

# MANCHESTER CANCER USER INVOLVEMENT NEWSLETTER

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



L-R: Lucie, Michelle, Tanya and Jonathan

## IN THIS ISSUE

### Bex's Story

"I want to be part of making a difference for future cancer patients."

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

- Questionnaire Task and Finish Group
- Buddy System Focus Group

### Meet the team...

Lindsey Wilby is the Macmillan Project Manager for Living with and Beyond Cancer.

### Cancer Vanguard Event.

## BEX'S STORY



At the age of seventeen, Bex was diagnosed with Hodgkin Lymphoma and went on to receive chemotherapy and radiotherapy treatment at The Christie Hospital.

Since then, Bex has taken part in a host of fundraising activities, from sponsored walks and runs to skydives, but she wanted to do something else to help; *"I know that raising money for charities based around cancer is so important but I wanted to do more."* As soon as Bex read about Manchester Cancer, she knew it was something she wanted to be involved in and didn't waste any time getting in contact with the User Involvement Team.

Bex's experience of being diagnosed with a Stage 4 cancer, led her to develop a real interest in early diagnosis and also the aftercare available for patients following treatment. *"When I finished my treatment I wasn't offered any help or support and surprisingly that's when I found that I needed it the most."*

Bex has recently taken up a role as a patient representative with the ACE 2 (Accelerate, Coordinate and Evaluate) steering group, working on an early diagnosis initiative. *"After my experience I really wanted to give something back. I want to be a part of making a difference for future cancer patients and I'm excited about the user involvement opportunities at Manchester Cancer."*

## DATES FOR YOUR DIARY

<b>4<sup>th</sup> February</b>	<b>9<sup>th</sup> February</b>	<b>15<sup>th</sup> February</b>	<b>1<sup>st</sup> March</b>
User Involvement Steering Group Meeting	Buddy System Focus Group	User Involvement Matters Induction session 2	User Involvement Induction session 1

For more information about these events, please contact the Macmillan User Involvement Team on 0161 918 2368 or email [mc.userinvolvement@nhs.net](mailto:mc.userinvolvement@nhs.net)

# HOW YOU'RE HELPING US MAKE A DIFFERENCE

## Questionnaire Task and Finish Group

A questionnaire task and finish group took place in January that worked to develop questions and themes for two patient surveys. The first of these supports the work of the Skin Pathway Board and is looking to establish if there is a need locally for a skin cancer support group. The second questionnaire supports the Living with and Beyond Board, examining the main themes within a questionnaire to assess 'life 12 months post treatment and beyond'. The group also worked to develop a set of questionnaire 'rules' that will help to inform the design of patient surveys in the future.

## Buddy System Focus Group

The Living With and Beyond Pathway Board are looking to explore the use of Buddy Systems as a supportive tool for patients experiencing cancer.

A focus group is set for the 9<sup>th</sup> February that will examine where a buddy support system would be useful, the key features it requires and the expectation of being part of such a system. This focus group will form a part of a wider buddy system project looking at:

- What a buddy system is and the expected benefits.
- What current systems are being used nationally?
- How can a buddy system be implemented within Greater Manchester and East Cheshire cancer services with recommendations to healthcare providers.

If you would like to take part in the focus group, please contact [mc.userinvolvement@nhs.net](mailto:mc.userinvolvement@nhs.net) or call 0161 918 2368 to reserve your place.

## CANCER VANGUARD EVENT

The second Vanguard engagement event took place on Wednesday 27<sup>th</sup> January at the AJ Bell Stadium, Salford.

Over 150 people attended the session to hear about progress made to date. The event began with the première of the Vanguard's [new video](#), which features four patients reflecting on their cancer experience and their perspectives on the Vanguard. Delegates then heard from the Vanguard Leads of some of the key areas of work, including cancer prevention and living with and beyond cancer.

More information, including a link to the new video, available from [www.gmcancervanguard.org](http://www.gmcancervanguard.org), or if you are a Twitter user: @GM\_Ca\_Vanguard

## LET'S MEET... LINDSEY WILBY

Lindsey is the Macmillan Project Manager for Living with and Beyond Cancer responsible for managing the Innovation Fund.

Graduating with Master's degrees in both Psychology and Publishing, Lindsey worked for Oxford University Press and Blackwell Publishing before moving into healthcare in 2002. Lindsey spent four years investigating serious complaints against the NHS at the Parliamentary and Health Service Ombudsman and the Healthcare Commission and has held various roles at the National Institute for Health and Care Excellence (NICE).

In 2014 Macmillan Cancer Support awarded Manchester Cancer a £350,000 Living With and Beyond Cancer Innovation Fund to give Pathway Boards the opportunity to develop and test innovative ideas for improving the outcomes and experience of those who are living with and beyond cancer. You can find out more about these successful projects [here](#)



## 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.

To find out more, please call us on 0161 918 2368, or email [mc.userinvolvement@nhs.net](mailto:mc.userinvolvement@nhs.net).