

Head and Neck Cancer Pathway Board

Annual Report 2015/16

Pathway Clinical Director: Dr Susi Penney
Pathway Manager: Claire O'Rourke

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Pathway Manager:	Claire O'Rourke
Date agreed by Pathway Board:	To be ratified at September 2016 pathway board meeting
Date agreed by Medical Director:	
Review date:	January 2017

Executive summary

The Head and neck board pathway board vision is that every patient in Greater Manchester and Cheshire has access to all pre-treatment assessment and diagnostics, quality and timely information on the types of treatments available to them and their side effects, detailed transfer of care and support in the community by 2018.

Head & neck cancer is a cancer that effects the older population, but it is becoming increasingly prolific in younger people. There are over 30 specific sites for head & neck cancers, with the major ones being oral cavity, laryngeal and pharyngeal cancers. There are around 7,000 head & neck cancers diagnosed a year in England. This group of cancers is the 8th most common in England and makes up 3% of all cancers.

It is clear that there is a considerable amount of service redesign and engagement of key stack holders to deliver against the vision of the Head and Neck pathway board. Key to goals to achieving this vision is:

- Improve all aspects data recording for Head and Neck patients by 31st March 2017.
- Ensure patient is able to fully access all aspect of care pre, during and post treatment and is fully informed by 31st of March 2019
- Improve education for public, patients and referrers to the service 31st March 2019
- Actively engage in Research trials with the aim to increase trial recruitment year on year.
- Engage patients and people affected by cancer in all aspects of the Head and Neck board.

Key Achievements

During 2015 a new Pathway Directors was recruited to manage the Head and Neck pathway board and as made a positive start with the redefining of the clinical standards of care across Greater Manchester for Head and Neck cancer patients.

- The board is intricately linked with the emerging vanguard work which commenced in late 2015 (particular focus on GP education).
- The board has fully embraced to user involvement programme with MacMillan and a new patient affected by cancer is now represented on the board and has set up a patient reference forum with the support from Macmillan.
- The Head and Neck BC established at Central Manchester is now being mirrored at other Trusts including Pennine, Stockport and Salford Royal.
- Full engagement with the Living with and beyond cancer with extensive work to support the recovery package and setting up health and wellbeing clinic at CMFT
- A project looking at stratification of patients undergoing non-surgical treatment to identify those who would benefit from early intervention from the speech and language therapy team. This has led to the recruitment of an additional Speech and language therapists at the Christie to support patients prior to starting treatment.
- All referral pathways and guidelines have been reviewed and amended by the board.
- The board undertook an audit on 2 week wait referrals and how to manage step downs from the Cancer pathway and how this is organised, with the next step to continue this audit in other Trusts

- The board is has fully engaged in the recommendations of the National Head and Neck Cancer Audit published in Autumn 2015 and an action plan has been developed to deliver against key findings.
- The board is fully engaged in the Living with and beyond cancer (LWBC) board agenda and is supporting the roll out of the recovery package and supporting health and well-being events at CMFT. The board will also be supporting the LWBC vanguard work programme in 2016/17.

Key Challenges

The first challenge has been the realignment of services. This has been a key challenge for 2015-16:

- Central Manchester Foundation Trust (CMFT) MDT have taken the decision to relocate their MDT so there can be an improvement in data flow between the Christie and CMFT, with the proposal to adopt live data collection. This is effective from September 2016. An improved IT interface, to enable access to an up to date reporting structure which will impact on treatment choices and use of CWP needs to be considered when this is rolled out in the future.
- A full project plan is in place for this and currently all recruitment is in place to meet this September deadline.
- It is vital that all MDT working should be strengthened, in terms of decision-making, treatment and research should be MDT driven. Work should take place on different Head and Neck cancers to identify where packages of care are needed with multiple treatments, in line with the findings from the national audit published in 2015.
- All MDTs should apply agreed standards of quality assurance to established therapies (radiotherapy and surgery) and imaging protocols.
- There will need to be a focus on the implementation of a 'Manchester' Trust for head and neck, incorporating NMGH, CMFT and UHSM and aligning this with the aims and objectives of the Cancer Vanguard and pathway board.

The future

There are a considerable number of developments in place for Head and Neck cancer patients in Greater Manchester and the head and neck pathway board want to be the key drivers for this. There is an opportunity now to review of provision of Cancer services across Greater Manchester and redesign service provision to meet the needs of Cancer patients.

The board is particularly interested in the expansion of GP education and training programme as part of the vanguard project work. The educational program to date has been focused on dentists in primary care and it is important that we are given the opportunity to contribute to educational events aimed at GPs. This has already started with online virtual recordings of Head and Neck cancer key symptoms for GPs. Further sessions planned during the coming year to maximise this platform.

The formulation of comprehensive Quality standards is now a priority for the board and this will be achieved with involvement of key stakeholders, clinicians, nurses and AHP teams as well as the operational management teams. Key to this is the involvement in patients affected by Cancer in this fundamental area of service change and redesign.

1. Introduction – the Pathway Board and its vision

This is the annual report of the Manchester Cancer Head and Neck Pathway Board for 2015/16. This annual report is designed to:

- Provide a summary of the work programme, outcomes and progress of the Board – alongside the minutes of its meetings, its action plan and its scorecard it is the key document for the Board.
- Provide an overview to the hospital trust Chief Executive Officers (CEOs) and other interested parties about the current situation across Manchester Cancer in this particular cancer area
- Meet the requirements of the National Cancer Peer Review Programme
- Be openly published on the external facing website.

This annual report outlines how the Pathway Board has contributed in 2015/16 to the achievement of Manchester Cancer's four overarching objectives:

- Improving outcomes, with a focus on survival
- Improving patient experience
- Increasing research and clinical innovation
- Delivering compliant and high quality services

1.1. Vision

Every patient in Greater Manchester and Cheshire has access to all pre-treatment assessment and diagnostics, quality and timely information on the types of treatments available to them and their side effects, detailed transfer of care and support in the community by 2018.

- Improve all aspects data recording for Head and Neck patients by 31st March 2017
- Ensure every patient is able to fully access all aspect of care pre, during and post treatment and is fully informed by 31st of March 2019
- Improve education for public, patients and referrers to the service 31st March 2019
- Actively engage in Research year on year.
- Achieve world class standards of Head and Neck Cancer Care by 31.03.2019.
- To ensure at least one person affected by cancer is represented on the head and neck Pathway Board, representing the wider community and where there is already one, to recruit another.
- For People Affected by head and neck Cancer to be fully involved and treated as equals.
- To recruit patients and carer's to form a wider community of people affected by head and neck cancer involved at different levels through coproducing a menu of opportunities.

1.2. Membership

NAME	ROLE & TRUST
Susannah Penney	Consultant ENT surgeon, Tameside FT & Pathway Director
Claire O'Rourke	Pathway Manager
Kerenza Graves	CNS , Bolton
Frances Ascott	SLT, CMFT
Mark Price	Patient effected by Cancer
Philip Bryce	CNS, CMFT
David Makin	Patient Lead
Debbie Elliott	Thyroid CNS, Christie FT
Kate Garcez	Oncologist, Christie FT
Suzi Bonington	Consultant Radiologist, Christie FT
Rachel Hall	Consultant pathologist, PAT
David Thomson	Consultant oncologist, research lead, Christie
Maria Round	Macmillan Head & Neck CNS, PAT
Chetan Katre	Consultant, PAT
Kate Hindley	CNS, CMFT
Helen Doran	Surgeon, SRFT
Miss L. Ramamurthy	Thyroid Surgeon, Stockport FT
Mazhar Iqbal	Maxillo Facial Surgeon, UHSM
Hannah Kelly	Dietician, CMFT
Cath Cameron	Head and Neck Cancer Nurse Specialist, WWL
Lucie Francis	Macmillan User Involvement Manager
Helen Rust	Principal Speech and Language Therapist, Christie
Kathleen Mais	Nurse Clinician Head and Neck Oncology Christie
Jonathan Hobson	UHSM

The new pathway director has recognised that there is often limited representation from some organisation or regular attendance of board members. The New pathway director has taken steps to ensure members attend regularly and attendance has improved considerably.

Membership to this board is crucial to ensure the board continues to motivate clinicians, nursing teams and Allied health professional to ensure the board is fully supportive of the key services changes that are required to improve care and patient experience in Manchester. Board members will be held accountable for actions driven by action plans and task and finish working groups. It vital to the head and neck pathway board that there is continued focus on the patients effected by cancer and their views and we are delighted to have one patient representative supported by MacMillan and a user involvement manager who supports our patient.

The Board has named leads for the following key areas:

Area	Lead name and role
Palliative Care	Shared by CNS members
Early diagnosis and education	Miss L. Ramamurthy, Thyroid Surgeon, Stockport FT
Pathology	Rachel Hall, Consultant PAT .
Radiology	Suzi Bonington, Consultant Radiologist, Christie FT
Surgery	Helen Doran, SRFT
Oncology	Kate Garcez, Oncologist, Christie FT
Specialist nursing	Shared by CNS's members
Living with and beyond cancer ('survivorship')	Philip Bryce , CNS
Research	David Thompson, Christie FT .
Data collection (clinical outcomes/experience and research input).	Mazhar Iqbal, Maxillo Facial Surgeon, UHSM
Patient representative	Mr David Makin/ Mark Price.

The board now has primary care (GP and General Dental Practitioners) and SALT membership. Macmillan, in partnership with Manchester Cancer have funded a team to facilitate a User Involvement Programme of work that will establish a structure and platform for people affected by cancer to influence and steer the design of cancer services locally. The Head and Neck Board is now supported by a Macmillan User Involvement Manager who came into post in August 2015.

1.3. Meetings

5. The Head and neck board have met on three occasions during the period of June 2015 and March 2016 below is the listed dates and the link for a copy of the minutes on the website: **Pathway Board meeting attendance is documented in the minutes.**

18 th November 2015	13 th January 2016	10 th March 2016
18th Nov minutes H&N.pdf	M:\Services\04 Pathways\Head and neck\Pathway Board meetings\Pathway Board meetings 2016\13th Jan\13th January 2016 minutes.doc	10th March 2016 Head and Neck Minutes (2).doc

Classification of objectives and review dates:

Pathway	Objective	Tasks	Start date	End Date	Nominations
Head & Neck	Engagement in Palliative care	Awareness and access pain and symptom control guidelines	Sep-15	Sept-16	COR
		Referral guidelines to specialist palliative care teams	Sep-15	Sept-16	COR
		Awareness of local palliative care teams	Sep-15	SEpt-16	COR
	LW&BC	develop plan and pilot end of Treatment summaries for patient with curative intent	Nov-15	Mar-16	COR
		Engage with LW&BC identify all H&N late effects post treatment	Sep-15	On going project	Engage in the survey once developed by the LW&BC and share with patients 12 months post treatment
		Engage with LW&BC late effect patient experience audit	Sept-15	June-16	COR/ SP
		Innovation fund Health and wellbeing clinic	Apr-15	Jun-16	PB/HR
		Pathway stratification for therapy patients	Apr-15	Sept-16	SP
		HSC audit	Initial findings	Aug-15	Sept-16
	Final report of audit		Aug-15	June-16	SP
	Research recruitment	Identify blockers for engagement in clinical trials	Mar-16	Dec-16	COR/ SD
		Develop tools for engagement in research recruitment at MDT	Mar-16	Dec-16	COR/SD

2. Summary of delivery against 2015/16 plan

No	Objective	Alignment with Provider Board objectives	Tasks	By	Status Green = achieved Amber = partially achieved Red = not achieved
1	Improve all aspects of data recording for Head and Neck patients by 31 st March 2017- <i>this is dependent on the reconfiguration of the national data set and CWP which is still outstanding.</i>	Improving outcomes, with a focus on survival	To assess the current practice of data flow in MDTs		Red
			Identify measures outside of the national requirements and collect data and national dataset being reconfigured.		Amber
			To extract data from current systems to assess current stage of disease at presentation		Red
2	Ensure patient is able to fully access all aspect of care pre, during and post treatment of Head and Neck.	Improve patient experience	Map current service provision with respect to CNS, dieticians, speech and language and dental care and ensure regular CNS meetings.		Green
			To assess organisation and, ease of cross referral and flow of information.		Amber
			To assess availability, quality of patient information and appropriateness, using patients effected by cancer to review all information and ensure user involvement is key.		Amber
			To fully engage with the Living with and Beyond and Palliative Care service mapping to ensure full assessment of Head and Neck delivery of care. Delivered against by health and well-being event, and increase in SALT support at the Christie.		Green
3	Improve education for public,	Improving	Liaising with the prevention, early detection		Amber

	patients and referrers to the service.	outcomes with a focus on survival	and screening Pathway Board-this is now monitored through vanguard work and redesign of 2WW form.		
			Providing primary care (GP, GDP) education on key tips for early detection yearly.		
			Ensure referral guidelines and proforma's are up to date, accessible and easy to use. New referral form already in place across Manchester.		

3. Improving outcomes, with a focus on survival.

3.1 information:

3.2

The incidence of most head and neck cancers has increased year on year. Cancer of the oral cavity has increased by more than 30% while the incidence of oropharyngeal cancer has more than doubled.

- Survival for most head & neck cancers has however improved. Oral cancer has seen significant improvements in both 1- and 5-year survival rates with 5-year survival now at 56%. Oropharyngeal cancer has seen a 12% increase in 1- and 5-year survival rates with 5-year survival rates at 52% , with a change in which HPV-related disease is an important factor.
- Thyroid cancer is rarer with around 1,800 cases in the UK a year. The incidence has doubled which may be due in part to the increased detection of small papillary carcinomas.
- It is recognised that many head & neck cancer patients have a poor prognosis whilst the majority of thyroid cancer patients will be cancer survivors.
- There has been a 10% increase in 1- and 5-year survival rates in thyroid cancer patients since 1990, with the 5-year relative survival rate for the most recently diagnosed cases at 87%.
- The national statistic's recognise that head and neck cancers will increase by around 500-1,000 cases a year and an increase in smoking and alcohol consumption in younger age groups will be a contributory factor. The incidence of HPV-related oral and oropharyngeal cancer will continue to increase.

The importance of viable data to support the rationale to increase outcomes and survival can only be generated through audits.

The tenth Annual Report from the National Head and Neck Cancer Audit was published in September 2015. The aim of the Audit was to provide organisations with data and information which will support Trusts to improve the quality of care of patients with head and neck cancer by raising standards of care to match those of the best performing services and Trusts.

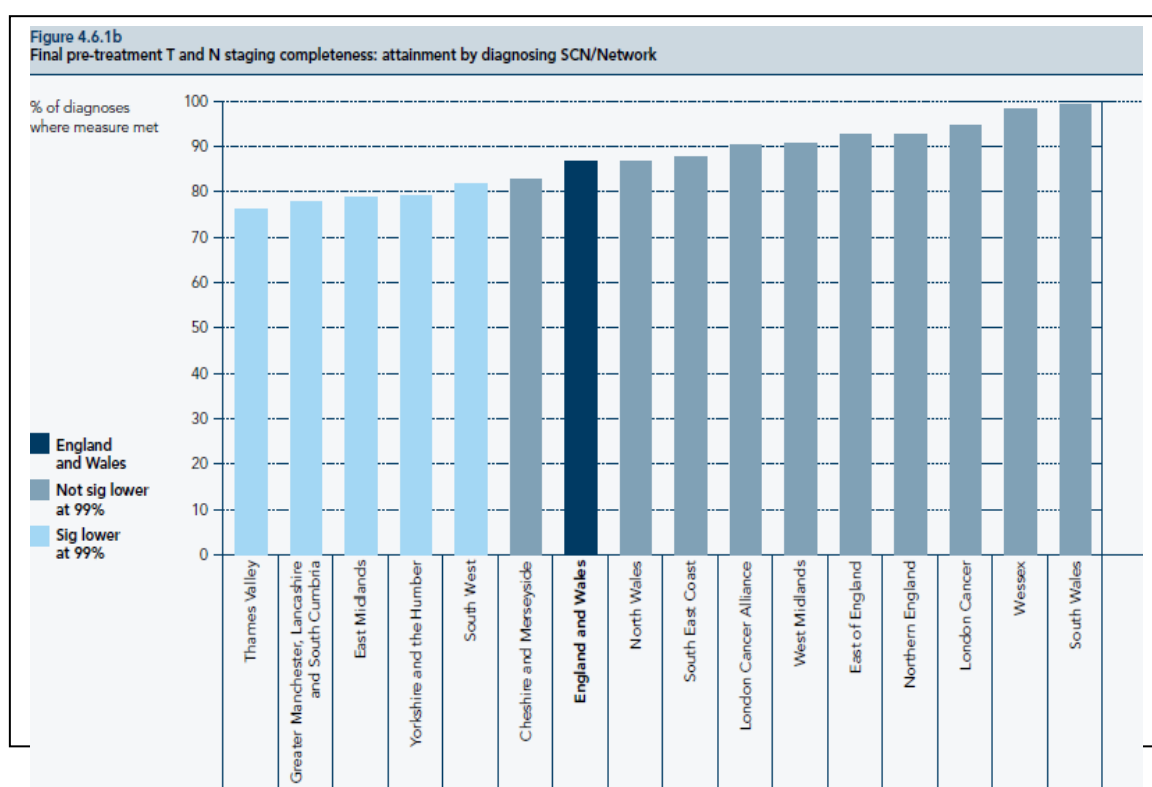
The head and neck pathway board wanted to demonstrate that head and neck services across Manchester are improving outcomes and survival for patients affected by head and neck Cancer have been impacted by this.

The Audit focuses on evidence of delivery of appropriate primary treatment, including adjuvant therapy, in the management of head and neck cancer by a multi-professional team, and delivery of care to agreed standards and the care provided by specialist nurses, dieticians and speech and language therapists. The Audit was commissioned by the Healthcare Quality Improvement partnership (HQIP) and funded by NHS England and the professional body overseeing the Audit was the British Association of Head and Neck Oncologists (BAHNO). The Audit results are summarised below.

3.2.1 Survival:

- The Audit has looked at four year survival (this reflects deaths from any cause, not just from cancer). Four year survival ranged from over 60 per cent in larynx to only 33.3% in hypopharynx. The influence of stage at presentation was also significant with early stage larynx cancer showing a 75.1% four year survival and late stage 44.7%, similar figures were seen in oral cavity. In oropharynx the difference between early and late stage was less, 73.8% for early stage compared to 58.5% for late stage. The Audit confirmed the link between improved survival rates and early diagnosis and treatment.

Table 1: of pre-treatment T and N staging: Manchester and Lancaster/ south Cumbrian in same statistical bundle.



- TMN staging:** Nine out of 15 SCNs/networks achieved over 85% staging recorded. This confirms the focus now given to this important case-mix variable by MDTs. However, variation remains between SCNs/networks and MDTs. From the staging submitted it has been possible to categorise 84.2% of submissions into early or late stage disease. The report highlighted therefore that focused effort is required in some SCNs/networks and their contributing MDTs, who have consistently failed in adequately recording stage.
- Survival and larynx cancer:** at an early stage had survived at four years, but this fell to just fewer than half of patients diagnosed at a later stage. Similar figures were seen in oral cavity cancer.
- Human Papilloma Virus (HPV):** the audit recognised the testing for HPV across England for the first time. HPV has become a recognised and increasingly frequent cause of oropharynx cancer. The results showed that of the oropharyngeal

squamous cell carcinoma (OPSCC) patients that had a HPV test performed, 72.8% had a HPV positive result.

Cancer outcomes and services data set (COSD)

	Jan-14	Feb-14	Mar-14	Apr-14	May-14	Jun-14	Jul-14	Aug-14	Sep-14	Oct-14	Nov-14	Dec-14
All diagnosed cancers discussed at MDT												
Diagnosed	113	76	62	98	83	92	68	77	68	83	46	45
Diagnosed with a Treatment Record Submitted	42	46	46	70	48	45	47	48	40	55	39	32
Diagnosed where the First Treatment was Surgery	28	30	28	40	33	27	32	34	27	36	22	17
With a Basis of Diagnosis	66	76	58	88	54	56	55	57	46	70	44	42
With a Histological Basis of Diagnosis	65	67	57	81	54	55	53	55	45	63	43	41
With a CNS indication Code Submitted	20	14	15	24	10	12	16	14	7	18	10	3
Diagnosed who had a CNS Contact	20	14	14	19	9	11	16	14	6	17	10	3
Diagnosed where Age at Diagnosis is under 25	2	0	1	0	1	0	0	0	0	4	0	0
Which are Stageable	113	76	62	98	83	92	68	77	68	83	46	45
Which are Stageable and have a Full Stage at Diagnosis	56	64	43	56	36	55	39	39	38	45	26	20
Discussed at an MDT	103	69	52	79	73	80	51	65	59	67	35	32
Discussed at an MDT with a Performance Status	51	30	32	38	35	41	27	41	34	43	23	22
Discussed at an MDT which are Stageable Cancers	103	69	52	79	73	80	51	65	59	67	35	32
All stageable cancers discussed at MDT												
With a First Treatment of Surgery	24	28	25	32	27	24	23	30	24	28	19	15
With a Full Stage	51	61	41	49	35	52	33	39	36	42	22	17
With a Full Stage and have a Performance Status	30	29	30	33	23	37	22	27	28	29	16	11
With a Full Stage and have a TNM Version supplied	44	61	41	48	32	42	32	37	31	39	21	17
MDT staging												
With a Full Stage Section	51	61	41	49	35	52	33	39	36	42	22	17
With a Partial Stage Section	17	2	6	11	13	7	9	10	5	6	3	3
With a Full Pre-Treatment Stage	49	56	38	44	32	50	29	35	31	42	19	16
With a Partial Pre-Treatment Stage	17	2	6	10	12	7	9	9	5	5	3	2
With a Full Integrated Stage where the First Treatment was Surgery	12	17	18	21	13	15	14	19	20	12	9	3
With Partial Integrated Stage where the First Treatment was Surgery	0	0	0	1	2	0	0	1	0	1	1	1
With a Site Specific Stage	0	0	0	0	0	0	0	0	0	0	0	0

Table : COSD data National Cancer registry service Jan 2014 to December 2014, National Cancer Intelligence Network

3.2.2 Mortality:

- During the year of the audit overall mortality was 11.5%. There is both variation between anatomic tumour sites, but also variation in mortality between networks/SCNs. Overall head and neck surgery is safe with a 1.7% peri-operative mortality rate (death within 30 days of surgery) and a 2.7 % mortality rate within 90 days of surgery being carried out. For those undergoing non-surgical treatments (radiotherapy, chemotherapy and chemo-radiotherapy) the 30 and 90 day mortalities were 2.3% and 5.2 % cent respectively. Despite the complex nature of head and neck cancer treatments, they remain safe.

3.2.3 Organisational variation and services:

- **Organisational variation:** There was consistent variation between MDTs and networks/SCNs. All organisations need to investigate the functional arrangements for the delivery of head and neck cancer where in any MDT a large number of patients is recorded as not having their case discussed at MDT, this must be improved.

- **Nursing investment:** Organisations need to support investment in Clinical Nurse Specialists to reduce the variation seen across the country.
- **Pre-treatment speech and swallowing assessment:** this occurred in 28.8% of patients, a rise of 2.1%, but again there was wide variation between networks/SCNs, with one submitting less than five per cent assurance.
- **Radiotherapy waiting times:** Waiting times for radiotherapy treatment for those with head and neck cancer have improved on average from 42 days to 41 days. There remains a wide range of waiting times from referral to radiotherapy starting with one in four patients waiting 54 days or more from diagnosis to start their treatment.

3.3 Progress

The Audit has highlighted to the head and neck pathway board that such national audits, as well as Peer Review and the National Cancer Patient Experience Survey 2016, provide the board with a framework to look for evidence of excellence in the provision of care, and also areas where evidence of quality and assurance is lacking.

The head and neck pathway board therefore need definitive plans to ensure that these vital aspects can be delivered in full. In 2016/17 the board will maintain commitment to audit to ensure that assurance of high quality care can be evidenced.

This will be delivered by:

- Ensuring multi-professional care is delivered throughout the head and neck cancer pathway to every patient in greater Manchester and provides assurance of this to patient groups and commissioners, through audit.
- Ensuring that where appropriate patient length of stay is minimised and work with community services to support early discharge where safe.
- Ensuring all head and neck patients are discussed at MDT. There needs to be a concerted effort to distribute best practice between the best and less well performing organisations to reduce avoidable variation to a minimum.
- To assess the current practice of data flow in MDTs and identify new models of collection and recording to support Trusts and the pathway board, in an attempt to meet national standards and provide evidence of a quality service. This will be reliant on the development of the clinical web portal and evidence from the national data set.
- Identify measures outside of the national requirements to provide more up to date local intelligence to gain additional understanding of the current services.
- To extract data from current systems to assess current stage of disease at presentation and to then collect similar staging data yearly – to allow assessment of impact of educational program with intention that disease is picked up earlier.

3.2.1 Data collection

Data collection recorded for head and neck cancer services have been developed using Somerset Cancer Register (SCR) during the MDT. However not all organisation use the SCR, including the Christie, therefore leading to wide variations in data flow. The monitoring of outcomes is therefore utilised as an internal mechanism only set up by individual Trusts.

Pennine MDT is also unique, in that the referring surgeons from the diagnostic centres are in attendance and able to fill in additional information. It appeared that whilst all relevant information was discussed, there was transfer of almost none of this back to data collection teams in cancer services.

CMFT MDT have taken the decision to relocate their MDT to the CMFT to improve data flow between CMFT and the Christie, with the proposal to adopt live data collection. This is effective from September 2016, with the hope that the Head and neck service will form part of the next wave of CWP development plan.

The head and neck pathway board have suggested further areas of data collection that are consistent with the findings of the National Audit in 2015:

- Breakdown of Classification of Malignant Tumours (TNM) staging per MDT and no of cases where this was available
- Length of stay within each organisation
- Cancelled operations, major head and neck cancer resections (suggested by some to be an issue)
- Mortality analysis.

Mortality data is published nationally to the link:

<http://www.nhs.uk/choiceintheNHS/Yourchoices/consultantchoice/Documents/Head%20and%20Neck%20Cancer%20Surgeon%20Report.pdf>

Data reported for all 3 surgical centres suggests no issues compared to other centres nationally. This data however highlights lack of complete data collection, particularly for the CMFT team, where the number of procedures reported seems extremely low.

The methods of collecting full complete data across all aspects of the patient journey therefore remains a priority and should be considered high on a list of needs for this group. This is the clear objective of the pathway board. In summary of data collect for head and neck cancers remains a priority and the roll of the CWP system, is essential to delivery this.

3.2.2 Education and interactions with referrers (primary care)

The results of the recent Cancer Patient experience survey 2015 found that 63% of respondents said that they thought the GPs and nurses at their general practice definitely did everything they could to support them while they were having cancer treatment. This is an area where clear improvements need to be made in the communication and education of colleagues in the primary care setting.

The head and neck pathway board have ensured a continued review of education pathway in primary care:

- The pathway board has developed a new GP referral proforma designed in conjunction with GPs and the pathway board. The Pathway Director for head and neck presented to the commissioning group and GP teams in March 2016, regarding the recommended that the current draft of the 2WW referral form. The GPs were receptive to this and a new form was issues in June 2016. This will be the new 2WW form for Manchester, which has been accepted by all CCGs. There is now a GP recruited to support the pathway board to ensure consistency of advice.
- The pathway board have recognised the need to continue with the focus on early diagnosis, in line with the vanguard project work stream and the outcome of the national head and neck audit in 2015. Therefore a key objective will be to focus on the GP education work stream as part of the vanguard programme.
- Liaising with the prevention, early detection and screening Pathway Board and dentist screening. Providing primary care (GP, GDP) education on key tips for early detection yearly. The board will ensure continued to communicate with the dental community via a newsletter articulated which will be distributed to all practices. The board has also identified a method of communicating with all dental practices through National Health Service England (NHSE). The board will aim to expand our educational programme for public, patients and referrers by 2018.
- Ensure referral guidelines and proformas are up to date, accessible and easy to use.
- Develop visual aids/handbook of early signs to improve confidence and knowledge.
- Developing world class standards across Manchester and sharing of access to this information.

3.3 Challenges

Data collection remains a significant issue and the head and neck pathway board have serious concerns about the completeness and accuracy of data which is presented to the board. It is apparent that the method of data collection historically used at MDT's made it impossible to provide a complete dataset for each patient. The moving of the MDT of CMFT will improve this.

It will however take at least 2 years to see if these changes result in improved data and because the data from all 3 MDTs working in collaboration.

Once the data systems are put in place it will however take 2-3 years to access the quality of the data and embark on robust reporting structures. High risk identified therefore in the next few years, will be without meaningful data, it is impossible to assess our performance and identify where improvements can be made.

The pathway board for Head and neck cancer will await the roll of the CWP and data collection tool. This data collect process will need to be developed in all centres from diagnostic, surgical and non surgical treatment centres, the MDT and then in the place of follow up to allow a complete data set for all patients. The ability to extract outcome data is necessary to identify any variations or outliers and to act on these and they will formula part of the new standards set by the pathway board.

4 Improving patient experience

A diagnosis of head and neck cancer can have a profound effect on a patient as this cancer directly affects a patient's ability to communicate, swallow, eat and drink, and is often visible, causing significant psychological and social distress. Treatment can exacerbate these problems, with weight loss and malnutrition common. The stagnant five-year survival rate for head and neck cancers makes quality of life (QoL) increasingly important. The Head and neck pathway board had a number of key initiatives to address the gap.

- To improve patient experience and ultimately improve Outcomes, the board agreed to the implementation of the 'Recovery Package' to help improve the outcomes of cancer patients after completion of treatment. One element of the Recovery Package is a 'Health and Wellbeing Clinic', a post treatment information event offered to all patients and family members to increase their knowledge regarding all aspects of the Survivorship phase of their journey.
- The board has with the support of Macmillan user involvement team, set up a small community of patients affected by Head and neck cancer and they group have produced a report on this.
- The board has supported a project at the Christie in which a new role has been introduced into the speech and language therapy team (SALT) to support patients during radiotherapy treatment. The project started in February 2016 and will run for 6 months. Full outcomes will be published in November 2016. This was one of the key recommendations by NICE Guidance (2004) that of speech and language therapists such support patients with Head and neck cancer prior to starting cancer treatment.

4.1 Introduction: health and well-being clinic at CMFT

The Head and Neck pathway board supported CMFT to host four Health and Wellbeing Clinics for patients and carers who have received treatment for their Head & Neck Cancer. Health and wellbeing events provide an opportunity to inform and educate patients about the clinical and holistic aspects and on-going management of their health which are not always provided at their routine clinical follow up. They serve to impart information about local facilities, supportive care and opportunities that are available to individuals and their families.

Rationale

Most Head & Neck cancers are treated by surgery, radiotherapy or a combination of both and for some patients this will involve extensive plastic or reconstructive surgery. 81% of patients who are undergoing treatment for head & neck cancer experience pain whilst undergoing treatment. Head and neck cancer patients can experience poor quality of life post treatment and commonly cited symptoms are dysphagia, problems with swallowing, speech, breathing, eating, fatigue, dental problems and psychological morbidity. This supports the anecdotal feedback received from the local support group where patients continue to have symptoms issues for many years post treatment, and are unaware how to access support once out of that traditional follow up period.

At a local level further evidence was obtained by the team to identify what key issues should be included in the H& WB clinic. A survey was undertaken in outpatients by the team which highlighted four key issues which patients felt should be included in the event.

- Speech & Language
- Lymphodema
- Recurrence
- Diet & Nutrition

Nationally, Health & Wellbeing events are being established, although evaluative evidence both for generic and specifically the Head& Neck Cancer patient cohort is lacking. Early evaluations provided by NCSI (2011) are positive with patients reporting improved confidence and wellbeing. However further evaluative work is required to establish long term outcomes.

At a local level it was identified that there are no post treatment services specifically for head and neck cancer patients in the Manchester Cancer area which address survivorship needs. Health and Wellbeing events are seen as one element of the Recovery Package. Guidance from NHS England states that the aim should be that every individual with cancer should be offered the opportunity to attend an H&WB event at the end of treatment; this will be part of the commissioning specification for cancer. (Achieving world class cancer outcome: A strategy for England 2015 -2016; Implementing the Cancer Taskforce Recommendations: Commissioning patient Centred Care for People affected by cancer (NHS England 216).

Proposal

The proposal included the delivery of four Health & Wellbeing events over a 12 month period. In addition the production of 3 videos, with more specific information for people living with or affected by Head & Neck Cancer.

Based on experience of patient flow through the Head and Neck service, it was felt that around 50-60 patients per quarter could be offered this as part of their follow up. Within a 12 month period therefore, potentially 200-240 attendees would benefit from increased knowledge regarding their cancer, treatment, signs of recurrence, and living with and

beyond cancer. In addition to the patients, their carers' and families would also benefit from attendance.

Although many Head and Neck patients will continue to need standard clinical follow-up to allow for FNE (scope) to examine, for example, vocal cords, it would be anticipated that the HWB clinic be integrated into the Head & Neck patient pathway. Further scoping work is required as to whether this would replace a standard follow up appointment and what tariffs would be applied.

The project was to be evaluated through audit of patients attending, pre and post event, to ascertain the impact of the various sessions, and to enable improvements to the structure and organisation of the day. Prior to this 15 patients were consulted to identify 5 key areas which would inform the content of the session. The project also planned to receive feedback from the Living with Task group (Living with and Beyond and Palliative care Board) patient focus groups planned to run during January and March 2015.

Governance was provided via the Steering group; Head & Neck Divisional lead and liaison with Manchester Cancer Lead.

It is the responsibility of the pathway board once the learning is shared to identify how the clinics can be replicated across the Manchester Cancer areas to benefit all Head and Neck patients.

Aims and Objectives of the projects

- The aims of the project was to improve the quality of life through raising awareness, increasing knowledge and confidence for patients and carers living with or affected by Head & Neck cancer.
- To support patients with integration back into their community, equipped with the knowledge of what services are available and how to access them.
- Long term the introduction of the HWBC will reduce the demand for outpatient attendance adopting risk stratification process.

Objectives

The Head and Neck pathway board wishes to implement a Health and Wellbeing Clinic for patients and carers, with its first pilot in the Central Manchester MDT area. Patients and their carers who have received treatment (surgical, oncological, or combination) for their Head and Neck Cancer will be invited to attend a holistic clinic post treatment as advised by The National Cancer Survivorship Initiative document LWABC (2013) to support the recovery and wellness of patients and carers alike.

Methods and approaches

Pivotal to the success of the proposal was gathering a project team together to design the elements and monitor progress. Key members were identified by the Project Lead and informal discussions regularly took place explaining the aims of the project. It was quickly identified that the contribution of the Trust Lead Cancer Nurse was fundamental to its success, as was the input of the Cancer Information Centre Manager.

The project lead raised awareness of the project with the wider multidisciplinary team at CMFT and Christie, both verbally and via email. At the weekly Cancer MDT meeting, a brief presentation explained what the Recovery Package entailed and the rationale for this. This included a focus on the H+WBC format, and the vital need for clinician buy-in to ensure success. Various clinicians agreed to assist with the design and delivery of the project, including consultant surgeon, dietician, SLT and Physiotherapist and Christie CNS.

It was recognised early in the project that patients would also need to be consulted to help determine content and format of the events. 15 patients currently under follow up after treatment several years earlier were given paper questionnaires asking for their input, and these helped the project team decide on priority content for the event, and length of the event.

Project Outputs and Outcomes

The project application included the delivery of 4 Health and Wellbeing Clinics over the project period. This was achieved in full, with all 4 events being successfully delivered.

As part of the project two videos were commissioned (application initially envisaged 3), and are in the progress of final production. Based on a survey of what current information is locally available and on line for patients and carers to access, it was decided by the project group that for patients affected by head& neck cancer oral and dental hygiene should be the focus. Particularly, management of sugar intake, teeth brushing and the importance of regular dental reviews. This is a collaborative exercise with the Dental Team who are key members of the Head & Neck MDT. The videos will be utilised at future H+WB events at CMFT but also are to be shared with other Manchester Cancer areas to augment their H+WB events.

All of the presentations and videos will be invaluable tools to support education and training of clinical staff which can only enhance patient experience.

Project Evaluation

The project application envisaged 50-60 patients and family members to be invited to each of the events. The breakdown of the actual numbers is as follows:

Table 2. Number of people who were invited and actual attendance at the H&WB event.

Total	Event 1	Event 2	Event 3	Event 4	Total
Total patients invited:	56	52	47	42	197
Patients attended:	19	16	20	12	67
Carers attended:	15	6	20	5	46
Total attendees:	34	22	40	17	113

Gender & Ethnicity

With regard to the gender and ethnicity of those who attended and completed the evaluation forms, 60% were male.

Age: With the majority of participants between the age 40- 74.

With regard to the number of attendee's the total number of patients invited largely reflected that envisaged in the application (197 as opposed to 200-240) the number of actual attendees (patients) was somewhat lower at 67 (34%) However, if one adds the number of patient and carers across all four events, the number of attendees was 113 (57%).

With regard to ethnicity 94% recorded their ethnicity as White British. Further analysis is required to establish whether patients from BME community were invited and chose not to attend. Engagement with BME groups is a recurring theme that has been acknowledged at both local and trust level to identify how we ensure these groups also access services which can support them post treatment.

Patient Experience & Evaluation of the H&WB events

Outcomes were measured through the collation of patient/carer experience. Patients and Carers were invited to complete an evaluation sheet at the end of each event. A further questionnaire was then also posted to patients at approximately 4 weeks after the event. Total number 113 patient questionnaires were given out. With a total number of 87 returned.

The data from patient feedback is as follows, which shows the success of the event.

- Overall 80% of patients / carers who completed the questionnaire found the event very helpful with 100% of participants recommending the event to fellow patients & carers.
- Patients and carers responded that they had learnt new information about what support services were available in the community; followed by what to expect once treatment has finished and support about speech & swallowing.
- 75% of those who attended the event found the market place very helpful

- 100% of those who attended also reported that they felt more confident about managing their health & wellbeing both as a carer and person affected by head& neck cancer

Of those who completed the questionnaire at four weeks; the number of responses was poor. Although the team was challenged in the organisation and administration of this and consideration needs to be given how this could be improved at subsequent events.

Patients reported that the presentations and networking with peers was the most useful aspect of the Health & Wellbeing event. Patients who responded also stated that they felt more confident and aware of potential side effects and when they should seek advice. Please see Appendix 3 for data relating to the evaluation.

Further data around head & neck cancer was obtained with the support of the patient experience team, which highlighted key issues around their care pathway and treatment to date. Please refer to Appendix 2.

In addition to the above patient experience was also captured at the event by a patient representative who spoke of his cancer journey six years into his recovery. The session was recorded so that it can be utilised when delivering training and education to staff and students. From a professional perspective the patient 's session highlighted the issues that patients can continue face many years post treatment, but importantly the message was positive, which was reflected in the title of his presentation 'Cancer can improve your life' .

Impact of project

From the patient evaluations that were provided there is no doubt that patients and carers living with or affected by Head& Neck Cancer following treatment found attendance at H&WB clinic to be a positive experience. Evaluations demonstrate that the information provided, the opportunity to discuss with professionals and peers was beneficial. The H&WB events provided the opportunity for patients and carers to consider the wider impact of their treatment upon their quality life which does not occur in the confines of the outpatient clinic. From the evaluations of the market place – questions around finances, support in the community was amongst the highest contacts.

However, evaluating the longer term outcomes was not demonstrated and would require further audit. The project team acknowledge that the challenge is to how this would replace a standard clinic appointment; it may that the establishment of these clinics will reduce inappropriate contacts with GP and community services and success would be measured via the patient survey or other metrics.

From a professional perspective the project has generated many positive outcomes. It has fostered a collaborative approach between two organisations with MDT professionals supporting the delivery of this project. The events alone provided all those professional groups from across primary, secondary and third sector to meet and have overview of the whole patient pathway for head& neck patients.

Following on from the completion of the events and alongside the completion of the videos, discussion has focused upon how these resources should best be utilised across Greater Manchester. As a primary treatment centre for the surgical management of these patients, the presentations will contribute to professional learning for both nursing and allied medical professionals and contribute to learning events across and external to the Trust.

Presentations and the Health promotion materials will also be made accessible to organisations in a digital format, combined with the project team promoting the project at local and national conferences. At a local level the project team have presented at divisional and executive board level to raise awareness of Recovery Package for Cancer Patients and stimulate discussion as to how this will be delivered going forward.

Discussion

The project has been an invaluable experience in how to implement a Health and Wellbeing Event here at CMFT, and has demonstrated to all health care professionals (HCPs) and managers involved how this element of the 'Recovery Package' benefits our patients and families/carers in assisting them in the transition from treatment to survivorship. The Head and Neck team as a whole is committed to continue such Health and Wellbeing events in the future.

In terms of its aims, the project almost met the target of 200-240 patients being invited to the 4 events of the year's duration (197 invited). Although 3 videos pertinent to Head and Neck issues were an aim, 2 videos were in fact produced (these will be completed in due course and will be available for use in the Greater Manchester Cancer area). Whilst the attendance of carers is of great importance, the number of actual patients attending (67 from 197 invited) was lower than hoped. Again, the project team will need to examine how this could be augmented at future events, perhaps through better advertising, personal invites and more comprehensive/timely telephone calls.

The feedback from all the attendees has been extremely positive, as detailed in Appendix 2. The large majority of patients learnt much from the events, and 100% who gave feedback would recommend such an event to others. This reflects the pilot work on the effectiveness of Health and Wellbeing events undertaken by Macmillan and discussed in the publication 'Living with and Beyond Cancer' (2013).

The event also proved to be beneficial to staff members who contributed to the events, as it facilitated increased collaboration between Trusts and with organisations in the 3rd sector. Individuals, who perhaps had never met in person for example, came together at the events and it allowed for informal discussion and better understanding of their services and working practices, building relationships.

The presentation element of the Event was augmented considerably by the inclusion of a Patient Presentation. After the first 2 events some HCPs and attendees commented that the event would be strengthened if a patient could convey their experiences as part of the event. A patient 4 years post treatment was contacted by CNS, and was keen to contribute. He presented at the 4th event and this was recognised by staff and attendees alike as a valuable addition to the event's programme.

The project lead also presented the Project to other tumour group CNSs within CMFT and shared experiences with them, to assist them in considering the practicalities of setting up their own Health and Wellbeing events in the future.

Areas of difficulty/for future improvement:

1. Patient numbers attending. The numbers of patients invited to the four events was 197. Nevertheless, the number actually attending was only 67, which was disappointing. In addition however, 46 carers also attended, giving a total of 113 attendees benefitting from the project. The Project team wonders how this could be increased in the future, and felt that the following would help - i) more timely and thorough use of telephone calls to patients as detailed above. ii) Face to face invites. Despite pull-up advert, posters and flyers on show in OPA, better verbal explanation of the events and personal invites to the events during routine F/U appointments, by consultants, CNSs and AHPs could increase attendance. It is recognised though that OPA can often be so busy due to patient numbers and other priorities. Such personal invites would have to be logged, and followed up with letter invite and telephone calls.
2. Administrative Support. The project included monies for the employment of a 0.2 WTE Band 4 to provide support. It was not possible to recruit into this, so the admin support that was included in the project related to a member of admin staff already in post, working overtime hours to work on the patient spreadsheet and send out invite and feedback letters. In future, a dedicated Admin officer would improve the effectiveness of the project's recruitment, amongst other things. Much of the admin support envisaged by the 0.2 WTE Band 4 detailed in the project application was in fact undertaken by the staff in the CMFT Macmillan Cancer Information and Support Centre. In terms of sustainability going forward this would have to be resolved, with a dedicated Admin support officer taking over much of this work.
3. A number of patients at the Health and Wellbeing events came with existing unmet needs, and they discussed these with the appropriate HCP at the event best suited to help them. Often discussion and clarification on the day was sufficient, but numerous onward referrals/appointment were arranged. This information e.g. volume and details of these referrals was not logged and so cannot be accurately quantified. In future the project team would need to devise and implement a way of logging these discussions and their outcomes.

Recommendations

The following recommendations are made by the project team based on the evaluation and discussions that have taken place during the project.

1. Continued Support for the commissioning of Health & Well Being Events for Head & Neck Cancer Patients going forward. Identification of tariff and integrated into the Head & Neck Patient Pathway
2. Identification of dedicated support services for the administration of and evaluation of these programmes.
3. Development of metrics to identify impact of HWB events on longer term patient reported outcomes.

4. Continued Patient and Carer involvement in the co design and evaluation of HWB clinics.
5. Publication and shared learning with professionals and peer groups.

Conclusion

The implementation of a Health and Wellbeing clinic for Head and Neck cancer patients and their families/carers, in the Central Manchester MDT area was of great benefit, both to attendees as reflected in their feedback, but also to all staff involved.

It enabled the project team to understand the requirements for establishing such events, and the resources necessary to achieve this. This learning will allow for the continuation of such events at CMFT for Head and Neck patients, so that progress towards achieving full implementation of the Recovery Package continues. Learning is also to be shared with others, not just within CMFT, but also of course those organisations around the Manchester Cancer area which are looking for guidance and recommendations in terms of setting up similar events in their local areas.

There are significant resource issues with regard to planning and running Health and Wellbeing clinics, particularly regarding CNS time and the recognised need for dedicated administrative support, and this must be addressed to ensure consistent and successful implementation going forward.

CNSs will also be closely involved with, for example the implementation of Treatment Summaries (another necessary element of the Recovery Package) as well as other priorities. Trust management needs to examine how best CNS time is utilised to result in the full implementation of the Recovery Package whilst balancing the other varied demands upon their time.

The project team certainly felt that dedicated and effective administrative support is vital for the organisation and management of Health and Wellbeing clinics in terms of future sustainability, and this must be examined not only by NHS Trust management but also, fundamentally as part of the reorganisation of cancer services across Greater Manchester in terms of the Vanguard process and Cancer Pathway work, including examination of tariffs to help fund these and other vital elements to facilitate world class, holistic cancer care.

4.2 Involvement of patients affected by Cancer in the Head and neck pathway board.

The head and neck pathway board are delighted that the MacMillan user involvement team have recruited 2 patients affected by Cancer on the pathway board and during the meetings they are advocates on behalf of people affected by cancer.

There have been a number of key developments in this area:

- A small representative community of people affected by Head and Neck cancers has been formed to act as a resource for the Service User Representative (SUR) to gather the wider views of patients and carers. The SUR will also act as a resource for the small community if they feel issues need to be raised at Board level.
- The SURs have been fully inducted through the User Involvement Programme, to ensure they have an understanding of the Manchester Cancer Structure they are feeding into and the involvement opportunities available to them.
- The SUR is also linked in with the User Involvement Steering Group where issues relating to the Board can be taken to gain the views of wider people affected by cancer.
- A report has been compiled by the SURs and the small community highlighting issues relevant to patients and carers living with Head and Neck Cancers (details below).

4.2.1 Service User representation (SUR) report:

This report has been prepared following a meeting of a newly created small community group of patients who have drawn from their experience of H & N cancer in the Manchester area to make recommendations for the improvement of Head & Neck cancer services:

Issue	Recommendations	Workstream
<p>GPs: The response of GPs was generally good for members of the group but one member had a protracted experience to referral for diagnosis albeit outside the Manchester area. There was awareness within the group of cases where diagnosis had been delayed severely caused by failure to refer. Experience within the group also of receiving a 2 week wait referral without explanation that this could lead to a cancer diagnosis.</p>	<ul style="list-style-type: none"> • Continued work within the Pathway Board working with the GP representative to engage with Primary Care around early diagnosis of head and neck cancers. • It is recommended that some form of targeted marketing campaign to GPs on signs & symptoms- is formulated and maybe a 'credit system' for a GP whose referral catches cancer early. • As an alternative to above - are there currently any educational events for GPs around signs and 	<p>H&N Pathway Board</p> <p>Vanguard GP Workstream</p>

	symptoms of H&N cancers? If not is this something we could look to develop?	
<p>CONSULTANTS/SURGEONS: Experience of receiving treatment was generally excellent. Issues mainly came around follow up post treatment with one member reporting having no more than 30 seconds following surgery with his consultant who then delegated a follow-up appointment to a junior and the patient never saw his consultant subsequently. One consultant miscommunicated by letter with the patient's doctor by saying he had discussed certain medical matters with the patient and he hadn't.</p>	<ul style="list-style-type: none"> • One recommendation came forward in that all surgeons spend some time in-depth with the patient after surgery. 	H&N Pathway Board
<p>CANCER SUPPORT NURSES & ADMINISTRATION: For the Group this was the major area of concern. Invariably diagnostics and treatment can involve up to three hospitals. Members who had to go from hospital to hospital stated that their experiences had been poor and highlighted a disparity of services between different hospitals. This caused unnecessary stress, confusion & delays for both patients and carers at an already difficult time. (*Case Studies available if needed.)</p> <p>Many patients within the group had not been linked with a Clinical Nurse Specialist and reported feeling 'lost in system' without having one focal point of contact.</p>	<ul style="list-style-type: none"> • Continued work around standardisation of services • Ensuring all patients are assigned to a CNS as early as possible to help with navigation of what can be a complex healthcare system for patients and carers. • Clear sign-posting to the services available from Macmillan for support services in the community. 	H&N Pathway Board
<p>SUPPORT NEEDS POST SURGERY: Whilst all members were highly complimentary about surgery areas of improvement were highlighted in ensuring support needs were addressed post-surgery. For example, challenges were noted around patients getting attention and help of healthcare staff after surgery for mouth cancer, where often patients are in pain and unable to speak. The husband of one member received superb treatment for surgery and intensive care but on being moved to a Ward the care deteriorated significantly. (*Case Studies available if</p>	<ul style="list-style-type: none"> • The Group discussed the possibility of additional training for staff on Wards around the specific support needs of head and neck patients to ensure needs are met. • Robust referral pathways to Allied Health Professionals. 	H&N Pathway Board

<p>needed.) Support services from Allied Health Professionals were noted as being invaluable in recovery - ensuring Dieticians and Physiotherapy are fully integrated services was considered a high priority.</p>		
<p>CAUSES/PREVENTION/EDUCATION: A need of education and awareness on factors relating to Head and Neck cancers.</p>	<ul style="list-style-type: none"> • Increased public awareness of symptoms related to H & N cancers to help potential patients address the referral process more quickly. • More feedback and explanation from clinicians on the potential causes of cancer e.g. mobile telephones, HPV, alcohol, smoking and what preventative action for educational purposes could be taken e.g. vaccination for boys in the case of HPV or other practices. 	<p>Vanguard Education Work stream H&N Pathway Board</p>

This report was just published in May 2016, the Pathway director will be acting on the information given in the report as the views of the SUR and small community are vital to ensure patient's opinions and concerns can be addressed and an action plan will be formulated from this as one of the core objectives for 2016/17.

4.3 Information

One of the four core objectives for Manchester Cancer is patient experience and the measurement for success is based on the National Cancer Patient Experience Survey. The last cancer patient experience survey was conducted in March 2015 and the results have just become available in June 2016.

The pathway director and pathway manager will support their board to undertake important work to improve patient experience, such as developing regional patient experience surveys, developing the use of patient-reported outcome measure and standardising patient information across the region.

4.3.1 Patient experience survey

A full patient national experience survey from 2015 for all cancer patients was released in July 2016 (attach results for the head and neck cancer patients).

Question		Christie
Q1	Before you were told you needed to go to hospital about cancer, how many times did you see your GP (family doctor) about the health problem caused by cancer?	76.2%
Q2	How do you feel about the length of time you had to wait before your first appointment with a hospital doctor?	74.5%

Q6	Overall, how did you feel about the length of time you had to wait for your test to be done?	82.1%
Q7	Were the results of the test explained in a way you could understand?	76.9%
Q8	When you were first told you had cancer, had you been told you bring a family member or friend with you?	85.7%
Q9	How do you feel about the way you were told you had cancer?	89.4%
Q10	Did you understand the explanation of what was wrong with you?	83.0%
Q11	When you were told you had cancer, were you given written information about the type of cancer you had?	69.8%
Q12	Before your cancer treatment started, were your treatment options explained to you?	85.4%
Q13	Were the possible side effects of treatment(s) explained to you in a way you could understand?	83.0%
Q14	Were you offered practical advice and support in dealing with the side effects of your treatment(s)?	72.3%
Q15	Before you started your treatment(s), were you also told about any side effects of the treatment that could affect you in the future rather than straight away?	71.7%
Q16	Were you involved as much as you wanted to be in decisions about your care and treatment?	76.1%
Q17	Were you given the name of a Clinical Nurse Specialist who would support you through your treatment?	93.2%
Q18	How easy or difficult has it been for you to contact your Clinical Nurse Specialist?	75.8%
Q19	When you have had important questions to ask your Clinical Nurse Specialist, how often have you got answers you could understand?	77.4%
Q20	Did hospital staff give you information about support or self-help groups for people with cancer?	88.2%
Q21	Did hospital staff discuss with you or give you information about the impact cancer could have on your day to day activities (for example, your work life or education)?	82.4%
Q22	Did hospital staff give you information about how to get financial help or any benefits you might be entitled to?	46.2%
Q23	Did hospital staff tell you that you could get free prescriptions?	70.0%
Q26	After the operation, did a member of staff explain how it had gone in a way you could understand?	65.4%
Q28	Did groups of doctors and nurses talk in front of you as if you weren't there?	88.6%
Q29	Did you have confidence and trust in the doctors treating you?	81.8%
Q30	If your family or someone else close to you wanted to talk to a doctor, were they able to?	80.0%
Q31	Did you have confidence and trust in the ward nurses treating you?	88.6%
Q32	In your opinion, were there enough nurses on duty to care for you in hospital?	74.4%
Q33	While you were in hospital did the doctors and nurses ask you what name you prefer to be called by?	69.8%
Q34	Were you given enough privacy when discussing your condition or treatment?	90.9%
Q35	During your hospital visit, did you find someone on the hospital staff to talk to about your worries and fears?	46.7%
Q36	Did the hospital staff do everything they could to help control your pain?	95.0%
Q37	Overall, did you feel you were treated with respect and dignity while you were in hospital?	95.5%
Q38	Were you given clear written information about what you should or should not do after leaving hospital?	95.2%
Q39	Did the hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?	97.6%
Q41	While you were being treated as an outpatient or day case, did you find someone on the hospital staff to talk to about your worries and fears?	70.0%
Q42	The last time you had an outpatients appointment with a cancer doctor, did they have the right information, such as medical notes, x-rays and test results?	100.0%
Q44	Beforehand, did you have all the information you needed about your radiotherapy treatment?	89.3%
Q45	Once you started your treatment, were you given enough information about whether your radiotherapy was working in a way you could understand?	65.4%
Q47	Beforehand, did you have all the information you needed about your chemotherapy treatment?	n/a
Q48	Once you started your treatment, were you given enough information about whether your chemotherapy was working in a way you could understand?	n/a
Q49	Did the doctors or nurses give your family or someone close to you all the information they needed to help care for you at home?	74.3%
Q50	During your cancer treatment, were you given enough care and support from health or social services (for example, district nurses, home helps or physiotherapists)?	51.6%
Q51	Once your cancer treatment finished, were you given enough care and support from health or social services (for example, district nurses, home helps or physiotherapists)?	50.0%
Q52	As far as you know, was your GP given enough information about your condition and the treatment you had at the	97.4%

	hospital?	
Q53	Do you think the GPs and nurses at your general practice did everything they could to support you while you were having cancer treatment?	52.4%
Q54	Did the different people treating and caring for you (such as GP, hospital doctors, hospital nurses, specialist nurses, community nurses) work well together to give you the best possible care?	54.3%
Q55	Have you been given a care plan?	43.8%
Q56	Overall, how would you rate the administration of your care (getting letters at the right time, doctors having the right notes/test results, etc.)?	95.7%
Q57	Overall, how do you feel about the the length of time you had to wait when attending clinics and appointments for your cancer treatment?	60.9%
Q58	Since your diagnosis, has anyone discussed with you whether you would like to take part in cancer research?	16.7%
Q59	Overall, how would you rate your care?	8.53

The results of the patient experience survey will be discussed at the September pathway board in 2016. It is clear however that Cancer patient are still reporting:

- Understanding If treatment was working
- Address health and social care needs, including financial support, social services and support at home
- Having a clear care plan
- Clearly psychological issues were not addressed which concerns about fear and anxiety
- Patients were still not being offered clinical trials.

The Head and neck pathway board will be addressing key actions in this with an action plan contained within the annual objectives for 2016.

4.2.3. Clinical Guidelines

We have reviewed and updated all our guidelines and referral protocols which the board are satisfied with, awaiting the findings of individual trust self-assessments to identify the support needed.

There is an opportunity to explore more user friendly method of accessing and using these guidelines i.e. digital or hand book example London Cancer Alliance Head and Neck Guidelines. All documents can be found following the link below on Manchester Cancer website <http://manchestercancer.org/services/head-and-neck/>

4.2.4 Challenges

The pathway board for head and neck cancer recognise that new guidelines and pathway standards must be agreed in 2016-17, similar to the process in Urology services have gone through and have developed their own clinical standards. The pathway director for Head and neck services have emphasised the need to put patients at the forefront of writing these standards and the collaborate approach to this will commence in September 2016.

5. Increasing research and innovative practice

5.1. Information

A yearly report is published for the Head and Neck Pathway board for trials report Q4: 2015-16. Recruitment activity window: 1st April 2015 – 31st March 2016 from the NIHR Portfolio.

Chart 1: Head and Neck Clinical Trials by Trust – Cancer Research Network Greater Manchester report June 2016 : Interventional studies.

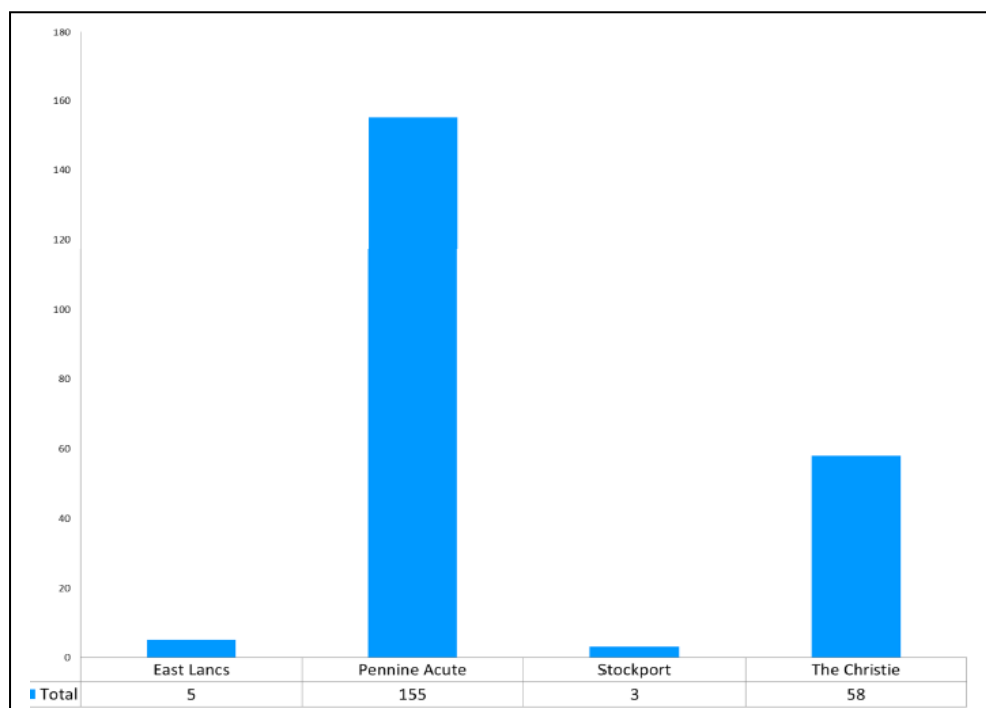
Design Type	Acronym	CRN Population source ONS (millions)													Grand Total		
		East Midlands	Eastern	Greater Manchester	Kent, Surrey & Sussex	NEast & NCumbria	North Thames	North West Coast	North West London	South London	South West Peninsula	TValley & SMids	Wessex	West Midlands		West of England	Yorkshire & Humber
Interventional	AMG 319 in HPV negative HNSCC												2			2	
	ART DECO	1	3		2	1	3	1		1			5	3	7	9	
	ARTFORCE Head & Neck (2-arm study)			4												4	
	CANC - 3354 Leukocyte Interleukin, Injection [Multikine] + SOC in oral cavity carcinoma							0	0							0	
	CANC - 3417 Phase III Study of MK3475 vs standard treatment in recurrent or metastatic			4			7			17	2			2		32	
	COAST - Cisplatin Ototoxicity attenuated by Aspirin Trial								7				6			14	
	CompARE Trial		2											8		10	
	DA-MANCA 21							1								2	
	De-ESCALaTE HPV	5	1		5	5	1	2			3			13	11	36	
	ElaTION	6	3	5			15		72	31			11	12		158	
	EORTC 1209EnTF									2						2	
	HOPON							2								7	
	INSIGHT										33					33	
	Intraoperative GE-137 fluorescence imaging in breast and oral cancer									6						6	
	IoN	10	6	11	1	7	7			11	5		2		8	75	
	NCRN - 3173 CheckMate 141: CHECKpoint pathway and nivolumAb clinical Trial Evalua			1									0			1	
	NCRN206 - LUX-adjvant Afatinib after chemoradiation in primary unresectable HNC									2						2	
	NCRN583 BKM120 + paclitaxel vs. paclitaxel + placebo						1									1	
	NIMRAD (NIMorazole/placebo plus RADiotherapy in head and neck cancer)		3	18	2			4		2				6	2	7	
	PATHOS				4			17						2	1	24	
	PATRIOT						3			5						8	
	Resources for Living (R4L) Pilot				2											2	
	SEND		1	1	1		2						2			7	
	T4 immunotherapy of head and neck cancer								6							6	
	TUBE Trial				1					2						3	
Interventional Total		22	19	44	11	20	39	27	72	125	10		28	44	30	72	563

Design	Short Name	East Lancs	Pennine Acute	Stockport	The Christie	Grand Total	
Interventional	ARTFORCE Head & Neck (2-arm study)				4	4	
	CANC - 3417 Phase III Study of MK3475 vs standard treatment in recurrent or metastatic HNC				4	4	
	ElaTION		5			5	
	IoN				11	11	
	NCRN - 3173 CheckMate 141: CHECKpoint pathway and nivolumab clinical Trial Evaluation 141				1	1	
	NIMRAD (NIMorazole/placebo plus RADIotherapy in head and neck cancer)				18	18	
	SEND		1			1	
	Interventional Total			6		38	44
Observational	GRAD		92			92	
	Head and Neck Cancer: molecular, cellular and immunological mechanisms		50			50	
	NCRN - 2376 Caprelsa in MTC				0	0	
	RAPPER		5	7	3	20	35
Observational Total			5	149	3	20	177
Grand Total			5	155	3	58	221

Chart 2: Head and Neck Clinical Trials by Trust – Cancer Research Network Greater Manchester report June 2016-observational studies.

Design Type	Acronym	CRN Population source ONS (millions)	East Midlands	Eastern	Greater Manchester	Kent, Surrey & Sussex	NEast & NCumbria	North Thames	North West Coast	North West London	North West London	South London	South West Peninsula	TValley & SMids	Wessex	West Midlands	West of England	Yorkshire & Humber	Grand Total		
Observational	Assessment of Quality of Life Tools in Medullary Thyroid Cancer (QaLM)	4.4	3.3	2.9	4.5	3.3	5.4	3.7	2	3.1	2.2	2.7	2.7	5.6	2.4	5.3			5	5	
	Developing a core information set for consent to oral cancer surgery															14			14	14	
	EORTC QL Questionnaire Development Phases I/II Thyroid			12																12	12
	Genetic factors involved in eyelid mBCC and SGC						18				5									23	23
	GRAD		41	92		38					63				21					255	255
	Head and Neck Cancer: molecular, cellular and immunological mechanisms				50										133					183	183
	MAGENTA									19										19	19
	NCRN - 2376 Caprelsa in MTC				0						1									0	1
	RAPPER		30	135	35	78	17	17	40	1	109	30	9	11	100	20	35			667	667
	THRIFT						1													1	1
	Value of PFS to patients: longitudinal study				1	3					1	1		4						10	10
	VoxTox - Linking radiation dose at the voxel level with toxicity				243						1	1								243	243
	Observational Total			30	432	177	81	18	73	40	20	179	31	9	169	100	34	40	1433	1433	
Grand Total			52	451	221	92	38	112	67	92	304	41	9	197	144	64	112	1996	1996		

Chart 3: Head and Neck Clinical Trials by Trust – Cancer Research Network Greater Manchester report June 2016-by organisation.



5.2. Progress

There is a significant piece of work required by the board to increase trial recruitment in Greater Manchester, with current data suggesting that there has been a reduction in trial recruitment across GM this year. The Cancer patient experience survey (2016) also highlighted that on average only 40% of patients across the network are being offered clinical trials.

One of the main objective of the head and neck pathway board will be to review this and working with the NIHR team to increase recruitment in clinical trials.

There has been some significantly positive process regarding a new clinical study supported by the NIHR Clinical Research Network (CRN) which was recently published showing ground-breaking results for the future treatment of head and neck cancer.

The global study, Checkmate141, looked at using the ground-breaking drug Nivolumab, for patients with recurrent head and neck cancers. This new type of cancer drug which is already available on the NHS for skin cancer treatment uses a patient's own immune system to fight tumours in aggressive cancer.

The study, supported by the NIHR, included 31 patients from the UK. The results were significant and showed a 19% increase in 1-year survival for patients who often do not survive in the first year. This study has highlighted that patients are benefiting every day from cutting edge 21st century clinical research, providing new treatments and better diagnosis.

6. Delivering compliant and high quality services

6.1. Clinical Audits : 2WW audit from Stockport NHS Trust

ENT “Switch Off” Audit was presented in January 2016 to the head and neck pathway board. The audit was completed at Stockport. The audit reviewed approximately 1000 HSC205 referrals per year to the ENT clinic. The audit aimed to look at outcomes of all 2WW referrals to ENT clinic from Jan 2015 to August 2015, reviewing:

- Days to switch off
- “Conversion” rate

Previously all patients referred stayed on the HSC205 pathway, until manually switched off.

Results: table 1: patient numbers/ days switch off cancer pathway.

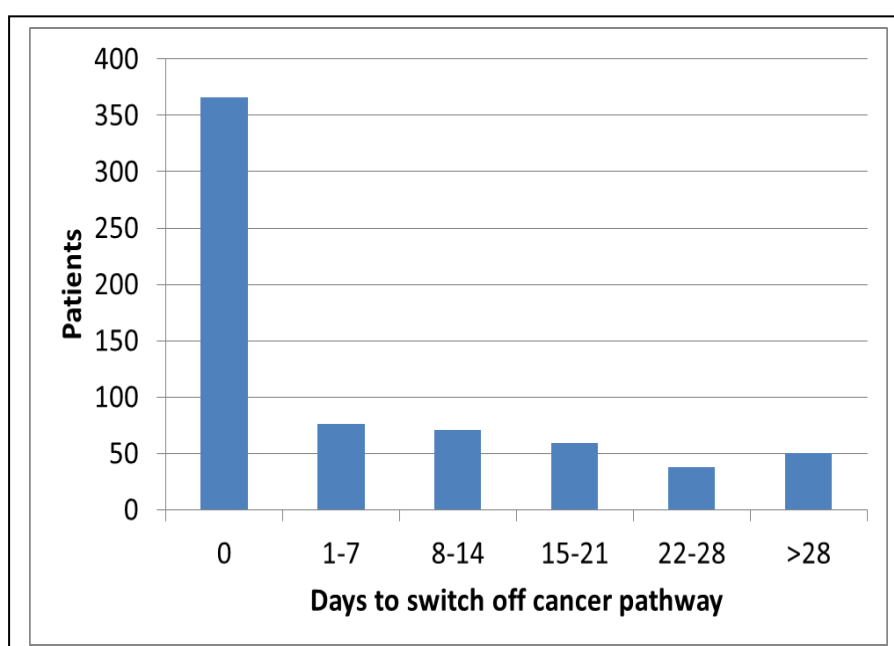


Table 2: conversions (rate 5.7%)

Days to switch off	Patients	%
0	366	55.45%
1-7	76	11.52%
8-14	71	10.76%
15-21	59	8.94%
22-28	38	5.76%
>28	50	7.58%

6.1.1 Findings:

A large proportion of outpatient workload is made up of “2-week wait” suspected cancer referrals. 5.7% of these referrals receive a final diagnosis of cancer.

ENT has a unique ability to rapidly exclude oral, pharyngeal and laryngeal malignancy in the outpatient clinic.

6.1.2 Outcome:

The introduction of a “cancer pathway” section in the clinic outcomes form in October 2014 has allowed rapid “switch off” of patients following exclusion of malignancy.

This has led to a reduction in workload for, ENT clinics, Radiology and Pathology. The head and neck pathway board would like to review if this can be replicated across all Trust as there is variation across the Trusts. It is also vital that clinicians who are responsible for the patients should be sharing this with the patients so they are aware regarding ‘switch off’ to let them know they are discharged. Communications to patients is therefore vital at this stage.

7. Objectives for 2016/17

Members identified the future improvement of patient experience and outcome is based on ensuring better pre-treatment care coordination and after care post anti-cancer therapies. There is a real focus in ensuring better recovery and survivorship agenda including the implementation of the recovery package. Below is an over view of the objectives agreed.

Patient Experience :

Audit on patient information regarding treatment, late effects following NCPES findings)

Palliative Care: Head and Neck pathway has understanding of the following;

Where to access pain and symptom control guidelines

Referral guidelines to specialist palliative care teams

Awareness of local palliative care teams

Outcome & survival:

Engage with Manchester Cancer to be part of the CWP project

End of Treatment summaries for patient curative intent

Engage with LW&BC identify all H&N late effects post treatment

Engage with LW&BC late effect patient experience audit

Research and Innovation:

Outcomes and report of two funded Innovation project

8. Appendix 2 – Pathway Board Annual Plan 2016/17

Pathway Director:	Board Members:
Susannah Penney	
Claire O'Rourke	Pathway Manager
Kerenza Graves	CNS , Bolton
Frances Ascott	SLT, CMFT
Mark Price	Patient effected by Cancer
Philip Bryce	CNS, CMFT
David Makin	Patient Lead
Debbie Elliott	Thyroid CNS, Christie FT
Kate Garcez	Oncologist, Christie FT
Suzi Bonington	Consultant Radiologist, Christie FT
Rachel Hall	Consultant pathologist, PAT
David Thomson	Consultant oncologist, research lead, Christie
Maria Round	Macmillan Head & Neck CNS, PAT
Chetan Katre	Consultant, PAT
Kate Hindley	CNS, CMFT
Helen Doran	Surgeon, SRFT
Miss L. Ramamurthy	Thyroid Surgeon, Stockport FT
Mazhar Iqbal	Maxillo Facial Surgeon, UHSM
Hannah Kelly	Dietician, CMFT
Cath Cameron	Head and Neck Cancer Nurse Specialist, WWL
Lucie Francis	Macmillan User Involvement Manager
Helen Rust	Principal Speech and Language Therapist, Christie
Kathleen Mais	Nurse Clinician Head and Neck Oncology Christie
Jonathan Hobson	UHSM

Summary of objectives

No	Objective	Alignment with Provider Board objectives
1	Improvement of data quality and audit	
2	Improve the experience of patient living with and beyond head and neck cancers	Patient Experience
3	HSC referral audit	Delivering high quality, compliant, coordinated and equitable services
4	Increase research recruitment	Increase research an innovation practice

Objective 1: Head and Neck pathway has a good awareness of caring for patients who are palliative

Objective:	Awareness and access pain and symptom control guidelines Referral guidelines to specialist palliative care teams Awareness of local palliative care teams
Rationale:	<i>What was the Pathway Board's motivation for choosing this objective? What is the expected impact on the quality and experience of patient care and on the health of the wider population?</i> Focus on whole pathway approach to improvements by improving the patient experience in palliative care.
By (date):	<i>What is the target date for completion? If completion is expected beyond 2015/16 what progress is expected in year? If a phased approach is to be taken indicate this here.</i> June 2016
Board measure(s):	<i>Which of the Pathway Board's key measures will show it that the objective has been met? What are the performance standards that will be expected?</i> Evidence the above objectives have been communicated at MDT level, board members provider feedback on the progress.
Risks to success:	<i>What factors will hinder or prevent the Board's ability to achieve the objective? How will these risks be mitigated?</i> None
Support required:	<i>What support does the Board need from Manchester Cancer to deliver its objectives and implement its vision?</i> None, the Pathway Manager also supports palliative care board and will be the key information sharer for the board to disseminate and verify the learning is taking place.

Work programme		
Action	Resp.	By (date)
HN to send briefing on the awareness and access pain and symptom control guidelines and each local palliative care team contacts. All board members to disseminate this communication at MDT to be recorded on the MDT minutes and Board.	HN/ALL	November 2015
HN disseminate Referral guidelines of specialist palliative care teams. All board members to disseminate this communication at MDT to be recorded on the MDT minutes and Board.		November 2015

Objective 2: Improve the experience of patient living with and beyond head and neck cancers

Objective:	Pilot end of Treatment summaries for patient with curative intent Engage with LW&BC identify all H&N late effects post treatment Engage with LW&BC late effect patient experience audit Innovation fund Health and wellbeing clinic Pathway stratification for therapy patients
Rationale:	<i>What was the Pathway Board's motivation for choosing this objective? What is the expected impact on the quality and experience of patient care and on the health of the wider population?</i> Improved quality of life for people living with and beyond cancer and ensure national recommendations are tested and supported within the pathway.
By (date):	<i>What is the target date for completion? If completion is expected beyond 2015/16 what progress is expected in year? If a phased approach is to be taken indicate this here.</i> June 2016
Board measure(s):	<i>Which of the Pathway Board's key measures will show it that the objective has been met? What are the performance standards that will be expected?</i> Audit of 30 patients end of treatment summary and pilot to implement change List of late effects post treatment shared with the LW&BC Report from the Health and wellbeing clinic and SLT pathway stratification evaluation for the innovation fund.
Risks to success:	<i>What factors will hinder or prevent the Board's ability to achieve the objective? How will these risks be mitigated?</i> None
Support required:	<i>What support does the Board need from Manchester Cancer to deliver its objectives and implement its vision?</i> None

Work programme		
Action	Resp.	By (date)
Develop audit methodology for end of treatment summaries		November 2015
Begin audit of 30 patient records		Jan- March 2016
Report on findings for end of treatment summaries		May 2016
Evaluation report on health and wellbeing clinic		May 2016
Evaluation report on pathway stratification for therapy patients		May 2016
List of treatment side effects and late effects for head and neck cancers		May 2016

Objective 3: HSC audit

Objective:	Explore options to decrease diagnostic delays in Head and Neck Cancers.
Rationale:	<p><i>What was the Pathway Board's motivation for choosing this objective? What is the expected impact on the quality and experience of patient care and on the health of the wider population?</i></p> <p>A key determinant of prognosis in head and neck cancer is the stage of disease at diagnosis. There are referral criteria for urgent referral for patients with suspected head and neck cancer (HSC-205) so that these patients are seen within 2 weeks of referral.</p> <p>The problem is that the vast majority of these referrals do not have head and neck cancer. The proportion of patients with head and neck cancer has been shown to be around 10% in published data[1-3]</p> <p>There is consequently a considerable usage of resources for the urgent assessment of patients with a relatively low probability of having cancer.</p> <p>Anecdotally, there may be an increase by GP's to use the HSC-205 pathway for referral, which may increase the burden on the service in seeing these referrals and also decrease the proportion with cancer further still.</p> <p>This project will ascertain the rate of head and neck cancer in patients referred via the HSC-205 pathway. This will allow scrutiny of data to ascertain:</p> <ul style="list-style-type: none">• Rate of malignant disease in patients referred via HSC-205 pathway• Rate of inappropriate HSC-205 referrals• Predictive value of different referral criteria <p>In a separate analysis, all patients diagnosed with head and neck cancer and referred to the central manchester head and neck MDT will be analysed to determine:</p> <ul style="list-style-type: none">• How they were referred to secondary care (HSC-205, routine referral, A&E etc)• With what symptoms according to HSC-205 referral criteria• Delay in referral and reasons why <ol style="list-style-type: none">1. Kennedy, A.M., et al., <i>Do GP referral guidelines really work? Audit of an electronic urgent referral system for suspected head and neck cancer.</i> Eur Arch Otorhinolaryngol, 2012. 269(5): p. 1509-12.2. Hobson, J.C., et al., <i>Outcomes for patients referred urgently with suspected head and neck cancer.</i> J Laryngol Otol, 2008. 122(11): p. 1241-4.3. McKie, C., et al., <i>The 2-week rule for suspected head and neck cancer</i>

	<i>in the United Kingdom: referral patterns, diagnostic efficacy of the guidelines and compliance. Oral Oncol, 2008. 44(9): p. 851-6.</i>
By (date):	<i>What is the target date for completion? If completion is expected beyond 2015/16 what progress is expected in year? If a phased approach is to be taken indicate this here.</i> June 2016
Board measure(s):	<i>Which of the Pathway Board's key measures will show it that the objective has been met? What are the performance standards that will be expected?</i> This will inform a better strategy for the early diagnosis of patients with head and neck cancer, with optimal use of resources. Recommendations to change the referral criteria. This project will be presented at a National meeting and written up in a peer reviewed journal.
Risks to success:	<i>What factors will hinder or prevent the Board's ability to achieve the objective? How will these risks be mitigated?</i> None
Support required:	<i>What support does the Board need from Manchester Cancer to deliver its objectives and implement its vision?</i> None

The programme of work through which the Pathway Board will achieve the objective should

Work programme		
Action	Resp.	By (date)
Initial findings	JH	Jan 2016
Final report and recommendations	JH	June 2016

Objective 4: Increase research recruitment

Objective:	Identify blockers in the engagement of research Develop tools for engagement in research recruitment at MDT Identify clinical trials specific to secondary care and the criteria to support engagement at MDT
Rationale:	<i>What was the Pathway Board's motivation for choosing this objective? What is the expected impact on the quality and experience of patient care and on the health of the wider population?</i> The research recruitment has decreased compared to the previous year for the pathway, key focus is to identify the reasons and support engagement to increase the recruitment.
By (date):	<i>What is the target date for completion? If completion is expected beyond 2015/16 what progress is expected in year? If a phased approach is to be taken indicate this here.</i> June 2016
Board measure(s):	<i>Which of the Pathway Board's key measures will show it that the objective has been met? What are the performance standards that will be expected?</i> MDT research list including criteria Monthly reports at MDT level
Risks to success:	<i>What factors will hinder or prevent the Board's ability to achieve the objective? How will these risks be mitigated?</i> None
Support required:	<i>What support does the Board need from Manchester Cancer to deliver its objectives and implement its vision?</i> None.

Work programme		
Action	Resp.	By (date)
Identify blockers in the engagement of research	HN/JH	November 2015
Develop tools for engagement in research recruitment at MDT	HN/AJH	November 2015

Appendix: Manchester Cancer Provider Board objectives

1. Improving outcomes, with a focus on survival

We aim to:

- have a cancer survival rate for all cancers one year after diagnosis that is consistently higher than the England average for patients diagnosed beyond 2012
- have a one-year survival rate higher than 75% for patients diagnosed in 2018
- narrow the gap with Sweden's one-year survival rate from 12% (now) to 6% for patients diagnosed in 2020
- approach Sweden's one-year survival rate by 2025, and
- have greater than 70% of cancer patients diagnosed in 2020 survive at least five years

2. Improving patient experience

We aim to:

- improve year-on-year the patient experience across the region (as measured by the National Cancer Patient Experience Survey), and
- have the best performance in core patient experience questions of any major city area in England by 2015

3. Increasing research and innovative practice

We aim to:

- increase the proportion of patients involved in clinical trials from 30% to more than 40% by 2019

4. Delivering high quality, compliant, coordinated and equitable services

We aim to:

- support our specialist commissioning colleagues to deliver compliance in the four historically non-compliant specialist cancer surgery services (oesophago-gastric, hepato-pancreato-biliary, gynaecology and urology) by December 2015, and
- maintain regional compliance with the national cancer 62-day waiting time target.