
3.3 Future planning – clinical effectiveness

- Implementation of a new recruitment system
- Embedding the new Vantage Incident Management System in collaboration with the business development team
- Complete recommendations from mock CQC inspection
- Recruitment of speech and language therapist and development of the role
- Recruitment of behaviour specialist and development of the role

3.4 Future planning – patient experience

- Explore how data could be collected on the demographics of those providing feedback to categorise the experiences of all service users.
- Provide information on the variety of services available to families and how they can share their experience, feedback, ideas, and suggestions in a way that speaks to potential service users

- Develop regular use of feedback ‘action plan’ tool, with IT solutions to support accountability, reporting, and clearer identification of gaps, themes, and trends in feedback from service users
- Further develop the ‘Young Voices’ group to gain a more comprehensive insight into young service users’ perspectives
- Gain service user input from a large feedback survey on all family services during the summer of 2023
- Develop ‘15 steps challenge’ mystery shopper-style project to understand the service user experience in Demelza’s physical locations
- Support the ‘My Views Matter’ policy influencing project – our Transition team will collaborate with an external partner, challenging behaviours to make improvements to the service user experience
- Support the South East London Paediatric End of Life Care for Children and Young People Transition project



Part 4

The Board of Trustees' commitment to quality

Demelza Trustees take their governance responsibilities very seriously and the Clinical Governance Committee Chair reports to the Trust Board at each meeting.

A patient story is shared at every Trustee Board meeting to ensure that all Trustees fully appreciate Demelza's purpose. Six Trustees attend the Clinical Governance Committee, and it is currently chaired by a trustee who is a senior nurse, other Trustees include a nurse who also chairs the Safeguarding Assurance Committee who report to the Clinical Governance Committee, a community paediatric consultant, a pharmacist who also chairs the Strategy and Transformation Committee and a key trustee, a parent/carer of one of Demelza's young people. Her input to the committee is essential in order that we hear the voice of the child and family.

We are proud and conscious that Demelza runs a nurse-led service and we have oversight of an extensive clinical governance agenda. We encourage other trustees and staff across the organisation to attend and observe how scrutiny and professional challenge occurs. The agenda includes safeguarding, risk management, quality assurance reports, policy and procedure updates, Care Quality Commission engagement, learning from patient safety events, incident and complaints and compliments reporting, infection control, recruitment, training and development, and workforce strategy.

Staff wellbeing and family engagement are key items and we have discussed in detail the necessary work to be considered on the transition of the children on our caseload to adult services. Over 25% of Demelza's caseload now falls into this category and we are very aware of the anxiety that this can cause families who use our services.

We chose to undertake and commission a CQC mock inspection by two very experienced clinical professionals and after intense scrutiny, they reported 'many examples of outstanding service provision across all 3 locations'.

We strive to continually improve and although we have confidence in the highest quality detailing continuous improvement, we remain responsive and aware of the need for sound governance and cost-effective use of our resources.

Safeguarding has continued to remain a real focus with staff and volunteers across the whole of the organisation. The Safeguarding Assurance Committee, with representatives from across the organisation, meet quarterly and reports to the Clinical Governance Committee. There is a designated safeguarding trustee in line with the charity commission guidance as is our designated safeguarding role and named nurse. The teams are linked in with local safeguarding boards in all areas we provide services. We have a policy of mandatory safeguarding training, with good compliance across all parts of Demelza and we have continued developing all of our team's knowledge and confidence to ensure that we provide and support safeguarding awareness in all of our interactions with children and families. The voice of the child continues to be a priority in all that we do.

We are proud to be trustees at Demelza and proud of the commitment and hard work of Demelza's teams, both clinical and across the wider organisation.

Part 5

Statements of assurance



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

Review of services

Demelza delivers extraordinary care to extraordinary children who are facing serious or life-limiting conditions throughout Kent, South East London and East Sussex. We are here to support them and their families at every step – from first diagnosis and for as long as we're needed. Demelza supports over 2,500 children and their family members every year.

When we're needed most, Demelza is here. By their side when they feel isolated, helping to celebrate the joy in family life and making precious memories during challenging times.

Our support is as unique as every family, providing creative therapies, short breaks, practical and emotional support for families and siblings and care towards the end of life.

Our specialist nursing and care teams provide expert advice on complex symptoms and medication regimes and are here every day and every night, all year round.

Collaborating with other providers

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

Participation in national audits

There were no national audits or enquiries relating specifically to specialist children's palliative care during 2022/23.

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 at team meetings, reported in the quarterly Clinical Governance newsletter and reported to the quarterly Clinical Governance Committee meeting. The 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)

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

During 2022/23, there were no clinical outbreaks of COVID-19 or other illnesses at Demelza.

We have a programme of mandatory training for all staff which includes infection prevention and control. This is delivered face-to-face for all clinical staff and electronically for all other staff and volunteers every year. During the reporting period, we achieved over 85% compliance of attendance.

At our South East London site, water safety issues pertaining to the risk of pseudomonas and legionella were safely managed, resulting in the completion of relevant works.

Our annual Infection Control audit, which covers both clinical practice and physical environments across all of our sites, registered over 85% compliance.

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

Our Clinical Governance team subscribe to the MHRA and patient safety alerts, keeping an accurate spreadsheet of those affecting the children and families at Demelza. During 2022/23, we received 54 alerts, 22 of which were shared with our teams and actioned where necessary to ensure safe practice for children and families using our service.

In 2022/2023 Demelza supported the following external research requests:

The team at Demelza are supporting the Children's Palliative Care Outcome Scale Validation Study C-POS.

The project aims to help test a questionnaire developed for children and young people who are unwell and their parent carers. The questionnaire assesses their concerns and is intended to ensure that health professionals ask about and address the things that matter most to children and young people and their families.

Part 6

What others say about us



Care Quality Commission (CQC)

The Care Quality Commission carried out a Direct Monitoring Activity (DMA) Microsoft Teams call with the lead team in East Sussex in February 2023 and the Lead team in SEL in March 2023.

Following the meetings, the CQC confirmed that no further regulatory activity is required at this time.

The CQC has carried out reviews of the data available to them about Demelza in Kent. They report that they have yet to find evidence that they need to carry out an inspection or reassess our rating at this stage. This could change at any time if they receive new information and they will continue to monitor data about our services. Our site in East Sussex is still waiting for its first inspection.

Referrers and Commissioners

Some quotes from healthcare professionals who refer children and their families to Demelza:



Demelza has been a huge part of the support that we are able to offer families in the community, whether this is in the form of short breaks, therapy for children and their families or symptom management support and end of life care. Families and children alike are grateful for the Demelza service and everything that it offers"

Continuing Care Nurse



Demelza offers support to many of our patients. This can take the form of respite, support with symptom management, family support or end of life care (both in the hospice or in families homes across the region). This offers families meaningful and supported choice when they require it. The families we care for tell us how important this is to them."

Consultant in Paediatric Palliative Medicine



Demelza offer support to children and families across a number of regions. As a key member of our Managed Clinical Network, Demelza provides clinical leadership as well as support with strategic development. Demelza works closely alongside our other partners such as: hospice providers, community nursing teams, GPs, acute hospital trusts, and London Tertiary Hospitals, to ensure children and their families receive the best care possible."

Programme Manager – Children's Acute & Community Paediatrics

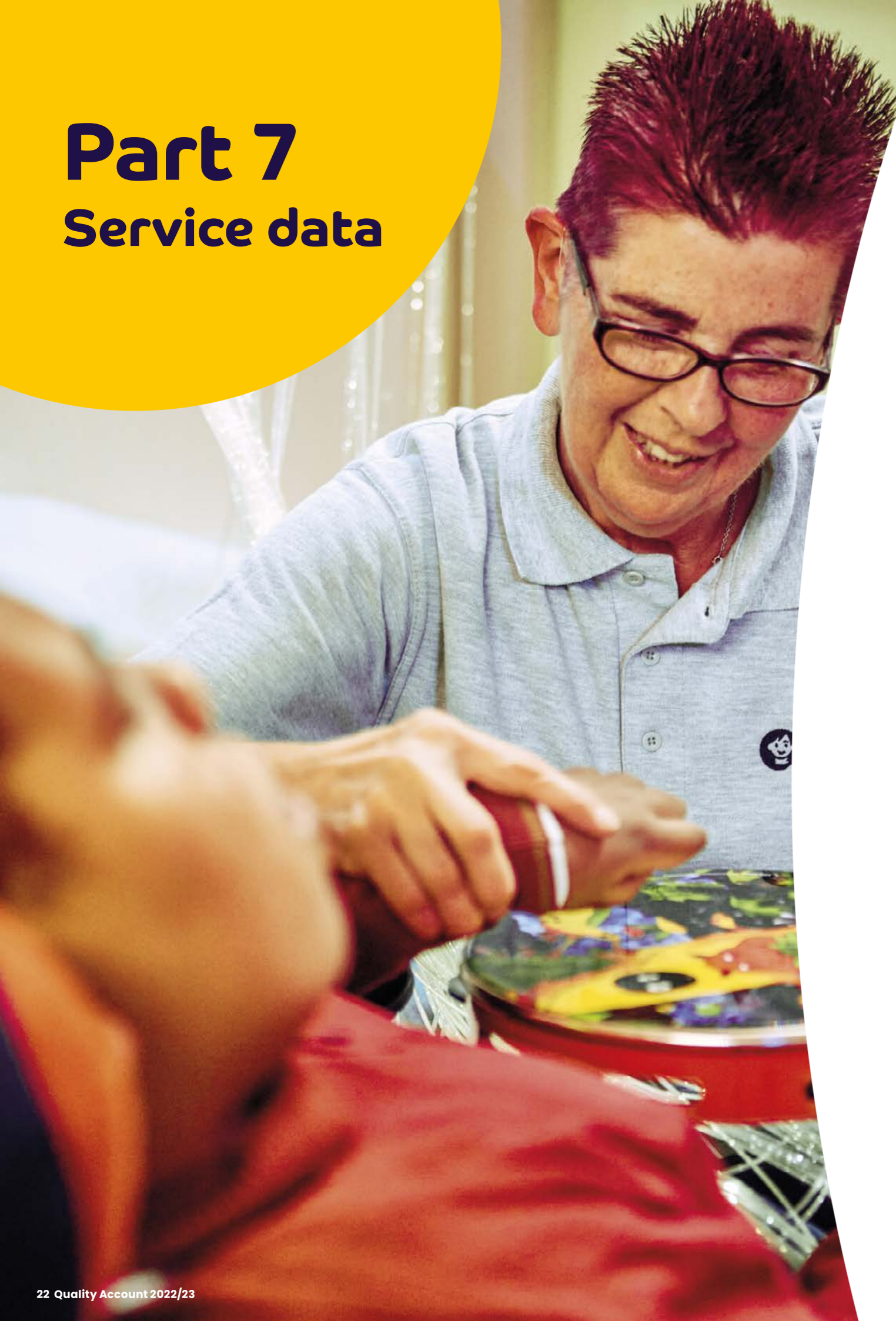
Data quality

In 2022/2023 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 Trustees meeting
- Annual data and accounts information to Together for Short Lives
- Data provided to the Child Death Overview Panel

Part 7

Service data



ACTIVITY REPORT

Community Care	East Sussex	Kent	South East London
Care at home hours	6,250	2,099	1,149
Financial year 2021/2022	5,345	1,412	680

Site Visits	Sensory/Garden/ Cooking (East Sussex)	Hydro pool (Kent)	Cinema Room (Kent)
Number of Family Led Bookings	36*	293	5
Financial year 2021/2022	117	223	6

*We believe not all sessions have been recorded on the database and we are working to improve this

Hospice Usage	Kent	South East London
Residential nights	944	657
Day Care bookings	161	77
Financial year 2021/2022 Residential nights	917	787
Financial year 2021/2022 Day Care bookings	130	53

Family Support Department	Child	Sibling	Family Member
FSD Event Attendance	260	378	674
FSD Therapeutic & Bereavement Group Attendance	585	61	720
Family Liaison Group Attendance	16	116	67
FSD Therapy Sessions	371	248	431
FY 2021/2022 FSD groups, 1:1 sessions & events	1,186	517	1,577

TRAINING COMPLIANCE

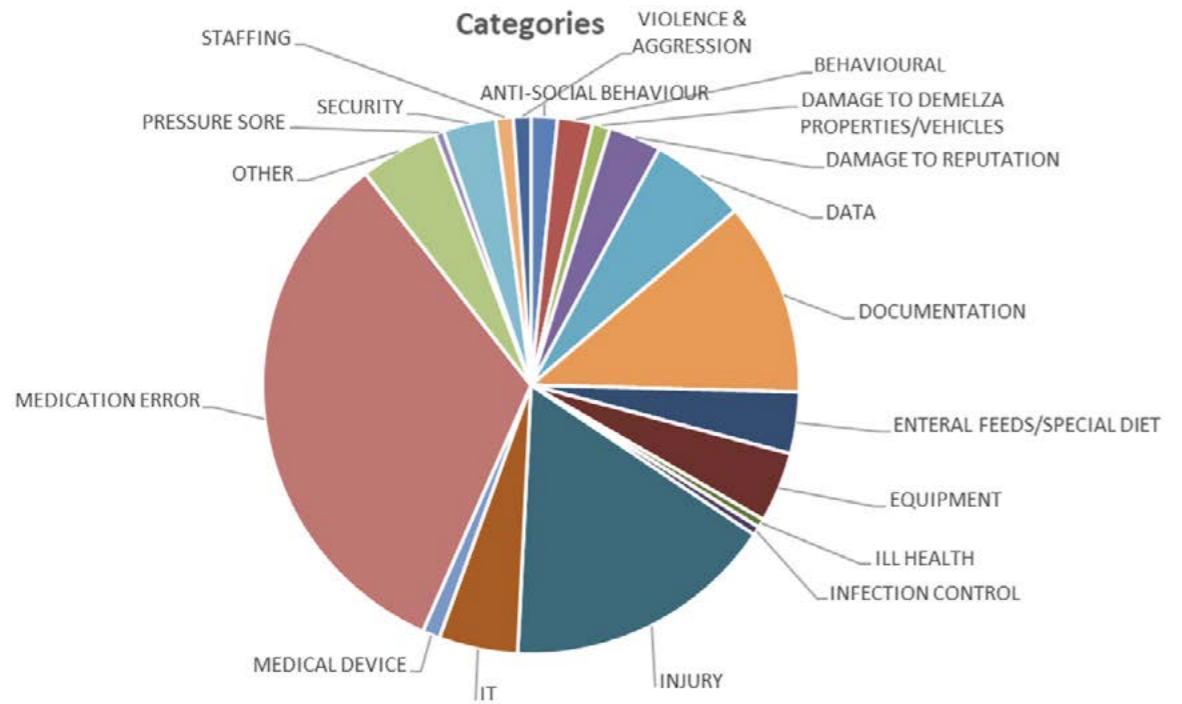
Nursing & Care Training compliance % (includes flexi, FS and Leadership)

	Kent	East Sussex	South East London	Average
Fire	88.31	90.91	97.62	92.28
Safeguarding	96.1	86.36	97.62	93.36
Moving & Handling	88.31	95.45	80.95	88.23
Data Protection	93.51	86.36	92.86	90.91
Infection control	89.61	90.91	100	93.50
MCA & DOLS	98.7	86.36	95.24	93.43

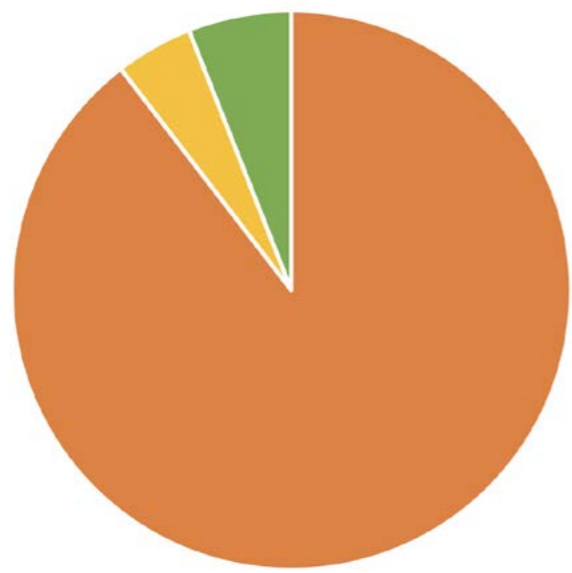
Non-care training compliance - not including self employed, trading or volunteers

Fire	89
Safeguarding	95
Moving & Handling	98
Data Protection	89

Incidents, accidents, complaints and compliments



- ANTI-SOCIAL BEHAVIOUR
- BEHAVIOURAL
- DAMAGE TO DEMELZA PROPERTIES/VEHICLES
- DAMAGE TO REPUTATION
- DATA
- DOCUMENTATION
- ENTERAL FEEDS/SPECIAL DIET
- EQUIPMENT
- ILL HEALTH
- INFECTION CONTROL
- INJURY
- IT
- MEDICAL DEVICE
- MEDICATION ERROR
- OTHER
- PRESSURE SORE
- SECURITY
- STAFFING
- VIOLENCE & AGGRESSION



- Compliment
- Comment
- Complaint

Finance and sustainability

2022-23 Income	£	%
Retail	4,200,000	29%
Fundraising	4,100,000	28%
Statutory	2,000,000	14%
Lottery	1,800,000	12%
Legacies	1,800,000	12%
Investments	400,000	3%
Other	200,000	1%
Total	14,500,000	100%

2022-23 was the first year of Demelza’s 5-year strategy. The charity was in a strong financial position at the start of the strategy. Reserves were above the charity’s policy due largely to two large legacies received in 2018 and 2020. Therefore, expenditure on clinical services increased by £2m to £9.4m, an increase of 27%.

The increase in costs has been funded from increased income and from reserves. Demelza plans to make deficits throughout the strategy, but these will reduce each year. The operational deficit

in 22-23 was £1.7m. By the end of the strategy, in 2027, we plan for the operational budget to break even.

Income in 22-23 increased by £2.5m to £14.5m, an growth of 21%. Our main five income sources are independent of each other and each contribute more than 12% to the organisation’s income. Due to this diversification of income and strong reserves, Demelza continues to be in a healthy financial position.

Duty of Candour

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

Equality, diversity and inclusion

We are continually striving to improve our approach to equality, diversity and inclusion.

The FREDIE Steering Group will guide and lead Demelza with Diversity, Equality and Inclusion and will support initiatives to ensure that Demelza creates an inclusive and engaged culture.

This is to ensure that:

- All people feel welcome and comfortable when receiving care or support from Demelza or when working or volunteering as a member of the Demelza Team
- We have a diverse staff and volunteer workforce that benefits from the innovation and richness that diversity brings
- We are playing our part in making a fairer society by tackling prejudice and privilege

FREDIE is recognised within the 'Investors in Diversity' as a way of implementing and

Safeguarding

Our Safeguarding policy has continued to evolve and further improvements have been made. Training is provided by an external company for the three yearly Level 3 requirement, and three Demelza Safeguarding Leads provide the internal mandatory updates and staff induction. Following staff evaluations, mandatory training updates are now being delivered face-to-face for clinical roles.

We have raised the profile of adult safeguarding due to some adult-based concerns raised by non-care departments, which has led to the introduction of an adult safeguarding e-learning for all staff. We have identified two Safeguarding Leads to be the Designated Organisation Safeguarding Lead and Named Nurse for safeguarding.

embedding change and buy-in from employees and volunteers to create a natural environment for an inclusive culture to flourish.

To create an inclusive culture, you have to build on the solid values of FREDIE.

- **Fairness.** Being reasonable, right and just
- **Respect.** Having due regard for the feelings and wishes of others
- **Equality.** Where every person has equal rights and every person has a fair chance
- **Diversity.** Diverse means different so diversity includes us all. The concept of diversity encompasses understanding, acceptance and respect
- **Inclusion.** Where every person feels respected, values and that they fit in with the organisational culture
- **Engagement.** Two-way commitment and communication between an organisation and its employees, volunteers and service users

The Safeguarding Assurance Committee meets quarterly and is well attended by staff across numerous departments. The Chair will soon change from one Trustee to another but will continue in the same format. The comprehensive work of the Safeguarding Assurance Committee was highly commended as robust during the CQC Mock inspection in early 2023.

The training matrix has been reviewed to ensure that all staff receive a level of training appropriate to their role, meaning that the level of training has been lowered for some staff groups, in line with the RCN intercollegiate document, 2019) as well as the addition of Level 2 Adult Safeguarding for relevant staff groups.

Case studies

End of Life:

At Demelza, we wrap our care around a family's specific needs – whether a family needs us for a few important days, or accesses us for years to come, their decisions are paramount, and our team will strive to deliver on those decisions. Demelza received a referral this year from the local Children's Community Nursing team (CCN), for a child diagnosed with acute myeloid leukaemia, a rare form of cancer that progresses quickly and aggressively. They had been receiving active treatment until very recently when blood counts sadly showed that the treatment was no longer working.

The child experienced a rapid decline in their health around this time and it was clear they would require end of life care, which the family wanted to receive at home, so a late referral was made to Demelza's community team in East Sussex. During this time, Demelza's focus was on supporting the family's decision to remain at home with their child. The child needed to have platelet transfusions to control their symptoms and our team helped seek permission from the local hospital trust for the CCN team and Demelza community nurses to support this at home as they were too unstable to transfer; this was innovative practice within paediatric services.

As the child's condition deteriorated, they required increasing support from the Demelza community team, and a 24-hour on-call rota was set up along with regular telephone reviews from the hospital Children's Palliative Care Team. The Demelza team visited the family daily and the Demelza community nurse supported taking samples to the hospital and returning to the home with appropriate medications, easing the strain on the family at a very difficult time.

Sadly, after continuing this care for a short while, the Demelza team received a phone call from the child's mother in the middle of the night to say that their child had died whilst they were all asleep. At the parent's request, they were given time alone with their child until the morning, then two Demelza community nurses visited to verify the death; the nurses then called the funeral director at the family's request. Bereavement care at home was offered, and the child could have remained at home for 48 hours with Demelza's support to give the family more time together, but the parents declined.

The child's mother asked if the nurses would be able to wash and dress their child, which our team supported – they then withdrew from the home, to allow the family further privacy to grieve before the child was taken to the funeral directors.



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Registered Charity No. 1039651



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