

## **Cancer Information Hub – Helping you take control of your cancer journey**

Alison Alexander, Safety and Quality Officer, Cancer Care Services  
Gary Power and Anita McGrath, Consumer Representatives

Breakout Room 1: 15/06, 11.30-12.00

**Suzanne:** It's my pleasure now to welcome - to talk about the cancer information hub helping you take control of your cancer journey from Metro North Cancer Care Services we have three presenters, Alison Alexander, from the HHS and two consumer, Gary Power and Anita McGrath. Welcome.

**Alison:** Thank you for the opportunity to speak with you today about our Metro North Cancer Care Services information hub. I'd like to begin by acknowledging the traditional owners of the land on which we meet today and I'd like to pay my respects to the elders past present and emerging. In 2014 Metro North developed a health service strategy to address a range of challenges including increasing demand for services, changing care needs, pressure on existing infrastructure, and the need to maintain a skilled and committed workforce.

The strategy outlined priority actions to be delivered over a five year period. The strategy refocuses our efforts to provide connected scbl high quality services that help improve the health of the communities we serve while using our resources effectively. As part of this strategy, Metro North identified there was an opportunity to connect cancer care services in each of the Metro North facilities to form a stream. With the vision of providing improved access to services and integrated connected care. Informing the Metro North cancer care services stream we believed it was of the utmost importance to hear from our patient, and community groups to determine what priorities we should be moving in in moving the strategy forward.

In December 2014 we conducted the Metro North cancer care services consumer and community forum that had 50 attendees, consisting of current and past patients, carers, and support groups from across Metro North area and staff from each of the facilities. The forum was

conducted - facilitated by the QUT Creative Industries Professor Judith McLean and her team and the forum began with a panel of eight consumers sharing their stories and through these stories common themes were identified. One of these was that patients either felt that they were overwhelmed with too much information or not provided enough information and so they turned to Dr Google for the answers, this often provided them with unreliable information and created anxiety and confusion. Following the forum the QUT team remained very passionate about assisting us to improve how patients accessed information related to their disease, supports and services, in December 2015 Metro North hospitals and health service introduced link funding to provide an opportunity to build partnerships and community engagement capability deliver efficiencies and improve continuity and quality care of patients.

The cancer care services team jumped at the opportunity to develop the cancer information hub. The project ran from December 2015 to July 2017. Our objectives were to collaboratively develop a web based portal as a central repository of resources and information, about different forms of cancer, their diagnosis, treatment and management, support services available for cancer patients, their families and carers and to support their cancer journey from prevention to survivorship or end of life. The team consisted of Metro North cancer carer consumer representatives so we have four representatives one from each of the facilities, where we had services available at the time, the QUT Creative Industries team Professor Judith McLean who is chair of the arts education and scholar in residence at QPAC, our cancer care services team consisted of our executive director Glen Kennedy, our nursing director and our assistant nursing director Michael Smith and myself as the project lead. And Metro North online publishing and design team. This was led by their manager and the team who worked tirelessly on this project.

**Gary:** I'm Gary Power, I'm a consumer representative. I've been so since 2013, I'm a cancer survivor and I had surgery chemo and radiation at RBWH and I was delighted right at the very start to become involved. I was at that meeting that Alison described and I was amazed that the enthusiasm generated in that meeting and that enthusiasm was maintained throughout the procedure or throughout the project. Led principally and enthusiastically by Alison. There were times I'm sure that Alison felt that the name of the project should be nailing jelly to a wall but she managed to personally carry on and get the job done. The theme that became evident even if it was not stated was partnership with

consumers. It is a notion that has taken a whole within Metro North from the highest level and it is through that sort of leadership and that sort of understanding of the role of consumers in the development of medical treatment that has meant that right across the board not only in cancer care services but in all areas of treatment at the hospital and I must say before and after treatment as well, that consumer involvement engagement has been at the forefront of thinking and I'm very pleased to be able to say that that theme of partnership was kept all the way through this. In respect of that partnership I suppose another buzz word that comes out of partnership is co-design and Alison and her leadership team saw early that if this patient hub which is designed for and will be used by patients, if it's going to succeed there needs to be some assistance in the design and the formatting by consumers and the leadership group was very keen at getting assistance and guidance and suggestions - I won't say guidance because there was nothing mandatory from what we gave, but certainly seeking and obtaining thoughts and suggestions from consumers was done at a very early stage and I have to say that the results of that is evident in the format and so on of the hub which Alison will show you in some detail later on. Alison has mentioned that QUT became involved and if I may say for anyone considering a similar project in the future, get the professionals involved very early. The creative industries faculty at Queensland Health is renowned. I say that principally because my son is studying there, but it is a wonderful faculty and it is full of wonderful facilities. The lady who was running it from the faculty, Judith, conducted a series of interviews with four or five consumers.

**Alison:** Thank you. We will be breaking for lunch very shortly. Whilst you're enjoying your lunch in the concourse you'll be listening to the Stairway project. This is a group of musicians which is driven by the notion and well researched evidence that live music and art is an essential element in the healing process and general wellbeing of patient, staff and public in hospitals and the medical centres so currently the Stairway project musician play the RBWH work and they're also in the oncology outpatients on level four every Monday and Wednesday from 8:30. So if you're a visitor to the RBWH you'll be able to enjoy their music as well as here so after lunch we'll be moving into our breakout sessions so there's in here the Queensland genomics health alliance will be here, in breakout room one, Brook Red work shop, in breakout room two there's a session with Sharon Boyce and in breakout room four, health consumers Queensland's fundamental training, there are limited numbers in the breakout rooms and we do ask that if you attended one

of HCQ's training work shops previously and you know that they're coming to health service near you, that you choose another session so that we can maximise the opportunity for those who have not been to a training session or don't have one coming up shortly. We also ask you once you to join us if you can remain in that session if possible, to minimise movement and interruptions during the presentations, after the breakout sessions you'll be coming back together in the concourse and opportunity to do more networking but also to have a drink. So look forward to catching up with you at 4:30. We do have a couple of our directors sitting in the board lounge at that stage who will also be helping you to fill in the survey that we're asking you to to but just before we let you go for lunch thank you once again for joining us over the two days, thank you to our sponsors to clinical excellence division and also to Queensland genomics health alliance and we look forward to not only a packed afternoon this afternoon but day two is looking very good as well, so we look forward to having you back tomorrow. So thank you very much.

(Lunch)

**Anita:** I remember just going into a glass cage and in that glass cage was blackness except I could see out but couldn't really talk to anybody outside, I couldn't hear what they were saying or doing. I was benefitted by having my wonderful wife who took time off work to shepherd me through the whole process but there are going to be people, many people as I found, during treatment and subsequently through support groups and so on that I've been involved in who don't have those sorts of supports so it needed to be something that was going to be accessible to people. Videos was a good way to do it. This QUT team sat us down, individually and over a very long protracted conversation guided by those dot points, extracted from us the sorts of information that they could then distill into a script and the script was then given to each of us interviewees to settle and to provide some sort of extra detail. The script was then given to professional actors. I cannot think for a moment why they would choose a professional actor instead of me to sit in front but they did and they did a reallied good job. There are four cancer types that are represented, they're head and neck which is my mob, there's lung which is Anita's mob, there's breast cancer and there's lymphoma. Each patient has - even though there's a stock set of questions, it's a wonderful journey if you want to go to the website and have a look at it, just how different individuals face each of those points and that has really been for me the sort of triumph of the exercise, that there can be so many different stories, so many different facets to the

same question and that came out really well. The sorts of tips and tricks that came out, the obvious one, ask questions, you know? There is natural hesitance for patients that they don't want to ask questions, they want to be picked up and cured and they don't really know the questions, they don't feel motivated to ask the questions, there's often a sense of a power gradient when they're talking to a white coat, they don't feel constrained or empowered to be able to ask the questions but by watching a video involving someone who has been down the track, if the recommendation is made by a screen it's a good idea to ask questions or to ask your buddy owner your carer to ask the questions as well, then that's a very important tip. There are other things like write the questions down before you go into see the clinicians or whenever you go in for treatment and go and ask the questions. Those things are made clear in the video presentations. We'll show one of those now. Someone's going to press a button to give you an idea. (Video plays) as a member of the matrimonial communication that happens in my family my wife when she saw that and the other ones to do with head and neck cancer, she said to me even though she knew what I'd been doing for some time, "this bloke has gone through the same process as you."

Concurrently happening at the same time, to use a Kath and Kim tortology, there was other work that was going on, again reflective of the way that the RBWH and Metro North want to do this. A couple of guys thought they would put together a video about the first day of radiation treatment, particularly in this case head and neck, because at the very start when they made up their mind to do this someone said to them "why don't you get a head and neck guy to have a talk to you?" They phoned me before they picked up a camera. They put together a magnificent depiction of the first day of radiation treatment for head and neck which is a terrifying event. When I went through the exercise around eight years before hand I'd been wheeled in or led in and sat down in front of a white wall waiting for my turn to come. I had no. I had to lay down on on a bed, quite a hard bed as I recall and have a piece of plaster of Paris put over my head and moulded to my face, that was going to be used to hold my head down while the radiation, I called it a barbecue circulated around me for the next couple of minutes. They did such a good job at that all by themselves, that it got on to this web page as well. There was a QUT student as well, again, working off her own bat and she developed herself videos associated with chemotherapy, wave finding and deep breath holding and did a great job, in this case we'd run out of money so voiceovers were being done by staff but they also acted out by staff members, so in the event the video aspect of the web page was the bit that I particularly enjoyed.

**Alison:** Sorry I have to stand at the back but this is the only way I can access the computer. When you go on to the site you can see that we give a bit of information about what is cancer and we link out to the Cancer Council. We have some early detection information because we have breast screen Queensland under our service line at the Royal Brisbane so there's a bit of information about preventative things that you can do. We'll show introduction to our cancer services across met Metro North and that's a video done by our executive director. We have links to the disease pages and it's really unfortunate that we can't show you that, but in those pages you get what your optimal care pathway might be, there's about 16 of those developed so if you click on that link you'll be able to see what happens during diagnosis, what testing you'll go through, what costs are involved with treatment, and what treatment options you might have and even down through end of life or survivorship information so it's really good just to get a really clear concise patient friendly explanation of all of that and that link. Then you'll see a link to the patient stories for - so you'll get all those tips like we saw before and then there's - there's a accelerate of three videos there around the patient stories, moving down you'll then get links into radiation therapy and chemotherapy, that's where you'll be able to access those videos of what happens when you go through those treatments.

We do have people from CALD come into QuiNH but so far we've not been able to recruit those populations along with the Aboriginal and Torres Strait Islander people. Can

(INAUDIBLE)

**SPEAKER:** It's about outing themselves.

(INAUDIBLE)

**Alison:** I think we could definitely reach out more to ethnic community, we obviously work with a whole range of different organisations on the periphery of drug and alcohol and that is something - how do we do this stuff better?

**Audience Member:** I'm employed for two days a week. I've got to put together...

(INAUDIBLE)

Anyone who wants to give any assistance.

(INAUDIBLE)

**Alison:** We don't only work with people who inject substances. I did a kava ceremony in Fiji, not like it's used here.

(INAUDIBLE)

**Sherryn:** Please join me in thanking Niki and company.

*APPLAUSE*

Welcome back our first presenters for questions about the Pasifika Maori youth and wellbeing project. I'll start with a question which is probably for Nicola or bub or Tamika, how did they find you? How were you chosen as a peer researcher? As you have shown quite an eclectic mix of the six and from very diverse backgrounds?

**SPEAKER:** We put it out through our community network. Through our own family and friends but also our partner organisations, other community organisations that exist.

**SPEAKER:** I found out through Facebook.

**SPEAKER:** I found out through my church.

**Sherryn:** How many interviews did you do?

**SPEAKER:** Five each.

(INAUDIBLE)

**Sherryn:** Any chance that you will turn your research into a publication?

**SPEAKER:** There's a uni involved. There's a chance it will happen.

**Audience Member:** I have a question related to your research study but your o MANA does that extend to the Ipswich area?

**SPEAKER:** It's not - MANA specifically is targeted at Logan so our office is in Beenleigh but we're open to providing cultural competence around youth in Pasifika as a case study. It can be transferred to other types of communities.

**Audience Member:** Will you put forward a Metro South health service about using your competency training within the service?

**SPEAKER:** We did some cultural competence work shops with the good start program and we'd like to extend that to Metro health. We're very purposeful with language. I was very interested in the word 'outing.' We don't really like having the term for us as like disadvantaged and vulnerable. We think that they're not strengths-based. They really give an impact of those narratives for us. MANA is the power and strength in our Pasifika language. So beyond the reef was taken from the MANA Disney film.

**SPEAKER:** We all know those songs. We set our own limitations and we go beyond the reef. We have pretty amazing people within our shores. They came up with beyond the reef to name the project so we're really purposeful with our words and want to make sure that it extends to how we define ourselves and our community.

**Sherryn:** Any final questions or comments. I want to close the session, you get five minutes good behaviour in a minute but firstly can I thank all of our presenters.

*APPLAUSE*

Particularly our Jennifer for sharing your story, so beautiful. And for our peer researchers, and for all of you who have been so actively involved and feel that in these two examples that you're giving people a voice and a way of starting to engage. There's still work to be done but I think there are two very good examples of how you're doing engagement differently, exploratory in both senses in different ways so that's what I take away from the session as well is that we're all on our own journey and everyone might think they're an expert in something but it turns out that



someone else is an expert. I like the way you did that. Afternoon tea is till 3:30 and the final session after that till 5pm.