University Hospitals of
Morecambe Bay
NHS Foundation Trust

Macmillan Information and Support Service Report

2021

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Macmillan Information & Support Manager (MCISS)

National Cancer Strategy

The NHS England National Cancer Strategy, *Achieving World-Class Cancer Outcomes*, was published in 2015 by the Independent Cancer Taskforce. The taskforce looked at how cancer services are currently provided and set out a vision for what cancer patients should expect from the National Health Service.

The report included 96 recommendations to help transform the care that the NHS delivers for all those affected by cancer. A plan was launched by Cally Palmer, National Cancer Director for England, to make these changes a reality.

The key priorities:

- Radically upgrade prevention and public health
- Lead a national drive for earlier and faster diagnosis
- Put patient experience on a par with clinical effectiveness and safety
- Transform our approach to living with and beyond cancer
- Invest in high quality modern services
- Transform commissioning, provision and accountability

This included the establishment of 16 Cancer Alliances across the country who led implementation of the strategy locally. With the three Alliances that formed, the Cancer Vanguard leading, rigorous piloting and rolling out of effective and efficient ways to plan, pay and direct the delivery of cancer services was implemented. The funding agreed with NHS England and NHS Improvement.

Cancer Alliances brought together clinical and managerial leaders from different hospital trusts and other health and social care organisations, to transform the diagnosis, treatment and care for cancer patients in their local area. **The Lancashire and South Cumbria Cancer Alliance** brings together the key organisations in our area, to coordinate and improve outcomes for the patients of Morecambe Bay.

The NHS Long Term Plan (LTP) was published in January 2019, setting out ambitions and commitments to improve cancer outcomes and services in England over the next ten years.

The key ambitions as detailed in the NHS LTP for cancer

By 2028:

- 55,000 more people each year will survive their cancer for five years or more; and
- 75% of people with cancer will be diagnosed at an early stage (stage one or two).

These ambitions will be delivered in a way that:

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

The NHS Long Term Plan for Cancer states that “where appropriate every person diagnosed with cancer will have access to personalised care, including needs assessment, a care plan and health and wellbeing information and support.”

NHS England Comprehensive Model of Personalised Care

This comprehensive model of personalised care establishes:

- whole-population approaches to supporting people of all ages and their carers to manage their physical and mental health and wellbeing, build community resilience, and make informed decisions and choices when their health changes

- a proactive and universal offer of support to people with long-term physical and mental health conditions to build knowledge, skills and confidence and to live well with their health condition

- intensive and integrated approaches to empowering people with more complex needs to have greater choice and control over the care they receive

The Model will help us to deliver this shift by bringing together six, evidence-based components or programmes, each of which is defined by a standard set of practices.

These are:

- Shared decision making
- Personalised care and support planning
- Enabling choice, including legal rights to choice
- Social prescribing and community-based support
- Supported self-management
- Personal health budgets and integrated personal budgets

Following cancer treatment, patients move to a personalised follow-up pathway which ensures they can get rapid access to clinical support should they suspect that their cancer may have recurred.

This stratified follow-up approach was established in the UHMBT for breast cancer in 2019, for prostate and colorectal cancers in 2020 and for other cancers where clinically appropriate by 2023.

The clinical teams continue to be incredibly busy supporting their ever-increasing workloads, and the UHMBT Macmillan Information and Support Service is an established vehicle to assist the team in meeting these recommendations. Systemised early referral to the MCISS is helping to ensure patients access personalised information and are signposted to appropriate local services. The MCISS acts as a conduit between the patient and the clinical teams**.**

So how have The UHMBT Macmillan Information and Support Service supported people through the Pandemic?

The Morecambe Bay area has a population of around 350,000 spreads over a large geographical area. The Macmillan Information and Support Services (MCISS) at UHMBT have evolved over the past 2 years in response to the pandemic.

The hubs situated at Furness General Hospital (FGH) and Westmoreland General Hospital (WGH) had to close. They were considered a risk because the 2-metre rule could not be achieved.

There were also reservations regarding the hub's positions within FGH and WGH and the potential risk of arson. The hub at Lancaster is modelled on an office and quite space which has met all the health and safety conditions and has been able to remain open on an appointments basis.

At the start of the pandemic, it was essential to keep staff, volunteers and patients safe. The volunteers across all 3 sites were informed that the hubs would be temporarily closing, volunteer input was paused. The MCISS Manager and Assistant worked from home in line with the Trust's recommendations.

There are strong links between MCISS and the Trust, working in partnership with Oncology, the Clinical Nurse Specialists, Cancer Services, Cancer Alliance and the 3rd sector. All teams were informed that the service was still available by telephone and online video conferencing. A flyer for the service was created and emailed to all concerned **(Appendix I)**. The trusts' Communications Team worked together with the Macmillan team to share service changes with the local media.

Joanne Gardner, MCISS Assistant shared their experience of working throughout the pandemic.

''The past two years have seen us have to adapt and evolve our service to meet the physical, emotional and ever-growing complex needs of our patients, their families, and friends and to support our fellow health care professionals.

During this time, we have been working from home which, in the beginning felt quite alien. For me personally, it took a while for me to physically and mentally adapt, organize my office space and be comfortable with the use of Zoom, Teams, completing paperwork over these mediums and the phone and of course having distressing and difficult conversations with patients and families without being able to hold a hand or give them a much-needed hug.

I felt out of my comfort zone and worried about being able to communicate effectively, not being able to see patient's faces would mean not picking up on non-verbal cues such as their facial expressions and body language. Would the level of service be enough to make them feel supported? The underlying thought of keeping them safe was the motivating factors to make this new way of working succeed.

Our service went from 'drop-in' to 'virtual' overnight and we needed to still have a personal touch and for people to be able to put a face to the name at the end of the phone. We adapted our service flyer to include our photographs, the feedback has been positive and are something we will continue when things return to 'normal'.

A positive to draw from these circumstances is the closer links we have formed with our Cancer Nurse Specialists, Cancer Support Works, GP's, Hospices, ICC's and Cancer care. In 2021 we became involved in a Collaborative Project with the Urology Team whereby all patients would be referred to us at the point of diagnosis. Although the project has come to an end the referral of newly diagnosed patients has continued and feedback from them has been positive. They feel supported, listened to and informed.

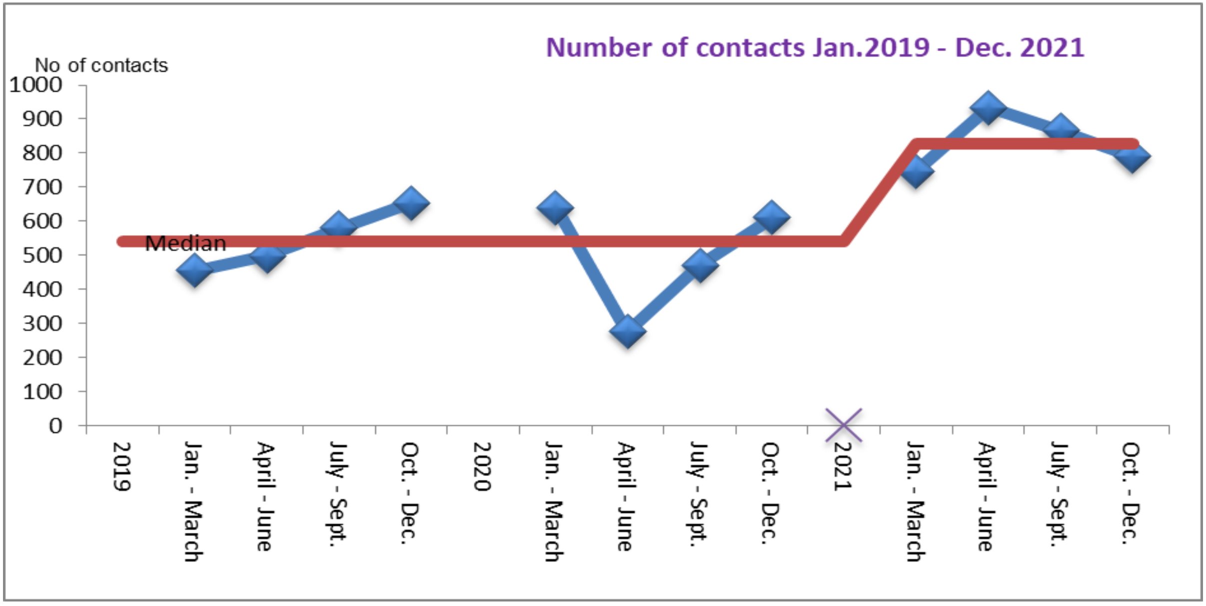
Whilst new team members have been settling into their roles within the Urology and Colorectal team, we have helped support them by carrying out Holistic Needs Assessments with their patient's. As new Cancer Support Workers started their roles within the different tumour groups a monthly meeting was arranged for us to get together. This has been very beneficial in terms of understanding each other's roles, offering peer support and sharing ideas.

We are a small team of two, soon to be three, and we are busier than ever before. We are very fortunate to work with a wonderful team of volunteers and have been able to stay in touch with them over the last two years over the phone and Zoom. It was important to include them, to see how they were coping and keep *them updated on the progress of the service. We are lucky that they still want to offer their support to our patient's when our Hubs re-open.*

My colleague Lorraine has been a tower of support during this time, always at the end of the phone or on teams to answer any questions and offering support when we are overwhelmed with work and life. Having never worked from home previously I wondered in the beginning if it was something I was every going to get used to. Seeing and hearing the positive feedback from our colleagues and patient's makes me realise we have succeeded in adapting our roles and still providing a high level of support.

In a lot of respects working from home has had a positive impact on my wellbeing and work/life balance and I can visualise how this can be incorporated into our work pattern moving forward. Re-opening our Hubs is something we are now starting to plan and it's very exciting to know that we will soon be offering a face-to-face service for our patients and their families again. Meeting and supporting their needs are at the core of everything that we do, however that may be''.

Number of contacts between 2019 to 2021.
The MCISS audit data for 2021 is shown in Appendix II.



Macmillan predicts there will be 4 million people by 2030 living with cancer, which is now considered a long-term condition. Whilst this is very positive, it also creates further challenges for health care professionals in meeting the psychological and information needs of each patient; with the provision of education, to enable them to live well with their cancer diagnosis.

The coronavirus pandemic hit the country in March 2020, and the NHS prepared for the huge wave of COVID-19 patients needing hospital care. Despite this, many people with cancer had vital appointments, surgeries and treatments postponed, cancelled or changed. This clearly has had a devastating impact. Meanwhile, thousands more with possible cancer symptoms were too worried about catching COVID-19 to seek support and advice from a health professional.

In October 2020, Macmillan produced a report The Forgotten 'C'? The impact of COVID-19 on cancer care investigating the true size of the backlog in cancer care:

- *Macmillan estimated that across the UK there were around 50,000 'missing diagnoses' – meaning that compared to a similar timeframe the previous year, 50,000 fewer people had been diagnosed with cancer.*

- *Fewer people in 2020 started treatment after a cancer diagnosis than in 2019. In England alone, between March and August 2020, around 30,000 fewer people had started their first cancer treatment compared to the year before.*

At the beginning of 2021, the local Cancer Alliance invited the local MCISS teams to take part in a pilot, looking at the availability and accessibility of health and wellbeing information. This gave MCISS the opportunity to work closely with the 'Right by You' Project Lead for Morecambe Bay Trust. Team's meetings were arranged with all the Cancer CNS Teams. Using a template, invaluable information was gained. It was also a further platform to promote the service to the teams.

Following the data collection and analysis, the report Availability and Accessibility of Health and Wellbeing Information and Support (HWBIS) for people affected by cancer in Lancashire and South Cumbria was produced.

The purpose of this report was to:

- Demonstrate how the needs of people affected by cancer in Lancashire and South Cumbria (L&SC) are being addressed; identify the gaps in current provision, equity of access and highlight areas of good practice.

- Evaluate the level of knowledge within the cancer workforce regarding the health and wellbeing support and information available both within the NHS and the wider environment, and how to access it or refer into it.

- Propose recommendations to address the issues raised.

The report showcased the importance of referring to MCISS, ideally at the point of diagnosis. This also links in with the on-going work of the Cancer Alliance to ensure that every person receives personalised care and support from cancer diagnosis onwards.

The three key areas of this work include:

- Providing personalised care and support interventions
- Providing personalised stratified follow up care
- Measuring quality of life

Cancer Alliances are working with Trusts and primary care to offer these personalised care interventions to people with breast, colorectal and prostate cancer and for other cancers by March 2022. They estimate that around 80% of cancer multidisciplinary teams (MDTs) are now offering Personalised Care and Support Planning

- **Personalised Care and Support Planning** (based on holistic needs assessments) ensures people's physical, practical, emotional and social needs are identified and addressed at the earliest opportunity.
- **End of Treatment Summaries** provide both the person and their GP with valuable information, including a detailed summary of treatment completed, potential side effects, signs and symptoms of recurrence and contact details to address any concerns.

Primary Care Cancer Care Review is a discussion between the person and their GP / primary care nurse about their cancer journey. This helps the person to discuss any concerns, and, if appropriate, to be referred to services or signposted to information and support that is available in their community and from charities.

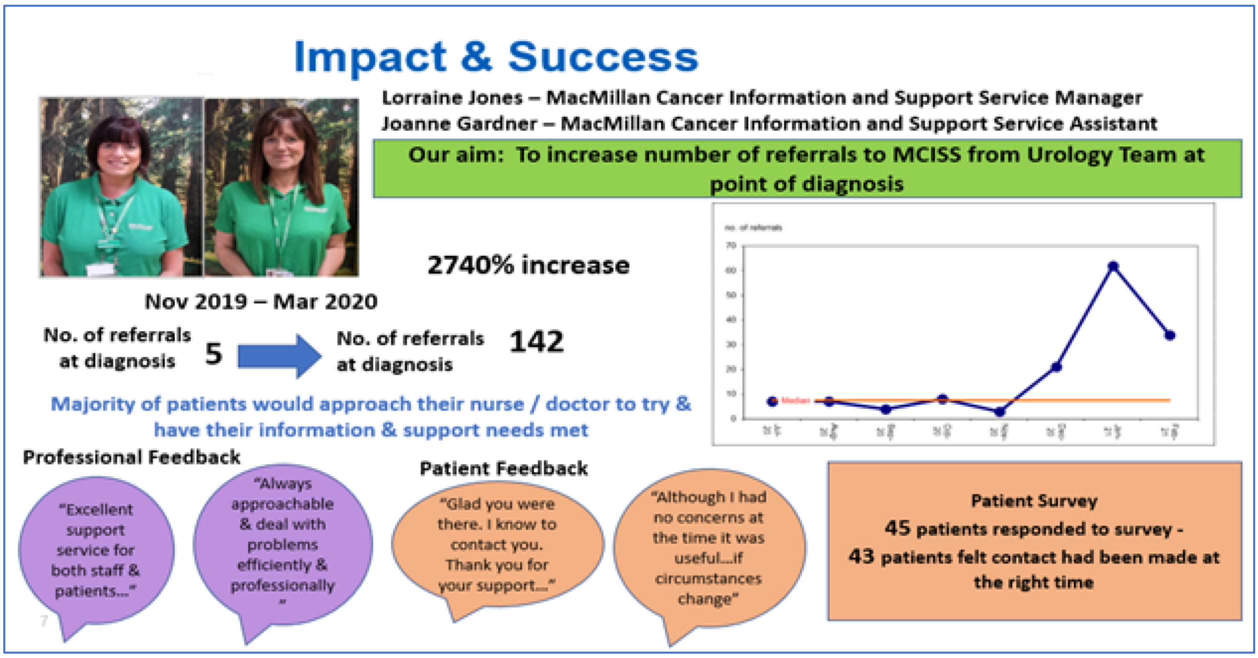
Health and Wellbeing Information and Support includes the provision of accessible information about emotional support, coping with side effects, financial advice, getting back to work and making healthy lifestyle choices. This support will be available before, during and after cancer treatment.

The service is linked with a large GP practice in Lancaster, being a documented contact for further information as part of their Primary Care Review. This is new to MCISS. The uptake from this will be audited and reported via the Patient Experience Group.

MCISS became embedded within the Urology Team, as part of their cancer patient pathway. Patients are offered the opportunity to be referred at the point of diagnosis. There have been over 500 acceptances / referrals since November 2020, with only 17 patients who have declined.

Initially MCISS offered all patients a Holistic Needs Assessment (HNA) with a Care plan sent out to them. This was until the Team resolved the staffing issues with the employment of a Cancer Support Worker (CSW).

The outcome of the project:



Impact & Success

Lorraine Jones – MacMillan Cancer Information and Support Service Manager
Joanne Gardner – MacMillan Cancer Information and Support Service Assistant

Our aim: To increase number of referrals to MCISS from Urology Team at point of diagnosis

2740% increase

Nov 2019 – Mar 2020

No. of referrals at diagnosis 5 → **No. of referrals at diagnosis 142**

Majority of patients would approach their nurse / doctor to try & have their information & support needs met

Professional Feedback

"Excellent support service for both staff & patients..."

"Always approachable & deal with problems efficiently & professionally"

Patient Feedback

"Glad you were there. I know to contact you. Thank you for your support..."

"Although I had no concerns at the time it was useful...if circumstances change"

Patient Survey
45 patients responded to survey -
43 patients felt contact had been made at the right time

The figures for Morecambe Bay's Urology Team were astounding and clearly evidenced the importance of the Service, not only for the patients of Morecambe Bay, but to the Cancer Teams, the Trust and the Cancer Alliance.

On the back of these results, MCISS offered to support the colorectal team in the same way, until their new CNS was in place and settled in the role. Referrals to the service at the point of diagnosis are haphazard as there are no set patient results clinics. To date, there have been over 130 referrals with HNA's and care plans completed. Previously, there had been none carried out.

Helen Miller 'Right by you' Project Manager gave her thoughts:

''Lorraine Jones (MCISS Manager) and I have worked on a number of projects around Personalised Care. Towards the end of 2020 we visited the Clinical Nurse Specialist (CNS) teams to discuss the Health and Wellbeing Information (HWBIS) Checklist as part of the local Alliance Cancer Collaborative Project. The HWBIS Checklist was coproduced by the NHS Cancer Programme, Patient and Public Voices Forum and Cancer Alliances

to help ensure comprehensive and accessible HWBIS is available for all people affected by cancer from diagnosis onwards and to identify gaps in service provision. An action plan was developed at Trust level and, through a Task and Finish Group, an Alliance-Wide report was produced and submitted to the Lancashire and South Cumbria Cancer Alliance and presented at the Lancashire and South Cumbria Clinical Forum.

When visiting the CNS Teams, we also utilised the opportunity to clarify how and when Personalised Care Intervention information was undertaken and encourage consistency of data capture.

The MCISS 2020/21 Collaborative Project's aim was to increase the number of referrals to MCISS at the point of diagnosis and the number of holistic needs assessments (HNA's) and Personal Care and Support Plans (PCSP's) by 10% on the previous quarter. The Urology team were identified as a potential focus for this work and agreed to refer all newly diagnosed patients to MCISS who contacted the patient, offered support and referred back to the Cancer Support Worker (CSW) and Cancer Care Coordinator (CCC) in Urology to undertake the HNA.

However, due to staff sickness within the Urology Team, the MCISS team also agreed to undertake the HNAs and Care Plans. The CSW and CCC recommenced completion of the HNAs and Care Plans in May 2021 when the full complement of Urology staff was achieved.

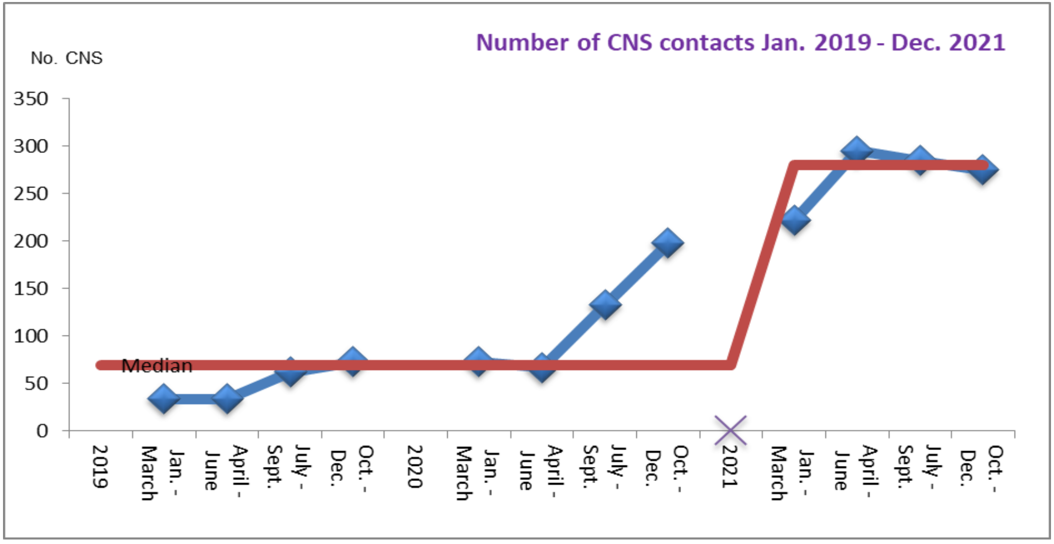
Over the period of the Collaborative project the number of referrals to MCISS increased by 2740% with excellent feedback from patients and the CNS team. The number of HNAs and Care Plans also greatly increased (11 in Q3 to 98 in Q4). Representatives from the Collaborative, including Lorraine, presented their findings at the national Combined Cancer Improvement Collaborative Recognition Event in April 2021.

Although the Urology CSW and CCC have now taken back the completion of HNAs and Care Plans, the Urology Team continue to refer patients at point of diagnosis to the MCISS team for advice and support.

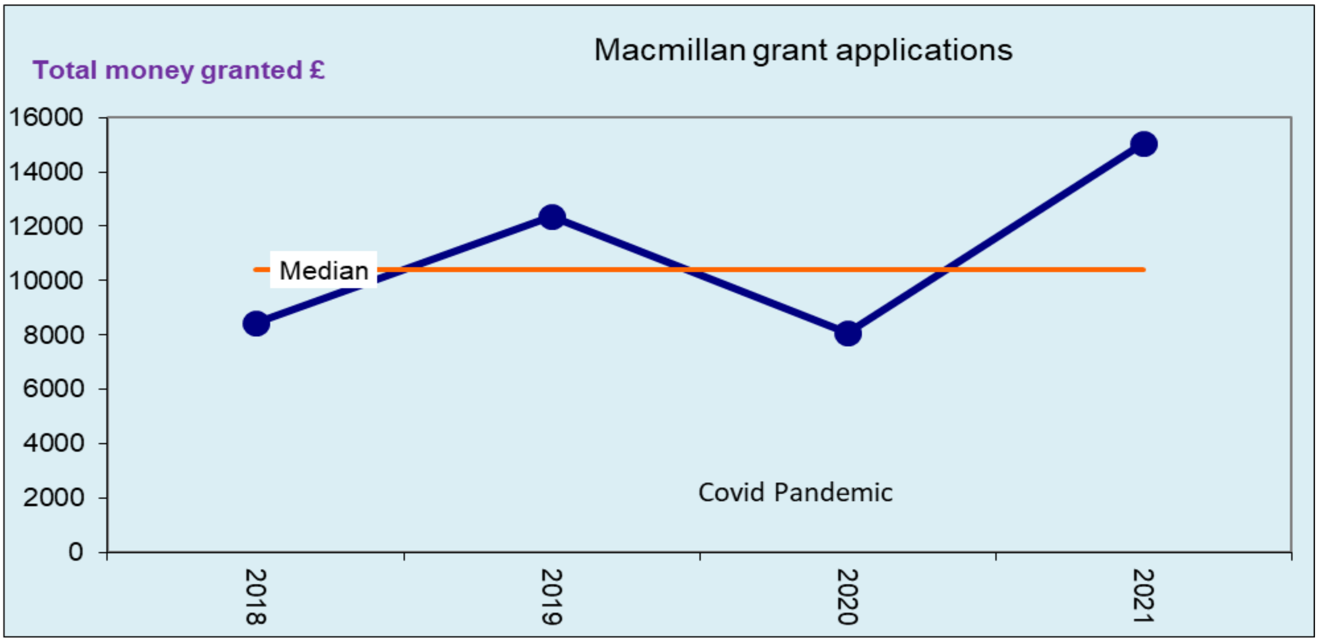
This project was so successful; Lorraine and Joanne are now working with Colorectal CNS and CSW colleagues by undertaking HNAs and Care Plans at point of diagnosis whilst vacancies in the CNS team are recruited to.

A Macmillan eHNA pilot project is also being planned and a number of CNS teams within UHMB have volunteered to take part including the MCISS Team".

The graph below shows the increase number of CNS referrals as a result of our partnership working:



The Pandemic clearly has had an impact on patients financially. The graph shows the amount granted to patients through Macmillan Grants submitted by MCISS. However, the increase is also as a result of more patients being referred to the service.



The NHS Long Term Plan for Cancer also states that ‘after treatment, the person will move to a follow-up pathway that suits their needs, and ensures they can get rapid access to clinical support where they are worried that their cancer may have recurred.”

Personalised Stratified Follow-Up (PSFU) is a vital part of delivering world class cancer services to people while addressing the serious challenges of demand and capacity throughout cancer pathways. The implementation of PSFU pathways provides better care and experience for patients.

By reducing the amount of time that professionals spend seeing patients who are doing well after treatment, it also frees up professionals’ time to focus on other parts of cancer pathways, such as faster diagnosis and treatment, or those with complex post-treatment needs.”

Having PSFU pathways means that when a person completes their primary treatment, they will be offered:

- information about signs and symptoms to look out for, which could suggest their cancer has recurred;
- rapid re-access to their cancer team, including telephone advice and support, if they are worried about any symptoms, including possible side-effects of treatment;
- regular surveillance scans or tests (depending on cancer type), with quicker and easier access to results so that any anxiety is kept to a minimum; and
- personalised care and support planning and support for self-management, to help them to improve their health and wellbeing in the long-term.

MCISS is working closely with the Macmillan ‘Right by You’ Project Manager, to be integrated into the cancer specific Education Workshops, to act as an information resource also at the end of treatment.

What have we learned?

The MCISS Team have learnt to ‘think outside the box’ in ways to access patients through the pandemic, using all forms of resources / contacts available to them. Initially, there was a feeling of isolation and uncertainty for the future, but the service quickly embraced remote working and flourished as patients soon realised the telephone was going to be one of their main modes of communication with the outside word.

The service offered other forms of communication such as Teams, Attend Anywhere and Zoom according to the patient’s preferences. The service also had to become competent and gain confidence using different systems.

Face-to-face appointments at the RLI have been on offer in line with the Trust’s Covid guidelines, but the numbers wanting this have been very small. There were actually only 11 patient requested face-to-face appointments in 2021.

Questionnaires have also been sent to patients using QR codes, via email / post, with excellent response **(Appendix III)**

The CNS Teams were also asked for feedback about MCISS **(Appendix IV).** The feedback given was again so positive and strongly supported the needs for the service and the difference it has meant to them and the patients.

As we come out of the Covid restrictions, the hubs at FGH and WGH will be re-opened, offering a more personal service supported by the fantastic volunteers that give up their time to support the service. Throughout the last 2 years, with regular team updates, the volunteers have remained loyal and are keen to return.

What does the future hold?

The Lead Cancer Nurse has retired; therefore MCISS now sits within Patient Experience portfolio led by Barry Rigg – Head of Patient Experience. This has been an amazing opportunity to work with Barry and the team, to support the people of Morecambe Bay. Although the role of MCISS is cancer specific, our main aim is to ensure people have access to the service with a positive outcome.

The service now has a more suited platform to share the work, celebrate achievement and to promote the service delivered in partnership between The UHMB and Macmillan.

The present MCISS Manager Lorraine Jones, will be reducing their hours to 22.5 over 3 days for a more work/life balance. The service welcomes the new MCISS Manager Sallie Robinson who will job share with Lorraine. Sallie will commence in post from the 9th of March 2022. This will provide new skills, thoughts and ideas with more flexibility.

The hub at FGH is to be relocated not far from its original position, in line with the Trust Health, Safety and fire teams’ approval. This is a joint venture between the Trust’s charity and Macmillan. Without their support and that from Barry, this would not have been possible. An excellent environment is being created to offer face-to-face appointments and drop-in for the local people of Barrow and the surrounding area.

The communal space at Westmoreland General Hospital in Kendal is being redesigned with a view of including the MCISS hub within the new build.

The Oncology Day Unit moved from the Royal Lancaster Infirmary (RLI) to WGH at the start of Covid. Unfortunately, they could not accommodate MCISS in Oncology or a suitable temporary abode at the hospital. The Oncology unit is looking to move back to RLI at some point this year, to a newly renovated area within Medical Unit 1 at the RLI, along the corridor from the MCISS Hub has been identified. The position is quite fortuitous, as most of the footfall will need to pass the MCISS hub; more so than where Oncology was previously.

Once visiting restrictions are lifted this will allow freer access to the MCISS service. This would also allow the volunteers to return to the 3 hubs. The service is looking to move into the community setting. Links are being made to support this venture.

The Team is dedicated to the service, reflecting on practice, adapting and changing to meet the needs of people of Morecambe Bay. We are confident that the MCISS will be able to expand to meet the increasing numbers using the service**. (Appendix II).**

Appendices

Appendix I Patient access information poster used during the pandemic

Appendix II MCISS audit / core data collection

Appendix III Service User Feedback 2021

Appendix IV Clinical Nurse Specialist (CNS) Feedback 2021

Appendix I
The UHMBT Macmillan Information and Support Service poster

Lorraine Jones **Joanne Gardner**

Manager **Assistant**

Your local service is here to support you:

- If you are lonely and in need of a chat
- Access to information resources, including ‘easy read’ and information in other languages
- Signposting to local and national services
- Access to counselling / emotional support services
- Close links with Cancer Teams for clinical information
- Help with completing a Holistic Needs Assessment (HNA) / Care plan
- Support with financial issues / concerns
- Links with local CAB Teams for onward referrals for financial assessment / work and employment issues

The service is over the phone, but we can offer appointments through Zoom, Attend Anywhere and Microsoft Teams

- **Face-to-Face appointments can be made at the RLI** (Covid safety rules in place)

Tel. 01524 51957 Mobile 07972639424 Email: Macmillan.info@mbht.nhs.uk

We are here 8am – 4pm Monday – Friday (Excluding Bank Holidays)

The UHMBT – Macmillan Information and Support Service would really appreciate your feedback.

Please click on the link https://forms.office.com/r/F7Scudir9v

Alternatively, you can use the QR code:

Hold your phone camera to the QR code and a link should appear.
Press this and you will be taken directly to the survey.
The survey should only take a few minutes but could make such a difference.

Thank you

Appendix II

MCISS Contacts 2021

	Total Interactions	**3339**
	First Time contact	1254
1a. Contact Made	Face to face	11
	Phone	2237
	Virtual Meetings	7
	Social Media	0
	Email	1034
	Text	11
	Other	31
	Not Asked	8
1b. Service User	**Person living with or beyond cancer**	**1633**
	Spouse or Partner	181
	Relative or Friend	194
	Health care Professional	**1077**
	Social care professional	21
	Carer	130
	Brief Visit*	0
	Other	106
1c. How Heard	**Accessed the service in the past?**	**2038**
	Just passing	4
	Local Media	4
	Family/ friend/ colleague	41
	Social Media	1
	Health Care Professional	1133
	Macmillan Support Line	3
	Macmillan publicity	2
	Macmillan Website	42
	Outreach Events	0
	Self-help/ Support group	2
	Social Care Professional	2
	Other	26
	Not Asked	21
2a. Primary Site	Brain and CNS	3
	Breast	180
	Cancer of unknown primary	15
	Endocrine	0
	Gynaecological	117
	Haematology	70
	Head and Neck	53
	Lower GI	419

	Lung, trachea and bronchus	463
	Sarcoma	0
	Skin	57
	Upper GI	210
	Urological	1234
	Multiple	1
	Not Asked	316
	Not Relevant	172
	Other	31
2b. Stage of Pathway	Undergoing tests	38
	Diagnosed	636
	Undergoing treatment	627
	Completed Treatment	33
	In Remission	0
	Living with Cancer	127
	Receiving Palliative Care / End of Life	489
	Cancer diagnosis - not clear	0
	Recurrence/ Secondary Diagnosis	26
	Not Applicable	679
	Not Asked	687
	Unknown	0
3. Support	Emotional - Relationship Issues	6
	Emotional - Wants to Talk	1268
	Emotional Support	200
	Emotional - HOPE	0
	Financial - Benefits/ Welfare Advice	1017
	Financial Guidance	59
	Physical - Complementary Therapies	29
	Physical - Diet, Exercise and Activity	33
	Practical - Blue Badges	521
	Practical - Travel/ Transport	88
	Practical - Work Related Issues	99
	Practical - Carer Issues	170
	Clinical - Treatment/Side Effects	274
	Clinical - Symptoms	149
	Clinical - Palliative Care	59
	Clinical - End of Life	17
	Fundraising/ Donations	15
	Other	2065
4a. Action	Verbal Information	1757

	Emotional Support	82
	Written/ audio/ visual information	1066
	Help/ Support with Information Received	344
	Attending a Group	0
	Help with Forms	67
	Macmillan Grants	22
	Other	4
4b. Signpost or Referral	Health Professional	621
	Non-Macmillan Benefits Advice/ Financial	235
	Local Macmillan Benefits Advisor	253
	Macmillan Support Line - Financial Support & Work	27
	Macmillan Support Line -Emotional Support and Practical Information	22
	Macmillan Support Line - Clinical Information	0
	Macmillan Online Community	138
	Macmillan Website	200
	HOPE	2
	Voluntary Sector (exc Macmillan)	316
	Self-help/ Support Group	108
	Complementary Therapies	30
	Local authority/ Social Care Professional	143
	Primary Care	6
	Safeguarding	1
	Other	389
5a. Level	Level 0	28
	Level 1	1409
	Level 2	1864
	Level 3	41
	Level 4	0
5b. Time Spent	Less than 5 minutes	1189
	5 - 15 minutes	498
	15 - 30 minutes	604
	30 - 60 minutes	835
	60 - 120 min	200
	Over 2 hours	8
Gender	Male	1229
	Female	2105
	Non-binary	3
	Transgender	0
	Prefer to self-describe	0
	Prefer not to say	0
	Not Asked	5
Ethnicity	White/ White British	3217

	Mixed/ Multiple Ethnic Groups	16
	Asian/ Asian British	4
	Black/ African/ Caribbean/ Black British	1
	Other ethnic Group	6
	User preferred not to say	0
	Not Asked	98
Age	Under 18	0
	18-24	1
	25-34	20
	35-44	60
	45-54	209
	55-64	370
	65-80	998
	80+	254
	User preferred not to say	0
	Not Asked	1430

Appendix III

Service User Feedback 2021

Please use the QR code or click here to access the full survey results:

Summary

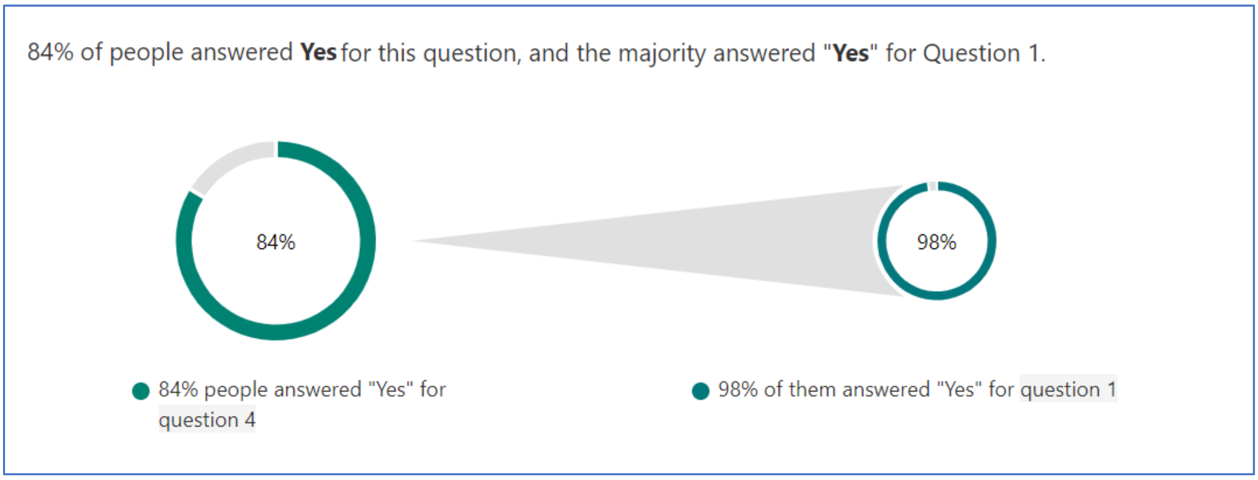
Question 1: Was the timing right following your diagnosis?

●	Yes	49
●	No	4
●	NA	0

Question 2: What was good about your experience?

23 respondents (**46**%) answered **support** for this question.

Question 4: Did you feel that any concerns you may have had were addressed?



84% of people answered **Yes** for this question, and the majority answered "**Yes**" for Question 1.

● 84% people answered "Yes" for question 4

● 98% of them answered "Yes" for question 1

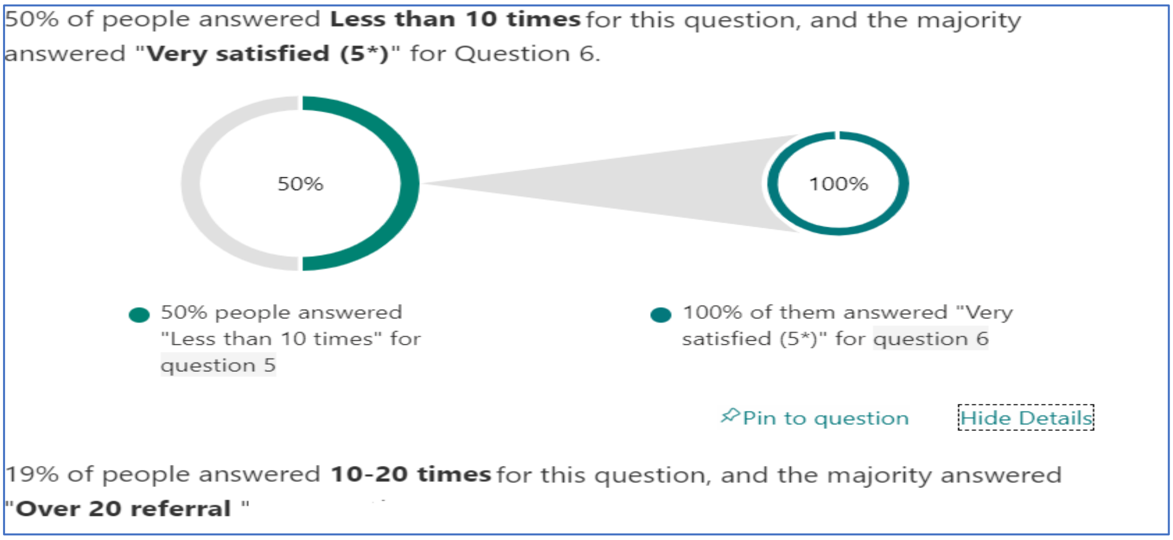
Appendix IV

Clinical Nurse Specialist (CNS) Feedback

Please use the QR code or click here to access the full survey results:

Summary

Question 5:
How often in the last 12 months have you used MCISS for your own information and support needs?



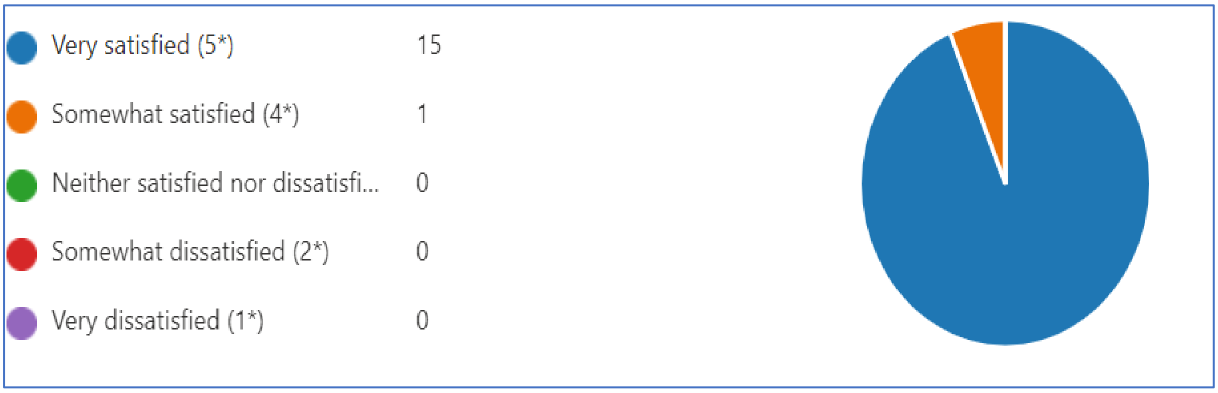
50% of people answered **Less than 10 times** for this question, and the majority answered "**Very satisfied (5*)**" for Question 6.

● 50% people answered "Less than 10 times" for question 5

● 100% of them answered "Very satisfied (5*)" for question 6

19% of people answered **10-20 times** for this question, and the majority answered "**Over 20 referral** "

Question 6:
Please rate how satisfied you are with the way your referrals are dealt with by MCISS



● Very satisfied (5*)	15
● Somewhat satisfied (4*)	1
● Neither satisfied nor dissatisfi...	0
● Somewhat dissatisfied (2*)	0
● Very dissatisfied (1*)	0

If you require this information in an alternative format or language or wish to discuss the content of this report in further detail please contact the:

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