

MANCHESTER CANCER USER INVOLVEMENT NEWSLETTER

KIRSTEN'S STORY

Welcome to the tenth edition of the newsletter from the Macmillan User Involvement team at Manchester Cancer.



L-R: Lucie, Tanya and Michelle

"I REALLY FEEL LIKE MY IDEAS ARE LISTENED TO, NOT JUST BY MANCHESTER CANCER BUT BY OTHER SERVICE USERS TOO..."



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"I cannot wait to sit on the TYA pathway Board and put our views forward."

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Kirsten was diagnosed with Non-Hodgkin Lymphoma in August 2014 at 24 years old. It was through Kirsten's experiences of living with cancer that she became involved with the 'Christie Crew'; a committee specifically for Teenagers and Young Adults (TYA) with the aim of improving services on the Young Oncology Unit. Kirsten later joined the Manchester Cancer User Involvement Programme as a member of the monthly Steering Group and has been nominated by her peers at the TYA Small Community to represent them at the TYA Clinical Pathway Board. *"I cannot wait to sit on the TYA pathway board and put our suggestions forward."*

One of the issues particularly important to Kirsten is improving diagnosis time, ensuring consistency and collaboration across service providers such as GP surgeries and hospitals. *"One of the issues I come across regularly on the Young Oncology Unit is late diagnosis; I personally visited my GP on 17 occasions over a 3/4 month period and attended A&E 3 times before finally being diagnosed."*

I enjoy meeting a variety of people that have very different experiences of cancer but all have a common goal. It's refreshing to see people so passionate about influencing services...and there are some great ideas being put forward! *I have made some lifelong friends...and we get lots of nice food at the meetings which is always a bonus!*

DATES FOR YOUR DIARY

29th July	4th August	7th September	8th September
Brain and Central Nervous System Small Community	Steering Group Meeting	Manchester Health and Care Innovation Expo	Manchester Health and Care Innovation Expo

HOW YOU'RE HELPING US MAKE A DIFFERENCE

FOCUS GROUPS



Greater Manchester Cancer Vanguard

One of the initiatives of the [Greater Manchester Cancer Vanguard](#) is to develop and pilot an early diagnostic clinic for suspected cancer. Dr Sarah Taylor and Hazel Warburton, two of the **Early Diagnosis Workstream** Leads, have started working with people affected by cancer to ensure that this service is fit for purpose. On 6th July, the MUIT facilitated a focus group during which key issues were discussed, such as the name of the service, the referral process, and the information patients will be given at the point of referral. Over the next few months, there will be further opportunities for people affected by cancer to influence this piece of work.

The Education Workstream of the Greater Manchester Cancer Vanguard is currently focused on the development of an e-learning module for GPs to promote the early diagnosis of lung cancer. This training tool will include a simulated consultation between a GP and a patient. On 13th July, people affected by cancer participated in a focus group to discuss the contents of such consultation, and more specifically the role of the patient in it. The discussions had during this meeting will inform the final script.

Prostate Cancer Community Follow up Focus Group

After a discussion at the [Urology Pathway Board](#) in April around community follow-up for prostate cancer patients, it was decided further input from user representatives on the issue was needed. Currently, there is little or no standard follow-up service in place across Greater Manchester and East Cheshire for prostate cancer patients and the quality of service variable.

The focus group, made up from patients, carers and health professionals was led by Mike Thorpe, Patient Representative on Urology Pathway Board and discussions led to a 'Gold Standard Care Model' for community follow-up being agreed. Mike Thorpe said, *"This is a great example of how user involvement works well. We all want what's best for the patient so it's good that we all get together to share our views."*

USER INVOLVEMENT TEAM DEVELOPMENTS



Selection Process

Over the last few weeks, people affected by cancer have worked with the Macmillan User Involvement Team (MUIT) to develop and carry out the selection process for the new members of the Team. It is expected that, by the end of the summer, two new Macmillan User Involvement Managers and a Programme Support Officer will be in post. One of the Managers will be fully dedicated to the Greater Manchester Cancer Vanguard, whereas the others will focus on the involvement opportunities within Manchester Cancer.

User Involvement Team Lead

The role of the User Involvement (UI) Team Lead will be taken up by UI Manager, Lucie Francis. Lucie has been part of the team for nearly 1 year and is looking forward building on the successes of phase 1 of the programme and leading the team through phase 2 and beyond.

Tanya Humphreys will continue to lead the Programme of work with a strategic focus across both Manchester cancer and the Greater Manchester Cancer Vanguard.

WANT TO GET INVOLVED?

Have you been affected by cancer? By sharing your experiences and opinions, you can help improve cancer services. If you're a patient, family member, carer or friend, we would love to hear from you.

Please call us on 0161 918 2368, or email mc.userinvolvement@nhs.net.