

MACMILLAN USER INVOLVEMENT NEWSLETTER

JULIE'S STORY

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



L-R Back: Paula, Natasha
Front: Wendy, Mel

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"...It has given me a voice and the opportunity to be heard as an equal with healthcare practitioners and managers..."

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Sarah Haworth has recently joined the team as the Macmillan User Involvement

In July 2012, at the age of 49, Julie was diagnosed with womb cancer following 5 months of investigation for unexplained vaginal bleeding. Unfortunately, Julie fell outside all of the norms for women likely to have womb cancer - being under 50 years of age, not being post-menopausal, never having smoked, having had two children and not being considered obese.

"I had found it challenging to find services to support me to live with my cancer experience and to move forward with my life," says Julie. Because of her experience, Julie is particularly passionate about extending holistic services to enable people living with and beyond cancer, their families and carers to access a variety of support systems and self-management tools in their local area.

Whilst looking for a way to give some meaning to her cancer experience and to enable her to make some sense of it, Julie responded to an opportunity on the Macmillan Cancer website to become involved in the Macmillan User Involvement Programme. Julie says, "It has given me a voice and the opportunity to be heard as an equal with healthcare practitioners and managers, in service redesign and delivery."

Julie has been involved with the Gynaecology Pathway Board and reflecting on the experience comments, "It has been a challenging but positive experience. I cannot overstate the sense of truly being accepted as an integral member of the board in all aspects of its work."



DATES IN THE DIARY

1st December

GM Cancer
Macmillan User
Involvement
Programme Board

11th December

Manchester
Cancer Research
Centre - Melanoma
Open Discussion

12th December

Psychological
Support Pathway
Board

13th December

Brain & CNS
Small Community

HOW YOU'RE HELPING US MAKE A DIFFERENCE

Patient self-referral pilot project

Through Vanguard Innovation, a system is being piloted that would allow people to refer themselves to a GP for further investigations for suspected cancer.

Greater Manchester has a disproportionately high percentage of people whose cancer is detected at later stages, and as a consequent patients' prospects are poorer and treatment options limited.

Vanguard Innovation's patient self-referral project will use a set of computer-based formulae that assesses an individual's symptoms and, where appropriate, recommends an urgent GP appointment, hence improving early diagnosis of disease and so saving hundreds of lives.

During the pilot, individuals will not take the assessment alone but will be supported by an appropriately trained member of staff from community pharmacies. The assessment is done through completing a computer model, Risk Estimation for Additional Cancer Testing (REACT) which will weigh up an individual's current risk of having cancer based on their self-reported symptoms.

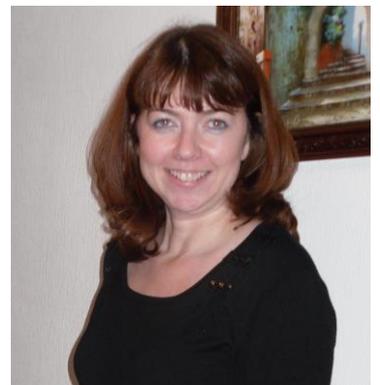
The project is led by Professor Ken Muir, Professor of Epidemiology at the University of Manchester, who said: 'Far too many people in Greater Manchester are diagnosed at a late stage and their prospects are, inevitably, much worse than if the symptoms had been picked up earlier. We want to tackle some of the barriers that prevent people contacting their doctor and by taking these resources into the community we can encourage people to engage with health services much sooner.'

A pilot scheme in South Manchester is scheduled to start in December which will recruit up to 100 people. The pilot will also give the project team the opportunity to gain feedback about how the assessment process works from a health professional and from an individual's perspective.

LET'S MEET... SARAH HAWORTH

Sarah joined the Team in September as User Involvement Programme Manager. She has a background in health and social care services. For the past 13 years, she's worked in the NHS, managing a range of services, in both hospital and community settings and also a Clinical Commissioning Group.

Sarah's NHS career started out in User Involvement 16 years ago in the Cancer Network. Sarah says, "It was being a cancer patient myself that led me to working in the NHS, whilst I then moved on to management roles, my driver and motivation has always been to improve services for patients." Sarah hopes to now bring to the Programme her personal passion and drive for user involvement, together with the professional skills and knowledge she has developed within the NHS. Sarah says "I think there are amazing opportunities in Greater Manchester for users to make a huge difference." "I'm very excited to be here with the MUIT and our Service User Representatives, working together to improve cancer services."



WANT TO GET INVOLVED?

Greater Manchester **Cancer**

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 2367, or email mc.userinvolvement@nhs.net.