

# MANCHESTER CANCER USER INVOLVEMENT NEWSLETTER

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



L-R Evangelie, Tanya, Paula, Wendy, Michelle and Lucie

## IN THIS ISSUE

### Mark's Story...

"I will always strive to get involved and support where I can..."

### How you're helping us make a difference

- Lymphoma Focus group
- Myeloma Pathway

### Meet the team...

Paula Daley has recently joined the team, managing user involvement activity with the Greater Manchester Cancer Vanguard



Mark was diagnosed with a brain tumour in 2009 after a year and a half of experiencing sensory seizures, "actually getting referred for a diagnosis was really hard as it took a long time, but once that happened everything ran incredibly efficiently." After receiving surgery and radiotherapy, seven years on, Mark is continuing to live with cancer whilst living a full family life.

When Mark heard about the opportunities for patients and carers to get involved in supporting the improvement and development of cancer services, he thought it was something that sounded really interesting; "I really wanted to give something back, but also, this felt like a massive chance to feel more involved and a part of the system that's working to support me."

Since then, Mark has become a member of the Brain and Central Nervous System (CNS) Small Community which gathers the views of patients and carers, and also sits on the Patient Experience strand of the Brain and CNS Clinical Board, working with clinicians to develop services that meet patient need.

When Mark was asked what he enjoyed about getting involved he said, "living with cancer made me feel quite isolated at times, but connecting and relating with people at different levels and having my voice and opinions heard has been an incredibly empowering experience for me. I feel really fortunate to have this unique opportunity to work alongside clinical professionals and will always strive to get involved and support where I can."

## DATES FOR YOUR DIARY

**27<sup>th</sup> October**

User Involvement  
Induction Session

**3rd November**

User Involvement  
Steering Group  
meeting

**3rd November**

Tanya's Farewell  
Party

**29th November**

Cancer Vanguard  
Event  
Aftercare

# HOW YOU'RE HELPING US MAKE A DIFFERENCE

## Designing Haematology Pathways...

### Lymphoma Pathway Focus Group

A focus group took place on Thursday, 13th October with people affected by lymphoma and Dr Patel from the Haematology-Oncology pathway board in order to co-design a pathway for use by doctors as a guide for the diagnosis and treatment of lymphoma. The representatives present discussed important points in the pathway, including the appropriate timings for breaking a cancer diagnosis, the support available for patients before and following a cancer diagnosis, access to psychological support, and the different formats information should be available for patients. Following this focus group, Dr Patel will feed the issues raised back into the Pathway Board for further development.

### Myeloma Pathway Development

Two people affected by myeloma were consulted about a pathway for the diagnosis and treatment of myeloma, which had been developed by the Haematology-Oncology Pathway Board. They raised important points including delays in the diagnosis of myeloma, access to a Clinical Nurse Specialist, availability of support for non-medical issues related to myeloma, and access to copies of clinic letters. This has been fed back to the doctor who designed the pathway for further development.



## FAREWELL FROM TANYA ...



"The time has come for me to bid farewell to you all. The last eighteen months have been exciting and memorable. I have enjoyed working at Manchester Cancer and I feel honoured to have worked directly with so many of you. I also feel proud to have led this programme of work, which has already changed the way people affected by cancer are involved in the commissioning, re-design, and improvement of cancer services across Greater Manchester. Although I will miss working in user involvement, I am looking forward to this new challenge and to start my career at Macmillan Cancer Support.

This is a small world so I am sure some of our paths will cross again. It is for that reason that I will not say goodbye but rather see you soon, or as we say in my native Spain: 'Hasta pronto!'"

## LET'S MEET... PAULA DALEY

Paula joined the team in August 2016 as a User Involvement Manager for the Greater Manchester Cancer Vanguard Programme. Paula joined the team with 30 years experience in Adult Social Care, including leading on developing a system for quality assurance with external care providers for a North West Local Authority. Paula is inspired by the exceptional achievements so far of the User Involvement Programme and is excited to work alongside people affected by cancer to build on this good work.

Paula lives near Runcorn with her partner, Paul, and dog, Spud, and when not at work is mostly likely to be in the garden, growing veg and keeping bees, cooking or out walking.



## 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](mailto:mc.userinvolvement@nhs.net).

