



PATIENT EXPERIENCE & INCLUSION ANNUAL REPORT 2021/22



CHIEF NURSE'S STATEMENT ON PATIENT EXPERIENCE

On behalf of the Trust Board and staff working at The Clatterbridge Cancer Centre NHS Foundation Trust (CCC), I am delighted to present our Patient Experience & Inclusion Annual Report for 2021/22.

Once again I am incredibly proud of the commitment and dedication shown by all our staff to ensure a high standard of oncology care and treatment was provided for our patients. This year, as the world began to open up we focused our attention on the safe transition from full lockdown to welcoming people back into our hospital sites whilst still maintaining a level of enhanced biosecurity to keep our patients, their families and our staff safe from the ongoing prevalence of COVID-19.

We have continued to develop our services and make improvements to patient experience throughout 2021/22. In February 2022, a CCC patient became the first in the UK to receive a personalised vaccine against head and neck cancer, tailor-made to his own DNA.

It is fantastic that we can now deliver early-phase 'first-in-human' trials like this, which were not possible without CCC-Liverpool and its rapid access to acute specialties in the Royal Liverpool Hospital.

The same month, the Aintree University Hospital haemato-oncology team joined CCC, creating a single blood cancer service for Liverpool, following extensive patient engagement in summer 2021. Bringing the teams together in this way means patients can now benefit from expert blood cancer care at their nearest hospital (Aintree University Hospital or CCC-Liverpool), with all the wraparound support that comes from being part of a specialist cancer

centre, and it paves the way for a wider range of innovative treatments that we will be able to provide from next year.

Once again, we were rated one of the best trusts in England in the CQC National Adult Inpatient Survey, with patients particularly praising our staff and the quality of the facilities we offer. We co-produced our new Patient Experience Commitment (published in April 2022) and I'm immensely grateful to the patient representatives, carers and staff who helped to develop it. Our incredible Enhanced Supportive Care team won a HSJ Value Award in 2021/22 for their work to help people with cancer to have a better quality of life by reducing pain, side-effects and unnecessary hospital admissions.

Together with Wirral University Teaching Hospital, we opened a community diagnostic centre at CCC-Wirral for people referred by their GP, so they can more quickly get the tests and scans they need. Our multi-award-winning 'Clatterbridge in the Community' team opened a new hub at Aintree University Hospital allowing them to expand and deliver chemotherapy at home to a greater number of patients.

I would like to take this opportunity to thank our patients, patient/carer representatives, volunteers, governors and staff for the professionalism, expertise and commitment that has resulted in the many achievements during challenging times, evidenced in this report.



Julie Gray | Chief Nurse



THE CLATTERBRIDGE CANCER CENTRE (CCC) AT A GLANCE

We are a tertiary cancer centre, providing non-surgical cancer care to patients across Cheshire and Merseyside. Our reputation and specialist services attract national and international cancer patients. Our three specialist cancer centres are in Aintree, Liverpool and Wirral.

We also provide specialist systemic anti-cancer treatment clinics in four of Merseyside's district hospitals – St Helens & Knowsley, Warrington & Halton, Southport & Ormskirk and Aintree University Hospital – making us one of the largest NHS providers of non-surgical cancer treatment for solid tumours and blood cancers.

Our clinical model also includes the provision of chemotherapy in the home and workplace.

Together, this enables us to provide a comprehensive range of inpatient care, acute oncology, radiology, advanced radiotherapy, chemotherapy and other systemic anti-cancer therapies including gene therapies and immunotherapies. We treat blood cancers and are host to the regional bone marrow transplant unit. We are also the only facility in the UK providing low-energy proton beam therapy to treat rare eye cancers.

What we do:

Tertiary non-surgical cancer care for the 2.4m people of Cheshire and Merseyside, including;

- We manage in excess of 382,000 patient contacts per year
- We care for over 33,000 patients per year
- We deliver over 76,700 Systemic Anti-Cancer Treatments (SACT) per year
- We deliver SACT at 6 geographical locations
- We deliver radiotherapy at our 3 centres
- We employ over 1,700 specialist staff
- We deliver outpatient care at 15 sites

Having delivered our five-year strategic plan, opening CCC-Liverpool and embedding our unique networked model of care, our attention for the next five years needs to be on maximising the benefits of these developments for patient outcomes and experience. To this end we have developed a new Five-Year Strategic Plan 2021-2025 that will support our mission to drive improved outcomes and experiences for patients through our unique network of specialist cancer care across Cheshire and Merseyside.

NATIONAL SURVEYS

CQC Adult Inpatient Survey 2021/22 Key summary and highlights

The National CQC Adult Inpatient Survey looks at the experiences of adults that have been an inpatient at an NHS hospital and involved 134 NHS acute and specialist trusts in England. The survey has been running since 2002 and is published annually. All eligible organisations in England are required to conduct the survey.

In total, we scored 9.1 out of 10 and were rated 'much better than expected' on 21 of the survey questions, 'better than expected' on 15 questions and 'somewhat better than expected' on two questions. There were no areas where we performed worse than expected.

CCC achieved the best scores in the country on 10 of the questions:

- Time spent on a waiting list before admission
- Receiving information from hospital staff about your condition/treatment
- Being able to discuss your condition/ treatment without being overheard
- Having enough privacy when being examined/treated
- The hospital doing enough to control your pain
- Hospital staff explaining how you might feel after treatment
- Getting enough information about what to do or not do after discharge

- Knowing before you left hospital what would happen next with your care
- The hospital doing enough to arrange social/community care
- Overall being treated with respect and dignity

Other particular areas of strength included patients feeling involved in decisions about their care, understanding the answers they got to any questions, feeling they could open up and speak to staff if they had any worries, and being able to have a peaceful night's sleep.

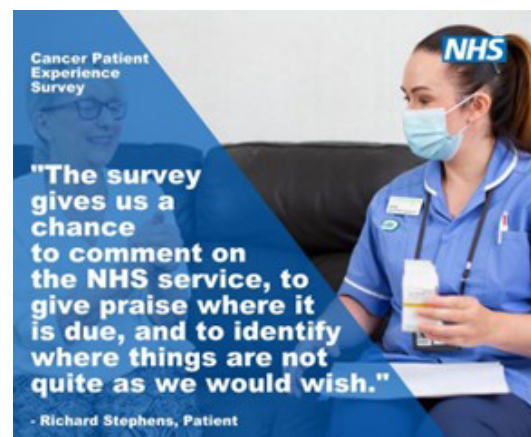
CQC use the results from the survey in the regulation, monitoring and inspection of NHS trusts in England. Survey data is used in CQC's monitoring tools that provide inspectors with an assessment of performance in areas of care within an NHS trust that require attention. Survey data is also used to support CQC inspections. These outcomes are then monitored by the Department of Health and Social Care.

An action plan to support these improvements in 2022/2023 has been developed and will be monitored via Divisional Quality & Safety Meetings with delivery assurance presented to the Patient Experience and Inclusion Committee (PEIC) on a quarterly basis.

National Cancer Patient Experience Survey (NCPES) 2020/21

We also participate in the National Cancer Patient Experience Survey (NCPES) as this is an important part of the national NHS Cancer Programme that places patient experience on a par with clinical effectiveness and safety as a key strategic priority. It has been designed to monitor national progress on cancer care and drive local quality improvements. It is commissioned by NHS England and Improvement (NHSEI).

The 2020/21 survey was offered to trusts on a voluntary basis, with CCC opting to take part. The 2020/21 survey involved 55 NHS trusts and as not all NHS trusts participated in the survey no comparisons to scores nationally are shown.



NCPES 2020/21 Key Highlights

The sample for the survey included all adult (aged 16 and over) NHS patients, with a confirmed primary diagnosis of cancer, discharged from an NHS trust after an inpatient episode or day case attendance for cancer related treatment in the months of April, May and June 2020. The fieldwork for the survey was undertaken between April 2021 and June 2021.

As planned pre-pandemic, a more detailed review of the questionnaire is being carried out, although given the development stages that are required, the revised questionnaire will not be available until the 2021 NCPES onwards. Please note, this means that any survey results collected during 2020 are unlikely to be comparable to the 2021 survey onwards.

CCC's survey results from the 2020/21 NCPES are very good and continue to show year on year improvement in particular areas. Sixteen (16) of the questions highlighted key areas where our 2020/21 score is higher compared to the 2019 scores. Whilst the overall patient experience score of 8.8 has been maintained from 2018, as a trust we must strive for continual improvements based on patient feedback.

Areas identified for improvement based on CCC 2020/21 survey results include:

- Q12 Patient completely understood the explanation of what was wrong
- Q15 Patient felt possible side effects were definitely explained in an understandable way
- Q25 Hospital staff told patient they could get free prescriptions
- Q37 Patient definitely found hospital staff to discuss worries or fears during their inpatient visit
- Q55 General practice staff definitely did everything they could to support patient during treatment
- Q56 Different people treating and caring for patient always work well together to give best possible care
- Q57 Patient given a care plan
- Q58 Overall the administration of care was good or very good
- Q60 Someone discussed with patient whether they would like to take part in cancer research

The above areas for improvement have formed the basis of the NCPES 2020/21 improvement action plan.

The progress of the identified areas & subsequent actions in the NCPES 2020/21 improvement action plan will be monitored via the Divisional Quality & Safety Meetings and the Patient Experience and Inclusion Operational Group (PEIOG) with the divisional leadership and matrons, providing bi-monthly progress updates to the group.

The full publications of the NCPES 2020/21 report and survey results are available by the following link: <https://www.ncpes.co.uk/current-results/>

At the time of writing this annual report the results for the NCPES 2021 were not available. However, an improvement plan will be produced to support any areas for development to ensure continuous improvement of CCC services.

STRATEGY & FRAMEWORK

Patient Experience, Engagement, Inclusion and Involvement Commitment (Strategy) 2021-2025

The Patient Experience, Engagement, Inclusion and Involvement Commitment 2021-2025 is aimed at patients and staff alike and was developed & co-produced by patients, families, carers, members of the public and staff. Working together, we can realise our mission, as a leading cancer centre.

The Patient Experience Commitment is in line with our mission, the core themes of our overall Five-Year Strategic Plan (2021-2025) and, importantly, our Trust values.

What matters to you matters to us, so patients, families, carers, members of the public and staff helped us to develop this Patient Experience Commitment.

Between February and October 2021, the Trust hosted a number of workshops for patients, carers and staff. The patients and carers were from different age groups and ethnic backgrounds, and had experience of various types of cancer. The outcomes of the workshops, along with local and national information collected about our services, were discussed with the Patient Experience & Inclusion Committee (PEIC) in July and September 2021. Following this process we have developed the following shared aim:

‘Patient experience being everyone’s business, which then drives improved experiences through delivering care together in an empathetic manner.’

Thanks to involving patients, carers, members of the public and staff when developing our Patient Experience, Engagement, Inclusion and Involvement Commitment, we now have a co-produced shared mission to guide us through the next five years.

Our vision is supported by the following four themes that make up the Trust commitment to you.

- ▶ ‘We will listen, hear, learn and act’
- ▶ We will communicate clearly in ways you can understand and demonstrate that hearing is happening’
- ▶ We will act upon your feedback, involvement and engagement demonstrating that what matters to you matters to us’
- ▶ ‘We will give patients a leading voice and support each other to develop innovative ways to obtain feedback, involve and engage with you’



More information about the Patient Experience Commitment can be found here;

<https://www.clatterbridgecc.nhs.uk/patients/our-commitment-patient-experience-engagement-inclusion-involvement-2022-2025>

Patient Experience Improvement Framework 2020/21

Good experience of care, treatment and support is increasingly seen as an essential part of an excellent health and social care service, alongside clinical effectiveness and safety. A person's experience starts from their very first contact with the health and care system, right through to their last, which may be years after their first treatment, and can include end-of-life care.

The patient experience improvement framework supports NHS and foundation trusts to achieve good and outstanding ratings in their Care Quality Commission (CQC) inspections.

The framework enables organisations to carry out an organisational diagnostic to establish how far patient experience is embedded in their leadership, culture and operational processes. It is divided into six sections, each sub-divided and listing the characteristics and processes of organisations that are effective in continuously improving the experience of patients.

It should be implemented using quality improvement methodology and embracing the principle of continual learning. It can be adapted to meet local CCC population and workforce needs.

Improving patient experience is not simple. As well as effective leadership and a receptive culture, CCC needs a whole systems approach to collecting, analysing, using and learning from patient feedback for quality improvement. Without such an approach it is almost impossible to track, measure and drive quality improvement.

CCC recognised the importance of the contents within the Patient Experience Improvement Framework report for people with cancer and those who support them. It is of equal importance that this framework is used to help CCC to focus on the key factors (including the underlying factors) that need to be present in the organisation focused on the needs of its patients. Thus bringing together the characteristics that consistently improve patient experience and enable the Trust Board to carry out an organisational diagnostic against a set of indicators.

The six CQC review themes support organisations to identify their performances against the following:

- ✓ **Leadership (for patient focus)** – Almost all NHS organisations profess to put the patient at the centre of everything they do but this principle needs to be clear in the values and behaviours of senior leaders. There should be a clear commitment to equality and diversity ensuring the needs of all are met.
- ✓ **Organisational Culture** – The organisational culture is patient focused and values behaviour that enhances the experience of patients.
- ✓ **Capacity and capability to effectively collect feedback** – The organisation has several routes through which patients can provide feedback.
- ✓ **Analysis & Triangulation** – The organisation has a systematic and consistent approach to analysing and making sense of patient feedback, and considers it alongside patient safety and patient outcomes data.
- ✓ **Using patient feedback to drive quality improvement and learning** – The organisation actively and routinely seeks out patient feedback to be a learning organisation which is underpinned by quality and service improvement work. The organisation can evidence that it uses feedback and staff know that patient feedback is used to drive quality improvement. Patients are actively involved in decision making as equal partners (Participation in the Always Events Programme is in place).
- ✓ **Reporting and publication** – The organisation regularly reports and publishes its patient experience data, and co-produces its quality improvement plans with a range of stakeholders including patients and frontline staff.

This framework does not cover everything. It is specifically aimed at supporting healthcare providers. However, we are increasingly talking in terms of integrated care systems and patient pathways across Cheshire & Merseyside, with an increased focus on empowering patients to fully participate in decisions about their care and treatment.

The objectives of using the Patient Experience Improvement tool at CCC are to:

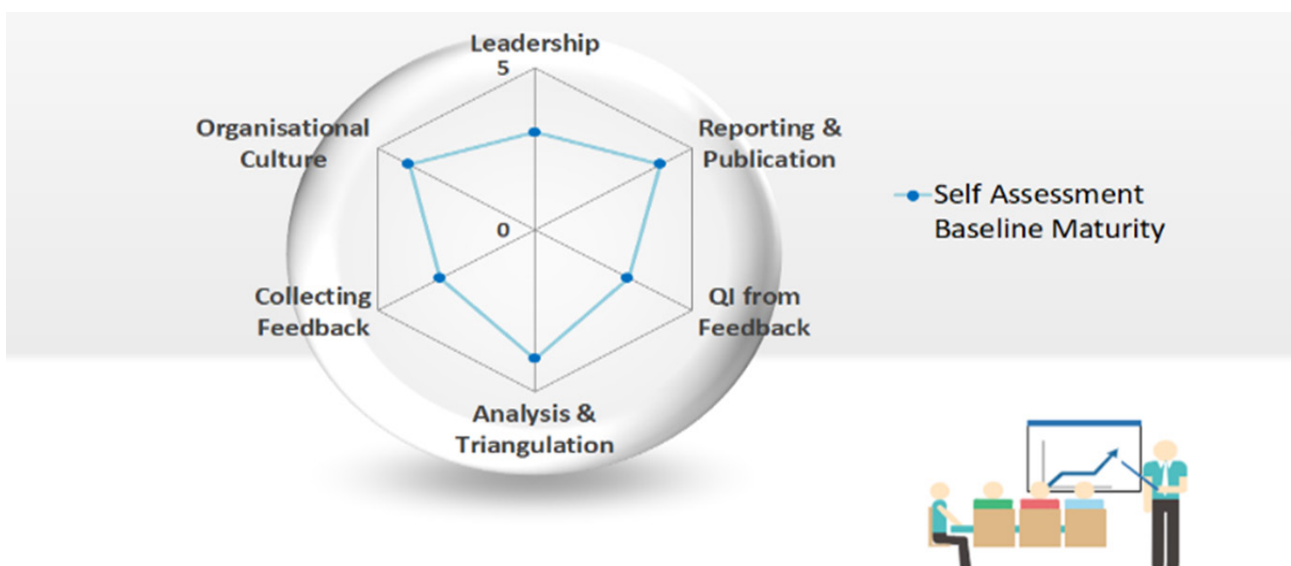
- Explore a wealth of patient and staff feedback, specifically in relation to the six CQC review themes
- Seek patient and staff views through scheduled virtual thematic workshops
- Identify areas to celebrate and areas to focus where improvement is required
- Form part of our continuous learning and quality development organisational culture
- Review annually and present to the Trust Board to demonstrate the priority of patient experience and quality improvement at Board level

Throughout February and March 2021, we completed organisational and patient/carer self-assessment scoring for each element of the framework as a basis from which to track quality improvement, but it is important to note this is not a comparison tool so any scoring is for the organisation's use only. What is important is being able to track the quality improvements over time.

As part of our response to the Patient Experience Improvement Framework and Improvement tool, this report is aimed to generate further collective discussion and agreement on next steps and recommendations to be taken forward.

Since sharing the last report at October 2020 Patient Experience Inclusion Group (PEIG), we have developed and co-produced through virtual thematic workshops with the Patient Participation Group (PPG) our patient and carer voice representatives, including Healthwatch and staff stakeholder engagement, a completed self-assessment, for each of the six CQC review themes (facilitated by the NHS England & Improvement Director of Patient Experience) to provide a baseline position to help further inform areas for organisational improvement & development, continuing to give patients safe, high quality, compassionate care. The findings are summarised below underpinned by a full self-assessment gap analysis and action plan.

Patient Experience Improvement Framework Self-Assessment Baseline 2021/22



- ✓ **Themes that scored highest** and what patients stated that they feel that we do well as a trust;
 - a. **Reporting & Publication** (scored 15/20 or 75% - Baseline average score 4/5)
 - b. **Analysis & Triangulation** (scored 29/40 or 72% - Baseline average score 4/5)
 - c. **Organisational Culture** (scored 39/55 or 71% - Baseline average score 4/5)
- ✓ **Themes that scored lower and require focused improvement** and further action by the Trust;
 - d. **Using patient feedback to drive quality improvement and learning** (scored 38/55 or 69% Baseline average score 3/5)
 - e. **Capacity & capability to effectively collect feedback** (scored 44.5/65 or 68% - Baseline average score 3/5)
 - f. **Leadership for patient focus** (scored 32/50 or 64% - Baseline average score 3/5)

In terms of next steps, themes and actions identified with patients and staff will form the basis for drafting the next five-year Patient Experience, Engagement, Involvement & Inclusion Commitment (strategy) with further focus group & interview engagement sessions taken place in Autumn 2021.

The Trust should use this patient experience improvement framework to identify areas where they need to focus to have the biggest impact. It should be part of our continuous learning and quality development and should be reviewed annually and presented to the Board of Directors to demonstrate the priority of patient experience and quality improvement at Trust Board level.



VOLUNTEER WORKFORCE FOR CLATTERBRIDGE CANCER CENTRE-LIVERPOOL (CCC-Liverpool)

Volunteers play a vital role in delivering services to the NHS and this is particularly so at CCC. The Trust recognises the huge role that our volunteers have in supporting patients, enriching patient experience and bringing communities together. CCC also acknowledges that volunteer roles are essential to reduce the pressure on services and support staff. They are part of the hospital team that delivers an outstanding patient experience across all our sites.

Key Achievements

In 2021, the Family Volunteers (FV)/‘Chatter buddies’ scheme was fully deployed onto the inpatient wards with a team of 16 offering daily support and who ensure that patients are able to have social contact with a Family Volunteer, in the privacy of their own single bedded room and to maintain bio-security measures during the pandemic & ongoing visitor restrictions.

- Ongoing recruitment of volunteers to support CCC-Liverpool and CCC-Wirral sites
- Recruitment process and support reviewed and updated
- Development of a volunteer page on the staff intranet site
- Access to and completion of the e-Learning for Healthcare (e-LfH) volunteer core skills training framework. This ensures that all volunteers undertake the training and development required for their role and successfully complete a transferable volunteer passport
- Support for patients at the main entrances of CCC sites helping to use the self-check in kiosks, meeting and greeting at the main entrance and ensuring hand gel and mask wearing guidance is adhered to and signposting patients to their appointments
- Providing free beverage services to patients on Chemotherapy, Main Outpatients and Day units at CCC-Liverpool and CCC-Wirral sites
- Achievement of 100% mandatory training compliance
- Fully supporting the development and needs of the Family Volunteer team with training sessions delivered by the Palliative Care / End of Life Team Family Practitioner
- Implementation of an electronic rota management system providing volunteers with choice of roles and ‘shifts’ to suit the valuable time that they give to support patients and visitors

Aims and Next Steps

- Continue to recruit ensuring a full volunteering service that provides a variety of unpaid roles across CCC sites
- Continually develop and explore further opportunities for the Family Volunteer (FV) Service (including ‘Chatter Buddies’), based on patient needs and FV feedback with further training sessions being delivered



Always Events Programme

This quality improvement programme supports CCC to ensure we are modelling the behaviours that make a positive difference to our patients first time, every time.

Always Events (AE) are defined as the aspects of the patient and family experience that should always occur when patients interact with healthcare professionals and the healthcare delivery system. NHS England / Improvement (NHSEI) have been leading the initiative to integrate AE into routine frontline services.

As AE are based on coproduction quality improvement, these fit perfectly with CCC's ambition to seek understanding as to what really matters to patients, people who use our services, their families and carers – and then co-design changes to improve experiences of care.

We undertook an extensive review of key patient feedback received where patients told us what matters to them. The feedback was received during patient experience 'rounds' along with written feedback from various national and local surveys.

Key achievements – Quality Improvement Always Event Project: Family Volunteers / 'Chatter Buddies'

Aim

The role of the Family Volunteer was created to provide a family befriending service for patients during their stay at CCC contacting family members at home, whilst also responding to emails received into the Trust from families/carers. In addition to providing a vital communication link between patients and their families/carers where necessary, the family volunteers also act as 'chatter buddies' providing much needed company during ongoing visiting restrictions.



Drivers & development

The Family Volunteers assist in the ongoing improvement of our patients' experience and maintain patient wellbeing by providing a practical means of communication with families and carers using digital tools. The role enhances the quality of care patients receive by enabling clinicians to focus on direct clinical care, and reducing social isolation and loneliness that the patient may feel during their stay in a single bedded room.

Outcomes & impact

Patients often comment how lovely it is to have a 'chat' with someone who doesn't need to ask about their cancer. Family Volunteers have reported talking about a plethora of subjects that matter most to our patients. Conversation topics covered family, knitting and football; some just a five minute chat and others lasting for more than an hour. Family Volunteers have an inclusive role and also provide much comfort to our patients' families too. One Family Volunteer has stated "that it not only helps the patient, but it's a really fulfilling role".

Next steps

In 2022, CCC will conduct a short second pilot using the improved 'Helping Hand' option on the TVs, allowing patients to request a visit from a Family Volunteer from the comfort of their bed/chair with a touch of a button. We will expand the number of Family Volunteers, wards and the hours in which they are available to patients.

RESEARCH AND CLINICAL TRIALS

Research Patient and Public Involvement (PPI) Forum

The Research PPI Forum was established in November 2020, when COVID was presenting considerable challenges for face-to-face gatherings, resulting in all meetings being conducted virtually. Members range from former patients, carers of former patients, Support Group Chairs and lay-persons with an interest in cancer.

Since its inception, members have contributed to the Research PPI Strategy, an audit of patients' awareness of research, as well as commenting on a range of issues such as research proposals and the process around

withdrawal of consent for research studies. Several members are now involved with research projects both at CCC and University College London (UCL) whilst one is on the Board of Governance for the CCC Biobank. Another served as a lay member of a team working with the Royal College of Radiologists to design a more consistent consent form for radiotherapy. The new form was piloted in breast and prostate before being rolled out to 10 other cancers. The team won the British Medical Journal Cancer Team of the Year.

Key Achievements

A quarterly newsletter is published which details the forum's activities as well as how to get involved with the group. The newsletter is available on the CCC website and members cascade within their own support groups.

In addition to influencing strategy and policies, monthly meetings also welcome researchers to present their work to the group. These presentations are well received and generate dynamic Q&A sessions. This year has seen presentations from:

Prof Christian Ottensmeier outlined his research to develop a vaccine for recurrent head and neck cancer, describing how immunotherapy has become a standard treatment. He is hopeful that eventually he will be able to develop a personalised vaccine by separating genes. His trial commenced early in 2022.

Charlotte Rawcliffe (University of Liverpool) gave a presentation outlining the collaboration between the University of Liverpool and CCC in the Experimental Cancer Medicine Centre (ECMC). She explained that ECMC bridges the gap between laboratory research and clinical trials. The Liverpool ECMC conducts translational research, biobanking and early phase trials. She also described some of the current studies

Seamus Coyle described his research into methods to accurately predict when people are dying. He has worked with lung cancer patients, collecting urine samples for analysis by Mass Spectrometry. This machine gives a breakdown of chemicals in the sample which is 90% accurate in predicting that a patient is in the last month and week of life. He anticipates a patent for this technology and a publication to follow.

The Group had requested some clarification around governance and ethical approval processes.

Dr Maria Maguire explained that historically each trust had a different process for ethical approval for research studies. However the Health Research Authority (HRA) has now implemented an integrated system which has streamlined the process and, although is still a work in progress, it is a much better system. Maria used the TACE study as an example of how an application for ethical approval operates. She went through the form that needs to be completed explaining the rationale behind the questions. She also explained how the questions differ for an audit.



Jon Hayes, the managing director of the Cheshire and Merseyside Cancer Alliance (CMCA), gave an overview of the Alliance explaining that it is an umbrella organisation comprising partners across Cheshire and Merseyside which is funded by NHS England and aims to improve cancer care by delivering the Long Term Plan, identifying, diagnosing and treating cancer to achieve better outcomes for all patients. He also gave a detailed update of the research supported by the Alliance.

Dr Lynda Appleton outlined her study, the aim of which had been to determine the mental health and wellbeing needs of cancer staff

throughout the pandemic. Lynda explained that wellbeing encompasses many factors and the study team had chosen to use the World Health Organisation (WHO) term which includes physical, psychological and spiritual. The study concluded that CCC needs to connect with staff, some were clearly managing less well, expressing feelings of guilt about not being on the COVID front line. Although CCC had provided wellbeing resources, these were not always accessible, particularly to ward-based staff with no access to email. The study also recommended support for long COVID and fatigue.

ARTS, HEALTH AND WELLBEING

The CCC Arts Programme aims to utilise the arts to benefit patients and staff health and wellbeing. The programme supports CCC in the delivery of the Trust's strategic priorities.

Our Arts in Health programme offers a programme of patient and staff creative activities and performances as well as collection of artwork to enhance the environment of our sites. We work closely with local artists, musicians and arts organisations to help improve the experience of our patients, families, staff and people visiting our sites.

We strive to provide our patients, families, staff and visitors with opportunities to experience and engage with the transformative nature of the arts in its many forms.

Our Arts in Health programme is currently managed by a part-time Arts Coordinator who is part of our Patient Experience Team.

Decisions for the Arts and Health programme are made in consultation with the CCC Arts Steering Group (ASG). The CCC Arts Coordinator is the chair of the arts steering group.

Our current programme is delivered under the following three strands:

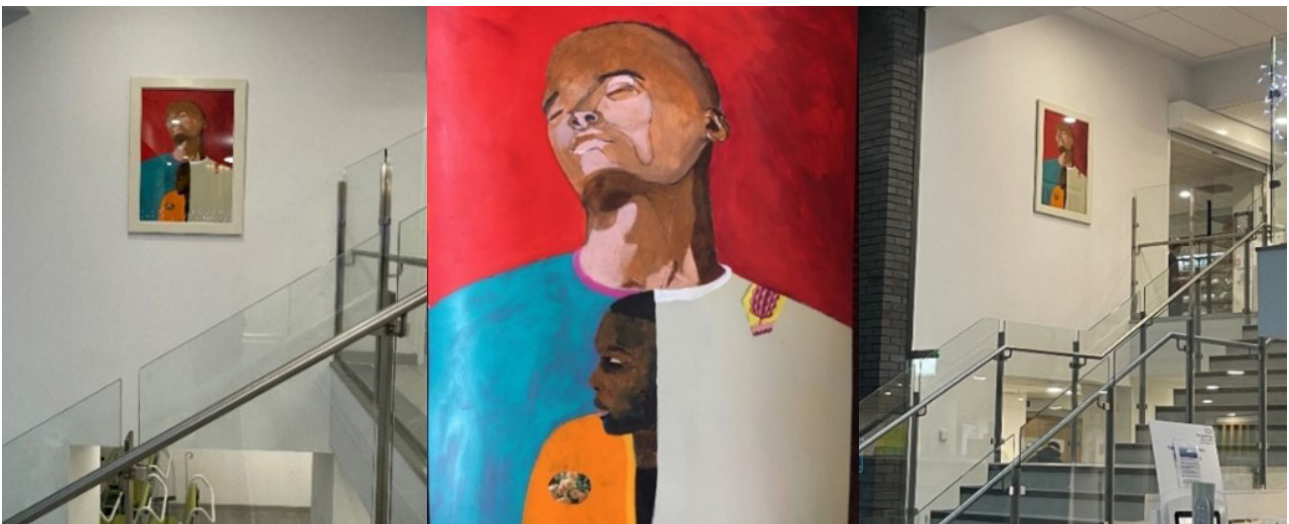
- Environment (artwork)
- Arts Activities
- Music





After a reduction in COVID restrictions in autumn 2021 we were able to complete a number of arts ‘in-person’ tasks and activities which had been delayed during the pandemic. Due to the new wave of COVID virus in winter 2021/22 and national and local lockdowns, we returned to online delivery only from December 2021 to March 2022. This resulted in a number of arts programme activities and tasks being postponed. Where viable these activities and tasks will be completed in 2022/23.

In the 2021/22 period we have installed 12 new pieces of artwork at CCC–Liverpool and a CCC poem written by Levi Tafari has been completed. The CCC Artwork Collection Management policy has been adopted and published. The CCC artwork collection valuation and cataloguing is ongoing by the Arts Coordinator. This year the Arts Coordinator has identified that the Trust currently has 120 pieces of art in its collection, 18 pieces in storage, 102 on display. Artwork acknowledgment panels for CCC–Liverpool were installed in March 2022. The panels have a QR code which once scanned will take the viewer to the arts page on the CCC website with further information.



“The painting is appreciated by the staff. It helps to have relaxing artwork on the wall, especially to interrupt the brightness of the blank white walls and give the eyes something restful to look at” - CCC staff member



Our music partnership with the Liverpool Philharmonic was launched in December 2021 with online activity taking place in winter 2021 and spring 2022. ‘In person’ and live music performance delivery will commence in summer 2022. We had 105 audience members watch music performances (online and live) 61 patients and staff participants worked with 27 artists on arts activity sessions. Over 50 arts activity packs were distributed to inpatients at CCC–Liverpool.



“I have reviewed this lady today and she was really complimentary about the effects of distraction / art packs. She talked of it being ‘all-absorbing’ for a few hours and has really helped.” – CCC staff member

We held positive discussions with potential partners and collaborative projects have taken place over the year including new long-term arts and cultural partners National Museums Liverpool (NML), FACT Liverpool and The Bluecoat Display Centre.

“Thanks for letting me be involved with the session. I think creatively it provided lots of sparks... It was a great way of seeing people beyond their cancer.” – Participant at NML online workshop

The Arts Coordinator supported the Clatterbridge Cancer Charity with fundraising for the CCC Arts Programme and we successfully raised £63,140 from trust and foundation bids. Clatterbridge Cancer Charity has supported the Arts Programme with funding for the Arts programme for the 2021/22 period.

Aims and next steps

Use artwork to transform and enhance our centres to create welcoming spaces to benefit the health and wellbeing of our patients, families, staff and visitors. In the 2022/23 period the Arts Programme will install up to five new pieces of artwork in areas of need to increase our artwork collection. The Arts Coordinator will update and manage the CCC Artwork Collection Catalogue and work with CCC communications and charity teams to ensure that the artwork is clearly identified and featured on our website to allow people to access information about the work.

Regular participatory arts activity for patients and staff, providing access to materials and resources for self-led activity are provided enhancing our patient experience and improving health and wellbeing. In 2022/23 the Arts Programme will work in partnership and on collaborative projects with local arts partners and community organisations to run arts workshops, readings, performances and events for CCC patients with links to external arts activity.

Across 2022/23 we will provide a music programme to entertain and engage our patients, families, staff and visitors with regular performances and a programme of person-centred music making activities. In this period we will complete our initial pilot project with the Liverpool Philharmonic and develop the partnership to have musicians in residence and regular live performances from January 2023. We will develop partnerships with other local music organisations to ensure that the music programme reflects our wider community.

A SNAP SHOT OF KEY PATIENT EXPERIENCE AND INVOLVEMENT INITIATIVES 2021/22

2021 in focus at CCC

From 1st February 2022, the Haemato-Oncology teams at Aintree University Hospital (AUH) and CCC-Liverpool will work as one team delivering a new integrated blood cancer service across Liverpool and the North Mersey area (Sefton, North Liverpool, Knowsley and West Lancashire).

Combining the expertise of staff at AUH and CCC-Liverpool in this way will deliver huge benefits for patients at both hospitals over time. It's the result of a huge amount of work over many years by teams in CCC and Liverpool University Hospitals.



New integrated blood cancer service from February 2022

Clatterbridge Diagnostic Centre opens November 2021

Patients across Wirral are benefiting from earlier diagnostic testing thanks to national investment in a new service called Clatterbridge Diagnostics.

This is one of the first Community Diagnostic Centres (CDC) in England that are being established as part of a national programme aimed at increasing diagnostic capacity.

CCC and Wirral University Teaching Hospital (WUTH) are working in partnership to deliver the service after being awarded a share of £350m national funding to create one of the 40 new CDCs planned across England.

Clatterbridge Diagnostics has been set up at CCC-Wirral and will offer an extra service for people referred to WUTH for tests, alongside the current diagnostics support at Arrowe Park Hospital.

The service offers earlier access to diagnostics, reducing the time that patients wait for tests for a wide range of conditions including heart disease, lung conditions and cancer and will therefore provide earlier diagnoses for people in Wirral. Importantly, it has been established in a way that means cancer care on the site will also be enhanced by enabling people to be diagnosed more quickly without affecting waiting times for treatment.

The service will deliver increased testing for MRI, CT, Ultrasound, X-Ray, Sleep Apnoea, Blood Tests, Endoscopy, ECHO, ECGs and respiratory testing.

The partnership approach will also see a new mobile CT scanner placed on WUTH's Clatterbridge Hospital site to further increase diagnostic testing for patients. Endoscopy testing will be increased on the Arrowe Park Hospital site in the bespoke Endoscopy Unit as part of the project.



Clatterbridge Diagnostics opened Nov 2021

“Chemo Chums”

Fondly calling themselves ‘Chemo Chums’, this group of fabulous inpatients at CCC-L get together during evenings in the ward’s social space; creating an array of colourful artwork whilst sharing pizza and non-alcoholic beers.

Ward 4 ‘Chemo Chums’ arts & crafts club Dec 2021



LEARNING DISABILITY AND AUTISM

Implementation of the Learning Disability Improvement Standards

In June 2018, NHS Improvement (NHSI) developed the new Learning Disability Improvement Standards for NHS trusts. They are intended to help the NHS measure the quality of service provided to people with learning disabilities, autism or both.

CCC has participated since 2019 in the NHSI Learning Disability Improvement Standards project. Our annual data submission provides evidence of our compliance with the standards including the views of staff and patients with a learning disability. An outcome report is produced by NHSI providing a baseline for the quality of care delivered to CCC patients with a learning disability and/or autism. This report facilitates a yearly work plan which is implemented and monitored through the Safeguarding Committee.

There has been great progress and achievements in the last 12 months associated with the measures within the Learning Disability Improvement Standards.

The progress and achievements are detailed below;

- Routine offer to use health passport or autism passport for patients with learning disability and/or autism to assist with reasonable adjustments
- Flags in Meditech to identify patients with learning disability and/or autism
- Mandating and achievement of over 90 % compliance for learning disability awareness training for all patient facing staff. Compliance is 97.47% in Q4.
- Completion of the Oliver McGowan Foundation training for all Trust Dementia / Learning Disability and Autism champions
- Development of a photobook for patients with learning disability / autism and dementia to help desensitise their anxiety when coming into the Trust
- Additional Needs Policy in place
- Film detailing the radiotherapy journey of a person with learning disability and/or autism
- Engagement with Cheshire & Merseyside Confirm and Challenge Group
- Safeguarding Team provide advice and support to staff caring for patients with learning disability and/or autism and will support staff to liaise with community teams including Learning Disability Facilitator

Aims and next steps

During the next 12 months CCC will continue to work in partnership to:

- Provide a more robust process for patients and carers/family with learning disability and/or autism to give feedback on their patient experience
- Ensure that the Datix reporting system within the Trust has the ability to identify patients with a learning disability and/or autism within their incident reports, and complaints
- Plan development of a further co-production film following a patient journey through chemotherapy which was delayed by COVID 19 pandemic
- Collaborate in the implementation of the Learning Disability Standards Framework
- Continue to work in co-production with patients, families and self-advocates via Confirm & Challenge Group and to develop the work plan and evaluation process for delivery of National Learning Disability Standards
- Review and revise the Learning Disability / Autism Strategy to reflect current guidance

DEMENTIA STRATEGY AND ADDITIONAL NEEDS

The Dementia Strategy was ratified in April 2019 and it set out a three-year strategic plan (2019–2022) for CCC. It is currently undergoing a review and revision at this time as it has reached the end of the three-year period.

The review process has recognised the following key achievements of the vision outlined in the strategy which were underpinned by the national framework.



Key achievements to date

- The Dementia / Learning Disability and Autism Collaborative Group continue to focus and achieve on the actions within the strategy utilising the Champions across all three sites
- Members of the Dementia / Learning Disability and Autism Collaborative Group have completed training from the Oliver McGowan Foundation for NHS staff
- Dementia Awareness training compliance achieved the target of 90% for all patient-facing staff and continues to be maintained at 98.13% in Q4.
- A digital photobook was developed and approved by the Members of Service Users Reference Forum (SURF) as part of work required for the Kings Fund Dementia Environment Tool. It is used as a desensitisation tool for all patients with additional needs to reduce their anxiety when visiting CCC.
- The Safeguarding Team continues to meet virtually with the Liverpool Dementia Action Alliance (DAA) to be updated about dementia friendly projects and local facilities available in Merseyside and to meet virtually the monthly SURF meetings to liaise with patients, carers and families about the work being completed in CCC.
- We have developed a Carers Policy to meet the criteria of the NICE guidance on carers in line with 'John's Campaign'.
- We have developed Delirium Guidelines to meet CCC requirements in relation to dementia.
- Audits were completed on the use of the Risk Assessment and Reasonable Adjustment Care Plan in Meditech and audit findings were presented to the Safeguarding Committee.
- Dementia friendly signage was installed at CCC-Liverpool. Plans are in place to install this signage at CCC-Wirral as part of the redevelopment.
- Continued engagement with the Dementia Action Alliance (DAA) and adoption of Dementia Friendly Hospital Charter.
- Submission of Health Education England's annual dementia training compliance.

Aims and next steps

The key areas of work to be undertaken in the next 12 months will be:

- The Safeguarding Team will review and revise the current Dementia Strategy in 2022 and build on the work achieved in previous 3 years
- An action plan will be developed following the revision of the Dementia Strategy to provide focus for the actions to be achieved
- Refresh of the staff who are Champions to review their commitment and attendance at the bi monthly meetings of the Dementia / Learning Disability and Autism Collaborative Group
- The Restraint Guidelines to be reviewed and revised in July 2022 as part of the 3 yearly review policy schedule
- The Helping Hands inpatient process on the TV to be re-commenced that allows patients access to snacks and newspapers by the Volunteer Workforce
- Review and revise (if required) the Dementia Strategy, once the Government publish their stand-alone Dementia Strategy in 2022



VETERANS AND ARMED FORCES COMMUNITY

In general, the health of the serving military population is good, due to the expected physical fitness required to join the Armed Forces, social support networks, and access to health care and employment. There are some conditions and/or issues however, which can be higher in the adult veteran community than the general adult population in Great Britain, often classed as an ‘underserved’ group. [Taken from Cheshire and Merseyside’s Health Needs Assessment for Ex-Armed Forces personnel and their families (March 2013)].

The solution comes in the form of NHS trusts having Veteran Aware status and Armed Forces Covenant Award, alongside system-wide working with neighbouring trusts to provide holistic needs & signposting for those Veterans and the wider Armed Forces Community living within Cheshire & Merseyside.

CCC currently holds Bronze Employment Recognition Scheme status, following the signing of the Armed Forces Covenant in 2019.

CCC was named a Veteran Aware Trust in August 2021, the first tertiary specialist cancer hospital in the country to receive this award in recognition of its commitment to improving NHS care for veterans, reservists, members of the armed forces and their families.

The accreditation, from the Veterans Covenant Healthcare Alliance (VCHA), acknowledges the Trust’s commitment to a number of key pledges, including:

- Ensuring that the armed forces community is never disadvantaged compared to other patients, in line with the NHS’s commitment to the Armed Forces Covenant
- Training relevant staff on veteran specific culture or needs
- Making veterans, reservists and service families aware of appropriate charities or NHS services beneficial to them, such as mental health services or support with financial and/or benefit claims
- Supporting the armed forces as an employer

The VCHA was inspired by the heroism of Captain Noel Godfrey Chavasse VC, a doctor who gave his life rescuing men on the battlefields of the First World War.

CCC is the first tertiary specialist cancer hospital, now one of 16 members of the VCHA in the North West and 87 members nationally and is part of a growing number of NHS trusts gaining this accolade.

On receipt of the VCHA certificate in August 2021, Kirsteen Scowcroft, then Head of Patient Experience & Inclusion and Veterans & Armed Forces champion at CCC, said: “The tremendous amount of dedication and commitment by everyone at CCC, throughout the challenges of the pandemic, to develop and embed veteran awareness and service improvements has been truly inspirational and now CCC is officially a Veteran Friendly Hospital Trust supporting Veterans, Armed Forces community and their families throughout their cancer journey.”

Professor Briggs, NHS National Director for Clinical Improvement and co-chair of the VCHA, said: “These trusts should be very proud of the commitment they have made to the service men and women of this country. Welcoming them into the Veterans Covenant Hospital Alliance is a major step towards our aim of ensuring every NHS trust in the country is Veteran Aware.”



Key Achievements

In addition to a successful submission and being awarded with Veteran Aware status in August 2021, we have continued to drive, embed and improve services and opportunities for the Armed Forces Community, not only within CCC, but by wider collaboration across Cheshire & Merseyside with the regional and national Armed Forces networks. Despite the continued and sustained challenges faced throughout 2021/22, we have:

- Optimised the Electronic Staff Record (ESR) and are now able to record workforce veterans status electronically for new starters to the organisation. Work is underway to record existing staff
- Collaborated with NHS England & Improvement Commitment for Carers Programme, and are part of a HOPE Network working group within Merseyside. In November 2021 we launched a Carers Passport, with a focus on family carers, which should provide support and guidance for veterans, and veterans caring for family members who are living with a cancer diagnosis
- Continued to improve support and signposting for the ex-Armed Forces communities by:
 - Forging new links locally with the Liverpool Veterans HQ
 - Raising awareness of a pilot project created in 2021 by patients/veterans living with cancer for other veterans going through the same experiences, called the Veterans Cancer Support Network: <http://veteranscancersupport.net>
- Supporting wider awareness of Op Courage and those particularly affected by the August 2021 events in Afghanistan. www.clatterbridgecc.nhs.uk/news/veterans-and-armed-forces-support
- Developed a page on the CCC website to include a dedicated Veteran, Armed Forces and Carers section, implemented in February 2022 <https://www.clatterbridgecc.nhs.uk/patients/general-information/veterans-and-armed-forces>. In addition, an intranet page to support the CCC workforce was implemented in December 2021
- Clinical teams can now record a patient’s veteran status via the Electronic Patient Record (EPR) notes
- Provide support and guidance to our colleagues at The Royal Marsden, shared lessons with colleagues at The Christie and offered to support a local specialist neurology trust (The Walton Centre), with their application for initial accreditation in 2022
- CCC commemorates Remembrance Day and Armed Forces Week annually.

Aims and next steps

CCC will submit an application to VCHA in July 2022 to retain its Veteran Aware status. This will entitle us to display the Veteran Aware logo to advertise to patients, families, carers and staff, and VCHA Cancer Specialist NHS Trusts in the country.

Following successful VCHA accreditation and upon receipt of the certificate in Autumn 2021, a formal Media/PR event was scheduled in December 2021, for a small formal presentation by the Lord Lieutenant of Merseyside and representative from 208 Field Hospital (Reserves). Unfortunately, due to rising COVID cases across the region, this had to be cancelled and will be re-scheduled at a future date when safe to do so. In the meantime, the Veteran Aware metal hospital plaque will be displayed at CCC-Liverpool main entrance and the framed certificate will be situated in the awards display cabinet.

We are informed that the work CCC contributed to in 2020 to create a veterans passport for health and social care will continue under the leadership and guidance of the Veterans' Places, Pathways and People Programme (VPPP).



EQUALITY, DIVERSITY AND INCLUSION

Key highlights

To mark Black History Month in October, NHS England put together a series of podcasts with their executive team, speaking to them about anti-racism, how they are making a difference and why it is important inside and outside of the NHS.

Hosted by co-chair of the BAME Advisory Group to Regional Executive North West, Devina Halsall, these honest discussions focus on the importance of recognising ethnic diversity within the NHS and how we can be better. The first in the series is with Regional Chief Nurse Hayley Citrine who talks openly about equality and diversity in leadership across the NHS, her own experiences of racism through her family and what she has done to forward equality in her work.

To celebrate and support Black History Month at CCC, the Blackburne House cafe in CCC-Liverpool served meals from different cultures every week during October 2022.



PATIENT LED ASSESSMENTS OF THE CARE ENVIRONMENT (PLACE)

PLACE is a system for assessing the quality of the patient environment. It is an organisational voluntary self-assessment which takes place annually, and applies to NHS trusts, voluntary, independent and private healthcare providers.

PLACE assessments involve local people (known as Patient Assessors) going into hospitals as part of teams alongside staff. Patient assessors make up at least 50 per cent of the teams assessing how the environment supports the provision of clinical care.

In 2020, the PLACE assessment underwent a national review, resulting in a significantly refined and revised question set. As the changes have been extensive, it is important to note that subsequent scores are not comparable to earlier assessments.

PLACE Assessment

Unfortunately due to COVID restrictions, the PLACE assessment was not undertaken during 2021. However, we are looking forward to undertaking a full PLACE inspection at CCC-Liverpool in 2022, welcoming patients and their representatives to review and assess our new inpatient facilities.

Full details of previous PLACE reports can be found here:-

<https://digital.nhs.uk/data-and-information/publications/statistical/patient-led-assessments-of-the-care-environment-place>

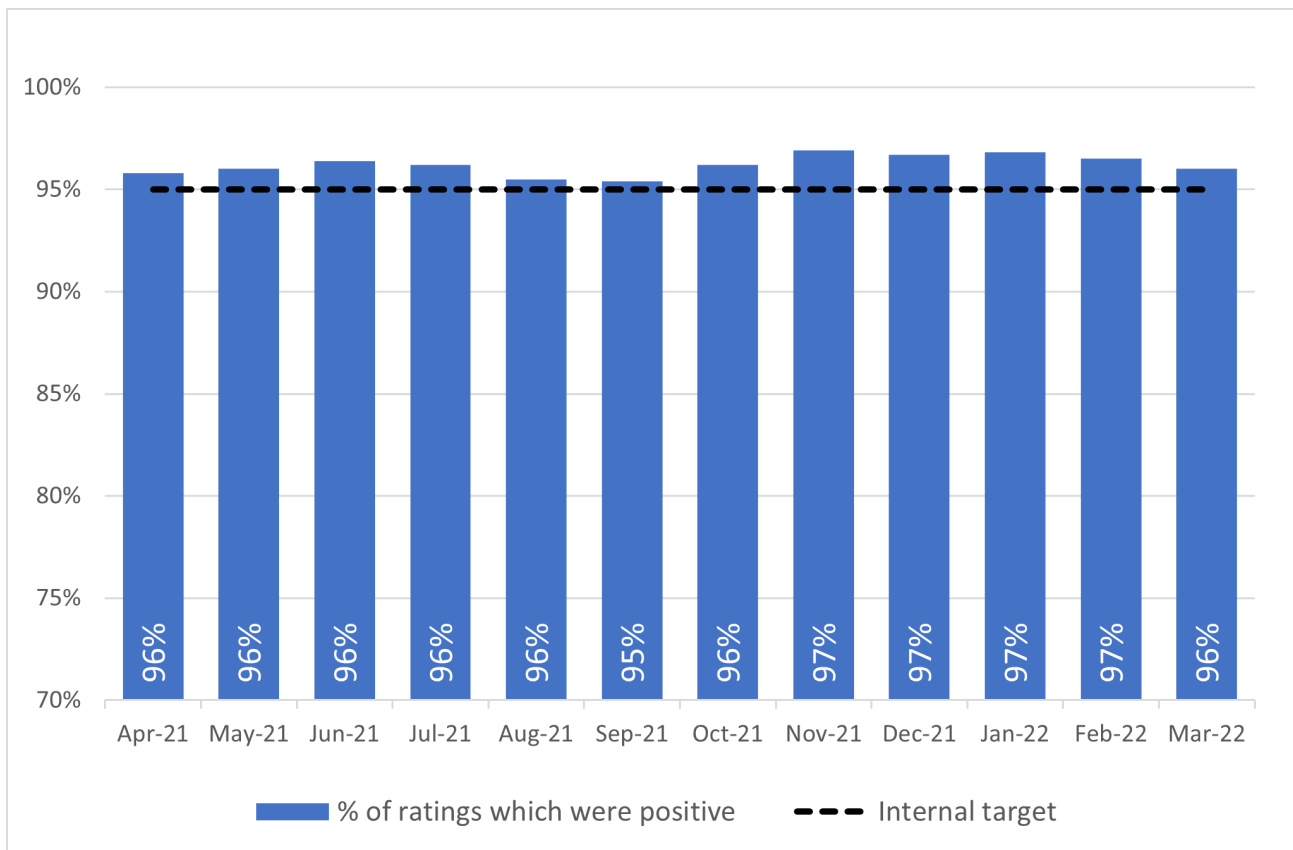
FRIENDS AND FAMILY TEST 2021/22

The NHS Friends and Family Test (FFT) is designed to be a quick and simple mechanism for patients and other people who use NHS services, to provide feedback which can be used to identify what is working well with the organisation and to help improve the quality of any aspect of patient experience.

It is made up of a single mandatory question - "Overall, how was your experience of our service?" - followed by at least one open free-text question so that people can tell us what they want us to know in their own words.

Hospitals should also make it as easy as possible for all patients and people using their services to use the FFT to give feedback. It is important to hear from all patients, especially those who may need more help or support to give feedback. 2020 saw the introduction of FFT SMS text reminder. FFT is also available on inpatient TV screens, mobile tablet devices and an easy read online form is under development for the CCC website, ensuring FFT is digitally accessible for all.

During 2021/22* CCC received 22,314 (96%) responses from patients who rated their experience of care at CCC as being very good or good, with 18,821 free-text comments received. These were reviewed, monitored, celebrated and actioned by the Divisional Teams and Patient Experience & Inclusion Operational Group (PEIOG) and Patient Experience & Inclusion Committee (PEIC). The information received via FFT is also triangulated with complaints and enquiries received by our Patient Advisory and Liaison Service.



**2021/22 data period covers April 2021 to March 2022*

PATIENT ADVICE AND LIAISON SERVICE (PALS), COMPLAINTS AND COMPLIMENTS

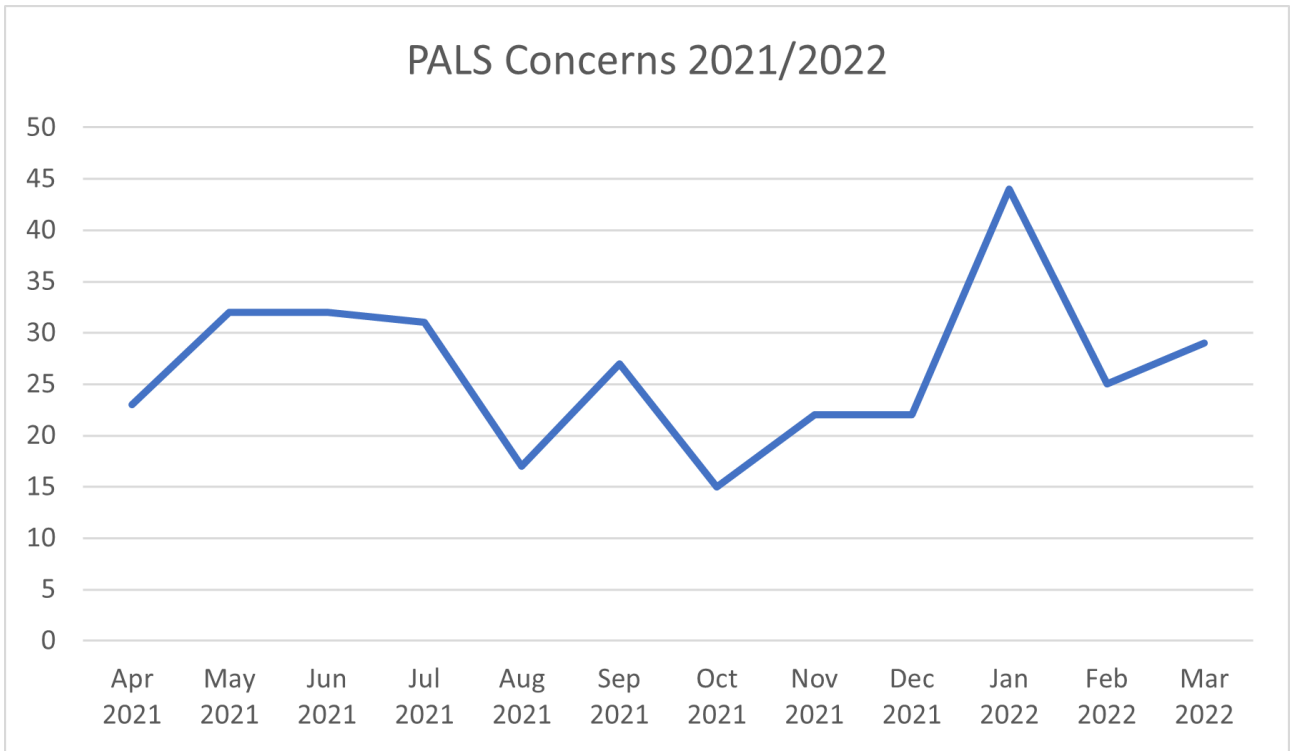
At CCC we triangulate PALS, compliments and complaints as well as other data sources, to understand and learn from identified themes and trends, to support consistent and continuous improvement across the organisation.

Patient Advice and Liaison Service

At CCC we welcome any feedback – good or bad – about any aspect of the hospital. These can be enquiries about needing some information but patients or relatives don't know where to get it. If somebody has a concern or a complaint or would just like to speak to someone but are not sure who, then our Patient Advisory and Liaison Team are here to help and support.

In 2021/2022 a total of **319** PALS contacts were recorded, a decrease from **347** in 2020/2021.

CCC places a strong emphasis on sharing learning from PALS and complaints across the patient pathway to improve patient experience and outcomes. We continue to support placing patient experience/feedback at the heart of service design and development, and we welcome the planned relocation of complaints management within the Patient Experience Team in 2022.

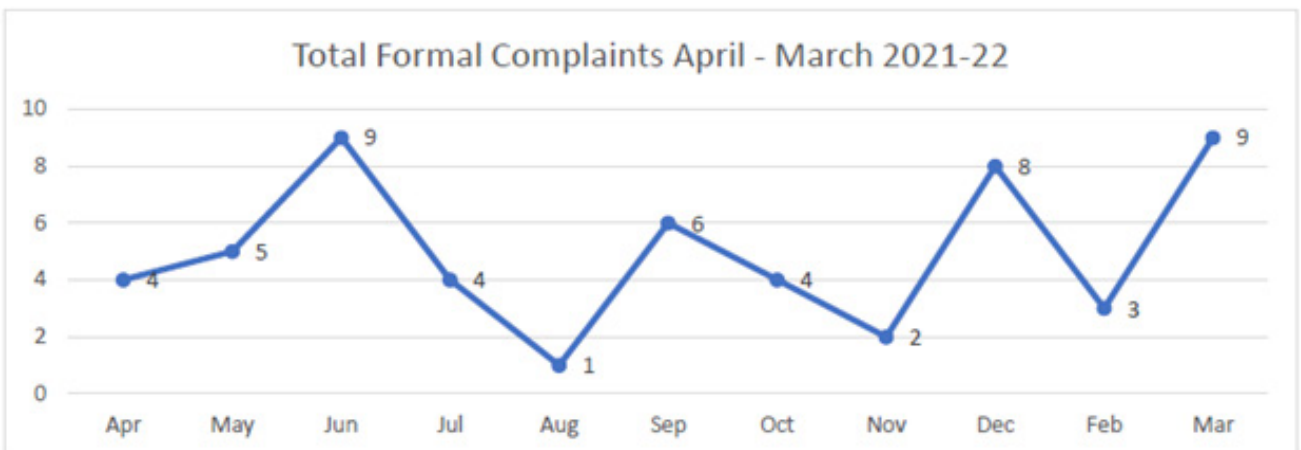


Complaints

During 2021/22 a total of 55 formal complaints were received by CCC. All complaints received in 2021/2022 achieved resolution. Of the 55 complaints received:

- 44 were routine complaints, with 65% responded to within the target of 25 days
- 11 were complex complaints, with 64% responded to within the target of 60 days

Any delays to complaint responses were discussed with the complainants and new response times agreed.



Tables – 2021/22 complaints received by month

Lessons learned from complaints

Learning and actions taken as a result of the upheld and partially upheld complaints received in 2021/22 include:

Description	Lessons Learned
Response required regarding issues with Hotline advice given to the patient	<ol style="list-style-type: none"> 1. Importance of administration systems working effectively 2. Correct phone numbers need to be on clinic letters 3. Patient expectations of CDU open 24/7 service. Hotline is a 24/7 service but CDU is not open of a weekend.
Complaint from daughter about lack of communication, questions about patient's last inpatient stay	Specialist Nurses - to record voicemail messages to direct patients to 24 hour hotline number if they are unable to take the call straight away. Review of the SALT pathway for stroke patients review of stroke pathway.
Complaint has had to chase for Drs letters, prescriptions that have been delayed during treatment.	Consultant reflection on communication and documentation.
Complaint unhappy with deceased husband's end of life care and support	Complainant wanted a central coordinator to coordinate care at end of life - Palliative care team at CCC already act in this role.
Patient complaint about long delay in informing him of significant changes in his condition following CT scan and lack of face-to-face consultation.	<p>Patients should be given the option of face-to-face clinics once re-introduced.</p> <p>Task and message function must be utilised to ensure appts such as bloods are booked appropriately.</p> <p>Learning re voice recognition errors to be shared at local Radiology learning and education forum.</p>

Compliments/Patient Testimonials

At CCC we continually strive for excellence within our services and are keen to know how we can improve. Below are just a few of the compliments (taken from the CCC website and from FFT), that we received in 2021/22:

July 2021 CCC-L Outpatients

"I am amazed at how the staff were friendly, helpful and most important of all they smiled."

August 2021 CCC-A Outpatients

"It was a telephone appointment, so I didn't have to worry about parking. I talked with the doctor whilst I was on the settee in my house and above all the call was made promptly at time that was indicated it would be made."

February 2021 CCC-L Radiology MRI

"Always helpful, smiling and friendly staff, nothing is too much trouble. Pleasant surroundings, comfortable and bright. Thank you for being there."

April 2021 CCC-L Inpatient Ward 2

"I was well looked after. The nursing staff are wonderful and made me feel relaxed. I gave the top rating - I was totally wowed by the inpatient service, nursing staff were incredible, made me feel very relaxed. Very professional and great knowledge and made their care so friendly - I was very happy with all the nursing staff."

April 2021 CCC-L Outpatients

"With everything being the way it is with the pandemic I've been lucky enough to receive my treatment with no interruption thanks to the staff at The Clatterbridge Cancer Centre and everyone at the Outpatients clinic."

Sept 2021 CCC-W Outpatients

"All the services were excellent. The nurses were very professional and provided first class service without any bias."

"I would like to thank all of the angels that work on Ward 3 for looking after my mum for the past week. Thank you all for being so caring!"

“Every single one of the staff at Clatterbridge Cancer Centre, including reception, cleaners, nurses, doctors, everyone I have met have been amazing!! They are all so friendly, helpful, and make it so it’s not a place you dread to come to. They are a credit to our NHS and I am so glad that I am having my treatment at this fantastic new Liverpool hospital.”

“I was referred to the clinic in August and cannot fault how thorough the testing has been. Today was my 5th appointment and I have been cared for by two amazing ladies who have made the whole process bearable. They have reassured me, wiped my tears and made me laugh... Mari and Thelma from the Breast Clinic, Thank You!”

PATIENT EXPERIENCE NARRATIVES

Sarah’s story

Sarah, a second year student nurse living on the Isle of Man with her husband and three children, kindly agreed to share her digital story at the January 2022 Trust Board meeting, as the first digital story to be presented at CCC.

In early 2019 Sarah was feeling really tired and in April 2019, Sarah stopped breastfeeding thinking that would make her feel better. Some blood tests were done, which showed Sarah had iron deficiency anaemia and she was prescribed iron tablets.

After three months, going back for a repeat prescription Sarah saw a different GP who asked more questions and put her on a two-week urgent referral for a colonoscopy.

The colonoscopy found a 10.5cm tumour in her ascending colon that had taken up the whole of the lumen. Sarah had a right hemicolectomy to remove the tumour and lymph nodes. Histology tests found an aggressive mixed cell tumour (70% neuroendocrine and 30% adenocarcinoma) which has a poor prognosis.

As there was cancer in some lymph nodes, adjuvant chemotherapy was required. As the neuroendocrine part of the tumour was larger and more aggressive, she commenced chemotherapy targeting this element, which was completed in March 2020, shortly before the first Covid lockdown.

Sarah found the physical side of cancer – from the surgery, recovery and chemotherapy to being hospitalised for a high temperature – relatively straightforward.



However, she found the mental side of the illness very hard. Due to it being a rare cancer, Sarah felt very much that she needed to be her own advocate and did extensive online research to her own detriment. She educated herself in her illness and searched extensively for research and stories to bring her hope. When she struggled to find any online positivity to cling to, she struggled a great deal.

Sarah is enormously grateful to the people at CCC and the Isle of Man who have cared for her. Everyone, from the surgical team to all at CCC, has been wonderful without exception at every stage.

Sarah is currently not on any medication and simply receives three-monthly scans. She is keen to underline her massive gratitude to the CCC team.

As a result of the pandemic lockdown, Sarah was able to spend time with her children, do Joe Wicks workouts and have video call appointments with the Consultant Oncologist, which was welcomed.

Sarah would like to say: “The most important tip I would share is to use Google with caution. The positive stories exist but are not always easy to find, and it is so easy to end up in a gloomy rabbit hole of over-research. Ring Neuroendocrine Cancer UK instead!”

Sue's story

Sue is a business marketing and innovation lecturer at Chester University who kindly described her full cancer journey from discovering a breast lump, to her reconstruction surgery in October 2021.

Sue was diagnosed with breast cancer in October 2019 and underwent a lumpectomy but then subsequently required a mastectomy one month later due to uncertain margins and histology results.

In February 2020, Sue was prescribed 6 cycles of chemotherapy, which she was given at the Delamere ward at CCC-Wirral. The pandemic struck part way through Sue's chemotherapy, so her first two cycles were a very different experience to her second two, due to having to attend alone when the visitor restrictions had to be implemented to keep all patients and staff safe. In Sue's opinion, attending appointments alone was one of the hardest elements of the pandemic.

The pandemic also caused a deviation in Sue's prescribed chemotherapy plan as the last two cycles were cancelled as the risk of being immunosuppressed and contracting COVID outweighed the benefit of completing the chemotherapy. This was a very difficult decision for Sue to make. In May 2020, Sue had 15 radiotherapy treatments at CCC-Wirral. This was at the height of the pandemic and Sue noted the anxiety amongst all staff and patients at this time. People behind screens, sitting metres apart in the waiting room and no visitors made it a lonely and isolating time.

Sue described how difficult the waiting time for results was and is, how confusing multiple appointment letters from different hospitals and departments can be and how sudden and scary the end of treatment feels.

Sue praised the CCC staff for continuing their good work throughout the pandemic. She experienced kind and compassionate care and she received vital after treatment support through the Maggie's Wirral centre who offered mindfulness and counselling sessions which is something Sue was very grateful for.

Sue would like to say: “Google will never tell you what will happen to you. You cannot google ‘what is going to happen to Sue’, but patient forums, support groups and speaking to other patients who have gone through the same treatment helps.”



Catherine's Story – World Cancer Day 2021

A young woman who began having what she thought were nightmares in her sleep, ended up being diagnosed with a brain tumour.

Catherine Cassidy, 32, from the Isle of Man, was asked by her partner Jim if she had been having nightmares – “I thought I'd been sleeping well, as I didn't recall having any nightmares,” Catherine explains. “But he said I'd been shouting and shaking in my sleep, which sounded like I'd had a really bad dream.”

When the nightmare-like episodes kept happening, Catherine arranged a call with her GP who initially diagnosed her with epilepsy.

As they became more frequent, she was booked for an MRI. This is when it was discovered that Catherine had a type of brain tumour called an Anaplastic Astrocytoma. Catherine says: “My diagnosis was a complete shock. Owing to COVID lockdown restrictions, telling my parents over Facetime was very difficult.”

Catherine had brain surgery to remove the tumour, in a successful operation lasting around eight hours. Following her surgery, Catherine spent three months in Liverpool receiving intensive radiotherapy at CCC-Liverpool.

“I received 36 rounds of radiotherapy from the team at CCC-Liverpool. The team were amazing and made a very strange situation that bit more bearable.”

Through her diagnosis and treatment, Catherine has been able to discover some positives – including a new friendship. She says: “We're a close-knit community on the Isle of Man and lots of people know each other. I met Pamela through mutual friends. She was receiving treatment for leukaemia at CCC just after my radiotherapy finished and we've been in touch throughout our journeys.

“It was amazing to chat to someone going through a similar experience to me and being from the same area, we had a lot in common.”



Both women are now back on the Isle of Man and have enjoyed lunch dates together. Catherine is still receiving treatment from CCC; however the treatment comes in the form of chemotherapy tablets taken at home.

“These tablets should get rid of any potentially dangerous cells and my last dose is in February so I'm looking forward to finishing them and getting my life back on track. I am positive about the whole situation; it takes far more energy to be negative so I try and push ahead the best I can,” explains Catherine.



LOOKING FORWARD – FIVE YEAR STRATEGIC PLAN

Summary Key Priorities for 2022/23

Description	Lessons Learned
<p>Patient Experience & Involvement Commitment (Strategy) 2021-2025 Theme 1 - Listening into Action</p> <p>(Also taken from Patient Experience Improvement Framework (PEIF) 2021 Theme 1 - using patient feedback to drive quality improvement and learning)</p>	<ul style="list-style-type: none"> • We will continue to collect your feedback in different ways to suit your needs • We will work with patient/carer representatives to streamline our committees, in line with feedback we receive • We will publish & display regular 'You said, We Heard' initiatives to keep you informed • We will provide individually tailored support for everyone who has concerns
<p>Patient Experience & Involvement Commitment (Strategy) 2021-2025 Theme 2 - Communicate clearly/ Demonstrate Hearing is Happening</p> <p>(Also taken from Patient Experience Improvement Framework (PEIF) 2021 Theme 2 Robust capacity & capability to effectively collect feedback)</p>	<ul style="list-style-type: none"> • Communicate with everyone in clear, easily accessible, jargon & abbreviation free language • Use a range of communication methods • Use learning from patient/carer lived experiences & shared stories • Improve partnership working between healthcare professionals, patients & carers • Monitor the responses and action plans and ensure patient experience is discussed by all staff/departments every day • Always learn lessons and share best practice

Description	Lessons Learned
<p>Patient Experience & Involvement Commitment (Strategy) 2021-2025 Theme 3 – Act upon feedback/ involvement/engagement – what matters to you, matters to us</p> <p>(Also taken from Patient Experience Improvement Framework (PEIF) 2021 Theme 3 Leadership for patient focus; to embed a culture across the organisation where patient experience is everyone’s business from Board to Floor)</p>	<ul style="list-style-type: none"> • Give everyone a say and leading role in development of our aims and visions for the future • Simplify access • Increase the involvement of people representing the communities we serve • Implement the NHSX Success Measure No 5 of the ‘What Good Looks Like’ Framework to empower citizens • Review the role the volunteers play • Provide support and training
<p>Patient Experience & Involvement Commitment (Strategy) 2021-2025 Theme 4 – give patients a leading voice & support to develop innovative ways to listen, involve & engage</p>	<ul style="list-style-type: none"> • Ensure patient involvement, engagement & co-production is central to CCC culture • Identify & develop new ways to learn from the feedback we are given • Monitor and maintain the effectiveness of all patient involvement & feedback • Implement the NHSX Success Measure No 7 of the ‘What Good Looks Like’ Framework for healthy populations • Lead the way in providing support and training for patient feedback and involvement

Description	Lessons Learned
<p>Supporting Carers</p>	<ul style="list-style-type: none"> • Building on the Cheshire & Merseyside Carers passport with carers, carer networks, NHSE&I NW Carers programme and Cheshire & Merseyside partners
<p>Supporting Veterans & the wider Armed Forces Community</p>	<ul style="list-style-type: none"> • Maintain VCHA Veteran Aware status with successful achievement of 1 year re-accreditation
<p>Be an organisation who delivers outstanding Patient Experience, Engagement and Involvement</p>	<ul style="list-style-type: none"> • To align CQC new five year strategy and become an 'Outstanding' rated Trust in all five domains

CONCLUSION

Positive patient experience, treatment and support are an essential part of an excellent healthcare service alongside clinical effectiveness and safety. The Clatterbridge Cancer Centre is a learning trust and patient experience and public involvement & engagement is at the heart of everything we do.

Our Patient Experience & Inclusion Annual Report 2021/22 aims to give an account of key elements and some examples of this ongoing work. It provides assurance that the new 2021-2025 patient experience, engagement and public involvement & engagement commitment was truly co-produced throughout 2021 to ensure as an organisation we are putting listening into action and helping to drive service development, positive change and research & innovation, alongside a number of future developments.

The overarching ambition of the Trust is to build on the fabulous progress and achievements made in 2021/22, whilst being bolder and braver, driving service improvement utilising the process of true co-production with greater frequency, taking patient experience and public involvement & engagement at The Clatterbridge Cancer Centre to 'Outstanding'.





The Clatterbridge Cancer Centre NHS Foundation Trust

www.clatterbridgecc.nhs.uk

