

Greater Manchester Cancer

Greater Manchester Cancer Board

Minutes of the meeting

Friday 3rd November 2017, Frank Rifkin lecture theatre, SRFT

In attendance

GM Health & Social Care Partnership Team		Richard Preece	RPre	Executive Lead for Quality, GMHSC Partnership (Chair)
NHS England/ presentation on personalised care		Hilary Garrett	HG	Director of Nursing, NHS England / Deputy Chief Nursing Officer, England
Lead CCG		Nigel Guest	NG	Chief Clinical Officer, NHS Trafford CCG
AGG of CCGs		Rob Bellingham	RB	Director of AGG of CCGs
Provider Trusts	Salford	Jack Sharp	JS	Director of Strategy
	Central Manchester (MFT)	Check rep?		
	Stockport	Ann Barnes	AB	Chief Executive
	The Christie	Fiona Noden (for Roger Spencer)	RS	Chief Operating Officer
	Pennine Acute	John Calleary (for Roger Prudham)		Clinical Cancer Lead
Patients effected by Cancer		David Makin	DM	-
Patients effected by Cancer		Nabila Farooq	NFar	
Patients effected by Cancer		Ian Clayton	IC	
User Involvement GM Cancer		Sarah Howarth	SH	Macmillan User Involvement Programme Manager
GM Director of PH Transformation		Jane Pilkington	JP	Head of Public Health Commissioning
Medical Director-GM Cancer		David Shackley	DS	Medical Director, Greater Manchester Cancer
Director of Commissioning – GM Cancer		Adrian Hackney	AH	Director of Commissioning – GM Cancer, NHS Trafford CCG
Vanguard Innovation Programme Director		Jenny Scott	JSc	Programme Director, Greater Manchester Cancer Vanguard Innovation

Macmillian Cancer	Tanya Humphreys	TH	Macmillan Services Programme Manager
Nursing Lead	Dawn Pike (For Cheryl Lenney)	DP	Director of Nursing, MFT
Third sector advisory group representative	David Wright (for Donna Miller)	DW	Lead Nurse TYA, Christies
MCRC and Christie Hospital	Rob Bristow	RBris	Chief Academic Officer, MCRC
Christie Hospital School on Oncology	Cathy Heaven (for Richard Cowen)	CH	Associate Director, Christie School of Oncology
GM Cancer	Claire O'Rourke	COR	Senior Manager, Greater Manchester Cancer
62 day Presentation	Susi Penney	SP	Pathway Director head and Neck GM Cancer
Genomics presentation	Fiona Blackhall	FB	Professor of Thoracic Oncology, University of Manchester
Genomics presentation	Bill Newman	BN	Professor of Genomic Medicine, University of Manchester
Genomics presentation	Anne Armstrong	AA	Consultant Medical Oncologist, The Christie
Screening Presentation	Christine Khiroya	CK	Senior Screening & Immunisation Manager, Nurse Consultant
Darren Griffith, Cancer Commissioning Trafford CCG		Catherine Perry, University of Manchester	
James Leighton, Greater Manchester Cancer		Ryan Donaghey, Provider Federation Board	
In attendance		Dutch Delegates observing the Cancer board	

1. Welcome and apologies

RPre welcomed members and apologies were noted. RPre welcomed all guest and speakers to the board including the Dutch Delegates in attendance to observe the GM cancer board as part of a 2 day visit to GM.

2. Minutes of the last meeting

The board approved the minutes of the meeting on 9th September 2017.

3. Action log and matters arising

The board noted the action log. It noted that all actions were complete or on the agenda.

4. Update from GM Cancer User Involvement Steering Group

DM discussed that the steering group meet up on the 2nd November. DM requested the board provide and update on bisphosphonates and the funding allocation to this, had this been agreed yet? DM has spoken to DG from Finance prior to cancer board meeting and was given some assurance around this. AH also updated on the situation regarding bisphosphonates and action was being taken on this.

DM highlighted some concerns regarding the Acute Oncology paper and the viability of Metastatic spinal cord compression service (MSCC). Claire Mitchell, Acute oncology pathway Director is addressing this as part of the service specification.

RPre welcomed the new Patient User representative Ian Clayton and Sarah Howarth, Programme Manager for Macmillan user involvement to the board.

5. GM Screening Programme Update: Presented by Jane Pilkington and Christine Khroya.

JP presented an update on the current screening Programme in GM, which has been supported by devolution in GM and Vanguard programme of work which has provided an opportunity to be innovative and test new ideas. They have commissioned a behavioural insight group to review the programme to develop a plan for engaging with the population in a way that has not been achieved in the past, in line with taking charge ambitions. The aim is to increase participation and uptake of the screening programme in GM.

The team acknowledge there has been a decline in screening in younger age group and they have engaged the behavioural insight team to test why this is the case. Evidence highlights that 7 out of 10 come forward for screening on average and there is significant work required to improve this.

There is a need to understand the barriers to uptake of screening and empower the population in GM to make the choice to attend. JP highlighted the need to align services to meet the needs of the future and reducing variation.

There is a need to implement new screening programmes, for example FIT screening in bowel cancer, which has the potential to increase participation by 7%. JP also highlighted the developments bowel scope roll out by 2020, which is ahead of plan.

There are several challenges to deliver the screening programme including workforce demands, there is a need for considerable collaboration if it to be sustainable and have capacity to meet the needs for the future.

The screening programme supports innovation and research done already in GM and the team's ambition is to take this forward to continue to improve the screening programme.

RPre questioned why there is a demonstration of 70% uptake in breast nationally, but GM doesn't achieve, therefore a lot of focus work is required to review this.

NFar highlighted that the uptake in BME groups is much lower and they must focus on this as a programme of work, particularly in cervical screening. CK discussed it is difficult to measure this through Health Equity Audits, but accepts we must review this across programme to understand barriers to uptake.

DW, representing the VCSE group, asked about engaging VCSE community as it has strong links within communities and screening team should engage with the group. JP and DW will discuss outside of the meeting.

RPre felt that the presentation overplayed the deprivation risk as the main factor as the decline in uptake in screening, but deprivation hasn't increased significantly in last 5 years.

JP acknowledged this and indicated the team would develop a more detailed analysis in early 2018.

RPre recognised that the GM screening results were the worst in England outside London and this is viewed as unacceptable.

AB discussed the need to review access to screening, as the younger population impatient and not waiting for appointments if they are limited, so we must review appointment system and open access for these groups.

JP agreed with this. DW discussed that education is vital so there is awareness in the population and we must get young people to engage and encourage parents to support this.

JP acknowledged that commissioning for screening in GM is fragmented and service delivery is affected and devolution gives us an opportunity to review this through the Cancer board.

RPre wanted to avoid having repeat conversation regarding the screening plan and wants to see an improvement in the screening programme and requested a clear action plan to March GM cancer board 2018. It is vital to bring back a plan and evidence to support this

Action: JP to provide an action plan and update on the screening to the GM Cancer board in March 2018.

6. Personalisation -why it matters: Hilary Garratt

RPre introduced Hilary Garratt, who is the Director of Nursing for NHS England and is discussing with Board today her experience as a cancer patient, the personal impact of this and introducing the discussion on personalised medicine. HG discussed her experience of being diagnosed with Breast cancer early 2017. HG wanted to discuss the impact this had on her family. She discussed she had 42 clinical appointments, all of which we felt were worthwhile, with the exception of two and she came quite dependent on her appointment, for support, advice and guidance. She felt she recovery quite quickly following a succession of treatments including two surgeries and radiotherapy, she completing treatment into August 2017, but she is still recovering from the consequences of this, both physically and psychologically.

HG discussed the care/cure dynamic and the amazing skills of doctors and nurses who cared for her, she felt that importantly that 80% was around good care and 20% was cure.

HG recognised the importance of personalised medicine in her case, particularly she had the second surgery and had her lymph node removed. HG decided to pay to have the Oncotype Dx test done in the USA, as she was not eligible in UK to receive this. HG had an awareness of 30% of patients don't benefit from chemotherapy. The test was positive and she was prevented from having chemotherapy.

HG discussed the importance of choice, which was really important in her cancer experience and the amount of information given is critical. It is vital is given at a right pace so it can be absorbed. You must also be given time to reflect and be allowed to change your decisions regarding treatment if needs be. The professionalism team helped to identify the right question and gave her permission to change her mind.

HG discussed that she took a team approach to this, as her family attended appointments and family were welcomed by the teams. The breast specialist nurse spent over 2 hours explaining the treatment options and included her Husband by saying 'I'm here for you too' and this stuck with him. HG discussed that she experienced post op issues with arm movement and the physiotherapy supported her to get back to normal life and listening to the family as well, which was important. HG stipulated that environments matter, for example the waiting rooms are an eclectic mix of mortality. It must not be underestimated the important role of the coffee shops, as they are little havens for patients.

Her experience recognised all staff including the volunteers with 'lived experience'; we cannot underestimate the value of volunteers and the importance of the environment in which you wait in for your treatment.

HG discussed the technological advancements in cancer and felt very fortunate to be able to access this in GM and was in awe of the skills of the teams and how safe this made her feel.

HG also pointed out the importance of rituals when you are having cancer treatment, such as ringing bell at end of treatment and all the patients and clinical staff clap at this time and everyone is part of it can this be very supportive.

As a cancer patient, HG discussed we cannot underestimate the currency of time for patients, highlighting we often talk about access to services and waiting for scans and appointments clearly can lead to periods of worry for patients and their families.

RPre stipulated the vital importance of listening to Patient stories and thanked HG for sharing this with the board so eloquently. The care aspect of a Hilary story strongly came through and whole 'team' focus and the importance of environment in hospitals for patients. RPre reiterated it is vital we review what we can do to improve experience and the care that really matters to patients.

DM reflected that Hilary had a good experience through cancer services in GM, but he felt this isn't experience of all.

RBrist discussed the issue of research and clinical trials, elements with HG, asking was there an opportunity to discuss clinical trials as part of her journey? HG was offered lots of trials and did partake in one study; she stipulated the importance of a discussion with a clinical fellow who offered her information on Oncotype Dx.

DW questioned how we could help less well informed patients and those who are less well supported, to have same experience as Hilary did. HG discussed the importance of health literacy for a patient is critical.

DS discussed he had 7 key comments to summarise what was discussed.

- It is important to listen to professional patient regarding articulation and understanding of their cancer and the impact of this.
- The vast majority of appointments Hilary attended were valuable and essential to patients.

- The value of patients been given information, this is noted as very good in breast cancer services and we need to get better in other cancers.
- We must not underestimate the importance of environments, as this is often overlooked, but this is key from a patients view point, as of vital importance to cancer patients
- The importance of family being included in all aspects of the patient's journey by health care professionals.
- The impact of time delay on patients, every wait for a patient is an extended wait and we must do more to reduce this, which will be discussed further through the 62 day pathway discussion later on in the board.
- Personalisation and personalised care, the value of nurses in Hilary experience, was excellent, especially breast specialist nurses. Personalised medicine identified in this story highlights the importance of GM doing more genomics testing and connecting to share decision making with patients.

7. Personalised Medicine: Fiona Blackhall, Anne Armstrong & Bill Newman.

FB thanked HG for setting the scene for the presentation on personalised medicine and precision medicine.

Personalised medicine identifies the molecular finger print of the cancer to identify patients who will benefit most from chemotherapy and spare those patients who will not benefit, such a test would be Oncotype Dx, used in breast cancer as discussed by Hilary.

There are a number of international guidelines for node negative breast cancers, and oncotype DX is NICE approved for node negative breast cancers, in which a risk score is generated and discussed with the patient. Hilary's Breast cancer was diagnosed at a point in time when evidence is being generated for patients with one node positive and is currently being reviewed through a number of trials in the UK to gather an evidence base.

Breast cancer in ahead of the game in personalised medicine currently, but this is expanding into other cancers including lung.

FB stipulated that the 100k Genomics project is so important to identify larger numbers of patients so the research teams can delve deeper into the genome, so we can identify clearer cancer signatures that can be extrapolated to wider populations and can be used clinically to improve outcomes. This will led to a reduction the need to give treatments to patients who will not benefit and reduce costs of giving unnecessary treatments.

Precision medicine can be explained by specific molecular changes in the cancer cells which drives cancer cell growth. Precision medicine are therefore targeted therapies which can switch off the cancer cell by using specific targeted drugs and there are a number of examples of these in use for many cancer including lung and breast cancer. A full explanation would be given in the slides set which will be distributed.

10% patients will get a benefit from precision medicine test, so very few will need treatment as a result of this testing.

FB summarised that the implementation of precision and personalised medicine is being led by GM, as the research laboratories in GM at the forefront of such testing and research. The teams have joined forces with pharmaceutical companies' horizon scanning for new developments and international colleagues to ensure key quality standards and quality assurance is maintained throughout.

FB discussed the future of research in cancer lies with tests such as liquid biopsies, in which a blood sample are taken from the patient to extrapolate circulating tumour DNA. This is vital to identifying cancer much earlier, with less invasive tests and means patients can start treatment much sooner. We therefore want to lead this in GM as the vision is for every patient in GM to have access to genetic testing, so we can answer the following questions:

- Which patients will benefit most?
- How do we ensure equity of access to these services for all patients in GM?
- Ready to get for prime time and these tests available, validated and assess the financial implications?
- How do we share best practice?

FB requested the Cancer support a new Genomics pathway board to review and monitor these.

RBris, acknowledged that the world experts in Cancer research are in GM, we must embrace this, as Director of MCRC he supports the need for this board and most importantly we must plan to review workforce and train next generation of cancer researchers, for example doubling the number of clinical fellows. There are also opportunities to lead on clinical trials due to the largest number of bio-markers lab in the country; we could lead this internationally as well.

BN, clinical geneticists and leads the genomics project, discussed that we are currently in a state of flux regarding the re-designation of laboratories in the UK, in which we will see a reduction in genetics labs in England from 17 to 7. The outcome of this will lead to a directory of tests which will be nationally commissioned and approved, which we have never had before. We will have a more directed set of tests which will be of significant benefits to patients. BN stipulated that there is an opportunity for researches in GM to do the next set of tests needed in the future and we could lead this in GM and be at the forefront.

RPre, suggested as a board we should all agree to the establishment of a genomics board, the board all agreed to this.

Action: DS to set up a meeting with the Key leads to develop the new board and report back to the GM cancer board in March 2018.

8. 62 day report: Cancer lead review of cancer systems in GM: Miss Susi Penny

SP was introduced to the board; she is pathway Director for the head and neck GM cancer board and lead cancer clinician at TGH.

SP discussed there is very clear challenges to delivery of the 62 cancer standard in GM and this has implications for all our patients across GM. Sustainability of

delivering on the 62 day standard is becoming increasingly difficult, with the standard just being achieved in a number of quarters in 2017.

SP stipulated that even when Trusts are delivering on the standard, patients still wait weeks for diagnostic results and then starting treatment, with over a 1000 patients falling out of the 62 day standard over the last year, which is not acceptable. There are variations in delivery of the 62 day standard across Trusts in GM, with up to 20% difference between the best and worst performing, we must therefore hold Trusts accountable for this.

SP was asked in June 2017 to conduct a review of 62 day performance from a clinician's perspective on behalf of GM cancer and the Director of Operations group. SP visited every trust in GM which delivered cancer services, met with cancer services managers, some lead cancer nurses and lead cancer clinicians who were available. She asked a number of key questions, but essentially what worked well within their organisation and what didn't.

SP identified a number of key recommendations, some short-term gain and mainly long term operational changes, which would be required if we wish as a system to ensure sustainability of the 62 day standard.

SP reviewed reporting structures within Trust, who attended key Trust cancer meeting and how Trust cancer systems worked. There was an acknowledgement that cancer referrals have gone up by 30%-40% which is putting considerable strain on the system, despite not seeing any more cancers. Pressure on diagnostics is considerable and patients often have to go to a number of providers and Trusts to access services.

SP summarised that we need to go back to basics, to review best practice guidance, change practice and scrutiny from GM cancer is an important part of this moving forward.

SP has detailed a report with a List of key actions and recommendations in a report which will be shared in January, as well as individual plans for trusts. It is also important that the pathway board are held to account for delivery on this, as well as lead cancer clinicians and Provider Trusts.

RPre stressed importance of delivering on this 62 day standard and we will not have access to treasury funding if this is not delivered.

IC discussed the ambition of the GM cancer plan is delivering world class outcomes and consistency achieve 62 day is not world class, in patients eyes this is a soft target, with many patients waiting beyond 104 days which is significantly too long and this is unacceptable. IC went to say he had reviewed the figures and as a board we should be recognised that Trusts like Pennine are consistently not achieving and there need to be consideration by the board as to why. IC identified which pathway and organisations are failing, what is the boards response this.

FN commented that has been some key achievement to the delivery of the 62 day standard are happening in many organisations, but some pathway and Trusts are failing and we need to support those that are failing and we need to set stretching standards, but these must be achievable.

JS feedback regarding the discussion on Pennine and stressed it recognised that there are considerable challenges within the organisation and effects the overall position in GM. Pennine is part way through a deep dive of cancer services to review current capacity and make some key strategic feedback, including capacity issues.

RPre expressed concern regarding Trust leadership from lead cancer clinicians, who had time in their job plan to leading the cancer agenda in their organisations. RPre requested DS to convened meeting with cancer leads, to secure ownership of the clinician's accountability for Cancer within their Trusts.

FN stipulated that there needs to be a triumvirate of the cancer lead, lead cancer nurse and cancer managers in order to develop this.

AE making sure patients are getting in earlier in the system, as patients getting through the system in 62 days do not have better outcomes.

Action: DS to set up a meeting with Cancer leads, lead cancer nurse and cancer managers and Director of Operations group in the next few months and report back to board in January 2018.

9. Haematological Malignancy Diagnostic Services (HMDS) external review: Summary Dave Shackley.

DS briefly explained we have experienced over 10 years of non-compliance for haematological malignancies diagnostic services in GM. Due to this many providers have been sending samples outside of GM, with a significant percentage going to Leeds HMDS. As a result of this an external review was conducted in June 2017 on behalf of GM cancer and the providers led by a Dr Robin, an experience haematologist from Kings London, this review concluded in October 2017.

Dr Ireland carried out extensive reviews of the services in GM, including discussions with providers, commissioner's key stakeholder and patients. This cumulated in a presentation to the providers of the services in GM, Manchester Foundation Trust (MFT) and Christie Foundation Trust (CFT). It was concluded that in order to deliver a compliant service in GM, the Lead provider will be MFT and key provider CFT, both organisation will be now be working together on an implementation plan over the next 18 months. The recommendations was presented at provider federation board (PFB) in November 2017, AB chair of PFB, confirmed unanimous support in this recommendation and stated the presentation of the finding by Dr Ireland was excellent. Dr Ireland will produce a final report in the next few months, summarising findings and recommendations.

Action: Dr Ireland's final report to be brought back to GM cancer board in January 2018 for final approval.

10. Greater Manchester Cancer: Vanguard Innovation update: Jenny Scott

JS described that the vanguard is reaching its final 6 months and there will be a comprehensive evaluation and recommendations to the next board in January. JS described developments and progress of the key projects which are all detailed in the paper.

JS discussed some highlights including the 'goals of care initiative', led by professor Janelle Yorke, what is important to patients around their expectations of treatments and this extensive piece of work with key oncologists, is rapidly moving and providing some key outputs and shared learning.

JS described a new pilot being used of patient self-assessment, led by Professor Ken Muir. This will enable individuals to assess their current risk of cancer and being armed with the information to fast track to GP to diagnosis. The vanguard team are working with Lloyd's pharmacy and the cancer champions on this. .

Finally the vanguard team are working with Macmillan on a project on 7 day palliative care services and have secured £2million of funding from Macmillan roll out 2 pilots on this in GM and Macmillan have been thanked for supporting this.

Action: RPre to ensure that Vanguard programme of work is brought to the top of the agenda for the next meeting in January to allow for time for discussion.

11. Paper for information for note:

Unable to discuss due to time constrains, to be reviewed post meeting.

Closing comments from RPre:

Ian Clayton our new patient representative was welcomed to the board. IC suggested that all papers coming to the Cancer Board should have a section that requires an explanation of how the content of the paper benefit patient outcomes, experience and efficiency, this was agreed as a good idea. IC also expressed concerns about the Vanguard on the commissioning project, need to know outcome on this, RPre asked for this to be discussed at the next board meeting due to time constrains today under the vanguard section of the agenda.

Helen Thompson was introduced as the interim CEO designate Stockport introduced to the Board, replacing Ann Barnes.

This was Ann Barnes final meeting and she summarised her thoughts. AB emphasised the power within devolution and the importance of seizing this unique opportunity in GM to do this differently. AB described how performance getting harder to maintain the 62-day target and we must be vigilant as it is becoming harder to maintain this due to finance constrains, increase in activity and demand, as this pressures increasing. She suggested adding 'innovation' into the title of the board. AB was thanked by the board for her support and leadership.

This was also David Makin's last meeting, so he shared his final thoughts. DM said he has enjoyed his time on board, describing the board initially as a quite disparate, before it got more organised in the last few years. DM found it quite frustrating that in some instances progress has been slow. He acknowledged that the system has moved on but he remains concerned regarding the speed of progress. DM wished the board well but encouraged the board to push for more. The board thanked DM for his support and determination to do the right thing on behalf of cancer patients in GM.