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Cancer Experience of Care Improvement Collaboratives in the National Health Service in England

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Cover Page Footnote

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Abstract

NHS England started the work described in this article with the ambition of using insight and feedback from the adult National Cancer Patient Experience Survey to grow coproduced service improvements leading to improved patient centred quality outcomes in experience for cancer patients. Based on the Institute for Healthcare Improvement's Breakthrough Collaborative Series, the approach of the Cancer Experience of Care Improvement Collaboratives (CIC) in the English healthcare system was developed, initially with 19 NHS provider organisation teams in 2019 as a face-to-face model, then developing into two collaboratives with an additional 15 NHS provider organisation teams in Cohort 2 and 8 teams in Rare & Less Common Cancers in a virtual framework. Each cohort has reported improvements in patient experience, staff experience and team working, but more fundamentally, have been able to describe a cultural shift in the way they work, together with people, leaving a lasting impact and legacy of this work. Key learning has been recognised with the increasing emphasis on involving people with relevant lived experience as partners and colleagues in the collaborative, alongside flexibility, responsiveness and adaptability as key to enabling project teams to continue where COVID-19 pressures allowed to participate.

Keywords

Human experience, patient experience, patient centred care, coproduction, patient engagement, quality improvement, patient and family centred care, measurement, quality of care, workforce engagement

Introduction

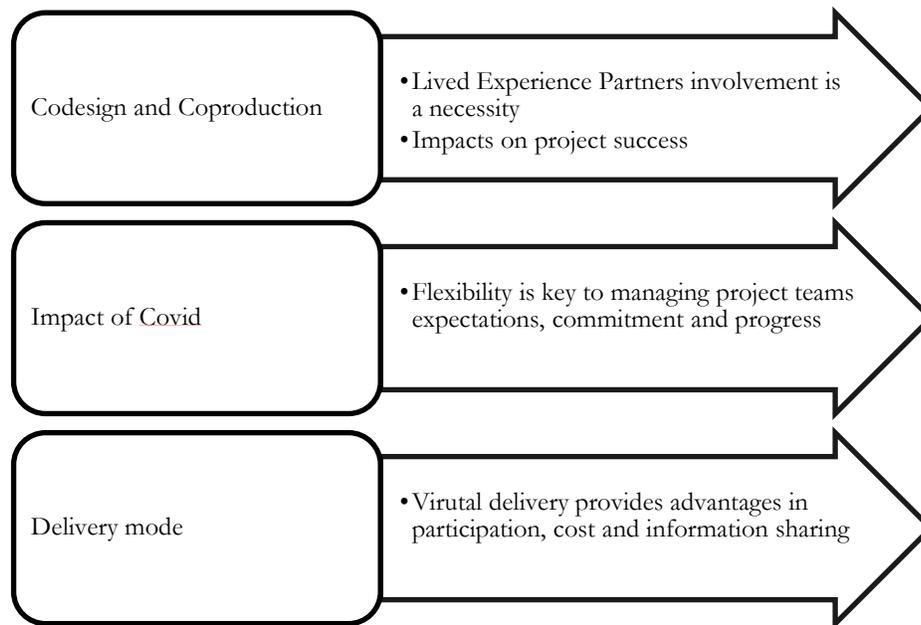
The COVID-19 pandemic has created something of a paradox. Whilst cancer services have been prioritised and continued to be delivered, other clinical services have necessarily been paused to varying degrees, leading to widespread concern about what impact that will have for individuals who must wait longer for treatment. However, at the same time, there has been a renewed focus on the core importance of experience, both in general – not least The Beryl Institute New Existence¹ work – and within clinical specialities.

The National Health Service (NHS) in England affords, by the nature of both a systematic planning and delivery structure (which includes multi-agency Integrated Care Systems, Cancer Alliances and a regional tier), and a singular, universal healthcare shared purpose, opportunities to run national programmes to improve

people's experience of healthcare. These programmes include both the spread of improvement science methodology for use in any setting (for example, Marshall C, Zambaux A, Ainley E et al., 2019²) and the continuing development of focus on improving experience in the context of clinical transformation programmes.

This is a case study with the main purpose being to describe the specific and tangible application of practice for the Cancer Experience of Care Improvement Collaborative (CIC) approach from initial introduction to the development of the framework, to create a learning system for improving the experience of cancer patients in England. It has been substantially adapted from the Institute for Healthcare Improvement's (IHI) Breakthrough Collaborative Series³ to be deliverable in the context of the pandemic. The approach has intentionally put people with relevant lived experience at the centre of the design and improvement process. There have been

Figure 1. Three identified key learning points for a successful collaborative



three key learning points illustrated in Figure 1, which will be described in more detail in the subsequent sections.

Steering groups for each cohort made up of relevant members’ expertise, including those with lived experience, have been key to success. Other success factors included regular sessions with the project teams, ad hoc support for team members and lived experience partners, team visits (Year 1, face to face and Year 2, virtual), the flexibility, responsiveness and adaptability of the framework, and finally the core team and improvement team responding to and meeting the needs of the project teams on an individual level. The core team consisted of the

Experience of Care Lead, and Programme Support Officer from NHS England. Each cohort has reported improvements in patient experience, staff experience and team working, but more fundamentally, have been able to describe a cultural shift in the way they work, together with people, leaving a lasting impact and legacy of this work.

In recent years, the NHS in England has increasingly advocated genuine partnership working with people with lived experience. A Model for Co-production was published in 2016⁴ and, in the context of learning lessons from the pandemic, ‘co-production as default’ has been

Figure 2: Key ambitions for cancer

By 2028, 55,000 more people each year will survive their cancer for five years or more; and

By 2028, 75% of people with cancer will be diagnosed at an early stage (stage one or two).

Care should be delivered in a way that:

- improves quality of life outcomes;
- improves patient experience outcomes;
- reduces variation; and
- reduces inequalities

Source: NHS Long Term Plan 2019⁵

adopted nationally as a ‘critical ingredient for change’. This article also explores how working with people with relevant lived experience has been embedded in, and had an impact on, the work of the CIC.

The Issue to Address

The 2019 NHS Long Term Plan⁵ set out ambitions and commitments for services and clinical priorities in England over a ten-year period (Figure 2).

The national Experience of Care Team in NHS England is responsible for supporting improvement in experience of care for people using the NHS. The team specifically supports the NHS Cancer Programme in the ambition to establish patient experience on a par with clinical effectiveness and safety.⁶

The NHS Cancer Programme is responsible for delivering on the Long-Term Plan for cancer and enables delivery through 21 Cancer Alliances across England whose role is to plan effective care across local cancer pathways, bringing together stakeholders from different organisations including healthcare and social care to transform the service for cancer patients to improve outcomes.

The team wanted to find a way to address the issue of better supporting cancer service providers taking action to improve experience of care using available insight and feedback. There was an opportunity and an appetite to support NHS healthcare providers directly to focus on improving experience of cancer care using the National Cancer Patient Experience Survey (CPES) results.⁷ The idea developed to bring together people who, by using insight and feedback, could grow coproduced quality improvements to support improved patient experience outcomes.

There had been previous experience of using the Improvement Collaborative⁸ approach in the NHS in England, for example, in improving frailty and falls services, and this led to exploration with cancer services. The improvement science methodology includes the Model for Improvement⁸ for defining the aim, understanding measures and testing change ideas using the plan, do, study, act cycle for continuous improvement and sustainability.

This approach was attractive as it had credibility and structure and there was available capacity and resource internally to support the work with improvement expertise. Subsequently, the decision was taken to fund the first cohort to launch in 2019. The funding covered hire costs of venues, speaker expenses, accommodation, and travel costs for steering group lived experience partners. There continues to be no charge to individual project teams to join the CIC. They are expected to release staff, pay travel and accommodation expenses, and reimburse lived experience partners in line with local policy.

This led to the formation of the initial steering group and delivery of Cohort 1 for general and all cancers in 2019-2020, followed by a further two collaboratives in 2020-21 (1. Cohort 2: general and all cancers; and 2. Rare and Less Common Cancers (RLCC)) which are the focus of this case study.

Methodology

The methods described in this section include the practices, and processes applied to enable the success of the improvement collaborative and why they were selected.

Overarching Design and Delivery Method

The key elements of the Breakthrough Series (BTS)³ outlined in Figure 3 underpinned the design of the CIC framework and delivery schedule in all cohorts.

Faculty Selection

In all collaboratives the core team worked with partners to shape the collaborative aims (Figure 4). Cohort 2 and RLCC collaborative overarching aims were adapted to strengthen the focus on coproduction and to align with a virtual delivery approach due to COVID-19. Therefore, project teams were asked specifically to recruit a lived experience partner wherever possible. All collaboratives developed the relevant delivery and measurement framework supported by the formation of a steering group.

The steering group members were selected for expertise in their field and included representatives from NHS England both national and regional, Cancer Alliances, lived experience partners and provider organisations. As a

Figure 3. Key elements of the Breakthrough Series

1	Topic selection
2	Faculty recruitment
3	Enrolment of participating organisations and teams
4	Learning sessions
5	Action periods
6	The model for improvement

Figure 4. Overarching aims of Cancer Improvement Collaborative

The overall aims of collaboratives were to support organizations to:

- Improve the patient experience and quality of care in cancer services by referencing the Cancer Patient Experience Survey (CPES) results and other insight and feedback to drive local quality improvements.
- Learn about quality improvement tools and techniques and put into practice
- Share best practice and innovation resources that are available to providers and participants.
- Share learning from the collaborative improvement projects across England
- Use learning from the collaborative to inform future CPES survey development.

Strengthened and shift in focus for Cohorts 2 and RLCC aims

- Trusts will codesign an improvement project underpinned by improvement science methodology through learning and application delivered as a virtual programme
- Actively promote coproduction and codesign with patient partners included in the project team
- Develop quality improvement skills for the teams taking part through virtual sessions

direct result of learning from Cohort 1, Cohort 2 and RLCC steering groups expanded to include more members with lived experience such as having a RLCC, and who had taken part in Cohort 1, and team members with improvement skills and knowledge. The purpose was both to strengthen the expertise and model the principle of working in coproduction with people with lived experience from the outset.

Topic Selection

The annual National Cancer Patient Experience Survey⁷ (CPES) covers a range of important topics to understand how care is being experienced. The survey data from approximately 60,000 respondents is vital in helping NHS provider organisations to identify the key areas in which improvements are needed, and to provide a baseline measure to understand where improvements had been made. It is not the intention of this article to reproduce the results of the survey. For each collaborative, themes were identified by the steering group, based on CPES results demonstrating a lower-than-average experience of care (against a high general level of experience), or a downward trend over time. Applications were welcomed from provider organisations under these key themes for improvement (Figure 5). The steering group agreed to keep the overall aim focused on improving experience of care allowing flexibility for individual teams to work on discrete local improvement projects which is different to the IHI BST Collaborative model whereby a single project aim is the focus for all.

As the published CPES data for RLCC must often be suppressed due to the small numbers of patients, alternative methods were sought to offer additional insight.

PEP Health (The Patient Experience Platform⁹) was commissioned to understand digital patient voices in near real time in relation to cancer care. The platform uses advanced algorithms to collect, sentiment analyse, and rate comments to form a score on the quality of care. Never before has digital data from social media been used in this way to understand what patients are saying about NHS cancer services. While it is recognized that there are some limitations to this approach, such as comments being posted publicly by people who choose to do so, the work aimed to triangulate with all the other data available to systems and organisations such as the CPES results, complaints, the NHS Friends and Family Test,¹⁰ cancer charity surveys, and Care Quality Commission inspection reports. The outputs from this work show exciting potential to improve the understanding of what people say.

Enrolment of participating organisations and teams

In line with previous identified best practice,² executive support was required alongside a formal sign-up process to ensure support and alignment of the improvement projects with national, regional, and local priorities. Teams were encouraged to work with lived experience partners as part of the CIC, and as mentioned earlier this was strengthened with an expected requirement in Year 2. There was and continues to be no financial fee to joining the CIC; however, provider organisations met costs associated such as time, resources and for Cohort 1, travel, and accommodation.

Figure 5. Key Themes using insight and feedback

Cohort 1 – All cancers	Cohort 2 - All cancers	Rare and Less Common Cancers
Home Care and Support	Reducing the variation in experience of care in Black, Asian and Minority Ethnic communities and seldom heard groups	Reducing the variation in experience of care in Black, Asian and Minority Ethnic communities, Lesbian, Gay, Bisexual, Transgender and seldom heard groups
Hospital Inpatient Care	Experience of care in Diagnostics - waiting, communication, understanding results	Experience of care in Diagnostics - waiting, communication, understanding results
Seeing your General Practitioner	Relational aspects of care - emotional health and support including sensitive conversations, worries and fears and uncertainty	Relational aspects of care - emotional health and support including sensitive conversations, worries and fears and uncertainty
Overall NHS Care	Experience of care for younger people 16-44	Experience of care for younger people 16-24
Other	Experience of care with digital changes	
	Primary and community services support	

Measurement Framework

Developing a measurement framework with different types of measures¹¹ (outcome, process, balancing) is key to ensuring:

- Overall aims of the Collaboratives were met
- Insight and feedback from teams and wider colleagues is gathered to facilitate continuous improvement and reflection; utilising the adopt, adapt or abandon approach
- Tailor the content and delivery of sessions based on team progress

Cohort measures included the number of project teams completing the CIC, evaluations of workshops, site visits, reported changes in staff and patient experience and team working, reported changes in confidence in using the QI tools and techniques and improvements in teams using the IHI Collaborative Assessment Scale¹². The scale was utilised in all collaboratives and subsequently modified for Year 2 to accommodate the changes to a virtual framework. It allowed project teams to track their progress on a scale of 1-5 and was completed before each of the QI sessions and the end of the collaborative.

All teams were provided with a final evaluation form, which used Kirkpatrick’s model of evaluation¹³ and The Model for Understanding Success in Quality (MUSIQ)¹⁴. This formed the basis of the evaluation reports which will be described in the measurable outcomes section.

Adapting to Delivery during the Pandemic: The differences in the Delivery of Cohort 2 and Rare and Less Common Cancers (RLCC)

In Cohort 1 during the improvement cycle (Figure 6), four in-person events were held for participating teams. These included presentations from external speakers to share good practice, opportunities for teams to network and share their improvement journeys, and taught QI tools and techniques sessions across a range of themes such as, the model for improvement, driver diagrams, plan, do, study, act cycles and sustainability and spread. The improvement science support was provided by the Clinical Improvement Project Lead for Nursing, NHS England.

In Year 2, due to capacity issues in the Nursing Directorate, the Quality Service Improvement Redesign (QSIR) team part of Mixed Methods, Improvement Directorate, NHS England provided improvement science and methodology expertise to co-design the CIC Framework. The Collaborative Bundle approach was developed to create a virtually delivered continuous learning system for project teams in Cohort 2 and RLCC.

There was a change in emphasis for delivery style in the virtual sessions from teaching improvement methodology, tools, and techniques to demonstrating application in a collaborative bundle learning system. This enabled individual project teams to have protected time together in the sessions and cross collaborate between other teams to learn and reflect virtually.

For the CIC to enable teams to apply improvement science methodology to their projects for sustainable quality improvement outcomes and to increase team

Figure 6. Cohort 1 Cancer Experience of Care Improvement Collaborative Design Framework

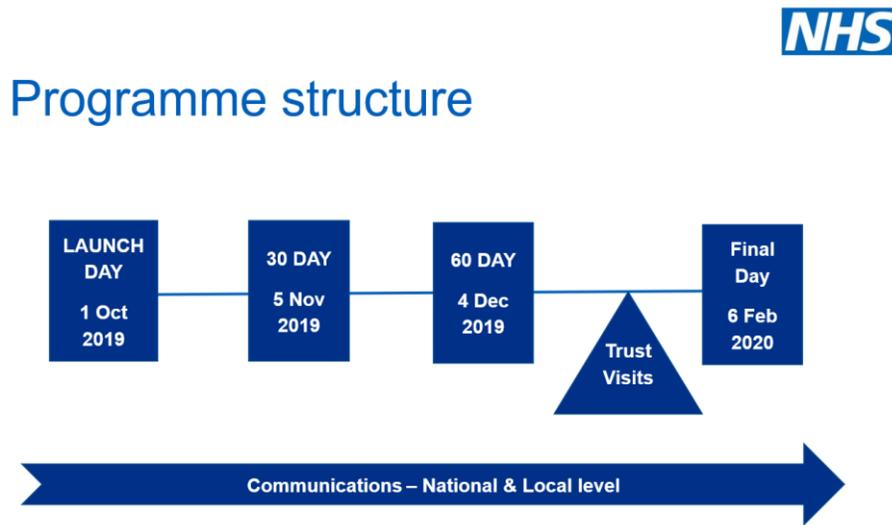
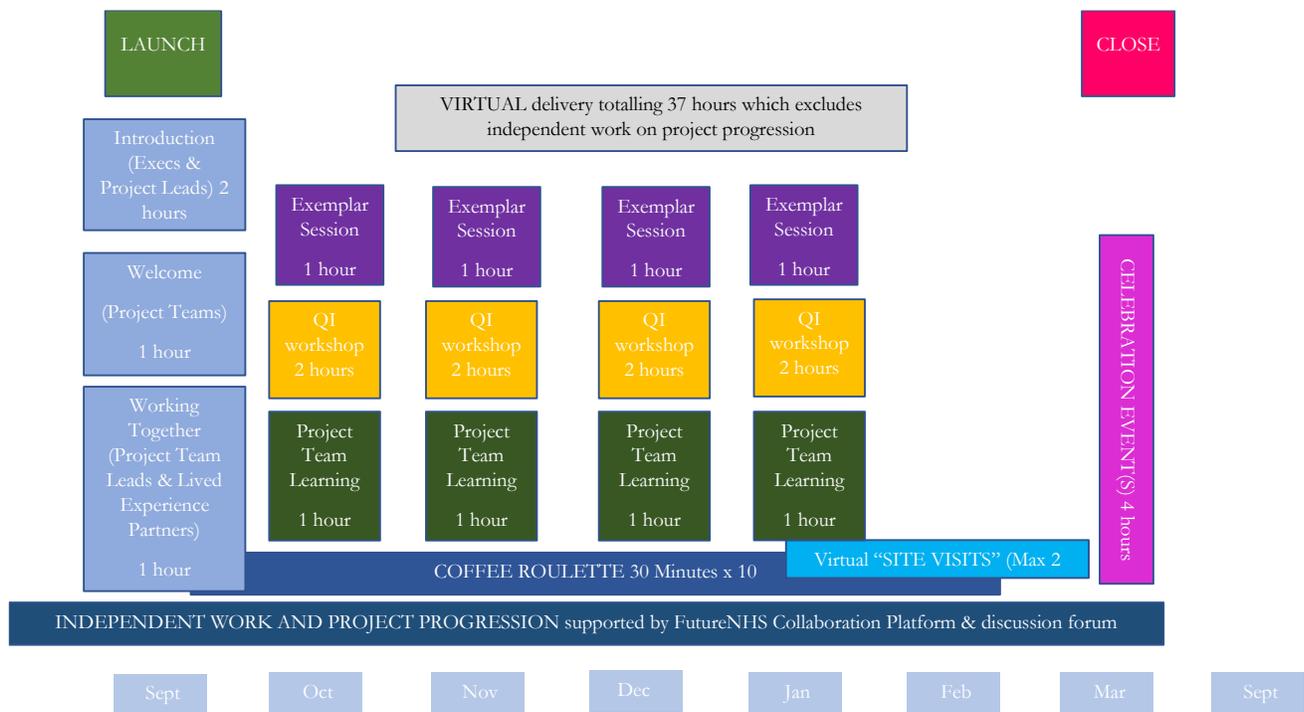


Figure 7. Cohort 2/RLCC Cancer Improvement Collaborative Design Framework



“The Cancer Improvement Collaborative (CIC) framework is underpinned by the principles of the IHI Breakthrough Series Collaborative model (ihi.org). The CIC framework was developed by the QSIR Team, Improvement Directorate, in collaboration with the steering group for the Collaborative led by the Experience of Care team, Nursing Directorate, NHS England. If redistributing, using for publication or promotion, please acknowledge the origins of this work.”

members confidence in their knowledge and skills, the design framework (Figure 7) needed the rigour and agility to create a learning system for participating project teams. Additionally, sharing learning and outcomes across the

project teams, with Cancer Alliances and provider stakeholders, needed to be embedded in the framework, as it was for Year 1 in person.

Figure 8. Cancer Collaborative Bundle Sessions

Cancer Collaborative Bundle:

Session	What you will get	What can we can expect from you
Exemplar Session	<ul style="list-style-type: none"> The experience of Cohort 2 project teams with what they did & the lessons learnt 	<ul style="list-style-type: none"> Listen & learn from different Project teams What & how will you apply the learning to your project journey
QI workshop	<ul style="list-style-type: none"> A demonstration of QI principles, & protected time for project teams to apply QI learning to their project 	<ul style="list-style-type: none"> Experience how the QI tools & techniques principles for the QI session are applied Work with your project team members to apply the learning during the workshop Understand the work that needs to be completed before the next QI workshop
Project Team Sharing & Learning	<ul style="list-style-type: none"> Consolidate knowledge in subject matter identified so far by you Peer discussion with other project teams 	<ul style="list-style-type: none"> Identify a topic of interest from the QI workshop Identify somebody amongst your team to facilitate a discussion Engage with other project teams across Cancer Alliances Contribute to each others learning and experience for a topic area that will add value to you at this stage

'The Cancer Improvement Collaborative (CIC) framework is underpinned by the principles of the IHI Breakthrough Series Collaborative model (ihi.org). The CIC framework was developed by the QSIR Team, Improvement Directorate, in collaboration with the steering group for the Collaborative led by the Experience of Care team, Nursing Directorate, NHS England. If redistributing, using for publication or promotion, please acknowledge the origins of this work.'

Each collaborative bundle (Figure 8) was designed to reflect improvement science methodology tools and techniques applicable by stage of project in the programme.

The Exemplar Session included hearing from Cohort 1 teams to reflect on their collaborative experience, application of improvement science, share lessons learnt with top tips and current state of their project. The Quality Improvement workshop focused on specific improvement science topics such as smart aims, driver diagrams, measurement framework, statistical process control charts, facilitated by the QSIR team to demonstrate application of tools and techniques. Project teams engaged with each other to apply QI learning to their project in breakout sessions. The Project Team Sharing & Learning sessions were facilitated by subject matter experts on a topic area identified by the project teams from the QI workshop to engage in a peer discussion and share their learning.

The Cohort 2, RLCC Steering Group members and one Cohort 2 project lead undertook a mid-point Reflect and Retrospect workshop facilitated by the NHS England Knowledge and Evaluation for Improvement (KEI) team. The discussion, along with a reflective session at the end

of Year 2 generated several recommendations which were implemented for subsequent years.

Online evaluation using Microsoft Forms (Year 2) was undertaken at the end of each session to shape and tailor the content of future sessions. A midpoint survey was developed, using a similar format to the endpoint survey, to enable the core team to understand any improvements made by participating teams over time. Cohort 1 measures focused more on skills learned. However, there was a change in focus to applying the knowledge for Year 2 collaboratives. The same survey was repeated at the end of the collaborative and comparisons drawn between these results and the midpoint survey.

One of the recommendations from the Reflect and Retrospect review was to understand the experience of the lived experience partners in the project teams and offer them support. An informal drop-in session was held monthly, led by Steering Group lived experience partners. A project lived experience partners survey was implemented at the end of Cohort 2/RLCC CICs as a means of capturing insight and feedback to improve the experience of future partners.

Figure 9. Additional benefits from all cohorts

- Building relationships with other teams, trusts reported working closer with IT colleagues, procurement or communications colleagues which will help future work in the trust;
- Sharing learning within cancer alliances;
- Networking with other teams across the country and learning from each other's experiences.

The next section will describe the measurable outcomes from the programme.

Measurable Outcomes

The measurable outcomes are drawn from the evaluations of all cohorts, evidence from the visits and the Celebration/Recognition events. It is difficult to draw direct comparisons between Year 1 and Year 2 due to the change in delivery model described above.

Participating Teams

In Cohort 1 seventeen out of 19 trusts completed the collaborative (89.4%, the target was 90%). Two trusts withdrew due to resource issues. Fifteen out of the original 21 trusts completed the collaborative in Cohort 2 (71.4%) and eight out of the original 11 in RLCC (72.7%). This achievement must be set within the context of the Covid-19 pandemic with significant pressures leading to reprioritisation of resources.

Each project team consisted of approximately 5-7 team members ranging from clinical staff to support and admin staff to lived experience partners. The demographics of the teams were not recorded. It is impossible to know who responded to the anonymous session evaluations and surveys and therefore there may be an issue of response bias in the results.

Overall Measures

Cohort 1 94 % of respondents (n=53) said there was an improvement in patient or carer experience because of the collaborative, 96% reported improvements in team working, and 85% reported improvements in staff experience of delivering cancer care.

In Cohort 2/RLCC 93% of respondents (n=29) reported improvements in patient experience, 89% reported staff experience had improved and 81% reported team working improvements. Additionally, 100% of respondents would recommend taking part in the improvement collaborative to their colleagues.

In Cohort 1 all the teams were expected to use QI tools and skills taught with 79% of respondents reporting improvements in their skills because of the collaborative.

In all cohorts all teams demonstrated improvements in the Modified IHI Collaborative Assessment Scale.

Coproduction experience varied between teams. However, through trusts modelling excellent coproduction, including 15 out of 17 project teams in Cohort 1 having a lived experience partner on their project teams, the benefits of the approach were evident. The teams found the experience enriching and valuable and for those who already had a strong culture of working with patients it reinforced the importance of doing so:

“Already empowered to do this. Patient partner input and codesign was off the scale with this project though which is a really positive change” Project Team Leader (Cohort 2)

Other benefits cited from all the Cohorts are included in Figure 9.

Themes from the trust visits (face to face Cohort 1 or virtual Cohorts 2/RLCC)

Seven key themes were identified (Figure 10) and four of these are explored in more detail in Figure 11.

Evidence of Local Improvement Projects

Teams worked on different projects under the collaborative key themes. Figure 12 (See Appendix) highlights three different teams (one from each collaborative) and demonstrates their project aim, measurement framework, change ideas tested and learning points. This demonstrates the success of the collaborative model in addressing the original issue.

Outcomes from the perspectives of Key Stakeholders

A key theme that resonates throughout this section on stakeholder perspectives is co-production. True co-production happens when different perspectives are not only articulated but heard. The perspectives of key stakeholders reflect equal partnerships with communities in spaces where power is shared, so that services can be more effective and efficient, and in the long-term more sustainable.

Figure 10. Key themes from visits



A shift to being empowered begins at the point of diagnosis, with a collaborative and interactive partnership between the person living with the disease and their healthcare team. This CIC gave everyone an opportunity to change practice and policy and to bring the clinician closer to the patient experience and the patient closer to the clinician. It reflected a true insightful experience where co-production and collective intelligence were fundamental values; experience of care and how this could be improved were the unwavering foci.

This insight was a rich seam in the feedback gathered from the key stakeholders, which included a partner with the lived experience, a patient facing charity which represented the voice of people living with a brain tumour, a clinical nurse specialist, the programme support officer, and a project team leader. Capturing the learning for individuals personally gives an added dimension to this case study and is an important point to support the evidence of unintended impact of the CIC as well as the overall CIC.

Uncertainty was a key theme, not only about how involved people with the lived experience would be, but also from the clinical perspective:

“While I had exposure as a patient partner working locally, this was a national stage with Trusts represented from all over the country. So, prior to the event, I was wondering how this would

work from a patient’s perspective and how involved they would be.” Lived Experience Partner

“This was my first experience working on a national project and initially I had reservations as I wasn’t sure my clinical experience would be relevant or wide-ranging enough to be beneficial to this group.” Steering group member – clinical nurse specialist

A contributing factor to the uncertainty was the virtual nature of meetings due to COVID 19 in Year 2. Implications for social interaction fall within four key domains: importance of face-to-face meetings in addition to virtual meetings, trust building, the role of virtual meetings in maintaining professional relationships and social agenda issues. The steering group meetings were virtual, the study days were replaced by Microsoft Teams enabled sessions which were well-attended and reduced financial and time costs to the participants.

The insights shared by the key stakeholders revealed how this uncertainty was addressed. Teamwork was identified as being a catalyst for change:

“On the project itself, we worked very much as one team and I was afforded every opportunity to act, not as a rubber stamper of other people’s ideas, but as a shaper of the initiative.” Lived Experience Partner

Figure 11. Four themes in more depth

Framework and Methodology	Coproduction	Staff Engagement	Barriers to progress
<ul style="list-style-type: none"> • Pace challenging with difficulty meeting deadlines • Maintained momentum • Recordings online positive resource to access (Year 2 only) • <i>“Being part of the collaborative really provided motivation, focus and direction”</i> Project Team Leader (Cohort 2/RLCC) 	<ul style="list-style-type: none"> • Many teams successful in recruiting lived experience partners • Positive and enriching experience for all • Active partners in presenting progress • <i>“The most beneficial and surprising thing was that we (patients) all had similar priorities for themes for improvement. It’s been lovely to explore those new ideas in a group forum”</i> Patient partner (RLCC) 	<ul style="list-style-type: none"> • Wider engagement key to success • Engaging at the right time with the right staff • Key learning in reaching out earlier to colleagues in IT, imaging and QI teams • <i>“I’ve been a GP for 35 years and I’ve never before seen primary and secondary care coming together in this way...this is meaningful, because it is based on what the patients are telling us they need”</i> Macmillan GP 	<ul style="list-style-type: none"> • COVID-19 single largest barrier with redeployed staff, sickness absence, operational pressures all led to reduced capacity to focus • Cohort 1 barriers were often outside of their control such as IT servers • <i>“It’s been a game changer for me—it’s changed the way I feel about working with patients...It has just 360 turned and ended up doing something else compared to what we thought we would do. Knowing we’re doing what the patients need, it’s been brilliant”</i> Lead Cancer Nurse (Cohort 2)

“Listening to the Lived Experience Partners (LEPs) Network group share what matters to them, was enlightening and emphasised the importance of coproduction; we can never assume we know what is best or what matters most to patients. Working with the LEPs provided a completely different perspective to navigating the collaborative, highlighting challenges I had not considered, which made me realise that there is always more to learn and improve.”
Core Team - Programme Support Officer

Almost everyone commented on how this project took people out of their comfort zone (words describing the initial response to participating included daunting, challenging, tentative) but as the project developed participants moved from the comfort zone to the growth zone. The process of moving zones was not linear and appreciating that everyone was in the same space helped in tolerating and reducing uncertainty.

“The collaborative has challenged me in many ways and often felt ‘behind’ with the added challenge of a global pandemic! Despite this the project continued due to the enthusiasm of the group; they were invested and part of the learning from the outset which I feel made this a success. The experience has brought me out of my comfort zone, and I have learnt about my leadership strengths and weaknesses.”

Project Team Leader

The sense of collaboration, of building high levels of trust, of creating collective intelligence were key factors at play in the success of this project – the openness and transparency enabled the group to expand the possible:

“There is a sense of pride in being part of a national programme and cohort of trusts to improve cancer patient experience; supporting and promoting everyone’s work and networking outside of the collaborative. The knowledge and skills I have learned have been invaluable and transferable to other projects I have led.” Project Team Leader

People with relevant lived experience as partners and colleagues in the collaborative

“Patients can tell you how the system actually works (not just how it should work – or how you think it works).” - Ceinwen Giles, Chair, NHS Cancer Programme Patient & Public Voice Forum at Cancer Experience of Care Improvement Collaborative Cohort 1 Launch Event, 1st October 2019

In 2019, at the outset of utilising the collaborative approach for the improvement of experience in cancer services there was a clear expectation that people with relevant lived experience should be involved as partners in participant organisation’s improvement projects. This was reflected in inputs at the launch event on ‘patient experience’ and ‘working with people who use our services’. However, only a minority of project teams attending the launch event included someone with lived experience and, whilst most subsequently recruited lived experience partners, some teams didn’t.

For those lived experience partners who did participate in Cohort 1 it was a rewarding experience; they were fully engaged in the process of co-designing solutions, providing practical insights into what would work best for patients and challenging assumptions where necessary. This, in turn, led to better improvement project ideas, diversity of patient representation also added a layer of richness to the initiatives, bringing a range of skills to complementing those of the health professionals: one project lead commented that, *“this has been so powerful...because it came from patients.”*

For Year 2 it was clear there was a need to do much more than simply exhort clinical staff to involve patients, when in most cases they had no experience of doing so. The steering group recognised that improvements could be made by including lived experience partners from the outset. Sessions on co-production with people with lived experience were run prior to Year 2 launch and the overarching collaborative objectives explicitly included: ‘Actively promote coproduction and codesign with patient partners included in the project team’.

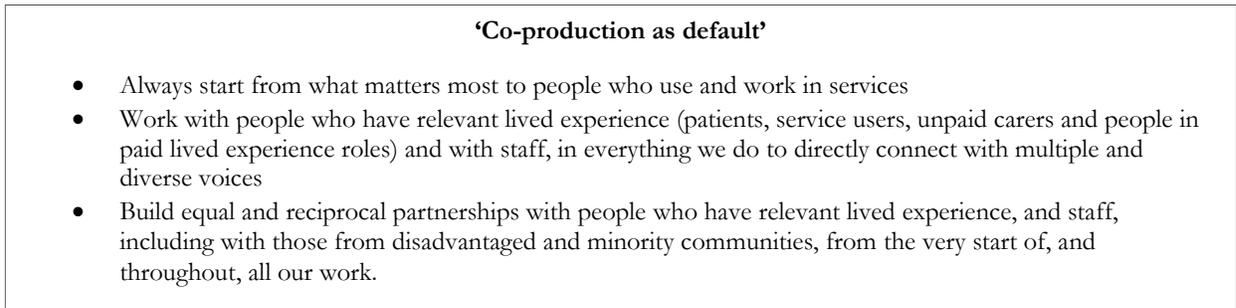
Midway through Cohort 2/RLCC programme, a survey of lived experience partners was undertaken. All respondents felt they were an equal member of the team and that their contributions were valued and listened to. The views of patient partners and project leads on the difference having lived experience partners made is illustrated above (Figure 13). An informal lived experience partners network forum was set up in January 2021, to explore common areas of interest. Three successful events were held, generating lots of ideas about ways to better involve people, setting expectations on roles and commitment and how to reach out and build confidence for partners who have had less experience of patient involvement.

In addition to the significant part that lived experience partners have played in project teams, some have also played leading roles in the launch events and a specific Cohort 2/RLCC Lived Experience event. All CIC steering

Figure 13. The difference having lived experience partners made

<i>(Quotes taken from the lived experience partner survey and the Cohort 2/RLCC evaluation)</i>	
Lived Experience Partners	Project Leads
“Not only hearing the voice of the patients but making it be the focus from the beginning is really important and valuable”	“Patient partner input and codesign was off the scale with this project ... which is a really positive change”
“The rewards of being part of a project team which is focused around improving patient experience are immense”	“Our service users enlightened us in ways we did not anticipate”.
“Being involved in the collaborative ... gives me a level of assurance that the changes the team are making are going to happen”	“There was no hierarchy, and everyone’s opinion was valued”

Figure 14. Coproduction as default



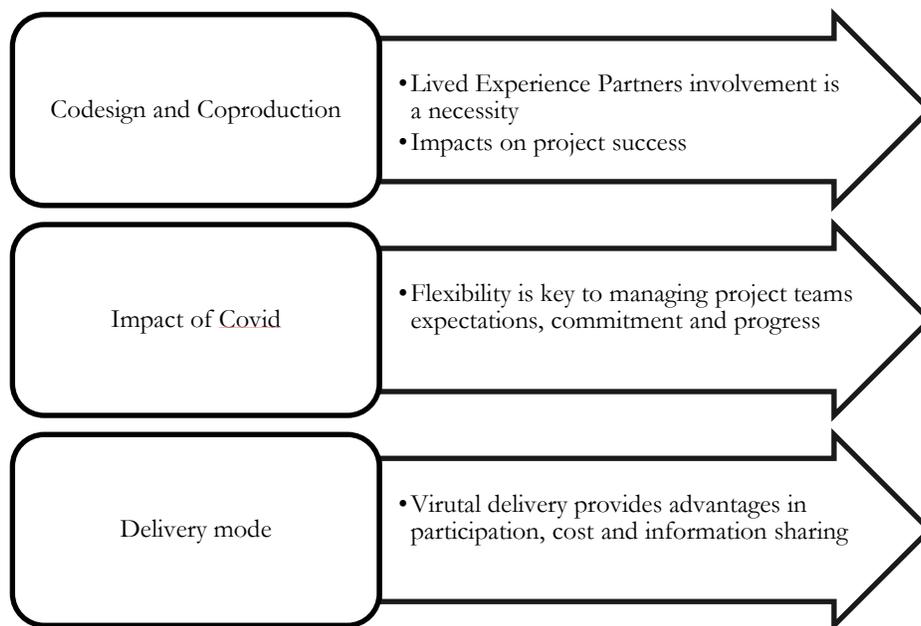
groups have had two people with relevant lived experience who have made an equal contribution to multifarious deliberations, such as on how to better embed lived experience partners and how to manage the collaborative in the context of the pandemic. They feel that they have been able to have a real influence on decision making. The learning from developing the involvement of people with lived experience as real partners in the work of the collaborative has contributed to the thinking behind the NHS in England recently adopting ‘co-production as default’ as a ‘critical ingredient for change’ in how learning from the pandemic should be taken forward. The expectation across the healthcare system has been articulated as shown in Figure 14.

Conclusions

There are three main points to highlight from this case study shown in Figure 15.

The changes made to co-producing with people with relevant lived experience illustrate how learning lessons from the way the collaborative has been delivered has been built into the approach, both year on year and, particularly in 2020, in year. The first wave of COVID-19 delayed the start of the collaboratives in spring. The relative hiatus in the pandemic in the summer of 2020 presented an opportunity to mobilise the collaboratives in September. No sooner had the launch taken place COVID-19 cases and related hospitalisations began to rise again in England, with significant regional variations, and from the end of December 2020 the country entered a more extensive ‘wave’ of COVID-19. The operational pressures the pandemic created for participating healthcare provider

Figure 15. Three key points



organisations was necessarily, from an early stage, something the steering group considered and managed.

The guiding principle was to make it clear that judgements about continued participation were for each organisation to make, and that there was no national expectation or pressure, given that the COVID-19 response had to be everybody's priority. A supplementary aspect of the approach was to be flexible in terms of organisation's participation status; rather than simply being in or out, organisations were able to continue participation, pause or drop-out. This meant that as COVID-19 affected different parts of the country at different times, teams would be able to shape their projects and timelines around their local operational pressures.

Having to make the shift from delivering the collaborative activities face-to-face to entirely 'virtual' delivery had several unforeseen advantages. Virtual delivery made it easier for staff and people with lived experience to participate, removing the need to travel and sessions were delivered in smaller 1-2 hour 'bite-sized' chunks. In addition, the virtual approach enabled all sessions to be recorded and uploaded onto a shared online platform for access at any time.

Flexibility, responsiveness, and adaptability were then key to enabling project teams to continue, where COVID-19 pressures allowed, to participate. Project teams told us that staying with the collaborative had enabled a continued focus on improving experience for cancer patients, despite COVID-19 operational pressures, and provided them with some respite from those same pressures. Furthermore, the learning will be valuable for them in sustaining a focus on improving experience in the period of 'recovery'.

Limitations and recommendations for further improvement

As with the any chosen model there are always limitations and improvements that can be made in the implementation and evaluation of the CIC. By the nature of the CIC, it is a voluntary, optional model and as such the work is completed with the willing providers of healthcare. This creates an additional limitation on being able to spread the outputs of the project teams and share the learning for implementation country wide without a mandated national framework.

Although the previous section identified the importance of the flexible adaptable approach to the virtual delivery, and the positive benefit of the session recordings being accessible to all participants 24/7, there is no doubt that some teams have found the pace of the collaborative bundles and topics covered in the QI workshops to be mismatched to their own pace and progress. A recommendation is to allow the teams more time between

the collaborative bundles to complete work on their projects. This will be implemented with future cohorts, extending the time out to 9-10 months of participation.

The CIC approach is also best suited to healthcare systems who have wider support available within their teams. For example, those teams who can resource project management, analytical, experience of care and improvement science skills appear to be more successful in completing the CIC and sustaining and spreading their learning. After expert advice, the core team has decided not to use the CIC approach for improvement work in specifically in primary care due to the organisations being significantly smaller with limited access to the resources noted above.

The move to the virtual delivery mode has created some limitations in the ability to network with other teams. The dedicated FutureNHS collaboration workspace discussion forum was underutilised, and a Year 2 virtual coffee roulette for project teams in pairs did little to deliver those human connections. Teams also reported that although the virtual sessions were more accessible, they would often be juggling competing priorities with multiple Microsoft Teams chat notifications in the background and back-to-back meeting schedules leaving little time to process or reflect on the sessions themselves. These distractions are often reduced when there is a requirement to physically travel to a face-to-face event, or protected time is supported by the executive sponsor. A recommendation would be to explore a hybrid model of delivery in future cohorts.

The completion of session evaluation, midpoint and endpoint surveys has been challenging in the virtual delivery framework. It is impossible to determine the sample size, and whether the responses are representative of the groups' views or those of a small minority. It is a recommendation to use a range of methods to seek feedback to understand experience and impact of the collaborative. The methods for future cohorts include using the evaluation forms, deeper dive surveys, project team leaders 121 meetings, shaping the agendas for the virtual team visits, and the templates for the Recognition Events as sources of insight.

Implications for further practice

The CIC has developed in response to the needs of the healthcare system in the context of a global pandemic. There have been many learning opportunities, and this continues with the constant shaping and responding to both embedding coproduction, and to the changing needs of the project teams themselves.

Over the two-year programme, the best practices previously identified by Marshall C, Zambeaux A, Ainley E et al in 2019² appear to hold true:

1. Partner with people with lived experience from the very start and throughout every phase
2. Integrate quality improvement, experience of care and person-centred care
3. Identify an executive leader champion who can support you
4. Keep an open mind and don't be tempted to predetermine what changes need to be made
5. People who use our services and staff know the challenges and can co-create change ideas for improvement
6. Involve staff from the beginning

The sustainability of the improvements in experience of care are of the utmost importance. Many of the projects were still in their infancy when each of the formal collaboratives ended, but the emphasis on the collaborative being the beginning of the journey and not the end holds true. The Experience of Care Team co-sponsor, with the charity Macmillan Cancer Support, a dedicated award at the annual Patient Experience Network Awards¹⁵ focused on using insight and feedback from, for example the CPES survey, to grow improvements in care experiences. The purpose is to share learning and shine a spotlight on examples of good practice. Two of the case studies included in this article have been award winners.

After this article was originally submitted in 2021, NHS England launched Year 3 (Cohort 3) in 2021 with the single focused aim of improving the understandability of test results for people from ethnically diverse communities, supporting the reduction of health inequalities through the Core20PLUS5 approach.¹⁶

The participating teams found it restrictive with one aim and difficulties in identifying baseline data led to some incompatibility in the pace of the delivery framework compared to the required slower pace from the teams. As a result, the overarching aim was not achieved in the timeframe of the collaborative. This is not to say this collaborative has not been successful in different ways with the identification of key learning points and the start of a cultural shift in organisations addressing the needs and critical focus of reducing health inequalities.

The 3 key learning points focused on the importance of

- Recording accurate ethnicity for cancer services to understand the experience of specific population groups
- Codesigning and delivering culturally appropriate services

- Using trusted community partners to reach out into ethnically diverse communities to reduce barriers to cancer care.

In June 2022, NHS England launched Year 4 (Cohort 4) using insight and feedback from the first ever National Under 16 Cancer Patient Experience Survey,¹⁷ published in October 2021, to improve experiences of cancer care for children under 16 and their parents and/or carers. This will conclude in April 2023.

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Appendix

Figure 12. Three case studies of local improvement

Trust	University Hospitals of Leicester NHS Trust	East Lancashire Hospitals NHS Trust	Northampton General Hospitals NHS Trust
Cohort	Cohort 1	Cohort – Rare and Less Common Cancers	Cohort 2
Aim Statement	Improve Local Cancer Patient Experience Survey Results for in-patients to be able to discuss their worries and fears with staff by 3%	Develop a database of 95% of Neuroendocrine tumour (NET) patients by end of Jan 2021 to improve their experience of care.	By February 2021, 76% of patients with a prostate cancer diagnosis will report that they find contacting their Clinical Nurse Specialist (CNS) easy
Changes Implemented	<ul style="list-style-type: none"> Weekly Information and Support Rounds on a 19 bedded Oncology Ward (Weekly as average length of stay is 5 days) Information agreed based on most popular information that is requested from the Macmillan Information and Support Centre and top concerns identified by patients on completion of their electronic Holistic Needs Assessments The Oncology Matron and a Macmillan Patient Information and Support Officer introduce themselves to the patients to provide them with the opportunity to elicit their worries and fears. The patients may also help themselves to a range of information leaflets and resources from the trolley 	<ul style="list-style-type: none"> Early discussions on the requirements of the database with key stakeholders – not yet implemented. However, there will need to be ongoing evaluation of the service, and the database, to ensure that there is a quality improvement in the care, delivered to NET patients across the region, and that the database is fit for purpose. Feedback received from patient partners led to a change in direction: The priority was identified as increasing the level of knowledge and understanding of NETS by generalists. As a result, an additional system was developed in conjunction with IT colleagues, that sends out an alert whenever a patient with a NET attends either Emergency Department or Medical Assessment Unit – this means they can be followed up by the NET Clinical Nurse Specialist (CNS) and, thus, opportunities for sharing information and knowledge be facilitated. NET CNS commenced in post 	<ul style="list-style-type: none"> Dedicated contact clinic Monday-Friday Utilisation of different media to communicate with patients Pilot telephone triage system to sign post patients to the help they need in a timely manner Development of webinars/videos to support self-management Promotion of other services to address patient/carer needs in the form of a dedicated sticker

Appendix (cont'd.)

Figure 12. Three case studies of local improvement (cont'd.)

Trust	University Hospitals of Leicester NHS Trust	East Lancashire Hospitals NHS Trust	Northampton General Hospitals NHS Trust
Cohort	Cohort 1	Cohort – Rare and Less Common Cancers	Cohort 2
Process Measures	<ul style="list-style-type: none"> Number of patients supported by the ward round Number of ward rounds that took place 	<ul style="list-style-type: none"> A steering group has been created, meeting monthly initially and then quarterly, to ensure the work of the CNS remain on focus. Number of patients with NETS flagged on system in ED/MAU Number of patients seen by NETS CNS Number of training sessions delivered (when education sessions begin) 	<ul style="list-style-type: none"> Calls answered vs calls to voicemail for CNS. 45% of contacts were answered directly by the CNS Team at baseline Number of views of cancer self-management videos + webinars: <ul style="list-style-type: none"> Jan 21 - 1888 Feb 21 - 2771 Mar 21 - 1681 Apr 21 - 1860
Outcome Measures	<ul style="list-style-type: none"> Post-ward round patients complete a survey supported by a volunteer, to enable measure the effectiveness of the round. 	<ul style="list-style-type: none"> To understand the impact of the change idea on the experience of care a patient satisfaction survey, based on a tool used by the Acute Oncology Team, is being designed in coproduction with patient representatives Repeat qualitative patient stories 	<ul style="list-style-type: none"> Local patient experience survey – telephoned 39 patients and asked % of patients who found it easy or quite easy to contact their CNS and identify which change actions had a positive impact on their experience and which did not
Balancing Measures	<ul style="list-style-type: none"> Staff Experience including feeling able to manage difficult conversations Staff availability to sustain the rounds Number of patients unable to complete questionnaire (end of life care, in isolation or unable to complete survey) 	<ul style="list-style-type: none"> Evaluation of the education sessions for staff 	<ul style="list-style-type: none"> Staff Experience
Results	<ul style="list-style-type: none"> The team implemented the ward support & information round and haven't been able to review the national data set since then due to COVID-19. However, the local survey results demonstrated that 71% of 46 respondents felt that having the information and support team available to talk to had helped completely or to some extent. 	<ul style="list-style-type: none"> The NET Patient Administration System (PAS) Alert system for emergency admissions has been implemented at one Trust site and initial results are being collected 	<ul style="list-style-type: none"> 87% (vs 45% baseline) of patients found it easy or quite easy to contact their Clinical Nurse Specialist. 11% reported they did not need to contact their CNS because their needs were addressed through other methods developed as part of the project 100% of patients found the dedicated information sticker beneficial The most popular method of contacting the CNS was via mobile telephone with 58% using this form of media

Appendix (cont'd.)

Figure 12. Three case studies of local improvement (cont'd.)

Trust	University Hospitals of Leicester NHS Trust	East Lancashire Hospitals NHS Trust	Northampton General Hospitals NHS Trust
Cohort	Cohort 1	Cohort – Rare and Less Common Cancers	Cohort 2
Top Tips/Key Learning	<ul style="list-style-type: none"> To keep project principle simple using SMART objectives. Project meetings fortnightly have led to PDSA cycles of change Patient engagement is key. Feedback methods from the team and patients has altered throughout the project to capture data more effectively Balancing measure have helped to address challenges – the team have adapted the way we staff the project All eligible patients on day of round have been offered opportunity to discuss their worries and fears 	<ul style="list-style-type: none"> Recruit your patient partners on boards AS SOON AS POSSIBLE and LISTEN to them – they know far more than we ever could Set realistic goals – be ambitious enough to motivate everyone but not so big they are unachievable Be prepared to wait for the cogs to turn slowly – they will keep turning 	<ul style="list-style-type: none"> Listening to the patient voice is essential to understand their individual needs Baseline data indicates, the reason patients contact the CNS varies with opportunities to sign post patients directly to services to meet their individual needs Statistical Process Control (SPC) chart demonstrates statistical sustained improvement in patients being able to directly contact their CNS Patients like choice in the use of different media to contact their CNS
Sustainability and Rollout	<ul style="list-style-type: none"> Link it with another patient focused tea trolley teaching round to facilitate ward staff to participate across oncology and haematology wards. Matron cannot attend the full information and support round weekly due to staffing pressures but an address concerns from patients around treatment or in-patient experience at the end. Continue to evaluate patient feedback as part of UHL in-patient survey. Development of virtual concept due to changes in response to COVID-19 	<ul style="list-style-type: none"> The NET Patient PAS Alert system for emergency admissions has been implemented at one Trust site and if effective will be rolled out to other Trust sites. 	<ul style="list-style-type: none"> The dedicated sticker has been rolled out to all tumour sites Other tumour sites are expanding the methods by which patients can contact them. Other tumour sites teams now utilising mobile phone include haematology, secondary breast, Head & Neck Upper Gastrointestinal (GI), Skin Cancer, Gynaecology Dedicated telephone triage system now being piloted in secondary breast and Upper GI Now undertaking “live” patient experience survey across different tumour sites to understand where team are getting it right for patients and where there is a need to explore changes with patients Work with teams to roll out the model to other tumour sites based on the learning from pilot - completion September 2021