Patient Experience Network
Case Study Series:

Cancer Experience

May 2022

Welcome

At the Patient Experience Network (PEN) we are privileged to run the Patient Experience Network National Award (PENNA) programme. 2022 will be the 12th year that PENNA has opened for entries, and we are amazed each year to receive so many incredible and inspiring examples of best practice, things people and organisations are doing to improve the Patient Experience. This includes the experience of care for not just patients, but families, friends, loved ones, carers and service users. As the staff and their experiences are key to delivering a great Patient Experience, we also include examples where the focus has been on improving the Staff Experience.

In this Best Practice resource, we have collated examples from our finalists and winners over the recent years which have a focus on the Cancer Experience. These include any examples of best practice submitted that were short listed, where the focus was on improving the experience for patients with cancer, regardless of which category they entered.

As you will see we have 23 examples in this resource, which include 6 from the CPES (Cancer Patient Experience Survey) category and 4 from the Fiona Littledale category. These two categories specifically have a focus on Cancer and Oncology, and all the other Case Studies included in this report come from our remaining categories whilst still focusing on the Cancer Experience.

Format

This is a rich resource full of thoughtful and thought-provoking content. Organisations submit their best practice to us and are encouraged to include the following information:

- An introduction to their organisation
- Some general information about the context and project
- Rationale and background
- What planning and preparation was undertaken
- The impact that the project made
- Suggestions about relevance to others
- Any standout information
- Key learning points

Summary

We have a wide range of brilliant, practical and pragmatic case studies to improve the experience of care for cancer patients. When reviewing them some consistent themes came out from the authors. Most will not, perhaps, be surprising, but we have summarised these here:

- When planning and running your project be sure to truly place patients are the heart of your work and remember involve them throughout; challenge yourselves on how inclusive you really are
- Identify who your stakeholders are and identify who you should inform, involve and consult across the project. Be as wide-ranging as possible. Include commissioners and non-clinical.
- Set clear outcomes and identify evidence of impact. Be realistic. Measure where possible before the project to establish a baseline
- Be clear with your stakeholders about what the project is and is not. Stay focussed; allow your self to be flexible and adaptable while keeping the goals in mind

- Engage with the executive/ leadership where possible to gain buy-in and profile
- Learn from other services where possible (and go beyond your own specialism), tap into expertise inside and out, or use literature searches to examine what is already available. Collaborate where possible
- Start with the end in mind and consider wider implications, for example impact on tech and integration
- Be willing to invest, if possible, in people training, time, support and systems
- Communicate and share – both what worked well but also lessons learned!

Contents

In summary you will find the following case studies in here:

Project Title	Organisation	Year	Category	Page
A Mobile App for Breast Care Patients	Ashford & St Peters NHS Foundation Trust	PENNA 2016	FINALIST – Innovative Use of Technology, Social & Digital Media	4
Patient Cancer Care Improvement Group	Blackpool Teaching Hospitals NHS Foundation Trust	PENNA 2019	FINALIST – CPES Award	7
Developing A Shared Service Culture Book	Cambridge University Hospitals	PENNA 2019	FINALIST – CPES Award	9
Developing a Patient-centred Service for Neuroendocrine Cancer across South Wales through Commissioning and Co-production	Cardiff and Vale University Health Board	PENNA 2018	WINNER –Turning it Around When it Goes Wrong	11
CDDFT Cancer Patient Experience	County Durham and Darlington NHS Foundation Trust	PENNA 2019	FINALIST – CPES Award	13
Cancer Survivorship Support Event for the Deaf Community	Chesterfield Royal Hospital NHS FT	PENNA 2021	FINALIST - Fiona Littledale Award	17
In Patient Refreshment Service	The Clatterbridge Cancer Centre	PENNA 2021	FINALIST -Partnership Working to Improve the Experience	21
Flower Sculptures for Cancer Services	Derby Teaching Hospitals NHS Foundation Trust	PENNA 2017	FINALIST - Partnership Working to the Improve the Experience, FINALIST – Using Insight for Improvement (Accessibility)	24
Co-Producing Together, Lincolnshire Macmillan Cancer Co-Production Group	Every-One	PENNA 2021	FINALIST - Engaging & Championing the Public	26
To Ascertain the views and experiences of patients aged	Hull University Teaching Hospitals NHS Trust	PENNA 2021	FINALIST – CPES Award	30

between 16-24 years of age diagnosed with a cancer				
Developing Digital Technology Solutions to Improve Care for Cancer Patients	Nottingham University Hospitals NHS Trust	PENNA 2019	RUNNER UP – Innovative Use of Technology, Digital and Social Media	34
Beads of Courage	Nottingham University Hospitals NHS Trust	PENNA 2020-21	FINALIST - Fiona Littledale Award, Personalisation of Care	37
Purple Rainbow Pancreatic Cancer Stories	Purple Rainbow	PENNA 2017	FINALIST Access to Information	42
With You In Mind, Teamwork and Collaboration	Royal Devon & Exeter NHS FT	PENNA 2019	RUNNER UP – CPES Award	45
qFIT	Royal Cornwall Hospitals NHS Trust	PENNA 2021	RUNNER UP - Fiona Littledale Award	48
Emotional and Physical Pathway Improvement for Head and Neck Cancer Patients	Royal National ENT and Eastman Dental Hospital, UCLH	PENNA 2019	FINALIST – Environment of Care	50
Providing Support and Resources for People Affected by Cancer	Shrewsbury and Telford Hospitals NHS Trust	PENNA 2021	WINNER - Integration and Continuity of Care	53
Screening People with Learning Disabilities for Bowel Cancer	South Tyneside NHS Foundation Trust	PENNA 2015	WINNER – Communicating Effectively with Patients and Families	57
Caring for my Family With Cancer	Velindre Cancer Centre	PENNA 2016	WINNER – Communicating Effectively with Patients and Families	60
In-Patient Support and Information Rounds	University Hospitals of Leicester NHS Trust In partnership with NHS England Cancer Collaborative and LLR Alliance	PENNA 2019	Winner – CPES Award	63
Prostate Cancer Remote Monitoring	University Hospitals of Leicester NHS Trust	PENNA 2019	WINNER – Partnership Working to Improve the Experience	65
Setting up a Neuroendocrine Patient Service	University Hospitals of Leicester	PENNA 20-21	WINNER - Fiona Littledale Award	68
Improving Access to Cancer Nurse Specialists and Key Workers	Wessex Cancer Alliance	PENNA 2019	FINALIST – CPES Award	71

A Mobile App for Breast Care Patients
Ashford & St Peters NHS Foundation Trust
PENNA 2016
FINALIST – Innovative Use of Technology, Social & Digital Media

Organisation

Originally established in 1998 from the merger of Ashford and St Peter's Hospitals, the Trust has been on a long journey of development and improvement to its current position as the largest provider of acute hospital services to Surrey residents and having become a Foundation Trust in December 2010.

Ashford and St Peter's Hospitals NHS Foundation Trust (ASPH) serves a population of over 410,000 people and employs 3,700 individual members of staff with a turnover of £263 million.

The Trust provides a whole range of services across its two hospital sites in Surrey - Ashford Hospital in Ashford, and St Peter's Hospital in Chertsey. The majority of planned care, like day case and orthopaedic surgery and rehabilitation services, is provided at Ashford hospital, with more complex medical and surgical care and emergency services at St Peter's Hospital.

Each year we see approximately:
25,000 emergency admissions
40,000 planned inpatient and day case treatments
100,000 A&E attendees
400,000 outpatient attendances
4,000 births

General

In 2016, the Breast Care team at ASPH embarked on a journey committed to taking a co-design approach to improving their patient experience. Feedback was sought from patients over several months and Mr Manish Kothari, Consultant Surgeon, was particularly struck by how some described feeling overwhelmed at the start of treatment and unable to process important information about their condition and care.

Mr Kothari worked with patients to address this need and, working closely with the clinical team, developed the concept of a mobile app which provides the most important information in a way that is clear and easy to access at a time that is right for patients.

Based on patient engagement, the app was developed and downloaded over 100 times in its first month and continues to receive excellent feedback. The app and the project approach are transferable to other care groups and other organisations and staff are beginning to find creative ways of using it to share information.

The project has provided excellent learning on the benefits of patient involvement in quality improvement, and we are keen, through the great platform that PEN provides, to share with others and to recognise the collective achievement of our team.

Rationale

In 2015, the Breast Care team at ASPH started an 'experienced-based co-design project', which aimed to work with patients to identify and make improvements in the care they provide. The team spent a number of months talking to patients about their experiences in receiving treatment for breast cancer - identifying what worked well and what could be improved.

Mr Kothari and the clinical team were passionate about the project from the start and were committed to finding innovative solutions for the issues and areas for improvement that patients identified.

Mr Kothari describes how the experienced-based co-design project was "really enlightening and one of the things many patients talked about was information; some saying they felt 'bombarded' by it. In this digital age, everything is at our fingertips and the internet is flooded with information about breast cancer, but it can be difficult to navigate your way through and know which sites to trust."

Mr Kothari and the clinical team wanted to create something that pulled all the essential information together, was specific to patients at Ashford and St. Peter's and could be easily accessed. Together the team decided to create a Breast Cancer patient information mobile app.

Planning

As part of the project, the Breast Care team talked to dozens of patients about their experiences and how they received information about their care, our services and the options and support available to them. This led to a number of improvements being made, from the way hospital appointments are made to improved training and development for staff. It also provided much of the information that went into forming the design of the mobile app.

The clinical team then worked together with the service improvement team at ASPH in order to plan and build the app using a simple, user-friendly template. Using the feedback, they had received during the patient interviews, the clinical team took the opportunity to review all the information they provide – a huge task, which was only possible because of the leadership and tenacity of Mr Kothari and Breast Care team.

Each member of clinical team who provide support for patients along their pathway were involved in the design and collation of information about their services. For example, the Infusion Suite team produced a short video to explain the care they provide, which was then made available via the mobile app.

Impact

The mobile app for breast cancer patients was created based on first-hand feedback from patients, who stated that the written information they received at the time of their initial diagnosis was overwhelming and difficult to navigate.

Patients are now able to access all the information they need, when they need it in a very simple application. Patients can learn about the members of the team caring for them, find out what to expect at their first appointment, how and when they will receive their results or read about the different treatments available.

In the first month since its launch the mobile app was downloaded 100 times and received over 2,500 page views by service users, it has also received really good reviews from users.

Relevance to Others

The mobile app developed for Breast Cancer patients is transferable to both other care groups and to other organisations. The team have already started to work with other teams in the organisation to develop a similar platform for their own patient information, and this innovative use of simple technology to share information is now also being adopted for staff.

As well as the mobile app, the approach of experienced-based co-design for improving to a service has also been adopted by other teams. Mr Kothari has led and supported his team to share their approach and presented to the leadership team and others with great enthusiasm.

The team have had interest from other organisations and from the media who are keen to learn and share the story in order to inspire others to take a similar approach.

Standing Out

ASPH is an organisation committed to developing a culture of curiosity and creativity, in which staff feel supported and empowered to make improvements to quality and safety. The team believe that what makes this initiative stand out is that it was driven directly from patient feedback and based on asking 'what matters to you?'

The Breast Care team asked patients how they could make changes to improve their experience and the receipt of information at such a difficult time was a key issue raised. The mobile app was designed by the clinical team in response to patient feedback and provides a huge amount of information in a simple to access way.

The use of mobile technology to communicate and provide information with this patient cohort is a breakthrough innovation for our organisation and the tenacity and commitment from the whole team will provide inspiration to others to participate in similar projects.

Key Learning Points

The key learning points for the team in leading and participating in this project include:

- Talk to patients about what matters to them
- Don’t assume you know all the improvements that can be made to a service, or what patients would prioritise
- Involve patients in the design of changes to services and use their feedback to influence others
- Provide logistical support to the clinical team to maximise the chances of success
- Don’t let what you can’t do stop you from doing what you can do!

Patient Cancer Care Improvement Group
Blackpool Teaching Hospitals NHS Foundation Trust
PENNA 2019
FINALIST – CPES Award

Organisation
Blackpool Teaching Hospitals is situated on the west coast of Lancashire and operates within a regional health economy catchment area that spans Lancashire and South Cumbria, supporting a population of 1.6 million. The trust provides inpatient, day care and outpatient services for people affected by cancer and hosts a Macmillan Cancer information and Support Service where patients and their loved ones can receive free information and support from a dedicated team of Macmillan Professionals.

General
Our Nominee for this category are the Patient Cancer Care Improvement group which was established in 2015 and supported in its set up establishment by both CCG and acute Trust and from 2017 supported by the Macmillan Funded service user engagement lead. This initiative deserves recognition to promote how involving patients in service design and delivery has seen measurable improvements in patient experience and CPES results. The varied and challenging demographics across the Fylde coast led the team to think outside of the box and look at integrated ways of working to ensure the sustainability of the work beyond Macmillan service user involvement project funding. Fundamental to this has been empowering service users to lead on co-productive events. This initiative is a key example of how different ways of working have improved outcomes and ensured sustainability for the future.

Rationale
The aim of the PCCI group was to act as advisor and patient carer voice to the Fylde Coast Cancer Steering Group and its work programmes. From its early days it set out to be a partner to all we do and has continued to evolve to a patient led group with its own work plan and patient carer identified and developed improvements.

The PCCI group is still supported by our teams however developed to patient led group where we are invited members their work programme develops in accordance to their advice. They have recently held their own conference to promote and celebrate their work, share developments and to encourage others to become involved - the same event was utilised as focus group for the National Patient Survey results to be reviewed and scored priority areas for the group to support and lead on.

Planning
The group has developed over the years to partners who direct our improvement plans and who we know can co-produce, but also lead and develop as a group. We have a strong collaborative history where input has been provided through the group, its workshops and focus groups/listening events to engage input but more recently by connecting through the Fylde Coast community and support groups patients and or public this has transformed their working to a very different level.

Impact
The PCCI group have made a significant difference to service improvements across the Fylde Coast as per co-production and patient-led examples below:

- Evolving PCCI group and work programme with involvement in commissioned work, peer review, members sitting on other groups e.g., personalised care, Cancer Alliance
- Patient led conference- agenda attached
- Supporting and prioritising improvements from NCPES 2018/19
- Development and support in design programmes for patients, for example Gardening groups, Craft groups, singing groups and a walking group with walk leaders developed from group.
- With cancer I can calendar - patient led idea
- Transport directory developed solely by patients
- Engaging with community / support groups to promote the group and its work -, recent supported the rotary club to fund the next 2 years of cancer health and well-being events
- Involved in NHSE Always event project – to co-produce an information prescription for urological cancers

- Recently nominated for Trust volunteer of the year awards
- Speaking at and supporting events, video resources have supported Trust groups and many already involved in support groups and other groups

Relevance to Others

This initiative is relevant to other internal and external organisations as it will hopefully promote and encourage teams to ensure patient views and opinions remain at the heart of what we do. We hope that by recognition of this initiative it will encourage teams to see the advantages of patient involvement.

Standing Out

This nomination has been made in loving memory of a long-standing member Karen Woods - “a true patient partner” (rest in peace 28/01/2020). Karen will remain in the hearts and minds of all we do across Fylde Coast Cancer Service - she stood for all we are developing and never stopped until the end. Her independent Cancer Charity "Community Cancer Hub" was formed to provide a local place for people affected by cancer to go across the Fylde Coast and in her last days she has continued to work to ensure this is firmly secured in its future. The Hub is planning on opening in May 2020.

Key Learning Points

Whilst the project enables solutions that are always patient centred and relevant, it allows local people to make a difference to the health economy and impact the services delivered to people in their local community

Key learning points include:

- good working relationships with service users are vital to ensure the concept of true co-production
- funding to support patient led initiatives can be helpful to take forward actions and ensure delivery
- patient involvement should be fundamental process and have more impact if involved from the onset
- Important to have a clear purpose and terms of reference for patient group members
- Recognise the importance of patient involvement and ensure they have high visibility within the organisation to influence change

Developing A Shared Service Culture Book
Cambridge University Hospitals
PENNA 2019
FINALIST – CPES Award

Organisation

General

Our service received positive patient feedback, however we found that there was a lack of engagement with perceived “little” jobs and “unnecessary” competences. We have increased the engagement of staff within the Paediatric Recovery and Day Surgery team, by developing a culture of two-way trust by aligning values and strengthening workplace culture.
By using examples from retail (Pike Place Fish Market) and industry (Zappos), the proposal and ideas were communicated effectively to the team.
The service leaders served as supportive and credible role models, and by relinquishing control have created empowering attitudes, encouraged innovation and commitment to quality of care.
The team goals are reviewed monthly at departmental team meetings, then progress is discussed at the weekly “mini-meeting” to continue to drive us forward, ensure focus and that improvements are sustained. The values are to be reviewed annually to ensure their validity.
This work has been presented trust wide and can be adopted by all teams regardless of the focus of the work.

Rationale

Our team consists of 20 staff, 17 registered Children’s nurses and 3 health care assistants. In addition, we welcome Student Nurses and Adult Nurses as learners. We care for children, young people and their families in 7 different areas across our trust following General Anaesthetic for surgery or radiology procedures. The team reported having good morale but appeared to lack engagement. There were gaps in the audit scores of quality safety checks, and difficulties getting staff to complete additional “non-essential” competences. The service received good patient feedback, but the frequency in which it was received was low. The team have a high percentage of part time staff who reported it was hard to feel part of the service. As the team covers 7 geographical ward and recovery areas across the trust, it is difficult for the Senior Nursing Staff team to support staff through the shift. In addition, the Trust had recently announced that in 2023 a Children’s Hospital will be built in site, creating a massive transition and evolution of services.

Within our Trust, there are core values of Safe, Kind and Excellent. The team worked to these, and there were no concerns regarding their behaviour. However, these values are adopted rather than created by the team.

After reading about the positive impact that a culture book had within “Zappos”, an online shoe shop, we decided to explore the benefits that this could have to our team. In Zappos the Culture book aims to provide a glimpse of the Zappos culture to new starters, their vendors and partners – and anyone else who is interested. It is made up of unedited employee submissions about what the company culture means to them.

Planning

We started by asking each staff member to create a list of 10 words for their “core” and “wish” values. These were then themed and prioritised anonymously by the whole team using Mentimeter. This is an easy to use, online feedback and presentation app. The top 5 “core” values are used to focus care and action plans and the top 5 “wish” values are used to focus training and education.
Following this, each appraisal team was given a morning where they were asked to consider:

- What is important to you about the way we look after our patients?
- What is important to you about the way we look after each other?
- What is important to you about the service?
- What is your vision for the service over the next 5 years?
- How are we going to get there?

We then bought together all of the ideas and suggestions and identified theme actions. The actions were prioritised by the whole team, and all members took ownership for individual actions. We now share updates weekly through our mini-meeting and review our vision monthly as a team. We encouraged the importance of regular small changes to make a big impact to our patients and team.

Impact

We have received 100% in our safety audit checks for the last four months, prior to this the scores were in **the** high 90's, which although good, is not acceptable for safety checks.

Within Paediatric Recovery, patient feedback has increased from 1-3 FFT survey responses per month, to 15-29 per month, and we continue to achieve a 100% recommender score.

One action was to collect feedback for our day surgery ward (previously unrecorded) and in September 2019 we achieved a 100% FFT response rate.

We have 0 Vacancies. Up until this point, the lowest vacancy rate we had over recent years been 20% of Band 5 Staff Nurses.

To date, we have made 43 improvements to our service. Some have been "small", some larger. Some examples of these changes are:

Changing the structure of morning handover, to incorporate a safety huddle style, rather than a simple list of patients and procedures.

Creating a crib sheet to support staff during pre-operative visits.

Adding reflection into 1:1 meeting.

Restructuring the learning opportunities to learners.

Developing a Braille Bravery Certificate.

Relevance to Others

This work can be applied to any service or staff group as it is about creating ownership of behaviours and working culture rather than a specific patient or staff group. We have demonstrated that it is particularly helpful in teams where staff engagement is low or where staff have not felt ownership due to working less hours or being in a satellite area.

Standing Out

This work can be applied to any service or staff group as it is about creating ownership of behaviours and working culture rather than a specific patient or staff group. We have demonstrated that it is particularly helpful in teams where staff engagement is low or where staff have not felt ownership due to working less hours or being in a satellite area.

Key Learning Points

- Before you start, provide clear examples of how the process has worked in other areas in order to give the team clarity about expectations and possible benefits.

- Ensure that all staff are given the time to share their thoughts in a safe and open space.

- Don't be too rigid with deadlines – somethings take longer to embed in daily practice than you may think!

- Flex and adapt your ideas – some ideas take several attempts to get right!

Developing a Patient-centred Service for Neuroendocrine Cancer across South Wales through Commissioning and Co-production

Cardiff and Vale University Health Board
PENNA 2018
WINNER – Turning it Around When it Goes Wrong

Organisation

Cardiff & Vale University Health Board is a large and complex NHS organisation providing a wide range of health and wellbeing services to the local Cardiff and Vale population and on a wider-Wales basis through primary, secondary and tertiary care. Welsh Health Specialised Services Committee is a joint committee with the responsibility to ensure that the population of Wales has fair and equitable access to safe, effective and sustainable specialised services.

General

Care for patients with Neuroendocrine Cancer across South Wales has been transformed since September 2017 by developing a nationally commissioned patient-centred service across Welsh NHS organisations. Historically, a fragmented service received significant negative feedback. Led by a Gastroenterology NET expert, working with commissioners and patient groups through co-production, options of the model of care were appraised and implemented at a central and local level. Two cancer nurse specialists have been trained and provide support and education regardless of geography. There is more effective communication from the NET multidisciplinary meeting with equality of access to specialist expertise, diagnostics and treatments. The new service has gained the confidence of patient groups with overall satisfaction rate increasing from 19% to 99%. Using patient reported outcome measures (PROMS), there is a statistically significant reduced burden of gastrointestinal symptoms with 93% of patients feeling their symptoms are being addressed. To achieve sustainability, activity is recorded to guide devolvement of resource. Working with local clinicians has provided education to provide some local follow up for simple cases, guided centrally, which encourages sustainability. The success has been shared with national Wales commissioners, other NET centres in the UK and Europe through conference presentations and social media.

Rationale

Neuroendocrine Tumours (NETs) are uncommon cancers of increasing incidence, mainly affecting the gastrointestinal tract. Requiring the input of numerous specialities, they can be complex with aspects of both a cancer and a chronic disease. An historic, fragmented service existed with inequalities across health care organisation boundaries in South Wales. A patient survey suggested little nurse specialist input, lack of confidence in specialist expertise, poor communication and coordination from the multidisciplinary team meeting (MDM), poor access to specialist investigations and treatments, lack of attention to symptoms and quality of life, and sparse patient information. This resulted in an overall satisfaction score was 19% and a high burden of gastrointestinal symptoms which were unaddressed.

Planning

Led by an expert from an international centre of excellence, a gastroenterology-led service was nationally commissioned across 7 NHS boards or trusts (incorporating 16 hospitals) in Wales centrally from Cardiff. This was the result of a ‘Task and Finish Group’, exploring the patient survey and opinions with representatives from South East Wales and South West Wales NET patient groups, the wider UK NET patient foundation charity representative and clinicians from various specialities across Wales. Options for a service model were appraised by the wider group of patients and their carers in Wales, in addition to commissioners and experts from international (European NET Society) centres of excellence. As the service was implemented, regular stakeholder partnership meetings were held informing patient groups of updates and asking for ongoing feedback into the service on an iterative basis. The core parts of the service implemented were improvement of the processes of the MDM, recruitment and training of 2 NET cancer nurse specialists for patients, administration support, a specialist central NET clinic, improved patient information with specifically designed literature and website, and coordination of the complex pathway across a number of different healthcare organisations (NHS health boards/trusts) for specialist, and local investigations and management.

Impact

In a short space of time (one year), the NET MDM has been transformed, with accurate real-time digital records and timely communication to clinicians and patients with emphasis on accurate coding and database input. Excellent feedback has been obtained from health professionals in all organisations. Two specialist nurses have been appointed, trained through a bespoke training programme and are accessible to all patients regardless of geography and organisational boundaries, providing important patient information and support. Patients have access to a specialist NET expertise in a clinic based in Cardiff with a smaller hub in Swansea. On a repeat patient survey, overall patient satisfaction rate has improved from 19% to 99% with free text answers demonstrating positive patient stories. Previously, 62% of patients reported that they would have preferred more information communicated to them on their disease. After implementation of the new service, this reduced to only 6%. The proportion of patients reporting difficulty in access treatments reduced from 40% to 12%. Patient reported outcome measure (PROMS) were used to evaluate symptoms and quality of life (GI-NET21 and GI symptom rating scales) in addition to a repeat patient experience survey. Regular engagement with the two patient group meetings in Cardiff and Swansea was established for patient education, talks, Q&A and drop-in sessions. With the focus on symptoms and quality of life, 93% of patients felt their symptoms were being addressed. There was a reduction in all symptom categories reported with impact of GI symptom score reducing from 7/10 to 5/10. GI-NET21 and GI symptom scores were lower in the new service ($p=0.006$ and $p=0.004$).

Relevance to Others

The is relevant to other specialist disease areas where care requires the coordination across NHS healthcare boundaries. Despite an extremely negative public image with resulting poor service, it is still possible to ‘turn around’ the situation with genuine, honest and transparent engagement with the patient groups. Through co-production and an iterative method of developing a service with repeated feedback from the patient voice, a successful service which is valued by patients is achievable.

Standing Out

This is the first time that specialist care for people with Neuroendocrine Tumours has been commissioned on a national level in the United Kingdom which has been noticed by international patient groups. A very successful service has been achieved, highly valued by patients which is a transformation from an extremely negative situation. In addition to the complexity of the disease (which is heterogeneous), this initiative has involved complex pathways across financially independent organisations and cancer networks. From the outset, co-production has been the approach in this service facilitated by Welsh Health Specialised Services Committee, with patients centrally involved throughout the process.

Key Learning Points

Despite an extremely negative public image with a resulting poor service historically, it is still possible to ‘turn around’ the situation with genuine, honest and transparent engagement with the patient groups over a wide geographic area. Through co-production and an iterative method of developing a service with repeated feedback from the patient voice, a successful service which is valued by patients is achievable.

CDDFT Cancer Patient Experience
County Durham and Darlington NHS Foundation Trust
PENNA 2019
FINALIST – CPES Award

Organisation

County Durham and Darlington NHS Foundation Trust (CDDFT) is in the North East of England and comprises two acute hospitals, six community hospitals and 80 community sites including outreach services, serving a population of over 650,000. We employ over 8000 staff, and our Trust is the biggest provider of the widest range of services across the largest number of sites in the North of England. CDDFT is a designated Cancer Unit and we have approximately 3,900 new cancer cases diagnosed per year (CRUK, 2019). The Trust provides services to three CCGs: Darlington, North Durham and Durham, Dales Easington and Sedgefield (DDES) and additionally to some patients in Sunderland and North Yorkshire.

As more people survive a cancer diagnosis the physical and emotional needs of patients are increasing. The services provided by the staff and volunteers based within CDDFT's acute hospital settings are pivotal to support these needs and it is essential that we listen to the experience our patients in our care have and how we can continually look to improve this.

General

The 2018 National Cancer Patient Experience Survey (NCPES) results for County Durham and Darlington Foundation Trust (CDDFT) triggered engagement in the NCPES Improvement Collaborative (IC) to address 1 of the 3 questions that scored below the national expected range. A committed steering group were formed, led by the Macmillan Lead Cancer Nurse, to undertake the 90-day cycle of improvement.

The commitment and passion to improve and better understand the experience of patients and staff in CDDFT was at the core of the steering group and was supported by our Director of Nursing.

The IC process was challenging but the learning from the programme was invaluable. The success was not only measured on the detail of information we gained about what, when and how our patients want to receive support and information but also how better to support our staff to deliver this.

Sustainability and structure of gathering more standardised and timely feedback was discussed at each meeting point and the 5 for 5 project evolved out of the learning and discussions.

Having an iterative and achievable rolling programme of cancer patient experience feedback underpinned by a co-production group and digital platform could be applied and adapted to any organisation.

Rationale

The aim of the project was to focus on increasing the number of staff giving financial and benefits advice to cancer patients, in turn increasing the number of cancer patients receiving financial and benefits advice. The National Cancer Patient Experience Survey 2018 identified that CDDFT has scored below the national average in this respect and we would like to better understand how and when patients want to receive this information/support. We also wanted to understand more about how staff perceive asking patients about this topic and whether they are aware of where to signpost patients for support and/or information. The Northern Cancer Alliance supported CDDFT to take part in the National Cancer Patient Experience Survey Improvement Collaborative (NCPES IC). This involved a rapid 90-day cycle, so the steering group chose to focus on achievable data points from breast and colorectal tumour groups, as these also had the lowest patient experience scores.

Planning

The NCPES IC Team

Members of the NCPES IC steering group were:

- Noel Scanlon – Director of Nursing and executive sponsor for the IC project

- Clare Doney – Macmillan Lead Cancer Nurse and IC project lead
- Jason Cram – Associate Director of Nursing and Patient Experience Lead
- Denise Inskip – Cancer Services Manager
- Pat Wright – Macmillan GP
- Matt Hackett – Macmillan GP
- Jo Mackintosh – Northern Cancer Alliance Engagement and Co Design Project Manager
- Maggie Kennedy – Macmillan Volunteer and patient

The project support team includes the Macmillan Personalised Care Project Manager, the Macmillan Information and Support Centre Facilitator and the Personalised Care Cancer Care Coordinator. This team, together with Maggie Kennedy were responsible for collecting data from staff and patients. Data analysis and reporting was completed by the Macmillan Personalised Care Project Manager and Personalised Care Cancer Care Coordinator.

The steering group planned the delivery of surveys to both staff and patients (breast and colorectal) over a 12-week period in order to understand the concerns, barriers and enablers regarding the offer and provision of financial information and support. The questionnaire was designed by the NCPES IC steering group in collaboration with the Macmillan Personalised Care Project Manager and was delivered to staff and patients in three of CDDFT's acute hospital settings by the project support team.

A number of interventions were delivered during the 12-week period to see whether they had an impact on staff and patients' knowledge of how to access information and advice about financial support. The interventions included:

- Ward huddles – information shared about the survey and the need to ask patients the question

- Staff survey raising awareness with both staff and patients

- Posters in clinical areas – promoting Macmillan Information Centres and the Information booklets available

- Audit of HNA quality – Holistic Needs Assessments include a section on financial concerns and the NHS Long Term Plan states that all Cancer patients must receive an HNA following diagnosis

- MIC Strategy and action plan – learning from the IC included and patient experience feedback woven through the action plan. Public and staff consultation events held to ascertain a better understanding of how patients and staff want to receive information and support for cancer in the centres.

Impact

Data was input to the SPC tool provided to CDDFT by the Improvement Collaborative national team.
The SPC results should be interpreted with caution as it was not possible to obtain a standard number of responses from patients each week, due to the challenges presented above. Due to the difference in the number of responses collected each week, the data has been presented as a percentage rather than unique numbers. The number of responses obtained each week varied based on a number of different factors including:

- winter pressures which meant that staff had limited capacity to undertake completion of the surveys

- being unable to identify enough patients on the wards that were well enough to take part

- decreased willingness of both staff and patients to repeat completion of the questionnaire.

CDDFT also collected and analysed qualitative data to support an improved understanding of patient and staff needs in relation to the provision of financial support and advice. A copy of both the staff and patient survey are included as an attachment.

The data obtained from the survey provided excellent insight into why patients within CDDFT had scored lower than the national average on the NCPES question about the provision of financial advice and support. The learning will be used to inform future action planning to raise awareness amongst the staff and volunteer workforce about how to support patients who may have financial concerns. It has also helped the IC team to understand when, where and how the information should be provided to patients, which will help the delivery of appropriate and timely support to them in the future.

More information about the results is in the attached poster and animation video

Relevance to Others

As the initiative is focusing on cancer patients experience, we have felt that it is important to understand that experience at every intervention point from diagnosis to follow up care and living with or beyond a cancer diagnosis in the community setting. Collecting patient experience in a collaborative and cross organisational way will require excellent communication and engagement to reduce the concern of what we may or may not hear from our patients and how this is fed back. Our learning from this process and the integrative approach with primary care and the Cancer Alliance is something we want to share to enable and support a similar approach where others feel there would be a benefit and the Northern Cancer Alliance are keen for us to actively share this for the region.

Standing Out

This initiative focuses solely on the experience of cancer patients and the subsequent roll out of the 5 for 5 projects will standardise the patient experience each tumour group gathers on a rolling basis. This will allow for timely intervention where required and will ease the burden on each CNS team to manage their own patient feedback data collection. The digitalisation and project style of the process during the first year will allow for regular PDSA cycles and a sustainable methodology. There will be a project plan which will withdraw the steering group over the year once the co-production group is well established.

The NCPES results should validate the findings of the 5 for 5 initiative and all findings will be triangulated with what we already know and other data we collect from our patients and staff.

The steering group membership, delivery team engagement and passion for improving the patient experience in CDDFT has been integral to its success.

Key Learning Points

What we have learnt from the process:

- Involvement and engagement are crucial– time of year; avoid the Christmas period, communication strategy to gain engagement, get everyone involved
- Be realistic about the volume of data collection – set achievable targets
- Ask minimal questions and preferably have less free text – too many questions can be a barrier to engagement
- Appropriate data collection team and forum – engaged team members with the capacity and skills to undertake the survey roll out will enable the success
- Keep the Trust board and senior members of the clinical teams informed and included in the process

What we have learnt from patients - DO NOT ASSUME:

- They want to feedback their experiences but also want to be informed of the outcomes from them sharing their thoughts
- They are eager to leave their contact details to be asked further questions or get involved in focus groups

What we have learnt from staff – DO NOT ASSUME:

- Staff who don't work with cancer patients want to understand how they can better support their patients and where to signpost them to
- A number of staff think it is someone else’s job to ask patients certain questions

Cancer Survivorship Support Event for the Deaf Community
Chesterfield Royal Hospital NHS FT
PENNA 2021
FINALIST - Fiona Littledale Award

Organisation

The Macmillan Information and Support Centre (MCISC) opened in June 2017 in the new NGS Macmillan Unit at Chesterfield Royal Hospital serving the population of North Derbyshire. Since opening the centre we developed a comprehensive range of information and support services. These services are based on the needs of people in the area, and we have an active Reference Panel of users meeting three times a year to review and advise.

An important part of our support work is the survivorship needs after a person has undergone cancer treatment. The National Cancer Survivorship Initiative 2010 was co-led by the Department of Health and Macmillan Cancer Support with the involvement of a large range of stakeholders. The initiative has set out to understand the needs of those living with cancer and develop models of care that meet their needs, the goal being to support cancer survivors to live as healthy and active a life as possible, for as long as possible. The ambition of the Centre is to provide services to take forward the initiative. As this submission will demonstrate the needs of the Deaf community were not met by existing survivorship support services and a service event was delivered to establish the needs of this group.

The Centre is staffed Monday to Friday by the Macmillan Support Lead and two Macmillan associates.

General

Our MCISC team identified Deaf people were at a distinct disadvantage during their cancer experience and lacked appropriate information and support despite seeing many healthcare professionals. This was noticeable during the survivorship stage when self-care and returning to a healthy lifestyle is key.

The Lead Cancer Nurse led a team consisting of the centre staff, Macmillan Beyond Diagnosis Project Lead for deaf people and the welfare and psychology service staff working in the centre. An innovative cancer information service event for deaf patients was planned based on the specific needs of this group, supported by BSL interpreters.

The support event was planned based on the specific cancer survivorship needs of the Deaf community to improve the provision of appropriate information for Deaf people living with a cancer diagnosis. The event aimed to give deaf people open and easy dialogue with a range of health and social care professionals using BSL interpreters to ensure easy and clear communication.

Rationale

Deafness is the third most common disability in the world but is largely invisible and often misunderstood by healthcare professionals, making deaf people's experience of using healthcare potentially problematic. Many deaf people use BSL as their main language, and as such experience challenges when trying to access healthcare and communicate with healthcare professionals. For example, it is not generally understood that BSL is a distinct language, and that people can be fluent in sign language but not in English. However, communication with deaf patients is overlooked in most national guidance (National Cancer Action Team 2011), and few healthcare professionals receive training in how to communicate with deaf people.

Within the deaf community, English is commonly learned as a second language and as a result, literacy rates are likely to be below average in this patient group which suggests that printed healthcare information routinely given to cancer patients can often be unhelpful to deaf people.

The needs of deaf patients are not identified in the National Cancer Patient Experience Surveys (NCPES) (NCPES 2019). However, we started to investigate into the experiences of our Deaf patients and identified obstacles in accessing relevant information and support. We found a few papers reporting on cancer educational interventions to improve deaf people's knowledge and attitude toward cancer reporting short and long-term knowledge improvement and we considered our proposal for working on a support event worthwhile.

Planning

A Cancer Survivorship service event was planned for the Deaf community using the experiences of our patients, available evidence and input from the wider centre team to design a bespoke support event. The centre had run regular survivorship courses since opening and these were used as a framework and adapted by the project team to make them appropriate and relevant for deaf patients with any cancer condition.

The topics featured in the sessions were managing stress and fears; nutrition and cancer; and getting active. A welfare and benefits session were added as this was identified this as a priority issue from initial work with the deaf community. The managing stress and fears topic was led by the centre's psychologist and used simple slides in a deaf friendly way, for example using pictures, simple diagrams and avoiding too much text and idioms. The nutrition and cancer topic were adapted from the centre's cancer survivorship courses welfare and benefits topic was delivered by a member of the centre team who worked at Macmillan. In addition, on the first day of the event the group of attendees was asked if they had questions about physical or emotional effects of cancer they wanted to discuss in depth at the next session.

To provide enough time to cover the topics and include the extra time needed for interpreting, the course was run for two full days over two weeks. A team of three interpreters were engaged to cover the two days.

Deaf patients were identified through their clinical nurse specialists; those attending the centre, through a local deaf support group; and through a new 'Deafinitely Women's' group. The centre's social media was also used to promote the event, but the usual recruitment procedures such as leaflets and phone calls would not have worked.

A total of 14 people attended day one, and 16 people attended day two.

Deaf awareness training was organised for the staff who would be facilitating the event and delivering the sessions to ensure their knowledge of the specific needs of this group.

Attention was given to the room layout to ensure the speakers and interpreters were positioned away from windows to avoid glare and distractions such as posters and pictures were reduced. Staff wore non-patterned clothing to enable group members to focus on the staff members' hands and face.

Additional pre-planning included amending car parking procedures, as the hospital car parks rely on people buzzing and then talking to security staff to exit.

Paper evaluation forms were adapted from the centre's cancer survivorship courses and the questions were posed at the end of each day by an interpreter who wrote down individuals' responses. The responses and discussion about the sessions overall were video recorded with group members' consent.

Impact

The written evaluation comments show high levels of satisfaction with the course and the transcribed evaluation highlight relief in having the information delivered in an appropriate manner for people from the Deaf community. Several people commented they previously had no access to accessible information and as a result their understanding had been poor.

Group feedback on the managing stress and fears topic indicated this was a helpful topic to cover. The psychologist delivering the topic reported that it felt valuable, but that many of the emotions and fears expressed by the group members related to their lived experience as deaf people rather than to their cancer diagnosis.

All group members reported that the nutrition and cancer topic was useful and that they had learned more about nutrition. It became evident during Eatwell guide. discussions that group members were unaware of basic health campaigns and resources, such as the Public Health England (2018)

‘I was quite shocked about all the different types of food. I didn’t have any knowledge of this before I came, and I have learned a lot. I’m really pleased that I have come, and I feel that the information will be really beneficial to me. I have learned things I didn’t know before, thank you’

The getting active session was evaluated positively. The group wanted to know how to improve their health but lacked knowledge about how to access deaf-friendly activities.

The welfare and benefits topic generated much discussion and identified the challenges experienced by deaf patients in understanding the benefits system. The Macmillan-funded Welfare and Benefits centre is delivered by the local council and feedback from this topic was able to be fed back directly.

The interpreter noted that there was lots of frustration among attendees around barriers for deaf people, as they require support to fill in forms or speak on the phone.

Attending these sessions also offered people the opportunity to ask questions and to discuss and understand issues that are important to them. The evaluations suggested that attendance at this type of event is potentially beneficial in deaf people’s recovery and return to a healthy lifestyle.

Relevance to Others

This type of service has huge relevance across healthcare. A starting point for health and social care professionals wanting to improve the support of their Deaf patients and families has to be that Deaf Awareness is seen as important training for health care staff to have some appreciation of the needs of deaf people.

Cancer information and support must be tailored to the needs of the individual to avoid giving large amounts of written information if English is not that person’s first language. Consider use of easy read information booklets and videos.

All staff need to be familiar with the booking of BSL interpreters in their areas.

At Chesterfield we plan to work with the regions Deaf Cancer Support group to offer cancer survivorship sessions at their meeting rooms in the future.

Standing Out

This service event was an initiative based on the actual experience of our patients using the centre. By listening and investigating we identified a gap in the support and information needs of people who are Deaf which we were able to work as a team to address. The days had some challenges in the delivery and as staff we were working in a very different way, but we were all pleased to rise to this challenge.

The main feedback from the group was their overwhelming relief in having information delivered in an appropriate manner for Deaf people, which we considered the main achievement.

From the evaluation we have been able to work to help make our centre as Deaf friendly as possible and are now looking at the wider hospital environment and Macmillan National services to improve inclusion.

Key Learning Points

Engaging and involving the Deaf community to help plan similar events and also recruit is essential.

Taking time to plan the programme based on the needs of people in your area e.g., we found a huge need for welfare and benefits advice which may not be as relevant elsewhere.

It is worthwhile to conduct a literature search will further inform your plans as you will see there is not a huge amount of research in this area of cancer care. Our hospital's medical librarian was particularly helpful in this and widened the search when the initial search had low yields. However, it is important to also appreciate that Deaf people often have a poorer understanding of general or basic health knowledge, which in practice means their general awareness of issues such as the national recommendations for health eating and being activity may not be understood which means delivering these types of sessions needs adapting.

Based on our experience our main advice has to be that working with Deaf groups you may feel 'out of your comfort zone', but that's how Deaf people feel every day, so it is a worthwhile service to develop!

In Patient Refreshment Service
The Clatterbridge Cancer Centre
PENNA 2021
FINALIST - Partnership Working to Improve the Experience

Organisation

The Clatterbridge Cancer Centre NHS Foundation Trust is one of three specialist cancer trusts in England, providing tertiary care and treatment to over 30,000 patients every year from Cheshire and Merseyside.

Operating across three key sites, and with a further 15 satellite clinics across the region to bring cancer care closer to our patients, The Clatterbridge Cancer Centre aims to deliver its services right in the heart of the communities it serves.

The trust currently employs 1,500 members of staff and 70 volunteers.

General

In a complex environment such as a specialist cancer hospital, partnership and collaborative working is an essential component in providing excellent patient care. The COVID-19 pandemic has posed a particular challenge for hospital trusts when it comes to offering patients a first-class experience.

With restrictions on third-party suppliers and friends and family entering our Liverpool hospital, inpatients being treated in our wards were at increased risk of loneliness, isolation, boredom and anxiety. All these negative factors would have been detrimental to patient’s wellbeing and their experience of being treated by our Trust.

With patient experience an utmost priority, the need to support patients in a more holistic way during the pandemic was identified. Working in partnership with our hospital charity, The Clatterbridge Cancer Charity, the Trust’s Patient Experience Team began providing inpatient experience packs.

Containing items ranging from food and drink items, to toiletries, newspapers, magazines and art materials, the packs provided patients with welcome distractions and activities, uplifting their wellbeing, knowing they were being supported in this way. These items were all provided free-of-charge to patients, with costs covered through a charitable grant obtained by The Clatterbridge Cancer Charity.

Following the success of the patient experience packs and positive feedback from patients who received them, the Trust extended the project to a collaboration with our in-house catering partners, a social enterprise named Blackburne House.

Having identified the benefit of this kind of holistic support for patients and acknowledging the challenges posed by the pandemic in providing this sort of service, Blackburne House and the Trust established a trolley service for inpatients. This service secured the long-term future of this initiative, ensuring we could continue to provide this service to inpatients, regardless of COVID-19 restrictions and funding.

Rationale

The Clatterbridge Cancer Charity raises funds to provide an enhanced patient experience within the Clatterbridge Cancer Centre NHS Foundation Trust.

The charity aims to support the work of the NHS whilst also providing facilities and improvements to our sites which enhance the standard level of care offered by the NHS, for example supporting the implementation of artwork around our sites.

With this in mind, the Trust and the charity worked in partnership to enhance the patient experience for those receiving long-term care on our inpatient wards, during a time where, due to COVID-19 restrictions, the mental wellbeing of patients was at risk.

The Trust and the charity recognised a need to address this. The overall outcome, which was exceeded, was to support inpatients' wellbeing, boost their mood, stimulate their mind and improve and enhance their overall experience of being cared for by our Trust.

Planning

This initiative was an initial response to a request from an inpatient for a newspaper. Resulting in a collaborative partnership including CCC Patient Experience and inpatient nursing teams, Volunteers, Estates and Facilities (Propcare), CCC Charity and donors, MacMillan Information Support, Blackburn House and Wholesale suppliers. The team quickly established what inpatients required in the form of 'inpatient experience packs' and worked together to make it a reality for patients in a matter of days and weeks. Despite the pandemic restrictions and limitations, it was a testament to all the partners hard work involved to improve inpatient experience during visitor restrictions, as a result of the Covid pandemic.
The Trust has continued to use the model however adapted it to ensure it is sustainable, so patients are able to benefit from the service long into the future.

Impact

Verbal feedback received during the patient experience ward rounds was that the newspapers, snacks & drinks and toiletries were greatly appreciated, particularly for those who had been admitted in an emergency/unplanned from CDU and without visitors bringing those items in with them for the patients.

One gentleman told the team "It was a little bit of normal daily life, during a topsy turvey time". Another patient stated that they "looked forward to the newspaper round and reading about the outside world".

There are 110 inpatient rooms at CCC Liverpool, with the majority of rooms receiving a 'pamper' pack of toiletries, which there is a stock held on the wards at all times now for newly admitted and all patients to the wards to access, over 50 arts packs, which continue to be from the Trust's Arts Coordinator today as 'boredom busters' and over 1200 free of charge newspapers during the period of the initiative.

The initiative ran from October 2020 to December 2020, until the Blackburn House Café was opened, and the trolley service could be safely implemented.

Relevance to Others

The initiative had been particularly effective due to the COVID-19 pandemic, which have placed restrictions on patients receiving visitors during their stay in hospital.

With the correct funding in place, this initiative is relevant to any organisation who may also be forced to impose restrictions for the safety of staff and patients. For example, acute hospitals, care homes or hospices may also be able to be inspired by this model.

Standing Out

This initiative was a true reflection of the Trust's desire to create a positive experience for people being treated as inpatients. The Trust believes in a whole-person approach to care and that supporting a patient's mental wellbeing is an important part of their cancer treatment.

This service acknowledged the needs of our patients as people, understanding how difficult an extended stay in hospital would be without the support of loved ones visiting.

The initiative was also as a direct result of patient feedback – having spoken to patients, we acted upon the information they gave us quickly and efficiently to improve their experience.

Long term, the initiative aims to support a local social enterprise whilst also empowering patients who have the option to choose and pay for their own snack and reading material, giving them a sense of normality during their treatment.

Key Learning Points

This project was a collaborative effort, so ensuring close communication and buy in from all other parties involved is essential to the success of the initiative.

From obtaining the items in the packs, through to promoting them to inpatients and gathering feedback, this required the work of a number of departments to ensure its success.

However, with everyone bought into the idea and united in our desire to provide a positive experience for our inpatients, the challenges face during the project were minimal.

Flower Sculptures for Cancer Services
Derby Teaching Hospitals NHS Foundation Trust
PENNA 2017
FINALIST – Partnership Working to the Improve the Experience, FINALIST – Using Insight for Improvement (Accessibility)

Organisation

Derby Teaching Hospitals NHS Foundation Trust is an acute hospital trust comprising of two hospitals – one acute and one community – in the city of Derby. We have around 8,000 staff and we treat around 1.5 million patients per year. Air Arts is the arts charity for Derby Teaching Hospitals, which aims to improve patient and staff experience through the arts and culture across the whole Trust.

General

As an alternative to traditional signage, Derby Hospitals worked in close collaboration with patients and their families at the end-of-life cancer unit to design and create an innovative and sustainable solution to their problem of wayfinding to the unit. The resulting 10-foot-high flower sculptures (Bluebell and Lily) are a bold and ambitious piece of artwork, which has changed the landscape of the hospital and changed the language used in supporting patients finding their way to cancer services. The work was delivered in close partnership by cancer services, the arts team, capital projects and facilities management with clear aims and objectives. The patients and staff were consulted at every stage and carefully planned focus groups enabled the work to be a true reflection of the wishes and needs of the unit. The collaborative work between departments has been replicated on projects in other hospital areas, most notably the building of a staff remembrance garden. Feedback has been gathered from patients and staff demonstrated the deeply positive impact that the process and resulting artwork has had on this group of people.

Rationale

The flower sculptures came about from a request from patients and staff for better signposting to the Macmillan unit. The building is tucked away with no visible landmarks and opposite a large car park. Directions to the unit were given as follows: 'park in car park 6, cross the road, walk alongside the director's car park and turn left at the end of the wall. 'Our cancer services are one of the largest in the country, where over 200 patients are treated every day, many for end-of-life care. This unit is sited on one of the largest hospital sites in the country, so effective signposting is crucial, particularly as many patients are distressed and very poorly. Getting cancer patients and their visitors to the correct entrance and car park for treatments had proved problematic and increased the anxiety for patients at a very stressful time in their lives. This project aimed to provide a more positive, reassuring welcome with clear landmarks to guide patients easily to the unit.

Planning

A consultation with the patients, staff and visitors led to the idea of sculptures as landmarks to sign the way to the unit and its car park, as an alternative to traditional signage. The hospital arts team worked with the cancer services team to form a commission panel to undertake a national call out for artists to submit proposals. Following this process, international blacksmith artist Jenny Pickford was commissioned to create the work. Jenny Pickford led focus groups for staff, patients and their relatives and carers to discover their favourite flowers and the memories behind them. Answers to 10 questions were analysed to create a project which best fitted most people's answers. The Bluebell and Lily of the valley were the most popular responses from the groups, evoking happy memories and positive feelings, so these were chosen as the most appropriate flowers to signpost people to the unit, particularly as the brand colour of the unit is purple. Creating two sculptures enabled us to provide a signpost to the car park and entry road, and one to the unit entrance.

Impact

The new flower sculptures make signposting clear, positive and straightforward. The flowers are over 10 feet in height, lit at night and clearly visible along the hospital loop road and entry road to cancer services. This provides clear, distinctive and beautiful signposting to the unit. The instructions are now 'park opposite the bluebell and walk alongside the path towards the Lily – the unit is on your left' It is difficult to measure the impact in a quantitative way, and we have measured impact by gathering verbal feedback and written quotes from patients, their visitors and staff. One particular testimonial refers to a lady whose decision to end her own life was reversed thanks to the flower sculptures being part of her daily trips to the hospital. This is an incredible testament to the uplifting and positive power of this artwork and has deeply moved everyone involved in the delivery of this work. A selection of quotes and testimonials are attached. 'They lift your spirit. They are absolutely beautiful so graceful.' Patient

Relevance to Others

This initiative is relevant to other departments to demonstrate the results which can be achieved from partnership working with patients, their families and staff. The positive impact on social interactions and collaboration between these groups was inspirational and gave many patients the opportunity to be consulted and involved in the creation of something truly beautiful and unique at a time when many opportunities are ending for them. Other healthcare settings can take inspiration from our project as a great example of collaboration to achieve something unique and meaningful for the patient groups they work with

Standing Out

True collaboration and detailed consultation with the patient group and staff has meant this project has been a significantly positive change for the unit. The collaboration with the cancer services team, the arts team, capital projects and facilities management has led to the successful design and construction of a permanent finished piece, part of the landscape of the hospital, lit and maintained by the hospital and highly effective as a way-finding piece. This has Truly brought these teams together to focus on the patient Experience Patients and their families love this work, as it gives them a sense of being welcomed and cared for before they even enter the hospital. Using local suppliers and a combination of traditional blacksmithing techniques and newer technologies has created a piece which is strong enough to withstand the elements but beautiful to look at. The leaves of the sculptures were worked with the fly press to create the veining on the steel to provide both pattern and strength to the leaf. The leaves are flexible enough to move slightly in the wind to give the sculptures an extra element of life. The glass flowers were made in Worcestershire at Top glass and the sculptures created in Hereford by Jenny.

Key Learning Points

Our lengthy process to find the right artist proved to be worthwhile as Jenny Pickford brought exactly the right combination of professionalism, understanding and collaboration to the project. Working with patients at end of life can be something that many artists find difficult, so it is crucial to find the right partners who will be sensitive and aware of patients' needs at this time. Working in close collaboration with both the patient groups and the staff was very rewarding and gave us a truly unique and beautiful piece of work which will last a generation. By adding the capital projects team and the facilities management team it has built lasting relationships between the unit and the rest of the hospital which is something we are looking to replicate across the Trust when looking at new projects. By using the Patient experience team as a conduit to this project it enabled a wider collaborative team effort because of the additional contacts they have which enhanced the project.

Co-Producing Together, Lincolnshire Macmillan Cancer Co-Production Group
Every-One
PENNA 2021
FINALIST - Engaging & Championing the Public

Organisation

Every-One is a Lincolnshire based charity that works for the benefit of unpaid family Carers and the people they care for. We do that by seeking to influence services whilst delivering a range of health and wellbeing initiatives empowering people to have a voice.

We work with people with lived-experience, commissioners, providers and employers to enable quality development, co-production facilitation, provide mentoring and awareness training alongside developing and incubating volunteer led activities. Our vision is 'making wellbeing personal'.

Every-One has grown over the last 5 years to become known as local experts in strategic co-production and person-centred approaches whilst also being involved in national programmes such as Integrated Personal Commissioning. We aim to be the continuing voice of people with lived experience within health and social care settings and to be the conscience on the shoulder of local systems and services to ensure that person-centred approaches are recognised, supported and embedded into business as usual beyond the range of short-term projects and initiatives.

Every-One employs 8 staff (full / part time) and a number of freelance Associates. Our Board of Trustees has 6 members.

We are a well networked organisation that fosters positive, can-do relationships with peers and commissioning services. With a small team, we are altruistic and influence beyond our capacity to help to shape services for people. We are open to partnership working, personal and organisational growth and learning.

More about our work programme can be found at www.every-one.org.uk

General

We believe that when you bring together services open to genuinely engagement, with people, who want to work positively to improve services for all…. that's where the magic happens!

The Lincolnshire Macmillan Cancer Co-Production Group was established in May 2019 to co-produce the Living With Cancer Programme. This group of people with lived-experience of cancer was enabled by the partnership of Macmillan, the Lincolnshire CCG and Lincolnshire charity, Every-One.

Together we have:

- Ensured joint leadership, listening, sharing and acting on feedback (Leadership)
- Embedded co-production throughout the core programme to support system wide change (Innovation)
- Engaged in meaningful activities that are important to people and services (Outcomes)
- Supported people with lived-experience who are now skilled and confident to engage alongside a legacy of people-led change (Sustainability)
- Maximised opportunities for dissemination of learning (Transferability)

This long-term relationship, where people's experiences have been valued and listened to has led to positive change for others in Lincolnshire.

Rationale

The Lincolnshire Living With Cancer Programme (LWBC) started in 2016. The Programme ensured co-production and co-design approaches ran through its veins. The programme aims are to:

'…Develop person centred, local support for people living with Cancer, their carers and significant others in Lincolnshire through a more holistic and person-centred approach to meet the needs of those Living with Cancer'. (LWBC Strategy 2017 - 2019)

It was fundamental to the programme that people receive and access timely, localised, seamless and personalised care to support healthier lives. Co-production is a vital part of the programme, to engage with those with lived experience to help drive change.

To ensure the programme was successful beyond its' existence, it has had to influence change through bringing people together across the systems and this included people with lived experience as a key part of that jigsaw.

The rationale for co-production, was to build a long-term relationship with people, to invest in their skills, knowledge and confidence to be equal partners throughout the remainder of the programme.

Planning

The Co-production Group was a long time in planning. It was important to all involved that co-production would provide real value to the programme whilst protecting and supporting those people engaged.

Time was taken to explore potential risks and opportunities, to establish appropriate values and ethos for the work.

Neutral facilitation was always an important part as it enables the conversations and relieves all from the burden of practicalities and logistics to ensure their time is spent focussing on having great conversations.

Commencing May 2019, it has been built on 6 key stages:

- Commitment and leadership – working with all staff involved to ensure they appreciated this as a different way of working and a change of approach as well as how to work with people with lived-experience.
- Contact and connect – recruiting to the group through an Expression of Interest. It was key to understand people's motivations for involvement and ensure they were ready to be involved in relation to their cancer experience.
- Agree a common purpose – reviewing the strategy to identify areas of mutual importance and getting joint sign up of expectations and approach.
- Build skills, knowledge and confidence – investing time in people and valuing them by supporting them to be able to engage. It took patience to build the group and ensure they are brought along with the work and not dictated to.
- Co-produce – working through a work programme of strategic and operational issues.
- Review impact – ongoing and planned evaluation to review and adjust ways of working / work programme from perspective of LWC Programme and the group.

A decision was consciously taken to balance the need for planning against the fluidity, evolution and autonomy of the group, leaving room for them to shape how we work.

Impact

The Co-production group work has been evaluated from 3 perspectives; that of the LWC work programme, the group members and programme leads.

The programme…

The work of the Co-production Group has had impact at both a strategic level and operational level and beyond. The LWC Programme Lead, Kathie McPeake said:

“Invaluable. The group has become valued members of the wider Living with Cancer team. Without the group, I don't think we would have been able to develop quality pieces of work…… It has served to consolidate my 'person centred' practice and remind me that I might work in this field, but I have no concept of what it's really like to receive a cancer diagnosis. It has also consolidated my view that this is the right thing to do.”

Examples of work completed include:

NICE Guidelines – The group were instrumental in contributing to the Lincolnshire response to the NICE consultation on Cancer Care Review guidelines.

Nurse’s script – The group worked with staff to draft a script for Cancer Care Review calls

Pre-hab training design – Co-produced with Chris Styranka, Occupational Therapy Project Lead Enhanced Recovery: Oncology & Haematology

Recruitment - supported recruitment to the LWC team

The work of the group has attracted great interest locally and has built a ground swell of co-production in policy and strategy across the health and care system in the county, with further groups developed, such as a Mental Health Transformation Co-production Group.

It should also be noted that whilst delivery by the group was initially paused at the start of the pandemic, it was quickly back up and running, adapting to new ways of working and contributing to the programme.

The group…

Evaluation with the group has been both formal and informal. Each meeting includes a ‘check-in’ to ensure everyone is happy with what has been planned for the next session. The group is facilitated to be self-determining, and this constantly shifts to ensure it meets needs.

It is evidence that individual group members have become skilled, knowledgeable and confident to engage, not only with the LWC Programme, but now also in further co-production activities as a result.

The staff…

The impact on each element of the work programme is fed back to the group in the spirit of reciprocity. An example of this is the co-production of the Pre-hab training content. Chris Styranka, who worked with the group said:

“The group's involvement has enabled us to really ensure that we have tailored our project/resources to the needs of the people we aim to support. All the way through I felt as though they wanted us to succeed; in return we wanted honest, objective feedback - which is exactly what we got…. It's truly made me realise that, as services, we need to constantly be stepping back and looking at whatever we do through the lens of our service users. But, beyond that, if we're not engaging our 'patient experts' then we're leaving ourselves blind to perspectives that are so critical to how we create and improve services.”

The impact on staff has been evident not just in the quality of the work produced together, but also in their personal growth. It has reinforced that it is not only the work programme that is of value, but also the quality of conversations with staff, where assumptions and attitudes may be challenged for the better.

Fiona Roche, the member of the LWC Programme team who worked the closest with the group said:

“I definitely think more about what the group think/say or suggest. I think it made me think more about the people that have cancer in the system and how I shape or change a service/programme of work I am tasked with. It has made me more aware of the decisions we make on our professional roles every day without even considering the people going through the system.”

In summary, the LWC Programme has been all the richer for the group's involvement, they have blossomed and become experts in co-production whilst the staff involved have reflected on their own practice and ethos and taken that with them on their careers.

Relevance to Others

Co-production can make be valuable in so many settings and this group has offered much benefit and learning that can be shared with others. The value of co-production has been demonstrated worldwide and is sharable.

As advocates for co-production approaches, Every-One is committed to sharing our learning and encouraging others to build it into their work. Every-One facilitates a number of co-production groups in the county and the Cancer Co-production Group is a key part of the community network.

Our model to co-production is transferable to other services, programmes or priorities, for example the Mental Health Transformation and Social Prescribing Programmes in Lincolnshire. It has also attracted interest from University of Nottingham as part of research into Co-production and National Voices in supporting voices of people with lived experience.

Our biggest impact however, is that in Lincolnshire, we now have group members and staff who are advocates for co-production and skilled in applying it.

Standing Out

Alongside the commitment and generosity of the individual group members who have willingly given their time and shared their personal experience, the Co-production Group stands out because:

- This group was a trailblazer in co-production alongside Macmillan.
- The investment of support through neutral facilitation – allows the balance and reflection in the discussions. Using a coaching approach with people with lived experience.
- The relationship between the programme leads and group members was open, honest, and mutually beneficial.
- The embedded values and ethos of the work ensures true co-production principles are applied.
- The determination to ensure the group works to consensus and speaks as one rather than a group of individuals.
- Positivity – ensuring an approach of doing this together and with, not to the system. Able to challenge and support at the same time.
- Valuing people – listening, feedback, expenses paid, and it was important to ensure fun and nice sandwiches.

Key Learning Points

Our key learning points are:

- Flexibility - during Covid-19 we needed to hold meetings online. Preparing people for digital is critical for crisis / the unexpected.
- Realistic expectations – it's not possible to co-produce everything, balance ambition while being realistic where you will make the most difference.
- Autonomy of group to refuse work – this has occasionally happened and as a result a Work Request Proforma was valuable in gaining clarity.
- Leadership buy-in – this is needed before you even speak to people with lived-experience. Get the most influential people involved from the start where you can.
- Patience – don't underestimate the time it takes to build the group.
- Honesty - need to be clear, honest and open about negotiables.
- The value of conversations – goes beyond the co-produced 'products'.
- Talk about emotions – there is power in sharing experiences, and it can be cathartic.
- Protect – once people know about the group, they will be asked to do everything. Protect the values, ethos and the group.

To Ascertain the views and experiences of patients aged between 16-24 years of age diagnosed with a cancer

Hull University Teaching Hospitals NHS Trust
PENNA 2021
FINALIST – CPES Award

Organisation

Hull University Teaching Hospitals NHS Trust (HUTH) is a large trust situated in Kingston upon Hull and the East Riding of Yorkshire. We have two main sites, The Hull Royal Infirmary (HRI) and Castle Hill Hospital (CHH). Our services include planned and unplanned general hospital services; a tertiary centre for Oncology and Haematology; centre for Cardiology and Cardiothoracic Surgery, Major Trauma Centre and a range of other specialist services.

We are also a partner in the Hull York Medical School providing comprehensive training placement and support to medical students.

The Trust's secondary care service portfolio is comprehensive, covering medical and surgical specialties, routine and specialist diagnostic services and clinical support services provided to a population of approx. 600.000 in the Hull and East Riding of Yorkshire area. The Trust provides specialist services to a catchment population of 1.5-1.8 million extending from York and Scarborough in North Yorkshire to Grimsby and Scunthorpe in North Lincolnshire and sits within the Humber Coast and Vale ICS.

As an organisation we value the contribution our patients, their families and carers can make to the improvement of our services. We have a Patient Experience Forum and a Patient Council to ensure their voices are heard.

The Teenage and Young Adult (TYA) Service is based within the Queens Centre at Castle Hill Hospital, which is part of Hull University Teaching Hospitals NHS Trust (HUTH). The TYA unit provides inpatient and outpatient services for 19-24 years old patients with a cancer diagnosis within the Cancer Alliance footprint and a shared care service for those patients aged 16-18 years having treatments at the Principal Treatment Centre in Leeds.

The TYA team at HUTH work closely all cancer site specific teams to enhance the care and support already given by the experts in their disease field. This collaborative approach aims to ensure the best possible clinical care with the advantage of expertise in Teenage and Young Adult care, including psychosocial and emotional wellbeing care.

The service has a bespoke 4 bedded ward with a dedicated outpatient area enabling care and treatment to be delivered as locally as possible. The TYA team consists of a Specialist Nurse, a staff nurse and a Youth Support worker who co-ordinate the patient pathway and deliver outreach care as required. This enables them to support our colleagues in other hospitals and community services who may have limited experience of caring for patients with a diagnosis of cancer within this age group.

General

As part of their NHS Cancer Improvement Collaborative project, Hull University Teaching Hospitals NHS Trust developed a patient satisfaction survey to make sure the needs and experiences of patients' need accessing Teenagers and Young Adults service at Castle Hill Hospital were heard and understood.

Often underrepresented in wider surveys, this engagement exercise provided the TYA team with the much-needed opportunity to turn up the volume of the voices of TYA patients and helped to identify what parts of the service were working well, areas for improvement, and the impact of Covid-19.

A high response rate of 67% allowed the TYA team to better understand the views of patients and develop action plans that quickly saw improvements implemented.

The results of the survey also helped to raise awareness of the service across the Trust and Cancer Alliance, and this project has provided the team with a baseline for future engagement and improvement activities.

Rationale

The Cancer Improvement Collaborative (CIC) programme improves experience of care in NHS cancer care services by drawing on data from the annual national Cancer Patient Experience Survey (CPES) and other sources of insight and feedback.

Focusing on rare and less common cancers, Hull University Teaching Hospitals Trust (HUTH) decided to use the 2020/21 CIC project to focus on the experience of care for younger people.

By working collaboratively with patients, Humber, Coast and Vale Cancer Alliance, the Teenage and Young Adult (TYA) service team and wider Trust representatives, the project aimed to address how patients aged between 16-24 can often be underrepresented in wider engagement exercises whilst achieving a better understand of the views and experiences of patients living with cancer within this age range.

The National Patient Experience Survey results, which are used by HUTH to develop action plans for improvement of services, had 1,025 responses in 2019. Only two of these responses were from people aged 16-24 and as the results cannot be filtered by age range, it is difficult to establish individual feedback.

As well as understanding patient's views and experiences from diagnosis to living with and beyond cancer, the project also helped the TYA team to measure the impact of Covid-19 to teenage and young adults. How had the shielding and self-isolation impacted them when they are already isolated from their friends and normal activities due to their illness or treatment?

Planning

Representatives from the TYA service at HUTH worked with Humber, Coast and Vale Cancer Alliance (HCV CA) and a patient partner (Rachel*) worked collaboratively to develop the survey. Whilst some generic questions mirrored those used in the National Cancer Patient Experience Survey, to allow a comparison to wider Trust results, other questions were tailored to the intended audience and aimed to measure the impact of Covid-19.

Thanks to the input of the project's patient partner, the development of the survey could benefit from someone with lived experiences of the service and Rachel helped to ensure the questions where relevant and understandable by the intended participants.

The TYA patient survey was sent via to 65 patients on Monday 9th November 2020. Ensuring the survey was accessible to all those invited was extremely important and although the survey was sent out via a digital link, a follow up call was made to offer the survey in alternative format if required. Conducted by Charlene Kent, Youth Support Co-ordinator, these calls also provided an opportunity to encourage patients to complete the survey and/or answer any questions they had.

The survey closed on Sunday 22nd November and 44 responses were received, giving an overall response rate of 67.7%. The results were analysed by HCV CA and a report containing the results, key themes and recommendations was provided to HUTH in December 2020.

*Pseudonym used

Impact

This project provided an important opportunity for teenage and young adults to share personal experiences of living with and beyond cancer. The results of the survey have helped to shape improvements to the TYA service at Castle Hill Hospital and are also helping to raise awareness of the service within the Trust and across the Humber, Coast and Vale region.

Producing a report based on the results of the survey has helped to communicate the key findings with relevant stakeholders. It has also helped to put the patient voice at the centre of action plans which aim to improve the TYA service and patient experience.

Overall, the feedback received from this questionnaire is positive, with the majority of respondents speaking very highly of the Teenage and Young Adult services at Castle Hill Hospital. This positive feedback has helped the TYA service to gain recognition within the trust.

Key themes that emerged regarding areas for consideration and improvement include:

- Additional support needed - Patients expressed a desire for further support at home, including support for parents.
- Shorter waiting times - Respondents noted that chemotherapy appointments could be improved.
- Workforce capacity - Although patients rated TYA staff highly, respondents felt staff were often stretched and noted the need for additional capacity.
- Impact of COVID-19 and the importance of social activities - one third of respondents said Covid-19 has affected their experience during treatment and follow up, including levels of support. Respondents also noted that Covid-19 had resulted in restricted visitations, delayed and/or cancelled appointments and reduced social activities. Patients were appreciative of the social activities on offer prior to COVID-19 and noted the benefits of attending activities such as ‘Look Good, Feel Better’ and Alton Towers. There is a strong sense of urgency to restart face-to-face activities when possible.

Following the publication of the survey report, the TYA team acted quickly to develop an action plan and the Lead Cancer Nurse, TYA Cancer Nurse Specialist, Ward Sister and TYA Coordinator have already implemented some solutions to the feedback highlighted above.

The introduction of weekly ward handovers has resulted in shorter waiting times for chemotherapy and improved communication across the ward, pharmacy and teenage and young patients living with cancer.

Balancing measures were added to the process and further feedback obtained from staff on the ward has positively impacted on day-to-day business of the ward. For example, the TYA team have expressed how they now feel more of an extension to the ward, rather than separate.

Relevance to Others

As the views of teenage and young adults are often underrepresented in wider pieces of engagement activities, the results of this survey have been shared with internal and external colleagues that help to deliver cancer services locally. This includes:

- Humber, Coast and Vale Cancer Alliance (HCV CA) Collaborative Voices Network

- HCV CA Primary Care Strategy and Delivery Group

- Patient and Public Experience Leads from other Cancer Alliances

- Patient Experience Forum at HUTH

Standing Out

This project has helped to provide a voice to a previously underrepresented group at HUTH. The high response rate has supported the TYA team to make changes that are relevant to the needs of its patients and the results have helped to improve working relationships and processes within the trust.

Utilising individual skill sets and experiences ensured the survey receive a high response rate. Rachel, the patient partner, was key to ensuring the survey was understandable to its target audience. Charlene’s already established relationship with patients, as TYA Coordinator, helped to encourage participation, and the Lead Cancer Nurse and TYA CNS helped to ensure the results could support service improvements.

During a time that has been challenging for patients and staff, the survey provided an opportunity for reflection and an understanding of what matters to patients using TYA service. The positive feedback received helped to boost staff moral and promoted the services achievements within the Trust, and the opportunities for improvement have helped to provide clarity on what is needed moving forwards.

Key Learning Points

- Involve patients from the beginning. This can be key to success further down the line.
- Measure the impact of Covid-19 on patient experience. This can help shape plans for recovery.
- Collaboration is key to achieving success. It is important to utilise existing relationships and skillsets.

Developing Digital Technology Solutions to Improve Care for Cancer Patients
Nottingham University Hospitals NHS Trust
PENNA 2019
RUNNER UP – Innovative Use of Technology, Digital and Social Media

Organisation

We're based in the heart of Nottingham and provide services to over 2.5 million residents of Nottingham and its surrounding communities. We also provide specialist services for a further 3-4 million people from across the region.

We're one of the largest employers in the region, employing around 16,700 people at QMC, Nottingham City Hospital and Ropewalk House.

- QMC is where our Emergency Department (ED), Major Trauma Centre, Nottingham Treatment Centre and the Nottingham Children's Hospital are based. It is also home to the University of Nottingham's School of Nursing and Medical School
- Nottingham City Hospital is our planned care site, where our cancer centre, heart centre and stroke services are based
- Ropewalk House is where we provide a range of outpatient services, including hearing services

We have 90 wards and around 1,700 beds.

We have a national and international reputation for many of our specialist services, including stroke, renal, neurosciences, cancer services and trauma.

We are at the forefront of many research programmes and new surgical procedures. In partnership with The University of Nottingham we host a Biomedical Research Centre carrying out vital research into hearing, digestive diseases, respiratory, musculoskeletal disease, mental health and imaging.

As a teaching trust we have a strong relationship with our colleagues at The University of Nottingham and other universities across the East Midlands, including Loughborough University, where we are part of the Olympic Legacy project.

We play a vital role in the education and training of doctors, nurses and other healthcare professionals.

General

The NUH Oncology Digital Technology team has been set up to enhance patient care in the 21st century. Our focus has been to:

- Improve access to treatments for patients across the East Midlands
- Reduce the need to attend hospital for face-to-face appointments
- Give patient more control over their secondary care, reducing their time and cost

We have developed, implemented and assessed two novel methods of interacting digitally with cancer patients.

1. Virtual video clinics for patients in the East Midlands with brain metastases who are being considered for treatment. Initial and follow-up appointments are offered for virtual clinic on Smart phone or computer. Highly successful programme to be rolled out now across oncology. Such positive feedback from patients that they preferred to receive bad news via virtual clinic rather than in oncology department.
2. ePROMS (patient-related outcome measures) using digital questionnaires to interact with patients at home as a substitute for face-to-face appointments. Currently used for patients on immunotherapy for metastatic cancer but wider roll out due. Excellent feedback from patients and 94% patients do not require a face-to-face appointment but can go straight to treatment. The 99% compliance rate in filling out questionnaires shows superb patient engagement.

Rationale

We decided to use 21st century digital technology to improve patient's experience of their cancer journey. To reduce their time spent at the hospital – to do reduce the impact that cancer treatment has on their everyday lives. This is novel work and new ground. Although digital work is being done elsewhere, nowhere else in cancer work is using digital technology as an alternative to face-to-face appointments. Patients always have a choice between digital and face-to-face appointments

Virtual video clinic (Teleclinic)
NHS England review of Stereotactic Radiosurgery (SRS) services showed that there was inequality of geographical access to stereotactic treatments across the UK, which is likely to significantly impact those with brain metastases accessing these services. NUH is the sole provider of neurosurgery in the East Midlands since 2016, Previously all patients have had to travel to Sheffield. The SRS service at NUH means a population of 2.9 million would be within an hours drive of an SRS centre. However, these patients can have complex disabilities and travelling to distant hospitals, even an hour away, can be difficult. The DVLA does not allow patients with brain metastases to drive. They all require hospital transport or a family member/friend to bring them. Allowing patients to have a clinic consultation on their Smart phone, tablet or computer was aimed to improve access to these regional services to a much wider group of patients and allow them a clinic consultation in their own home or indeed at work (just because someone has cancer that has spread to the brain does not mean that they don't want to continue their working life.)

ePROMS
Very significant breakthroughs have been made in the area of surgery, radiotherapy and drug therapy in improving both length and quality of life for people with cancer. At NUH, oncology follow-up out-patients activity showed 7-8% growth in 2018/19 and that growth is expected to continue increasing as new treatments become available.
Unlike chemotherapy, where patients are usually on a course of treatment for a few months only, the new targeted therapy agents and immunotherapy agents are given often every few weeks for several years. During this time, people receiving these treatments have to come to clinic for review prior to every single treatment. This swamps clinic slots and uses up ever more precious consultant oncologist and specialist nursing resources.

However, even worse is the personal and financial cost to the patient and their families. Most of the week outpatient clinics are full with not enough seating available. They may already have struggled to park their car close by. Some of these people are poorly, some have taken the day off work to come for review, some are in pain from their cancer, others may only be weeks from death. Many are exhausted by the effort of travel and waiting for their clinic appointment. Added to this, they may still have to take another day off for their actual cancer treatment. All deserve a better outpatient experience.

We have sought to replace at least some of the relentless 'on-treatment' clinic appointments with a digital clinic. Patients do a questionnaire on their Smart phone, table or computer and it is reviewed within 48 hours, and they get feedback as to whether they need to come in for a face-to face clinic appointment or whether they can just go straight to treatment.

Planning

Charity funding was sought for the two workstreams and gained via two grants. Macmillan Cancer support funded our Virtual clinic work in the East Midlands Brain Metastases service and NUH Charity funded our work in digital ePROMS. The oversight of both is via the Digital Technology Team (DTT). This is where clinicians, digital services, admin and operational team, Industry, NUH improvement and transformation team and patients all give input. Governance and safety sit with this team and has had to be rigorous. The DTT is chaired by Dr Judy Christian, holder of both grants. This work has fed into the wider NUH project of 'My Online Care' where oncology has sought to work with breast care services and orthopaedics to share our experience and help them develop their workstreams. Grant funding primarily bought staffing – a mixture of medical, nursing and radiographer staff.

Impact

Virtual video clinics
From April 2018 to October 2018 all patients attending the brain Metastases clinic were offered the choice of a teleconsultation in place of a face-to-face appointment. Feedback was assessed using a satisfaction questionnaire and data was collected on all clinic attendances. Sixty-nine individual patients had 119 appointments over the duration of the pilot. Of these, 36 were new patient appointments and 73 were follow ups. Of these, 24 patients (35%) took part in 41 (34%) teleconsultations. User satisfaction was high and no patients who took part in a teleconsultation reverted to face-to-face appointments. These patients avoided 2521 miles (61.6 miles per appointment) of hospital associated travel and travel costs of £441.48 (£10.78 per appointment).

"Wonderful to be able to speak to specialists in the privacy of our own home. This relieves the stress attached to travelling to and attending clinic. Thank you for offering this service. It would have cost us £50-£60 to attend"
"I felt that this was an excellent way to have an appointment and enabled me to continue caring for my wife as well as receive expert care."

ePROMS
Pilot work showed that immunotherapy and targeted therapy treatments were most likely to be of benefit to the patients. A pilot study was then launched in melanoma and renal immunotherapy. Over 100 patients have been enrolled in this study. There is a 99% completion rate of questionnaires by patients on their Smart phone or Tablet. No serious side-effects have been missed, in fact patients find that the questionnaire picks up more symptoms than a face-to-face doctor's appointment. A digital review clinic appointment takes 4 minutes by a specialist nurse. 93.5% of patients did not have to attend for a face-to-face appointment. Patient feedback was excellent, and no-one wanted to return to face-to-face appointments
'I felt that I was able to give more accurate answers as I was at home with a cup of tea and had more time to consider the questions.'
'Your work is very important to us patients and I personally would like to thank you for helping us to improve our journeys.'
'Easy to read and understand.'

Relevance to Others

Our work has created enormous interest across the UK oncology departments and has been presented across the UK – e.g., at the Christie, Manchester who are seeking to try to use our model. Because the benefit to patients is so significant and because some cancers are now being treated as a chronic illness, there is an imperative to change how we work our out-patient models from one developed in the 1950's. Wonderfully people are living so much longer with cancer that their lives no longer stop at a cancer diagnosis. Instead, they continue to work and live full lives – and we need to develop ways of interacting with patients that has moved on from always face-to-face. Our model is tested and safe. Patients love it.
It is being rolled out at NUH to other specialities such as breast surgery and orthopaedics – but there is interest from many other specialities too.

Standing Out

Our work is unique. No-one else in the UK is using virtual video clinics in the context of brain metastases to reduce the need to attend in person – yet specialist regional centres for radiotherapy are increasing and it is so important that people can access specialist advice without needing to travel long distances.
Other centres are developing their own ePROMS but none to replace face-to-face appointments.
Our detailed work has shown that Digital Technology can be used safely and to significant benefit for cancer patients. They get on with their lives and aren't spending unnecessary time in a crowded outpatients department.

Key Learning Points

This work needs a dedicated Steering group like our formal Digital Technology Team. It needs an interested IT team with time to develop the interfaces of hospital software and it needs dedicated staff to roll it out in the initial period. We are confident though, that once the initial infrastructure is there that it simply become a matter of scale and the requirement for dedicated staff reduces. So, it is an initial bust of effort which them hopefully reduces as the work becomes mainstream. And we must have a solution to the rapidly increasing number of outpatient appointments in our oncology departments every year otherwise patient care will suffer.

Beads of Courage
Nottingham University Hospitals NHS Trust
PENNA 2020-21
FINALIST - Fiona Littledale Award, Personalisation of Care

Organisation

Nottingham University Hospitals NHS Trust provides services to over 2.5 million residents of Nottingham and its surrounding communities. We also provide specialist services for a further 3-4 million people from across the region.

We are one of the largest employers in the region, employing over 17,000 people at the Queen's Medical Centre (QMC), Nottingham City Hospital and Ropewalk House.

QMC is where our Emergency Department, Major Trauma Centre, Nottingham Treatment Centre and the Nottingham Children's Hospital are based. In 2020 the Children's Hospital was awarded Pathway to Excellence® accreditation in recognition of its outstanding work and commitment to paediatric care and treatment. QMC is also home to the University of Nottingham's School of Nursing and Medical School.

Nottingham City Hospital is our planned care site, where our Cancer Centre, Trent Cardiac Centre and stroke services are based. In 2020 Nottingham City Hospital was awarded Magnet® accreditation with 12 exemplars of outstanding practice.

Ropewalk House is where we provide a range of outpatient services, including stroke, renal, neurosciences, cancer services and trauma.

We are at the forefront of many research programmes and new surgical procedures. In partnership with the University of Nottingham we host a Biomedical Research Centre carrying out vital research into hearing, digestive diseases, respiratory, musculoskeletal disease, mental health and imaging.

As a teaching trust we have a strong relationship with our colleagues at the University of Nottingham and other universities across the East Midlands.

We play a vital role in the education and training of doctors, nurses and other healthcare professionals.

Beads of Courage UK was formerly known as Be Child Cancer Aware (BCCA). It was initially created to increase awareness of all childhood cancers. BCCA produced and distributed symptom awareness cards outlining the most common signs and symptoms of all childhood cancers. The response and awareness that was raised was phenomenal.

One of the families responsible for setting up the charity was disappointed when their son was given a cheap plastic medal when he finished his cancer treatment. It was a poor memento of the immense journey that he had completed.

Collaborating with Beads of Courage in the USA, the family, along with two other families launched the programme at The Royal Marsden, Basildon and Birmingham Children's Hospital.

Beads of Courage are now widely used in children's and young people's oncology settings across the UK.

(www.beadsofcourageuk.org).

General Summary

Oncology Nurse Chloe, heard about Beads of Courage (BoC) from someone who had lost their young son to cancer.

In this innovative project young people are given coloured beads to mark a wide variety of therapies, treatments and experiences in recognition of their journey. They thread the beads on strings as a symbol of their courage in a difficult time.

Examples of beads include diagnostic biopsies, needle sticks, surgeries, chemotherapy and a range of other experiences.

Young people have a journal explaining what each bead represents and spaces for them to write dates and thoughts on the experience they have been through.

If the young person dies, their beads and journals become a precious memory for their loved ones.

Chloe was honoured with a DAISY Award for this initiative. This award recognises outstanding nursing care and practice. Through her tenacity and leadership Chloe has embedded this initiative into practice on our Teenage Cancer Trust (TCT) ward, empowering young people to feel in control of their treatment and help them make sense of their journey.

Healthcare professionals on the ward are engaged in this project, helping to promote and sustain it. Feedback from patients and families has been universally positive. The Teenage Cancer Trust has committed to funding the BoC programme, making it sustainable for the future.

The BoC programme offers beads for a number of other medical specialities, such as burns, neonatal intensive care, cardiology and chronic conditions. This makes the BoC a very transferable across our Trust

Rationale

Chloe, an Oncology Staff Nurse at Nottingham City Hospital, learned of Beads of Courage outside of work through a family that, on learning that she was a nurse, shared their child's cancer story with her. Unfortunately, their child passed away. Chloe was compelled by their story and the role that BoC played in their child's illness, and how BoC remain a vital source of comfort and an exceptionally precious memory of their child's journey. So inspired by what she had heard and motivated to transfer this initiative to her own place of work, she set out on an ambitious mission to deliver, and ultimately benefit and bring comfort to her patients and their families, during a hugely distressing time.

Chloe felt that the young people she cared for would benefit from this innovation, helping them to come to terms with their illness and the treatments.

She made enquiries and found that the kits were about £5000 to purchase. However, a phone call to the Paediatric Oncology Ward at our sister hospital revealed that they had kits that they were not using, and they very kindly donated them to her.

The beads are prescribed to the children and serve as a narrative of their medical care and tell the unique storey of their own journey.

The BoC are a symbol of their incredible bravery and is a way for them to track their treatment and also see how far they've come. They can be a means of starting difficult conversations and having open and honest discussions of their experience, helping them to become partners in their care and treatment, encouraging relationship-based care.

The goal of the programme:

- decrease illness-related distress
- increase the use of positive coping strategies
- restore a sense of self in children coping with serious illness
- provide something tangible the child can use to talk about their courage displayed during treatment and after.

Planning

Chloe shared her ambition for implementing the programme with colleagues. This included doctors, physiotherapists, phlebotomists, dieticians and many other health professionals. Through this support Chloe gained the buy-in and support to bring this vital initiative into our hospitals, in order to ultimately nurture and support the physical, emotional, and spiritual needs of Paediatric Oncology patients and their families.

Chloe contacted the paediatric oncology ward at our sister hospital (Queen's Medical Centre) to see if they had any insight into the Beads of Courage initiative. As it happened the ward had purchased the starter kit for BoC but did not have anyone to drive it and so it had been put away.

Chloe asked if they could be purchased from them, but they generously gave it to her.

With help and support from Sian, the Teenage Youth Support Worker, they started asking the young people coming to their ward if they would like to participate. This offer was enthusiastically taken up and one of the first recipients of the BoC, a young man called Lewis, used the beads to help him through his cancer journey. He and his family felt that they were a hugely helpful tool following a very difficult and traumatic start to his cancer journey.

Chloe contacted the BoC charity to register as an official ward, usually this would be accompanied by a great celebration, but COVID 19 restrictions have unfortunately prevented this. Chloe has also linked with the Teenage Cancer Trust (TCT), who have agreed to sponsor and fund the BoC initiative on Hogarth Ward.

Through word of mouth and via social media the BoC programme has grown, and word has spread. Patients and families have also been integral to spreading the word. One patient has a TikTok account and 500K followers. She has been documenting her journey through this medium and sharing her BoC along the way.

*Note: Lewis is his real name. Permission given by his mum.

Impact

Chloe has kindly shared, with permission, testimonials from two patients and their families to demonstrate how this initiative has helped those who have used it.

Lewis, who was mentioned earlier, had a traumatic start to his cancer journey, including misdiagnosis and surgery. However, when he arrived on the TCT ward, the staff went through his journey to date with him and immediately found that he had been through 167 procedures before he even got his first chemotherapy bead. His mum wrote that getting his beads helped to draw a line under his experience to that point and getting his silver acorn bead to show he was as resilient as a mighty oak was a turning point. The beads boosted Lewis' morale and gave him a voice.

All young people who access their service are offered BoC, and most do engage with the BoC programme and feel that it helps them through their journey and tells their story in a unique way.

It encompasses families too, so parents and siblings feel part of the narrative, bringing the family together in a shared experience.

Eden (real name, shared with permission), another young cancer patient, reports that it lightens up a hospital visit and shows what she has faced and overcome. She feels that the BoC programme could help many children and young people who have to face regular treatments and hospital visits and hopes that this will be expanded across different specialties.

The beads help children and young people to own, record, tell and share their story of their oncology treatment. They are a symbol of their bravery, courage and strength (Portnoy et al, (2016)).

With the help of the beads, even very young children can talk about their treatments, therapies and experiences.

There are ‘Bumpies’, which are glass beads with bumps all over them to symbolise a specific challenge they have faced, whether that relates to adverse reactions, side effects, or mobility changes. Beads are given for every single event, for example, they get one bead for each night they are in hospital, every single needle stick, every scan, medication, chemotherapy and surgery. The young people can end up with many thousands of beads and it is up to each child how they thread and display their collection.

A qualitative evaluation of the BoC programme was undertaken in 2010 (Baruch). The study evaluated the impact of BoC from the child’s perspective. The conclusion was overwhelmingly positive, children spoke of them as rewards for their bravery, a method of making friends with other children with cancer, tracking their treatment and measuring their journey. They spoke about them with reflection and affection after treatment had ended, as a reminder of the challenges that they had been through and overcome. The conclusion of the study states “that the BOC Program, as an Arts-in-Health program, strengthens resilience and alleviates suffering in children and adolescents receiving treatment for cancer.”

This is supported by Hall (2019) who confirms the positive impact of creative interventions to assist children and young people through oncology treatment.

The BoC programme has been running at NUH for just over a year now and the beads have been given to more than 20 young cancer patients during this time.

(Baruch, J.M. (2010). The Beads of Courage Program for Children Coping with Cancer. PhD Dissertation. The University of Arizona. Arizona. USA.

Hall, T., (2019). Creative, Culturally Sensitive Counselling for Paediatric Oncology Patients Undergoing Treatment. Journal of Creativity in Mental Health. Vol 14. (1). Pp. 70-80.

(Portnoy et al., (2016). Supporting young people living with cancer to tell their stories in ways that make them stronger: The Beads of Life approach. Clin Child psychol psychiatry. Vol 21. (2). Pp. 255-67.

*Note: Stories and testimonials use the patients’ real names and are shared with patient or family consent.

Relevance to Others

The Beads of Courage programme is an exemplar of personalisation of care and is not just for patients going through cancer treatment. There are programmes especially for a number of illnesses and conditions, including: refer to the category itself – ‘aimed at meeting individual needs’ – e.g., this programme of work is an exemplar of personalisation of care

- Cardiac
- Chronic Illness (Type 1 diabetes, autoimmune disorders, Epilepsy, Cystic Fibrosis, Cerebral Palsy etc.)
- NICU (gives parents a tangible way to record their baby’s journey)
- Burns
- Siblings

Parents and siblings also benefit from the BoC programme, prompting meaningful discussions and help form support networks with other families going through similar experiences.

Chloe would like to raise awareness with other departments and specialties to show how helpful BoC can be in supporting children, young people and families through their healthcare journeys.

Standing Out

This is not a commonly known programme in the UK. Through a serendipitous conversation with a bereaved mother, this fantastic initiative has been introduced into our Trust for our young cancer patients and we have been able to witness first-hand, the amazing impact that it has had on our patients and their families.

It transforms children and young people from passive participants in their care into the true heroes that they are, it helps them to feel seen, heard and celebrated through their journey.

The full Beads of Courage program recognises the impact of serious illness on the whole family and endeavours to include everyone, parents and siblings, as well as clinicians as part of the shared experience.

The scope to share this programme across a variety of healthcare specialities is also a testament to how a simple concept can be used and adapted to help reduce anxiety and engage children and young people in their care and treatment.

Key Learning Points

For anyone who is thinking about initiating the Beads of Courage programme, we would strongly encourage them to go for it, following the advice below.

Although the set-up is expensive, the benefits are immeasurable.

Seek out charity support, we have been fortunate that the Teenage Cancer Trust fund our BoC programme.

Share, share, share. Spread the word, get clinicians involved, post on social media (if appropriate).

Encourage families to share their feedback and experiences in testimonials.

Invest in a wide variety of beads.

Make sure you register with the Beads of Courage organisation – you have to make it official, and there's a big party to mark your registration (unfortunately currently affected by COVID-19 restrictions).

Purple Rainbow Pancreatic Cancer Stories
Purple Rainbow
PENNA 2017
FINALIST – Access to Information

Organisation

Purple Rainbow has been set up to raise awareness and funds for Pancreatic Cancer UK. It is led by Lesley Goodburn whose husband Seth died from pancreatic cancer in June 2014. Seth died 33 short and heart-breaking days after his diagnosis and Lesley promised Seth that she would share their story to raise awareness and funds but also to campaign for change. Lesley is supported in her Purple Rainbow Work by many people including friends, colleagues and often strangers who give time and support freely to raise funds and awareness.

General

November is pancreatic cancer awareness month; pancreatic cancer has dreadful statistics and to help the wider public to understand the emotional and physical impact of the disease a social media campaign was a launched. https://www.pancreaticcancer.org.uk/fundraising-and-events/pancreatic-cancer-awareness-month-2017/Each day throughout November a short digital story was published on social media, each day had a different story told by a patient, family member who had lost a loved one, professionals and supporters. The films shared an emotional and personal story that explained the impact of the disease and covered signs and symptoms of the disease as well of the heartbreak of loss, the challenges of survival and the dedication of professionals who support people with this disease. The project was developed by Lesley a patient leader who worked with the storytellers to write their story, and then identify photographs that would represent the story visually and then finally working with filmmaker who gave his time freely to develop the film. This project was entirely led by a patient leader to improve the experiences for people affected by pancreatic cancer. This work has been completed without funding and resource and has been completely achieved by two people who donated their time and expertise.

Rationale

Each year in pancreatic cancer awareness month the focus is always on the dreadful statistics for the disease and although stats are important, they do not always create an emotional connection, especially if there are people who have no experience or understanding of the disease. Having shared Seth's and my journey through pancreatic cancer via the play, film and educational package Homeward Bound, I found that many people affected by pancreatic cancer would contact me to share their stories. Unfortunately, the aggressive nature of the disease coupled with the limited treatment options and lack of awareness most scenarios result in death, with only 19% surviving 1yr, 6% 5yrs and 1% 10yrs. When people shared people their stories, they said incredibly poignant things like "when my mum got to the hospice, the staff swathed the family in bandages and soothed our souls" and it gave me the idea to share one personal story each day in November via social media. The purpose of the campaign was to • Share personal stories of loss, survival and professional perspectives on the disease to raise general awareness • To provide support and information for patients and families in treatment • To raise awareness of the often vague signs and symptoms of the disease • To help patients and families understand the perspectives of professionals • To help professionals to understand the impact of the disease on an individual and family level • To raise awareness on the charity Pancreatic Cancer UK • To improve the experience of patients and families by sharing an honest but balanced view of the disease from a patient/carer and staff perspective.

Planning

I sent out request via social media to ask people to contact me if they wanted to share their experiences of pancreatic cancer and also used the existing social media communities that support people and families affected by the disease. I contacted some people who I knew were survivors of pancreatic cancer and also asked some of the professionals that I have worked with to ask if they might contribute. After an explanation of the aims of the project I asked participants to reflect and confirm that they wanted to be part of the project and asked them to think about what they might want to share. This aspect was important, and many people were sharing very intimate details about the disease and often stories of sudden and traumatic loss. Many people chatted with me on the phone, and I took notes and developed the notes into a story which the person then amended and then we agreed the narrative. Many people would send their own notes, thoughts and stories and we would work together to develop a title and a golden thread through the story. The next step was to agree the pictorial representations and record the audio of the narrative. Once complete this was sent to our volunteer filmmaker who pulled together the short film. A great deal of thought was out into how and when to contact the participants as being bereaved myself, I know how impactful taking part in this type of work can be and how you might be sending something for approval or recording on a significant anniversary or date that you may be unaware of. Each morning the new story was published on Facebook, Twitter Instagram and the Purple Rainbow Website.

Impact

The campaign has achieved 236,000 impressions on Twitter with over 4000 views of the films and this combined with the activity on Facebook has resulted in over 7000 views of the films. That includes the statistics up until 28th November as the campaign is still underway and will continue to accrue statistics. There is distinct imbalance of the number of times the films have been viewed based on the date of their release and also the social media reach that was achieved with variation of between 133 and 7800 impressions. There have also been over 500 impressions on the Purple Rainbow website. We also used Instagram however this did not support the full length of the films and was used to signpost to other media. Evaluation against the aims of the project will be undertaken over the coming weeks and an initial set of surveys results in acted in the documentation to give a flavour of the impact on participants and non-related people who viewed the films through social media Ongoing evaluation will take place with people who have interacted with stories via social media to assess their responses to messages in the film. The films and their message have created a community of practice with people interested in the content and people talk of “feeling like a member of a conceptual pancreatic cancer club “ The results of the limited evaluation show that people are more aware of the signs and symptoms of the disease and this also the case for people who have survived the disease who have learned from hearing others experiences of depression, lethargy and living with type three diabetes after losing their pancreas to surgery. All free text comments from Facebook and twitter are currently being collated however they are positive an example of one is listed below it relates to the story Grey Hairs. “I know face book is full of cancer and other heart-breaking stories. It seems harsh to skim over them. . . but sure we are all guilty of this. November is Pancreatic awareness month. This silent cancer can hit young and old with limited symptoms. The attached blog is from the surgeon who diagnosed and treated my Dad. His passion made such a difference to my Dad and his 3-year survivorship. Not many achieve. . . . this milestone. Please take time to watch and be aware of the very few symptoms. “The limited evaluation so far suggest that all of the aims are being met with the exception of improving the experience of pancreatic cancer patients and their families and it is too early in the campaign to assess the impact and develop measurements.

Relevance to Others

There is the opportunity to embed this approach with other charities to raise awareness of the specific issues of various diseases and when the full evaluation is complete it may be worth approaching them with ideas. The work with has been shared with colleagues at Hospice UK and Pancreatic Cancer UK and we are currently working partnership to develop our approaches. Sharing the films across the internet with many varied health care professionals has promoted some discussion about the approach. All the stories can be found on our Facebook page at the link below https://www. Facebook. com/search/top/?q=purple%20rainbow%20pancreatic%20cancer%20stories

Standing Out

This project was initiated by person with lived experience of the disease and was undertaken on voluntary basis and received no funding. This campaign was a labour of love driven by a desire to connect to people to share the devastating impact of the pancreatic cancer diagnosis, the balance of hope and reality, the journey through surgery and treatment, the options for palliative care, the impact on the family of treatment and often loss and how people who work in professionals’ roles. The campaign has maintained the momentum across 30 days of awareness raising and encouraged people to more curious about the stories by giving them titles that don’t really tell you what the story will be about. This has been an initiative led by patient leader working patients, staff and people who have lost loved ones to the disease, a person working with people rather than an organisation working with people. The approach using storytelling and pictorial representations meant that I would work with people across the whole the country and people could record third own satires using the choice recorder on a smart phone and this could all be pulled together remotely and published. Taking the approach of publishing a mix of stories across the thirty days, with stories of loss, treatment, survival interspersed with stories from professionals and charity supporters.

Key Learning Points

- That people connect via emotions and can learn more about pancreatic cancer through the medium of storytelling than facts and figures alone
- That people who shared their story felt a sense of belonging and mental support and understanding through listening to the stories of others
- Social media has a wide reach the stories have been viewed across the world with some continued interaction with oncologists in USA and with health professionals across Australia.
- That people with a shared experience felt part of intimate club despite having never met each other people talked about being part of a conceptual club
- Evaluation takes time, and our future plans will compass evaluation however the timing of the submission means that their summary findings.
- A great job can be done using just expertise and time and that not all big improvement initiatives have to have lots of people resource and funding.
- Doing something independently frees you up from the governance structures and gives you more freedom to explore perspectives.
- Professionals are emotional too but keep themselves safe by having a role to play in the care of a person with pancreatic cancer.

With You In Mind, Teamwork and Collaboration
Royal Devon & Exeter NHS FT
PENNA 2019
RUNNER UP – CPES Award

Organisation

The Royal Devon and Exeter NHS Foundation Trust (RD&E) provides integrated health and care services across Exeter and East and Mid Devon. With about 8,000 staff, it manages a large acute teaching hospital, twelve community sites and provides acute and community services to a core population of over 450,000.

The RD&E has a long and proud history, dating back over 250 years. The Trust has earned an international reputation as a recognised provider of high-quality healthcare services, innovation, research and education. The Trust is nationally and internationally recognised for excellence in a number of specialist fields, including the Princess Elizabeth Orthopaedic Centre, the Centre for Women's Health (maternity, neonatology and gynaecology services), cancer services, renal services, Exeter Mobility Centre, and Mardon Neuro-Rehabilitation Centre.

As a teaching hospital, the RD&E delivers undergraduate education for a full range of clinical professions, is established as a leading centre for high-quality research and development in the South West peninsula and is the lead centre for the University of Exeter Medical School. The RD&E became one of the first foundation trusts in 2004 and this status, with accountability to local citizens through our membership and governors, is an important way of connecting with the people and communities we serve.

The Trust's strategy is focused on ensuring that it provides safe, high-quality services, delivered with courtesy and respect. This is reflected in the Care Quality Commission's latest report, published in 2018, in which the Trust was rated as 'Good' overall. It was also awarded a 'Good' rating for being effective, responsive and well-led, and received an 'Outstanding' rating for being caring.

The Trust has responsibility for Eastern community services, with many of the services run in the community hospitals in East Devon. By bringing acute and community services together under one organisation in Eastern Devon, we are able to offer more efficient and joined-up integrated care. Working together with health and social care partners and local communities, we are better placed to meet people's needs and keep more people well at home and supported within their community, ensuring a hospital stay only happens when acutely necessary.

The integration of care services is part of a wider ambition to establish a place-based system of care which promotes independence, prevention and wellbeing. This system places the needs of the individual firmly at the centre, supporting them to live the life they want to lead.

General

In collaboration with FORCE (Local cancer charity) our ambition was to develop existing electronic Health Needs Assessment (eHNA) software to report on the Top Ten Concerns (TTC) from patients across individual cancer sites. The reporting matrix provided immediate accessible data used to shape financial information delivered to patients.

The project purpose was communicated through the Living With and Beyond Cancer (LWBC) steering group and monthly CNS meetings. A PowerPoint presentation (appendix 1) sharing Cancer Patient Experience Survey (CPES) outcomes opened up our challenge and appropriate individuals were assigned specific tasks with measurable timeframes.

Progress for the project has been benchmarked against the CPES outcomes. Internally we are maintaining excellence in service delivery by continually assessing numbers of financial concerns soon after a diagnosis compared with completion of treatment. Simultaneously we review the numbers of patients visiting FORCE for financial information and support.

Following early implementation within 1 cancer site, specific financial information is now shared across 7 cancer sites. Implementation across the wider healthcare community of long-term conditions is easily transferable by sharing software design. To date we have disseminated the project within the Trust and to a wider audience at a local educational healthcare professional event.

Rationale

Our aim was to examine the impact of timely intervention through health and wellbeing education, information sharing and signposting to appropriate services when delivered early in the patient pathway. The intention was to facilitate a reduction of financial concerns by the end of the patient treatment pathway.

The National Cancer Survivorship Initiative recommended offering Health and Wellbeing Information (HWBI) at the end of cancer treatment. Locally, anecdotal evidence had suggested offering information at the front end of the cancer pathway, including signposting to appropriate services, would be more beneficial. Concurrently we developed an electronic patient facing holistic needs assessment tool to capture, support and care plan patient concerns.

Early analysis of concerns captured in the eHNA demonstrated financial concerns were selected as one of TTC's in 4 cancer sites (see appendix 2) and featured in other sites. As this was part of the CPES data we wanted to focus on improving patient experience and outcomes in this area.

Planning

An existing Living with and Beyond Steering Group was used for the development of both the eHNA tool and HWBI. The project was divided into 2 streams

1. Development of the Holistic Needs Assessment Tool.
Initially patients were offered the assessment soon after diagnosis. If we were to measure any improvements with the information, we delivered we would need to have a second point of analysis after their treatment had completed. Funded by FORCE, internal IT services developed the reporting capabilities of the eHNA tool enabling individual team to have immediate access to the information.

2. To better understand the patient perception
CPES outcomes were presented at the monthly Clinical Nurse Specialist (CNS) meeting, with a determination to improve financial education and advice.
Our first challenge was to better understand the usefulness and clarity of current HWBC financial information. Patient focus groups were set up in colorectal and Hand Neck services. A consistent message became apparent
a) Use of clear and plain English
b) Include more details on signposting
c) Indicate charges for travel certificates
d) Provide easily assessable free prescriptions information in OPD waiting areas.

Impact

Following implementation of the revised HWBI we looked at the following areas: -

- Patient Survey

We surveyed 200 attendees asking, 'Do you feel you have received information to manage the financial impact of cancer' (appendix 3). 200 questionnaires were sent out. The return response rate was 78%. 59% strongly agreed/agreed with the statement. 37% felt neither/nor with the information and 2% said they didn't require this information.

- eHNA data

Analysis from the eHNA tool demonstrated a reduction in people selecting financial concerns at completion of their treatment following early attendance of a HWBC

- 2018 CPES results

Indicated improvements in the following area

- Patient footprint accessing financial services at FORCE, local cancer charity

Increase in people accessing face – to – face financial support

Relevance to Others

Working to the patient agenda rather than a clinical agenda supports personalised care, a requirement of the NHS long Term Plan for all patient with a long-term condition. Since this concept, we have implemented specific financial support and signposting across 7 cancer teams with equitable success.

Managing financial worries is not exclusive to cancer patients and can be experienced with all long-term conditions. Improving patient experience and outcomes is relevant to all sectors of healthcare. Listening to service users and planning future service development and delivery within a 'what matters to me 'framework, including managing financial concerns, will be key in future healthcare provision.

Standing Out

We have demonstrated Patient experience can be prioritised within a clinical pathway and used to benchmark improvements in health care systems alongside a clinical pathway.

Maintaining a strong patient focus, we have listened and involved to patients in our service re-design, alongside data analysis to develop intelligent service improvements. Providing equity of high-quality information delivered at an identified point on the pathway can improve the patient experience as demonstrated in the CPES data.

Sustaining collaboration with the third sector to support innovation and a holistic approach to patient experience has enabled information gathering and analysis to better understand local issues.

This supports the whole team as patients are receiving care in the right place at the right time. At the same time, quality information can inspire patients towards supported self-management by enabling choice and control in an area of their life.

Key Learning Points

- CPES data is a useful and validated tool for organisation to benchmark future working against.
- Listening to the patient through focus groups and/or survey support service development aligned to the needs of the patient
- Information and support at the beginning of the patient pathway can help to reduce concerns at the end of the pathway
- Signposting to FORCE for local face to face support supports improvements to the patient pathway
- Offering choice and signposting to available services may support supported self-management
- Shared learning within an organisation and wider helps to ensure better sustainability of new services

qFIT
Royal Cornwall Hospitals NHS Trust
PENNA 2021
RUNNER UP - Fiona Littledale Award

Organisation

The Royal Cornwall Hospital Trust is the only district general hospital serving a population of approximately 570,000, covering Cornwall and the Isles of Scilly. The Trust is responsible for services across three main sites with 750 beds and 5000+ staff. I work as a colorectal consultant nurse leading and supporting the colorectal 2 week wait (2ww) service, which is managed daily by a team of 7 specialist nurses. Since 2014 when the service became nurse-led, referrals have increased year on year from 1500 in 2014 to 4000+ in 2020. The current weekly referral rate is approximately 83 and this has not altered considerably, despite the effect of COVID-19. The pandemic has put the service under considerable pressure, with endoscopy and radiology first stopping and then reintroducing limited services. This has led to the necessity for the 2ww service to adapt quickly and safely in order to continue to provide a robust, efficient and effective service for the people of Cornwall.

General

With a limited service on offer, we required an innovative, and clinically sound, way of triaging patients referred to the colorectal 2ww service by Primary Care with a suspected bowel cancer. One of the main changes was the implementation of quantitative faecal immunochemical testing (qFIT) as a first line test prior to investigation within colorectal 2ww. QFIT is designed to detect blood in stool samples, which is not visible macroscopically. It specifically recognises haemoglobin and is more sensitive than the previously used Faecal Occult Blood (FOB). Research has shown that the application of such a test, with a view to triaging symptomatic patients, means that there can be some assurance that limited resources (specifically radiology and endoscopy) are being utilised appropriately during the COVID-19 pandemic. Through April and May 2020, the majority of diagnostic services were suspended and, together with Cancer Alliance South West a decision to institute qFIT testing as part of the two week wait pathway was made. Patients meeting referral criteria without rectal bleeding or anaemia were sent a qFIT. Throughout April and May, patients in this group who were qFIT negative (<20) had their investigations deferred. This meant that patients in the higher risk group could be prioritised.

During this period of time two patients were admitted as emergencies with bowel obstruction from the Fit<20 group, this rang alarm bells and resulted in us inviting all patients in the cohort to a CT scan. Cross sectional imaging diagnosed cancer in 10% of the Fit <20 group of 88 patients. As soon as we had this evidence, we made a decision to reduce the threshold to FIT<10 and anyone under the threshold was invited to have a CT scan. The study was presented to the South West Cancer Alliance and has been used to change practice in the other Trusts. Furthermore, agreement has just be granted to continue with FIT<10 as a triage tool post the COVID-19 pandemic to streamline patients to the most appropriate investigation or pathway which will ensure sustainability of the colorectal 2ww service.

Rationale

Studies have previously been carried out to determine the credibility of employing qFIT as a way of ruling out invasive tests in symptomatic patients and consensus seems to indicate that this is the way forward, both in terms of patient safety and sustainability. At the Local Trust, this data led to the implementation of the COVID-19 qFIT algorithm for all patients without overt rectal bleeding, a rectal/abdominal mass or iron deficiency anaemia outside of the British Society of Gastroenterology Guidelines for the management of iron deficiency anaemia. In view of the contractibility of the COVID-19 virus, the population was advised to stay at home and to avoid all nonessential travel and therefore a move to mainly telephone clinics (a reduced capacity face to face appointment was offered when the referring symptom was rectal abnormality) enabled the service to continue to run when many others were forced to stop, as specialist staff were redeployed to cover acute services such as the wards and accident and emergency departments or forced to shield at home themselves. The staffing for the 2ww service was reduced from seven specialist nurses (who had multifaceted roles and conducted two clinics per week each) to three full time colorectal specialist nurses who delivered the service remotely from home.

Planning

A National Mandate for testing in patients with a FIT >20 was rolled out within the Trust and embedded in the colorectal 2ww service. A new pathway was set up in conjunction with blood sciences to allow the team to order the investigation, an option previously restricted. The team would then send the test with instructions to the patients. Once the result was reported, a decision would be made regarding discharge versus next steps. Within the first two weeks of this process, two patients were admitted to the acute trust as emergencies with bowel obstructions (tumour) from the FIT <20 group. This highlighted a need to review our process and an audit of our patient database enabled us to identify 88 patients in the FIT <20 group. A meeting was arranged with radiology and with agreement, all patients in this group were then scanned (non-luminal imaging). 10% of the total cohort were found to have cancer, 3 of which were right sided colorectal cancers, however the remainder were extra-colonic cancers, which could only have been diagnosed on cross sectional imaging. This data resulted in the service dropping the threshold to FIT <10 AND offering a CT scan in the negative group.

Impact

The agreement reached between the Trust and Cancer Alliance was that all patients with a qFIT <20ug Hb/g would be discharged without test back to GP to be re-referred after the pandemic if symptoms persisted. Positive qFIT results would be booked for a bowel clearing test, specifically colonoscopy or CT enema. As previously stated, the threshold was dropped to <10 due to emergency admissions within the <20 group. The combined cohort of all patients identified during the COVID-19 pandemic (6th April – 1st July 2020) through the colorectal 2ww service with a qFIT<10 consists of 120 patients. Concurrently the acute Trust was seeking to implement a non-site-specific pathway (NSS), for those who did not necessarily meet the criteria under the colorectal 2ww parameters. Whilst it was understood that in the presence of a negative qFIT, a patient's risk of having a colorectal cancer is thought to be low (<0.2-1.1%), the qFIT algorithm was altered to include this cohort and all qFIT <10ug Hb/g were booked for plain CT abdomen and pelvis to exclude non-bowel pathology. In the presence of weight loss, the CT was extended to include the chest. Findings at CT demonstrated a cancer detection rate of 7.5% (n=9). This data has been shared with the South West Cancer Alliance to shape the care of colorectal 2ww patient's through-out the wider community.

Relevance to Others

This will only be relevant to colorectal 2ww services and has been disseminated as above.

Standing Out

The collection and review of data in real time is what makes this initiative stand out. We have been able to implement a change necessitated by the global pandemic, assess its effectiveness and made amendments in an efficient manner to ensure that patient safety was not impacted. The successful implementation of qFIT at the right threshold to triage patients to the most appropriate investigation or pathway will remain even after the pandemic and will ensure an improved patient experience.

Key Learning Points

Integral to successful implementation of any change is the requirement of ensuring all parties are aware and involved. When the pandemic hit we had to make changes quickly and repeatedly, the most important aspect was good communication so that everyone understood the process and had the ability to raise concerns. Additionally, the recording of accurate information in an easily accessible database provided the opportunity for us to review the impact of the change and ensure that the service was maintaining safety and efficiency

Emotional and Physical Pathway Improvement for Head and Neck Cancer Patients
Royal National ENT and Eastman Dental Hospital, UCLH
PENNA 2019
FINALIST – Environment of Care

Organisation
University College London Hospitals NHS Foundation Trust (UCLH) is one of the most complex NHS trusts in the UK, serving a large and diverse population. We provide academically led acute and specialist services, to people from the local area, from throughout the United Kingdom and overseas. Every year we treat close to 100,000 patients in hospital, either as inpatients or day cases. We also see nearly 700,000 outpatients per year.

The Foundation Trust has a combined staff of over 8,000. Around 19% are doctors and dentists, 34% nurses or midwives; 14% are allied healthcare professionals; 9% are scientific and technical staff, and the remainder clinical and general managers and support staff.

Our vision is to deliver top-quality patient care, excellent education and world-class research. We provide first-class acute and specialist services across eight sites.

In September 2019 a new purpose-built hospital was opened combining the Royal National ENT and Eastman Dental Hospitals. This has provided the patients with multi-level care across the specialties.

General
A patient sees a dentist, who spots something in their mouth that concerns them. They are seen days later in the hospital and have a biopsy of the area. Turns out, it's cancer. Devastating news for the patient. Within a week they are having scans and other tests, and a discussion with a multidisciplinary team (MDT) telling them they need surgery/chemotherapy/radiotherapy. They are told after the surgery they may not be able to eat again or talk again. They may need a permanent tracheostomy to breathe. Their face will not look the same. A short time later they have a dental assessment by the hospital team. They want to remove 15 teeth. Tomorrow.

This is the pathway that every head and neck cancer patient faces.

With this in mind, we felt that this pathway needed to be streamlined with the patients' views, an ambitious task. New information leaflets were created, the assessment system has been moved to a single building, and the journey has become very simplistic to remove the prior complexities that were an added stress. At each stage the patient's opinions are being gathered with a view to modify this process as per their needs.

Rationale
Oral cancer is the 6th most common cancer worldwide, however with increased awareness of risk factors and earlier diagnosis and intervention, this malignancy can be effectively treated and managed with minimal post-operative patient morbidity.

Oral cancer can be treated with chemotherapy/ radiotherapy/ surgery depending on the type and staging of cancer. Radiotherapy to the head and neck regions are given in different locations depending on the location and spread of the malignancy. Communication with the medical team tell us how much ionising radiation is to be given to the patient and if these are to be high doses, e.g., over 54Gy. Understanding the radiotherapy fields allows dental assessment treatment planning to ensure any potential sources of infection are removed prior commencing cancer treatments. Radiotherapy can produce many oral side effects including, radiation induced dry mouth, oral mucositis and trismus which patients find extremely difficult to manage.

Royal College of Surgeons guidelines state that the oncology team is responsible for referring these patients for a dental assessment prior to commencing their cancer treatments. Oral care must then be delivered by the dental team through a coordinated multi-speciality approach within a strict timeline to prevent delay of cancer treatment, previously within 4 weeks.

The patient must be looked at holistically in terms of current oral hygiene and whether patient motivation will allow positive oral care to prevent further issues. Teeth which are restorable must be assessed in terms of whether these restorations will last or is the tooth likely to require extraction. The Royal College of Radiologists guidelines recently changed stating dental extractions should ideally be extracted no later than 10 days prior to radiotherapy, and that radiotherapy is to start 14 days after referral. This gives 4 days for a patient to be assessed and have extractions completed.

We felt that the pathway needed to be streamlined taking into account the patients' feelings. It is an incredibly stressful time for them, and anything we can do to support them throughout this journey would be beneficial.

Planning

The dental team including Oral Surgery, Special Care Dentistry, and Restorative dentistry were all involved in streamlining the pathway. This therefore also involved the head and neck team, and the education centre for hygiene therapy.

The MDT and dental assessments can now take place in the same building. This means one trip for the patient, and they can be taken to the dental assessment by the nursing team. This has worked very well and gives the patient another chance for further discussion in an alternative environment.

The dental assessments are now carried out by registrars and consultants, and any extractions are discussed with an Oral Surgery consultant. This is a robust process giving confidence to the patient. Information leaflets were made to inform the patient the reasons for removing teeth and the risks associated – when they understand the rationale for this it becomes part of their treatment plan rather than an 'extra' they have had to do.

Newly designed information leaflets were given that explains the whole pathway from diagnosis to lifelong care. It was designed by patients using their feedback about what they wanted to know, keeping it simple and easy to follow. We have continued to get feedback from patients via a patient satisfaction survey.

Impact

The impact these changes have made is incredible.

Our way of formally measuring the pathway is firstly by monitoring how many days it takes from MDT to dental assessment, to dental extractions. At the beginning of the process more than 70% were being completed within 1 week. More recent results show that EVERY patient is being seen within 1 week, usually within 4 days. Secondly, we could monitor the changes in the treatment plan. Previously, the patient often attended the Oral Surgery department with questions about why they needed this treatment, what the risks mean to them, what are the alternatives. This resulted in changes to the treatment plan to reflect the patient's wishes. As this discussion, alongside the patient information leaflets, now happens with a clear pathway, a focused mind, and experienced clinicians the patient's queries have been addressed and this is clearly reflected in the treatment plan; no modifications have been necessary.

The leaflet itself is also a dynamic process. We continue to get feedback from patients and can modify them as needed. The patient satisfaction survey to date shows the patients find it very informative, allows them to keep track of their appointments, and informs them of what to expect each time.

Relevance to Others

With the new cancer centre, the bespoke head and neck centre, and the main UCLH site within 390 feet of each other, we have a 'corridor of health' along a London road which our patients can readily access.

This is transferable to other Trusts which have shared care across multiple sites and specialities. As modern medicine develops, guidelines will inevitably change, and update and it is important that all Trusts in the UK adhere to them. It must not be forgotten that patient care is paramount and should remain the focus of the service. With this in mind we feel that our model can be used to streamline any pathway for any patient journey.

Standing Out

We feel that this initiative stands out for patients whom are having incredibly life altering surgery. Oral cancer is a debilitating disease that affects the quality of life of not only the patient but their family. Streamlining the patients pathway has allowed to focus on each individual patient's needs where they can tailor their care and organise their oncology, radiology, surgery, speech therapy and dietitian to name a few.

Building good relationships with the MDT and being receptive to patient feedback has allowed us to create a successful model and improved the patient journey.

Key Learning Points

When you are faced with a change in guideline that affects a group of patients that already have been given devastating news you have to take into consideration their emotional state but be wary of the time constraints.

We have learnt from patients about what information they would like to receive and how they would like to receive it. Ultimately this comes down to good informational leaflets and timelines alongside support from each sub-specialty.

Streamlining the dental pathway has greatly improved the patients experience as there is minimal disruption, and improved communication between the teams overall putting the patient first.

Providing Support and Resources for People Affected by Cancer
Shrewsbury and Telford Hospitals NHS Trust
PENNA 2021
WINNER - Integration and Continuity of Care

Organisation
The Shrewsbury and Telford Hospitals NHS Trust (SaTH) is the main provider of District General Hospital services for nearly half a million people in Shropshire, Telford & Wrekin and mid Wales. Shropshire has a population of approximately 300,000 and beyond the town centre the County is very rural with pockets of rural deprivation. The population is ageing with higher life expectancy and higher than average long-term conditions. Conversely the population of Telford & Wrekin is approximately 172,000 with densely populated areas of both ageing and young people. There are above average pockets of deprivation with higher-than-average obesity, smoking related deaths, alcohol related admissions and higher rates of cancer mortality in the under 75 age group. SaTH also serves Powys which is a sparsely populated area with a population of approximately 63,000. It has an ageing population with a generally good health status compared to the Welsh average but there are also pockets of rural deprivation.

Annually, it is estimated that 3,570 people are told of a cancer diagnosis; however, this does not account for those living with and beyond cancer. It is estimated that there are at least 50,000 people living with and beyond cancer (LWBC) within Shropshire, Telford & Wrekin and mid Wales and this is going to continue to rise as the population ages and cancer patients live longer due to advances in detection, surgical techniques and the availability of second, third and fourth line treatments which include Immunotherapies. The current figure of 2 million people LWBC in the UK is therefore set to climb by 3.2% so by 2030 there will be an estimated 4 million people LWBC.

A comparison of 160 Trusts has demonstrated that SaTH is the 13th biggest receiver of patients on an urgent suspected cancer pathway referral. SaTH is also 22nd highest treating centre for the 62-day pathway requirement. This data gives provides a context as to the demands on SaTH and the large numbers of patients we see and treat for cancer within a District General setting.

General
With support of Macmillan, SaTH has created a programme of initiatives to enable and empower people affected by cancer throughout their treatment and beyond. Working with patients, we have developed innovative tools to promote safe self-management, supporting recovery and survivorship. These innovations include developing a 'My Passport To Living Well', regular Living Well Sessions (LWSs) and resources through an online platform.

Our initiatives have been designed with patients and, where appropriate, encourages patient volunteers to take an active role in the delivery. We pride ourselves on this and recognise this as a marker of quality and innovation. We have gained over 120 people (with consent) who make up our LWBC Advisors Network. They have agreed to be contacted to review, offer feedback and contribute to future developments within cancer.

Rationale
Survivorship was recognised as an area that needs improvement within the NHS Long Term Plan for Cancer which states that every person with cancer should have access to several elements of personalised care, including a Holistic Needs Assessment (HNA) and care plan and access to Health and Wellbeing information/events.

We developed a 'My Passport to Living Well' to act as a handheld record. Patients can complete a HNA and be signposted to other services. The aim of the Passport is to empower the person LWBC to gain some control back following a cancer diagnosis and to provide support throughout their pathway so that they feel more confident once treatment ends. The purpose of completing a HNA is to ensure that the person LWBC has an opportunity to raise any concerns they have identified for themselves. Any concerns or questions they have is then discussed with a member of the team and a care plan is developed to ensure the person LWBC truly receives personalised care.

The programme created LWSs that are delivered to anybody affected by cancer, at any point in the pathway. The LWSs are delivered in venues across our locality to bring care closer to patients. Sessions are informal and interactive enabling patients to learn from and share their own experiences, tips and advice. Developed with patients for patients, these sessions are facilitated and led by trained patient champions alongside a trained member of the team. As an alternative to attending a session, we developed 'Living Well' videos. They provide online access to concise, accurate information about safe self-management and can be watched at the person's leisure. This resource benefits our more rural patients and was invaluable to patients during the Covid-19 pandemic when our face-to-face LWSs had to be paused. When developing these, we asked other hospitals within our region to collaborate with us increasing the scope of the impact from 30,000 people locally to over 100,000 in the region. We believe this to be the first type of collaborative working within this field nationally.

Planning

To ensure that people LWBC received the most relevant and desired information, the programme was person-centred from the beginning. We ensured patient representation was on the Programme Board to provide feedback throughout. We have developed excellent collaborative working arrangements at strategic, operational, local and third-party levels (Macmillan) as well as close working relationships with other acute provider Trusts and our dedicated LWBC Advisory Network.

Implementation began with robust programme plans using PRINCE2 methodology, supported by detailed Project Initiation Documents, activity schedules and Risk, Assumptions, Issues and Dependency logs. These have since been shared regionally as an example of good practice and have been adopted by other Trusts to develop their programmes. We ensured there was strong engagement from people LWBC in decision making and service delivery in all of the project groups.

One key challenge was the strategic context and priorities for the Trust and Clinical Commissioning Group. Time and competing priorities among staff initially resulted in variable clinical engagement. To overcome this, we utilised patient experience and feedback through numerous avenues including Lunch & Learns to provide the drivers and evidence within the system wide health economy to deliver these ambitions projects. In order to prevent fatigue and overload we held a Stakeholder event to map out all cancer projects. This identified project scope, key roles, provider responsibilities and timescales as well as potential conflicts and barriers. It proved to be highly effective and regarded as best practice within the region. The final phase of sustainability is the most challenging and crucial. Ensuring ownership of LWBC patient initiatives with stakeholders is key to sustainability.

Impact

By providing the Passport to the patient, it has enabled them to gain personalised care through the HNA and also have the control to make direct contact with local and national services that can support them. Feedback of the Passport has been hugely positive with the patients stating that it was "good to have all the information in one place" and be able to "write information during appointments so that I can look back at it later when it is not so overwhelming". Since the Programme started, data has shown a 47% increase in completed HNAs across all specialities, going above and beyond the NHS Long Term Plan of five tumour sites by March 2022.

By the end of the 11-month pilot, a total of 321 people had benefited from attending a face-to-face LWS and over 120 now form our growing LWBC Advisory Network. Some feedback from the day:

From people affected by cancer who attended LWSs:

- Lots of useful information

- I don't feel so alone anymore

- Information very helpful to me as a carer
- If only I had this information 5 years ago
- A lot of this information I needed 18 months ago!! It would have been extremely useful and of great benefit
- I found the session very helpful. Talking about my situation and learning from others

From staff who have attended the LWSs:

- It is great to understand what you talk about so I can encourage people to join on to an LWS
- It is fantastic that we are really promoting safe self-management so that people are able to cope better in the future
- There is a good balance between self-management of these concerns and reassurance that support is still available in both primary and secondary care: it was really well handled

A follow up survey was sent to patients three months post attendance to the LWS. The results showed that following the information they had received, they were accessing services available to them such as counselling and physical activity programmes as well as safely self-managing symptoms by adapting their lifestyle. Of the responses we received, 98% of patients had gained confidence by attending the LWSs.

Due to Covid-19 restrictions, the team modified the LWSs and delivered these online. There are benefits for patients being able to access this information and support from the comfort of their own home and without having to incur the costs and time of traveling. However, we recognise that this model of delivery is not for everyone. Therefore, Covid-19 restrictions permitting, we will offer a hybrid approach to give people the choice based on their preferences.

Within the first month of launching the Living Well videos, we received over 400 hits! Referrals to supportive services such as the Macmillan Welfare Rights Service have also increased meaning more patients are benefiting. In the past financial year this latter service generated over £3.6 million in terms of financial gains for patients with cancer which is simply fantastic for people LWBC.

Relevance to Others

Following the production of our ‘My Passport to Living Well’, we have been approached by staff and managers covering other long-term conditions. There is discussion around how this could be adapted to support patients in other areas too. We would support this and feel that the focus of all our work has been on sharing, transferability and collaboration. Our ambition to ensure the online Living Well videos have the potential to reach over 200,000 patients within the West Midlands could be expanded and rolled out nationally. The scope is there for the taking and we have the drive and ambition!

Standing Out

We believe our approach to supporting cancer patients has been innovative and collaborative. Designed with cancer patients for cancer patients, we have led the first cross provider, region-wide initiative to ensure maximum exposure. Designed to provide high quality advice and support to patients, 24 hours a day regardless of their mobility, rurality etc. Our work benefits patients, family members, CNS teams and other Allied Healthcare Professionals. They promote wellbeing and ensure consistent high-quality information is provided to all, both within England and parts of Wales.

Key Learning Points

Continuous planning! It is imperative to scope the current position and map that against the future ideal, identifying opportunities for improvement as well as what you consider to be the ‘rocks in your shoes’. Any service and improvement work for patients MUST involve them as they are experts by their experience. Ensuring engagement at Executive level and strong leadership via an Executive Sponsor and Clinical Champions ensures ownership within the Organisation and facilitates sustainability. During the testing phase, pilot various options and evolve in line with outcomes and evidence. Change is to be embraced and it will be with evidence, results and bringing the whole team along with you. Nothing happens in isolation but by working together, respecting others, having pride in your work, you can achieve something amazing.

Screening People with Learning Disabilities for Bowel Cancer
South Tyneside NHS Foundation Trust
PENNA 2015
WINNER – Communicating Effectively with Patients and Families

Organisation

South Tyneside NHS Foundation Trust is a £210m provider organisation in the North East of England, delivering a full range of community services across South Tyneside, Gateshead and Sunderland, and hospital services in South Tyneside. Employing 4700 staff, we are regularly ranked in the Top 40 hospitals and recognised as a high performing Trust. With over 600,000 patient contacts every year, our overarching Trust Value statement is, "We CHOOSE to go further to exceed our customers' expectations",

General

Bowel cancer is the second most common cause of cancer death in the UK. If it is detected at an early stage, it can be successfully treated. This entry describes how South Tyneside NHS Foundation Trust community Learning Disability Service addressed the bowel screening needs of those people with a learning disability in Gateshead and South Tyneside. People with learning disabilities have a shorter life expectancy and increased risk of early death when compared to the general population (Emerson et al, 2012). It is also widely known that adults with learning disabilities have high rates of physical morbidity and co-occurring physical disorders than the general population and are more likely to die from preventable conditions, due to inequality in access to services. A project was developed to improve and increase the uptake of bowel screening for those with a learning disability by improving the communication, education and support offered to patients and their families. Following a 12-week intensive programme of staff development, education and support facilitated by a project lead the service was able to demonstrate improved communications and understanding towards bowel screening which resulted in an increased uptake across the two boroughs.

Rationale

A number of national reports (Mencap,2007., Michael,2008) have highlighted that adults with learning disabilities often experience barriers to accessing healthcare services and poor levels of care. Patterns of health needs amongst adults with a learning disability are different to the general population (Emerson et al, 2012), and national screening programmes that target local population health such as bowel screening are often not designed to fully include this demographic group. The National Bowel Screening Programme offers bowel screening every two years to men and women in the England aged 60-74yrs, including those with a Learning disability. The lifetime risk of developing bowel cancer in the UK is 1 in 14 for men and 1 in 19 for women. The late diagnosis of bowel disease is becoming increasingly common and currently 41,000 people are diagnosed with bowel cancer in the UK each year, claiming around 44 lives each day. If detected at an early stage, more than eight out of 10 cases of bowel cancer can be successfully treated. (Cancer Research UK, 2008). Available data shows that incidence and mortality of bowel cancer for people with learning disabilities is lower than for the general population with the low mortality possibly attributed to the poor general take-up of bowel cancer screening by people with learning disabilities. Across our two local areas (South Tyneside & Gateshead) there are approximately 1,921 adults with learning disabilities known to GPs. Approximately 16% (311) of those known are between the age of 60-74yrs therefore qualifying for the bowel screening programme. Of those eligible 23% (72) had initially had bowel screening discussed with a member of the Community Learning Disability Team with less than half (47%) of service users taking up a bowel screening test. This is lower than the national average for mainstream population which is 60% (Turner et al, 2013). It was therefore decided that the Community Learning Disability service would undertake a project to improve access and the uptake to bowel screening.

Planning

The aim was to increase uptake of the screening test by at least 10% within an intensive 12-week project. A project co-ordinator was appointed to lead on the project and to collect and collate the data. The number of individuals known to the Community Learning Disability teams who fell within the age range (60-74years) was established by using the Health Action Plan databases in each GP practice which were already well established across both localities. The data confirmed that there were 311 people with a learning disability eligible for bowel screening and that 72 had already had bowel screening discussed with 34 having undertaken bowel screening. This left a group population of 239 to focus upon during the 12-week project. In preparation for the project initial contacts were made with learning disability user groups, cancer screening leads, the Community Learning Disability multidisciplinary Team, carers and families across the localities to explore their views and consider any reasons why those people with a learning disability may not take the bowel screening test.Through the preparation stages some common themes emerged and in order for the project to be successful improving communications were necessary to address these themes:1.Screening letters were not user friendly Using the guidance from the Department of Health regarding reasonable adjustments for people with Learning Disabilities (Turner & Robinson, 2011) we developed easy read letters which were designed by our Learning Disability speech and language team. Using photo symbols from a unique photo library for everyone making we used the symbols which were based on photos, so they are colourful and easy to recognize. 2.People felt embarrassed often failing to understand what was required to undertake the test We identified that not only the person with a learning disability and their carers may be embarrassed but our own staff where often embarrassed discussing the screening process as they didn’t always have that level of detailed awareness of what was expected. A training pack was therefore developed which included all of the relevant screening information and leaflets. Training was delivered by the project lead to ensure that all the community teams were supported to understand how the screening process worked and what was required. This increased their confidence and enabled them to better support the person with a learning disability and their carer in the community3.Issues with mental capacity were identified Understandably there were issues regarding whether or not the person with a learning disability had the mental capacity to consent to the screening. Those who were found unable to consent to bowel screening following assessment using the Mental Capacity Assessment framework process, where then subject to a best interest decision. These decisions included the person and their relevant persons representative to seek consent to use the person with a learning disability’s stool to enable completion of their bowel screening kit. The assessment must be specific to the decision which needs to be made and, in this case, it was used to request that a sample of faeces was to be used to smear onto the screening kit for testing purposes. Best interest decisions were considered for those who undertook bowel screening, 39 were found to have capacity and 78 required a best interest decision.4.No clear links between the Cancer screening hubs and General Practices or Community Learning Disability services to identify those who had a learning disability One of the concerns identified at the onset of the project was the difficulties that the screening service had in identifying those people with a Learning Disability who were eligible for screening therefore they were not able to make any reasonable adjustments at that initial contact stage. By working together and improving communications we were able to put in place a pathway between the Screening service, the GP and Community Learning Disability Team. If the person with a learning disability team is a non-responder at week 14 the letter reflecting this is sent to the persons GP and then checked against their learning disability database. If found to have a learning disability the GP practice then refer into the community learning disability team to revisit the screening with the individual and make the necessary adjustments to enable the bowel screening kit to be completed 5.No clear pathway between GP’s and Community Learning Disability Services when those with a learning disability were ‘non responders’ to the NHS BSCP Bowel screening letters We were able to address this by developing a pathway for those non responders between the Community Learning Disabilities Team and GP practices. This aims to ensure everyone involved are very clear about the processes and communications. Although most of the support was given by the Community Learning Disability staff, appointments were made for the project lead to visit at an agreed time to discuss the bowel screening and test with the individual, carers or family should that be further required. Support was also offered in obtaining and submitting the necessary specimens where required.

Impact

At the end of the project from the 239 people with a learning disability eligible to be included 36 refused to participate and 6 were unable due to ill health therefore 193(81%) had bowel screening discussed of which 117 (61%) undertook bowel screening. Of the 117 who undertook screening 99 (85%) required no further action however 18 (15%) did require further follow up of colonoscopy due to the presence of occult blood. It was therefore arranged that these individuals have the support of the Community Learning Disabilities Nursing Team to help understand this process. The outcome of the project demonstrates that by improving overall communications with patients, families, carers, other professionals and our own staff along with the training and supportive tools developed in the project the number of people who went on to screening increased from 47% to 61% which exceeded our target of a 10% increase and also that of the uptake of general mainstream populations. Although the project was very successful in increasing the uptake of screening, we are aware that due to the people who had already had a discussion pre project the number of screening uptake across Gateshead and South Tyneside this year remains 48.5% in total (151 screening from 311 people). We will therefore revisit those original people who had had a discussion to ensure the discussions include all the updated training information required to support a more informed choice.

Relevance to Others

We would recommend that consideration on how to adapt the same principles for increasing screening for other cancers and to other groups of patients who may require more support including those with a learning disability by:

- Offering on-going training and support to staff
- Being proactive in identifying those people with a learning disability falling within age range for specific cancer related screening each year
- Target individual and carers/families with advice and support
- Continue to record progress

Standing Out

Improving people's health by health promotion, health screening and early identification can be an extremely challenging area at the best of times and this project demonstrates that effective communications with people with a learning disability and their families or carers can have a significant impact on their health choices and uptake in screening programmes.

Key Learning Points

The key learning issues we found when undertaking this project was that; -

- Staff need to be supported through appropriate training to develop necessary information / education and communication skills to support patients to make appropriate health choices
- Organisations need to work together to ensure successful pathways for patients which link together and share information
- Collaboration with external agencies and national screening services can assist in ensuring the appropriate educational materials are developed and used with targeted groups to promote uptake
- Screening patients can help with early identification and preventative treatment

Caring for my Family With Cancer
Velindre Cancer Centre
PENNA 2016
WINNER – Communicating Effectively with Patients and Families

Organisation

Velindre Cancer Centre in Whitchurch, Cardiff, provides specialist cancer services to people living in South East Wales and is one of the 10 largest cancer centres in the UK. The Cancer Centre is a specialist treatment, teaching and research and development centre for non-surgical oncology, treating patients with chemotherapy, radiotherapy and related treatments, and caring for patients with specialist palliative care needs. We provide services to over 1.5 million people across South East Wales and beyond. each year we treat over 5,000 new referrals and around 50,000 new outpatients. Our dedicated staff of over 670 works as a close-knit team. Our aim is to provide patients & families with the best possible care and treatment.

General

Inspired by experiences of families, cancer nurse Michele Pengelly was concerned about the paucity of resources helping newly diagnosed cancer patients talk to their children about cancer and the impact on families. Resources were limited, mostly using heteronormative images, questionable for the diversity of modern-day.

Demonstrating a collaborative partnership with Equality Manger Ceri Harris, the idea followed to write a series of books which are fully diverse, accessible and fit for purpose including audio/BSL. Following consultation with patients, children and professionals the first "Caring for my family with Cancer" book was successfully launched in 2015. 150 have now been issued.

The series of 6 books is innovative as a completely diverse, accessible resource aiming to support cancer patients to talk to their children about cancer. Utilising modern technology and computer graphics, the books have provided positive outcomes to families' experiences, have longevity, are cost effective and include single parent and same sex families. This use of technology and charitable funding to support costs has meant that the series of books is fully sustainable. The simplicity of the family story has contributed to a project with transferability. The dissemination of this work has been through professional, public and third sector events.

Rationale

Michele Pengelly, a cancer nurse with 30 years' experience has worked with numerous parents who made decisions not to talk to their children about their cancer. Sometimes the parents' health deteriorates, and they sadly die with their children still unaware of the cancer and no understanding of what has happened.

Michele facilitates a children's bereavement group; listening to these children's stories and observing their pictures and memory jars she felt passionately that we could do better and take a more proactive approach. For parents who did want to explain cancer and their treatment the current resources were not always appropriate. Resources were limited, mostly using heteronormative images, questionable for the diversity of modern-day families (single parents, same sex) – to give a father a story book about breast cancer because there was nothing else available was not good enough!

Michele had the idea of writing a book to mirror the families we were meeting in clinical practice. In 2014 meeting with Trust Equality manager, Ceri Harris, 20 years' experience in equality, both felt passionately there was a need to create a resource that not only looked at gender concerns, but to develop a series of books; fully diverse, accessible and fit for purpose, including BSL and audio versions in several languages that would meet the needs of families who used the services at Velindre.

The aim was to meet a gap in resources and enable safe and open conversation about cancer within families so that children were part of the experiences in a positive way.

Planning

From the outset engaging & involving stakeholders was hugely important; equality groups, parents, clinical psychologists and nursing staff, to ensure the books met everyone's expectations and needs. Ensuring the language used was fit for purpose and that support was provided to parents in how to use the books effectively.

An internal governance group was established as well as a stakeholder group, so we were confident that the books met all obligations. Michele and Ceri worked closely with the artist and digital colourist to develop the characters within the books to reflect diversity.

Velindre fundraising were involved in the funding of the printing and additional costs. Clinical and nursing staff received training on how to use the books with parents and support them with any difficult questions and situations. We were fortunate that Cardiff born Hollywood actor Matthew Rhys, patron of fundraising, provided bilingual audio versions of the book, professionally recorded in a studio in LA, and sent for the launch. Matthew's beautiful tone and animated approach brings to life the story of the little girl Lucy and her family's experience of cancer.

The final version of the first book was agreed by the stakeholder group, prior to printing, so everyone involved was aware and agreed on the final product.

This year we have evaluated and revised the books following comments from staff, patients and their families and produced the British Sign language Version which we launched in November as part of Sensory Loss Awareness Month in Wales.

Books are issued to families together with a set of cuddly lions (one for the child & one for the parent) to reduce separation anxiety if the parent needs to come into hospital – the lions feature in the books too!

Impact

The impact has been so positive using both quantitative and qualitative methodologies including patient experience digital stories. We have attached as part of our application a video of Vincent, a little boy who received the book and cuddly lions when his mother was a patient with us. He speaks so eloquently about how useful and important the book was to him; how he recognised himself within the book and that he even thought he looked like the little boy, Jack.

We asked each family who received a copy to provide comments and feedback, this helped us evaluate and revise future versions. We spoke to clinicians, asking if they found it a useful resource. We keep data on numbers of families using the resource, ages of children and which type of book is most used.

What surprised us is that we are now seeing the lions appear in the children's memory boxes when they attend the children's bereavement group. This demonstrates how important the lions were as part of their own journeys, how they found comfort in the books and lions and the positivity they must have given during a very upsetting time.

An additional outcome is that the Trust has been approached by a number of health organisations not just from Wales but across the UK asking about the project and wanting to purchase copies of the books.

Relevance to Others

As identified throughout this application, the project has involved and seeks to involve more internal and external stakeholders. We realised the value of the books and how they have helped families and hope to develop future resources that can be used externally, whether for cancer or modified to be used for other conditions.

Standing Out

Velindre believes the reason this project stands out as it was inspired by real family experiences that had happened at Velindre Cancer Centre.

Acknowledging that there was a gap in the resources available which did not reflect the diversity of the patients we see.

There was a need to develop a fully inclusive product that wasn't heteronormative, which acknowledged the needs of those with sensory loss and was adaptable to changes quickly and efficiently, consequently minimising costs and stress to the organisation and families.

The books are future proofed, they can grow with diverse needs, they meet both current and upcoming patient needs.

Best of all, the families who have used them have loved them and found them incredibly helpful. For us that's the most worthwhile & positive outcome we could have ever achieved.

Key Learning Points

Engagement – It is essential to involve the parents and families from the outset and to keep their involvement throughout the pilot study and change management process. This gives a greater integrity and heart to the project.

Training – Collaborate with training departments and staff personal development reviews to help identify the training needs for those delivering care with the new resource. What additional support and advice they may need to deliver this service and build this into training programmes.

Technology – How can you best use current and future technology? For example, by using a digital colourist and artist we are able to create picture layers, so characters, and elements of the story can be easily added or taken away to develop further books.

Adaptability – The methodology could be used in other fields, for example "Caring for my family with motor neurone disease". The use of modern technology means it can be adapted and updated if cancer treatments change.

Sharing best practice – don't keep it to yourself. There will be lots of other organisations with similar challenges struggling to develop solutions. Through events, conferences and publications take every opportunity to share.

In-Patient Support and Information Rounds
University Hospitals of Leicester NHS Trust In partnership with NHS England Cancer Collaborative and LLR Alliance
PENNA 2019
Winner – CPES Award

Organisation

University Hospitals of Leicester are a large teaching hospital base across three sites with many specialist areas or expertise. It employs 15000 staff. We are based in caring for cancer patients.

General

This initiative is part of a National Cancer collaborative initiative to provide in-patients with cancer to have the opportunity to discuss their worries and fears with staff. The initiative involves an information and support mobile outreach team to visit patients on the wards to offer them the opportunity to help themselves to written information from the trolley, and /or have the opportunity for a one-to-one conversation surrounding any worries and fears they may have. The team have identified the need for the service by looking at the National Cancer Patient Experience Survey (NCPES) which has for the past three years identified a 5% below the national average in our survey results for this concern. We have a involved a patient representative and a volunteer with lived experience of cancer services.

We have used data collection, PDSA cycles of change and an overarching driver diagram to implement the initiative. Team relationships have been built with ward staff as well and they have had training and education as part of the initiative. The initiative has been evaluated positively by patients and it is aimed to be rolled out to a wider area in the next few months.

Rationale

The aim of the initiative is to improve opportunities for in-patients to discuss their worries and fears. UHL patients surveyed as part of The National Cancer Patient experience survey results demonstrated that only 48% of patients felt they had the opportunity to discuss their worries and fears with staff, against the national average score of 53%. The initiative is a Pilot scheme which involves a weekly mobile trolley-based patient and information support round on a 19 bedded oncology ward. This ward was chosen as we know from the cohort of patients that are sent the survey were predominately cared for in an oncology ward when they were an inpatient. The bespoke information trolley used on the ward rounds has been populated with written information tailored to the top concerns that patients identified as part of Electronic Holistic Needs assessments which are offered to all patients diagnosed with cancer.

Planning

The team were formed by The Lead Cancer Nurse. She led the bid to be part of the National Cancer Collaborative. The Cancer Collaborative provided us with study days, coaching calls and number of toolkits to help implement the initiative. A patient representative gave advice, and a volunteer joined the team to collect patient feedback via IPAD questionnaire. The team also consisted of a Deputy Chief Nurse for patient's experience. She led on formulating a patient questionnaire and data collection tools. A Deputy Lead Cancer Nurse co- ordinated the team and arranged fortnightly team meetings as well as email communications to keep the initiative on track. She was responsible for PDSA cycles, communication of the project and feedback co-ordination from the Team who visited the patients. The team who visited the patients were a Macmillan Support and information officer and an Oncology Matron. They regularly gave feedback at the team meetings and helped in communicating with ward staff and collecting patient opinions, stories and data.

Impact

Success was measured by patient feedback. They were surveyed after each mobile information and support ward round. Staff were also regularly asked about their thoughts and knowledge of the initiative. The impact of the round was that 60% of patients thought the ward round and speaking to someone was useful, the mobile information was also evaluated by 40% patients as useful. Narrative comments found that those who didn't find the trolley of benefit had been in hospital before or had a long history of cancer and had already had their needs addressed in the past. Staff feedback was positive and good relationships were forged with the information and support team, as well as educating the staff of available services for patients.

Relevance to Others

To continue to provide the service and roll out the initiative to the other oncology wards, a sustainability model was completed and PDSA cycles were initiated. The plan is to ensure that the round happens weekly alongside the tea and chat rounds which take place on the other wards. This allows ward staff to be involved, it is aimed to raise awareness for them as well and means it doesn't rely on a small team to deliver the round, it will have more staff trained and involved. We will continue to monitor patient feedback through our in-patient surveys.

It will have been reported on the National Cancer Collaborative forum as part of the project we are involved in. It has also been communicated as above. It will be reported to our patient user group as well.

Standing Out

This is a simple project on a small scale which is easy to roll out to other areas.
It makes a difference to a patient's well-being in all senses and gets them the help that they may not have had the courage to ask for before as an in-patient.

Guidance and toolkits from taking part of the National Cancer Collaborative project has helped keep it on track. The team itself have really engaged and enjoyed the new way of reaching out to patients. Excellent communication and regular meetings have kept the momentum of the initiative going. Using patients experience, a volunteer and patient feedback as also helped keep the project to a patients' point of view. Ward staff have engaged equally as they can see the benefits for patients, and it has raised their awareness of services and support available for their patients.

Key Learning Points

- Keep the project small, with a focussed aim.
- Ensure you involve patients at the beginning and all the way through, collect data.
- Have regularly planned meetings to assess the need to change tact if needed.
- Use excellent communication skills with the team and the ward staff to engage them and seek their feedback as well.
- Communicate the project widely so everyone knows what is happening.
- Use toolkits such as PDSA/SPC/Sustainability models to help evaluate and roll out the initiative to a wider area.

Prostate Cancer Remote Monitoring
University Hospitals of Leicester NHS Trust

PENNA 2019
WINNER – Partnership Working to Improve the Experience

Organisation

University Hospitals of Leicester (UHL) is one of the largest and busiest teaching trusts in the country, serving over one million residents of Leicester, Leicestershire and Rutland. The Trust comprises of three main hospital sites: Leicester Royal Infirmary; Leicester General Hospital; Glenfield Hospital. The Trust has a national and international reputation for the high-quality specialist care, particularly in cancer, renal and cardiac services. The Trust is at the forefront of many research programmes and new surgical procedures. There are currently over 15,000 staff working within the organisation, under a variety of job descriptions, but working as a team towards giving and promoting excellent patient care and experiences. We constantly strive to improve the care patients receive, looking at the ways we work, acting on patient feedback, ensuring staff are highly trained and encouraging research

General

Prostate cancer patients have said that their outpatient follow up appointment is often little more than confirmation that their blood test result is ok and receive a form to book the next test. The appointment can be inconvenient to the patient with no evidence of a positive outcome for survival. This puts an increased strain on hospital outpatient services and therefore we designed and developed a new pathway where patients didn't need to come into hospital. The previous pathway involved patients turning up to an outpatient's appointment, taking time off work, relatives taking time off work, travel time and money, waiting in outpatients for up to 2 hours to see a consultant for a consultation that lasted between 2-5 minutes.

The purpose of the remote monitoring service is to provide patients with a safe guideline-based service to monitor their prostate cancer. The service enables patients to be monitored remotely rather than attending the urology outpatient's department. This greatly reduces the inconvenience for patients, reduces the cost of travel for them and also generates outpatient capacity.

Since implementation of this pathway in October 2016, 1277, patients have been referred onto Remote Monitoring. That means over 3612 reviews have taken place and in April 2019, 206 patients were reviewed which equates to 51 outpatient appointments saved per week.

Rationale

Approximately 47,000 men are diagnosed with Prostate cancer in the UK each year. It is the most common cancer in men in the UK. The number of men diagnosed with Prostate cancer has been increasing over the last 10 years.

More than 11,500 men die from Prostate cancer each year but over 400,000 men are living with and after a prostate cancer diagnosis. Elderly men who are mainly asymptomatic make up for the majority of numbers of men with prostate cancer and are likely to have a good prognosis. Most prostate cancer patient s follow up is based on the PSA blood test. Therefore, a risk stratified pathway incorporating IT based Remote Monitoring system using infloflex to remotely monitor patients, leading to a safe, convenient and cost effective follow up for patients. The remote monitoring system was brought into practice to reduce time patients and their carers spend at the hospital unnecessarily, as well as being more convenient for patients as they do not need to travel to the hospital, pay for parking or take time off work to attend a hospital appointment. This system is a safer way to monitor patients PSA results as patients are given a date of when to have their blood test and then the PSA is reviewed, and the result is communicated to the patients and GP with 2-7 days. This system provides seamless individualised high-quality care ensuring good communication between primary and secondary care.

Planning

The project idea was initiated by a Consultant realising things could be done differently. Collaboration then started between the Macmillan Cancer Pathway Manager and Consultants who set up a working group comprising of GP representatives, representation from the clinical commissioning group, NHS England, Cancer nurse specialists and IT.

A Remote Monitoring Administrator and Prostate Cancer Nurse Specialist were appointed into role at the start of the project. All suitable stable prostate patients are referred to the remote monitoring system by their consultant via a simple referral form. The consultant specifies the grading stage of the tumour, and the patient is entered on the system by the remote monitoring administrator. The alert level for PSA is set according to the treatment the patient has had and the stage of cancer.

An introductory letter generated by infoflex is sent to the patient with an explanatory leaflet and a blood test form which specifies when they should have their PSA test done. Blood tests can be carried out at the patient's local surgery or at UHL Hospitals. Patients are also given the contact details for the remote monitoring team who they can contact Mon-Fri 9am-5pm.

Blood test results are monitored regularly by the remote monitoring administrator. If the result sis within normal limits a letter is sent to the patient and their GP automatically, stating that their PSA level is satisfactory and another blood test form with the date for their next blood test.

If an abnormal result is flagged up, the Clinical Nurse Specialist with take appropriate action, ranging from a phone call to suggest doing a 3-month monitoring instead of the usual 6 month monitoring or contacting the consultant of advice or to arrange and clinic visit

Impact

The benefits of this initiative have been improved quality of life for prostate patients. Patients are now being saved the stress and inconvenience of unnecessary hospital appointments, as well as relief from anxiety as patients are notified of results in a timelier manner.

The prostate cancer service has been improved as valuable clinic capacity is freed for patients needing to see the consultant urgently. The system is robust and secure electronic system ensures that no patient 'slips through the net'. Alerts, flags, automatic letters can be set up to respond to results more efficiently and to relieve administrative pressure.

A patient satisfaction survey has been undertaken and 92% of patients reported that their needs are being met in regards to their prostate cancer.

Between October 2016 – Oct 2019, 1277, patients have been referred onto Remote Monitoring. That means over 3612 reviews have taken place and in April 2019 206 patients were reviewed which equates to 51 outpatient appointments saved per week. 120 patients have been recalled to clinic for PSA rises.

Relevance to Others

Locally this initiative has also been implemented for the monitoring of Thyroid cancers and has informed the work going forward within Breast and Colorectal Cancer follow up pathways. Externally this could work of other hospitals and is aligned to the NHS 10-year plan for personalised care.

Standing Out

This initiative stands out due to the impact it is having on the whole system. For patients it means less time off work, less waiting for results, cost of travel to the hospital is reduced, as well as quick re-access into the system. All the patients on remote monitoring also have access to the nurse specialist having knowledge and expertise on hand and available when patients need it. To the organisation it has helped to free up outpatient capacity meaning that the more complex patient can be seen quickly.

Key Learning Points

Involve members of the multi-disciplinary team in project design to facilitate clinical team engagement and robust project planning. Engage with the clinical commissioning group at project commencement to ensure the project develops in line with all stakeholders' priorities and work streams. Work in collaboration with non-clinical colleagues to ensure processes and systems are correctly understood and fit for purpose. Ensure patients are involved, that their voice and opinions are heard and that they are at the centre of all improvements made.

All of this must be underpinned by a robust IT system that can monitor the patients.

Setting up a Neuroendocrine Patient Service
University Hospitals of Leicester
PENNA 20-21
WINNER - Fiona Littledale Award

Organisation

University Hospitals of Leicester (UHL) NHS Trust is a teaching trust that was formed in April 2000 following the merger of Leicester Royal Infirmary, Glenfield Hospital and the Leicester General Hospital. The Trust has approximately 1,800 inpatient beds and 180 day-case beds. It is one of the largest acute NHS trusts in England.

The Trust employs an estimated 12,600 full time equivalent staff and provides specialist and acute services to a population of one million people throughout Leicester, Leicestershire and Rutland. This accounts for 32% of people living in Leicester city, 64% in Leicestershire and 4% living in Rutland. The three areas have a varied demographical profile.

The City of Leicester has a younger population whilst the county areas have an older populace. The city of Leicester is an ethnically diverse population with over 37% of people being of Asian origin. In Leicester city, 75% of people are classified as living in deprived areas and there are significant problems with poverty, homelessness and low educational achievement.

Although there are pockets of deprivation in the broader Leicestershire area, over 70% of the residents are classified as living in non-deprived areas. In Rutland, over 90% of inhabitants are classified as living in non-deprived areas.

The Trust includes nationally and internationally renowned specialist treatment services in cardio-respiratory diseases, cancer and renal disorders that provide services for a further two to three million people from the rest of the country.

The Neuroendocrine Tumour (NET) Multi-Disciplinary Team (MDT) is a multi-professional group serving the University Hospitals Leicester NHS Trust. The MDT was started in 2018 to ensure that neuroendocrine patients were being assessed and reviewed by healthcare professionals who were specialised and experienced in the complexities of Neuroendocrine disease. The appointment of a Neuroendocrine Nurse Specialist to the service was made in November 2018.

Neuroendocrine tumours are rare, developing in different areas within the body and can behave differently, depending on the grading of the tumour. Grade 1 tumours tend to grow slowly however grade 3 tumours have cells that divide at a faster rate and will behave similarly to an aggressive cancer meaning that the prognosis is poorer. Some NETs will also make extra hormones, which will cause the patient symptoms that will need careful management and regular review.

General

Before my appointment as the Leicester Neuroendocrine Nurse Specialist (NET CNS), there was no cohesive support for neuroendocrine (NET) patients and families locally.

Since coming into post, my chief aims have been to provide cohesive support and information for those affected by neuroendocrine tumours. I have set up a nurse-led service for NET patients, to provide them with continuity and holistic needs assessments to ensure ongoing support.

I have established a regular patient support group and held a Patient Educational Day to meet ongoing information needs.

Keen to lead the nursing service to reflect the high standards of other NET specialist centres, I visited other trusts, to gain insight into their practice. Likewise, I have taken the opportunity to attend national and international conferences and was invited to serve on the nurses committee of the European Society of Neuroendocrine tumours (ENETS). I have conducted 2 patient satisfaction surveys to ensure that we are capturing and acting on the outcomes of patient feedback and offering a service that is sustainable. I have worked with hospital departments to ensure that we can offer our NET patients local specialist treatments and on a practical level, a home delivery service for their medication.

Rationale

As Neuroendocrine tumours (NETs) are rare, diagnosis is often delayed or misdiagnosed, leading to frustration and a degree of mistrust in the system. Patient information is not always easily accessible and with an uncommon diagnosis, patients often struggle to understand what their diagnosis means for them or their family. They can feel very isolated and misunderstood. My desire was to offer support, information and engagement with all NET patients, who had previously been scattered among the various tumour groups, as dictated by their primary tumour. Thereby addressing the importance of offering a cohesive and constituent service to patients and carers, not available to them previously.

The Neuroendocrine Nurse Specialist (CNS) service enables patients to have access to a nursing professional linked to their disease, whether in clinic or over the telephone. All patients are given my contact details, general NET information and local patient information and support. From a supportive element, patients meeting with fellow sufferers should never be underestimated and is invaluable. For patients to meet together helps with confidence in managing the disease, knowing that they are not isolated and in making the rare more common. This is remarked upon in patient feedback.

Planning

I am fortunate enough to be supported by encouraging nurse managers who desire the delivery of the best possible patient centred care.

I worked with the auditing team sending out patient satisfaction surveys in February 2019 to all neuroendocrine tumours (NET) patients to establish their views. This feedback guided the action plan of the service's direction. The subsequent one in February 2020 to ensure ongoing review.

Nurse led clinics ensure regular patient reviews of their neuroendocrine disease as well as opportunity for contact, information and holistic needs assessments. I submitted guidelines to ensure that the service offered safe and clinical competent nursing practice. These clinics commenced in April 2019.

The Neuroendocrine Support Group started in February 2019 after I was able to commandeer a suitable venue. Open to anyone affected by neuroendocrine disease, I hosted the meetings and invited a variety of speakers to informally speak to the group giving everyone the opportunity to question, discuss and to meet other fellow NET patients.

As regular support groups are not for everyone, I sought sponsorship from the Neuroendocrine Cancer UK charity, to hold a patient educational day. They agreed to fund the event and this one-day event was held in February 2020, open to anyone, free of charge and was advertised by posted invitation, verbal invitation, posters and social media. I advised the agenda, drawing on different aspects of the NET diagnosis, treatments, symptoms and psychological impact that patients experienced.

Impact

The impact of the Neuroendocrine (NET) nurse specialist (CNS) for the service can be measured by the second NET patient satisfaction survey and the feedback given. For example, the patients from the first survey were concerned regarding their monthly injections and getting the prescriptions in a timely fashion from the hospital. The NET service now offers home delivery of the injections which has eased the situation for the patients. Patients appreciate having a healthcare professional available that they can contact and talk their concerns through with. The Leicester Support group has also been well received with regular numbers being approximately 12-16 per meeting.

As the support group had been well supported, I then arranged and hosted Leicester first educational day, for patients, carers and anyone affected by neuroendocrine disease. The national charity 'Neuroendocrine Cancer UK' agreed to attend and sponsor the day. The feedback from this day was excellent and attendance was high.

Relevance to Others

The NET CNS service is supportive for patients coming into the service, as well as patients in other areas and hospitals.

NET patients, particularly those with known functioning tumours, are at risk of experiencing a serious exacerbation of symptoms, which can be life threatening, in certain clinical settings. I can guide and advised colleagues dealing neuroendocrine patients in their departments, so that the standardised level of care is given, as guided by the UKI and Ireland Neuroendocrine Tumour Society.

Patients are referred in from other hospitals for discussion, review and treatment outcomes. Communication is key to ensuring that patients get a smooth transition of service and that the NET service offered is uniform in its approach nationally.

Standing Out

I feel that this initiative is special as it is built on the advice and experience of patients' needs and that in doing this the patients' engagement has been fundamental in getting this service to where it is today.

It is important to understand this patient group's varying needs in a tumour where everything can vary, from symptoms to severity, surveillance to surgery, indolent disease to aggressive and rapid prognosis. Support at every stage remains fundamental to providing gold standard nursing care, whether on a physical or psychological level.

Only by understanding and interacting with your patients can you offer this support at the appropriate time.

Key Learning Points

- Seek out your patients' opinions on the service so that you can build a robust service based on patient engagement and need, not on what you think might be needed.
- Look at the services already available to you and what you might be able to potentially call upon/use.
- Go and visit other areas and centres nationally to ensure that you are keeping your service in line with other national centres, as appropriate.

Improving Access to Cancer Nurse Specialists and Key Workers
Wessex Cancer Alliance
PENNA 2019
FINALIST – CPES Award

Organisation

The Wessex Cancer Alliance (WCA) is responsible for overseeing the delivery of cancer care across Wessex, by supporting the Sustainability and Transformation Partnership in Hampshire and the Isle of Wight and the Integrated Care System in Dorset. The Alliance will ensure Wessex meets the requirements and goals in cancer care, treatment and out comes that were set out by the NHS Long Term Plan, published in January 2019.

The WCA brings together multiple partners, including patients and carers, to enable care to be more effectively planned across local cancer pathways. We are committed to implementing a personalised care approach for all patients from the point of diagnosis. Personalised care is based on what matters to people and their individual needs and should underpin the whole cancer pathway.

General

Over the past ten years the Department of Health has surveyed more than 250,000 people in England about their experience of being treated in hospital for cancer, via the annual Cancer Patient Experience Survey (CPES). This vital survey has shown one factor is consistently linked to good patient experience - whether people are given the name of the clinical nurse specialist (CNS) in charge of their care. The good news is that the number of people being assigned a CNS continues to rise, from 84% in 2010 to 89% in 2014. But this still means that around one in 10 people with cancer are denied the expert care and support that a specialist cancer nurse can provide. In some trusts, this rises to more than one in five. There is also huge variation in how easy people find it to contact their CNS. As the number of people diagnosed with cancer continues to grow, CNSs are facing an ever growing need to focus on the complex, specialist areas of care and many patients are voicing the fact that many of their more supportive needs are not addressed until the end of their treatment pathway – in Wessex we wanted to see if some of the concerns and issues could be identified at the point of diagnosis by the introduction of a Cancer Support Worker.

Rationale

The NHS Long Term Plan (NHS England, 2019) declared that personalised care should become ‘business as usual’ across the health and care system. Specialist cancer nursing teams are ideally placed to align to this goal through a range of activities that underpin the delivery of personalised care (personalised care and support planning, shared decision making and promoting supported self-management).

Access to a Clinical Nurse Specialist (CNS) has a positive impact on experience of cancer care. However, there is a national shortage of such specialists. Further, advances in molecular diagnostics, genomics, treatment and technology are adding greater complexity to the role of the CNS and placing mounting demands on their time. They are increasingly being asked to deliver more with the same or less resource. Policy makers have recommended testing new service models incorporating the introduction of key workers (Agenda for Change (AfC) band 3 or above) to improve patient access to specialist nursing support. The Improving Access to Cancer Clinical Nurse Specialists and Key Workers Project (“the project”) was implemented in response to these recommendations.

The project aimed to develop, introduce and evaluate a high-quality model of personalised supportive care, incorporating Cancer Support Worker (CSW) roles into specialist nursing teams to enable more efficient and effective care of patients with cancer from around the time of diagnosis. Two CSW roles were introduced to the gastrointestinal cancer nursing team at University Hospital Southampton NHS Foundation Trust (UHS).

Through a mixed method evaluation, data were collected to establish how to characterise “high quality personalised care and support”; the impact of introducing CSW roles on both staff and patients; and any key considerations. Qualitative and quantitative data were collected from both the cancer care nursing team and patients, pre- and post-introduction of the new roles.

Planning

The service model built on existing work during which UHS successfully introduced CSW roles to support patients at the end of treatment and beyond: Prostate Cancer follow up (TrueNTH Supported Self-Management) and several Macmillan Cancer Support funded stratified follow-up initiatives (Patient Triggered Follow Up). In developing the model, the project team drew on an extensive evidence base, including information on the introduction of the Macmillan CSW and navigator roles from Macmillan Cancer Support.

This work was a collaboration between the Wessex Cancer Alliance, the colorectal team at UHS and researchers from the University of Southampton.

Co-design principles (Roberts et al. 2015) were adopted to support the active involvement and participation of stakeholders in shaping the new service delivery model. The design process also incorporated findings from in-depth interviews with health professionals (n= 12) and patients (n = 4) undertaken between May and June 2018. The interviews asked specifically about aspects of the service (at baseline) that worked well or required improvement, and expectations surrounding the introduction of the support worker role (with consideration of the impact on patient care and staff workload, as well as potential challenges to successfully implementing such a role). In addition to shaping the new service, information gathered from these interviews also informed the evaluation design to ensure that the findings were meaningful for a range of stakeholders.

Impact

The project evaluation found that:

- Participants (patients and staff) characterised high quality service provision as: accessible, responsive, personalised, empowering, proactive, consistent and coordinated. CSWs have the potential to impact positively on all these domains. Augmenting nursing teams with the complementary skillset and additional capacity CSW roles bring is central to the delivery of personalised care.
- Introducing CSWs to the specialist nursing team resulted in a positive impact on access to assessment and care planning; community support services; practical and financial support; and health and wellbeing advice and support. Following the introduction of the CSW role, patients were more likely to report they were given contact details of a key worker and that the wider healthcare team worked well together.
- Health and wellbeing advice and support is often not an immediate priority for patients around the time of diagnosis and as treatment commences. However, this key aspect of the CSW role aligns closely with the prehabilitation agenda and lays the foundations for improving health and wellbeing during and beyond treatment.
- When reviewing the composition and skill mix of a specialist cancer nursing team, it is important to consider the implications of, and differences between, either substituting a CNS role with a CSW (and the impact on the skill mix), or introducing a CSW to the team, to whom tasks can be delegated by a CNS.

Relevance to Others

The evaluation report has been shared widely both within Wessex and nationally. We have continued to engage with service users through a number of channels including Wessex Voices, Macmillan Cancer Support, local groups and the Wessex Cancer Alliance Personalised Care Programme Board.

The evidence and learning from this project have been integral to current and future planning of services – including the implementation of the national prehabilitation guidance.

Work is now being undertaken, in collaboration with Macmillan, to identify whether the interaction between patients and the cancer support workers should take place within the hospital by trialling boundary spanning roles. This is where the interactions take place in primary care or the community setting – with the support workers spending 20% time in the hospital and 80% in primary care.

Standing Out

For a long time, supportive care services, including implementation of the Recovery Package, have focussed on the end of active treatment with minimal supportive care information given at the point of diagnosis. Patient feedback from several sources (HOPE courses, Health and Well-being events, focus groups) have time and time again reported that patients wished they had been given the information much earlier on at or around the point of diagnosis.

Historically health care professionals have ‘protected’ patients at the beginning of their treatment pathway, worrying about information overload. This project has identified that although patients can feel overwhelmed at this point, it is not necessarily with the information appropriate to their needs or wants. The ‘what matters to me’ question was rarely asked.

The key elements contributing to the success of this project was the width and expertise of the stakeholders, the methodology employed and the rigour of the evaluation.

Key Learning Points

Agree key stakeholders up front and a clear purpose and methodology. Agree the funding stream and amount. Design a robust evaluation, working with researchers who have experience of working with people affected by cancer.

- Ensure patients are at the heart of the project, using co-collaborative principles.
- Ensure the MDT has a clear understanding of what you are looking to achieve and the rationale, evidence for this. Have strategic and commissioning buy in/support from the outset – to ensure sustainability and replicability of the work if well-evaluated.
- Work with a team that wants to engage. Agree a communications strategy.

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