

Macmillan Cancer Improvement Partnership in Manchester (MCIP)

User Involvement Volunteer Testimonials



TOGETHER
WE ARE IMPROVING
YOUR CANCER CARE

WE ARE
MACMILLAN.
CANCER SUPPORT

NHS

St Ann's Hospital
Working in partnership in alliance
The Christie, Manchester, M20 9BX

MANCHESTER
CITY COUNCIL

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MCIP's User Involvement Volunteers

Patients and carers were at the heart of MCIP's work and considerable achievements.

Over the course of the programme more than 70 people affected by cancer gave their time, energy and goodness to a range of activities and events to improve cancer services and pathways.

Their roles included:

- Board and working group membership
- Focus group participants
- Communications advisers
- Panel discussion participants
- Engagement volunteers
- Service promotion outreach
- Networking events
- Film case studies
- Media interviews
- Mentoring
- Peer to peer interviewing

In the following pages we meet some of the ordinary yet extraordinary people who helped to shape and co-create new and improved award-winning cancer services for people in Manchester.

We thank each and every one of you.

Helen Adamson



I work as Deputy Manager in the Macmillan Cancer Information Centre at Wythenshawe Hospital and have had personal experience of having breast cancer in 2007 and a recurrence in 2011.

I joined MCIP at its inception in 2014. Since that time I have noticed clear improvements in care as a result of MCIP and a more cohesive approach to helping people affected by cancer with 'shared care' and a bigger focus on 'self-management and control'.

I have been fortunate to be invited to participate in a number of MCIP'S working groups as follows:

- The Breast Pathway Redesign Project
- The Mammographic Surveillance Sub Group
- The Personal Health Budget Task and Finish Group
- The MCIP User Involvement Group – Evaluation of Patient Letter / Questionnaire, Care and Support After Breast Cancer Treatment Leaflet / Ad hoc information and support / filming of e Learning Programme / Talking Heads Cancer Awareness Training Programme
- Breast Cancer Peer Evaluator Role

It has been fulfilling to be involved with so many different disciplines – all aiming to improve the way that people affected by cancer are treated – appreciating the importance of mental well-being after treatment and a greater emphasis on self-management with open access to support whenever it is needed.

I have met so many inspirational people along the way – some, sadly, no longer with us.

It is important to keep this good work going and to support all the initiatives which have developed along the way such as Health and Well-Being Events and Macmillan Active and Walking Groups through Macmillan Connections.

The importance of courses such as HOPE (Help to overcome problems effectively) and Breast Cancer Rehabilitation Programmes cannot be underestimated and greater emphasis on Care and Support Planning should help to strengthen the drive for future developments.

Berenice Cowan



I'd been diagnosed with secondary breast cancer and was determined to remain active and involved in all aspects of life for as long as I was well enough to do so. I attended a ballet class and became friendly there with Rachel, a member of the MCIP programme team, who mentioned to me that they needed volunteers to help shape and deliver the breast cancer pathway redesign.

I went along to an event at Chancellor's in Fallowfield where there must have been a couple of hundred clinicians, commissioners and volunteers all talking about how breast cancer care could be improved for all patients.

I found it hugely interesting and I really enjoyed giving my opinions and I got a sense immediately that everything I said was being listened to and really mattered.

I started going to meetings with clinicians from The Christie, where I was being treated, and from Pennine Acute. We were working together to try and find ways of improving communication between different areas of cancer care to patients with secondary breast cancer.

When you have secondary or advanced breast cancer you have complex needs which are often treated separately at different hospitals and through different teams. This can mean you have to tell your story again and again to different professionals. This can be worrying and stressful. I was able to explain all this from the patient's point of view in a series of meetings.

It resulted in a single letter being produced that clearly stated the patient's situation that was sent to everyone involved in their care. We also produced a key contact card and a booklet that explained what newly diagnosed advanced breast patients could expect in terms of care and support.

I was so impressed with how teams from across the city came together to sit down at the table with me in order to improve the patient journey.

I always felt listened to and saw first-hand that my views and suggestions became a part of the new way of working.

It was an immense privilege working alongside the clinicians and was something I enjoyed hugely.

I would encourage any patient or carer who is considering User Involvement volunteering to get involved as it is so very rewarding, interesting and actually very exciting!

David McLenachan



I joined MCIP in October 2014. I had been running a Health & Wellbeing event in North Manchester General Hospital and the Macmillan nurses said they knew of 'just the thing I should be involved in', encouraging me by talking about the important steps being undertaken, so I applied immediately.

With all I do for healthcare, I simply aim to make a difference for anyone who may experience the challenges of cancer.

I felt very strongly that on my cancer journey there was much I learnt belatedly, and better advice at earlier points would have been of significant benefit to me, so I hoped that I might be able to provide this for others.

I am very positive reflecting on the MCIP programme.

Above all else I believe we have made a serious contribution to improving cancer care in Manchester, and I have enjoyed the inclusiveness, friendship and involvement along the way.

I do voluntary work in many different fields, however the support I received at MCIP was second to none.

I was glad I could use my prior experience in business to assist with recruitment, in presentations and organising events. I intend to use this to advance my contribution in cancer care as best as I may, as I have felt gratified that the new opportunities and challenges arising to date have been a productive path to making a difference.

My advice to others would be to commit wholeheartedly, to express yourself with confidence even when face to face with clinicians and high-profile healthcare professionals - and never doubt the valuable contribution any of us may make in helping others see light at the end of the cancer tunnel.

Ruth Flanagan



I had been diagnosed with cancer for the second time and saw an MCIP poster in my GP's surgery. I had some spare time on my hands as I had lost my job because of my diagnosis. I had recently had some fantastic support from a Macmillan worker at Withington Hospital, who gave me wonderful advice and support.

This relieved a lot of stress for me, and had opened my eyes to the wonderful work that they do.

Despite feeling the impacts of the breast cancer

treatment, I was able to manage my health care needs very well. I am aware though that others may be totally lost at what to do. By joining MCIP in January 2015 I hoped to help others navigate their journey better.

I have been able to contribute in numerous ways. I sat on the discussion panel at a cancer improvement event at Manchester Town Hall; Became involved in a peer evaluation project; Reviewed new breast pathway booklets; Evaluated end of treatment summaries; A video of my story was used at a board meeting; Attended training days; Filmed my story for Macmillan online learning; Sat on an interview panel; Discussion facilitator at an event at Old Trafford Cricket Ground; Led the Legacy Armchair Project

I have really enjoyed working with all the other MCIP volunteers. We share similar stories and can empathise with each other – which is so important. I have also enjoyed being able to work alongside clinicians and commissioners making sure that the patient's voice is heard.

I have enjoyed being an integral part of something that is going to make a difference to many people's lives.

I have achieved a lot more than I thought I would! Being diagnosed with a second and completely separate cancer from my first pulled the world from under my feet. Along with my health and job my confidence was also taken. Being given the chance to complete the work with MCIP gave me my confidence back! I was treated the same as all the other professionals I worked with.

My advice to others who are considering volunteering on partnership programmes like MCIP is do it! You will get a lot more out of it than you think.

Thank you MCIP and all the staff I worked with. It was a privilege.

Jan Floyd



I joined MCIP in May 2016 after receiving the Talking Heath E-bulletin asking for breast cancer survivors. I was keen to get involved as my cancer journey had been so positive.

I initially wasn't sure what was expected of me but had the most amazing support from Mel Attack the MCIP UI Manager and the rest of the team. I attended focus groups; Was involved in letter/leaflet designs for breast and lung patients; Participated in breast monitoring and steering groups and many other meetings.

At my very first meeting I was surrounded by lots of clinicians who had years of experience. They were all very receptive to what I had to say. It was immensely important to me to be listened to. I was on the User Involvement Panel at the Tackling Cancer Care in Manchester event, which was a daunting but very worthwhile experience. I also did a short video which I hope will help people starting out on their cancer journey. Macmillan also provided me with training which enabled me to get more involved in their projects.

Through my involvement I have been able to provide support to friends and neighbours and helped them make informed choices about the care they receive. The knowledge I have is also helping me be more forthright with the clinicians involved in my future care.

My preconception of Macmillan was that they were only involved in end of life care. How wrong was I? Following my diagnosis, I contacted Macmillan for support with issues I had at work and around my mortgage. I imagine the people who supported me had been affected by cancer in some way. Through the support they gave me, I have been able to repay that by getting involved myself. When you're worrying about being off work, no money coming in and how you're going to pay your bills – I felt I couldn't have got through it without their help. I'll always be extremely grateful to them.

Volunteering isn't for everyone. But my experience couldn't have been more positive, and I wouldn't hesitate to get involved in future projects.

Hearing you've got cancer is the most frightening thing you'll ever hear. You immediately think the worst, but it doesn't have to be a death sentence – I'm proof of that! I've learned so much from being involved and hope that my input will help others in the future.

Leila Hamrang



I joined MCIP in 2016 when I was looking for a different group that supported people affected by cancer over the age of 25. I didn't know that Macmillan was such a group, as I was under the impression that they only supported and involved people over the age of 50. I soon realised that this wasn't true and I'm glad that I found this group.

Due to the lack of transitional support into adult services I had missed out on a lot of support, but finding MCIP filled the gap as I could talk to other people who could relate.

Since my diagnosis I have always wanted to give something back and to improve services for future patients. I achieved this through MCIP.

I have enjoyed working with a variety of clinicians as well as other volunteers.

Due to my treatment I have a lot of long term-health conditions. This means it is very difficult to know from one day to another whether I'm able to commit to a task or not. However, the whole team make sure that you are supported and understand if you are having a bad day. Working with the team is always a pleasure.

Joining MCIP has boosted my confidence immensely. When I first joined I was very shy and found it difficult making my voice heard. I have learnt that everyone around the table is the same and that if you don't say what's on your mind there will be no change.

I also like the variety of tasks we are involved with - from filming to upholstery. It's always a surprise!

Life after cancer is a world of unknown, it throws you all sorts of different hurdles. Having the support of the team and meeting new people every day helps you get through. There's always someone to talk to.

Tom Harrington



My partner had cancer, and we both realised that there were so many hurdles to go through, in terms of lack of information between clinics at that time.

For example, we received multiple copies of the same leaflets and booklets. There was a need to improve customer service skills and communication over delays. Care plans needed to be more informative for both patients and GPs. The needs of carers needed addressing further, particularly after the passing of a loved one (feeling abandoned, like a light switch had been turned off for support at a time of bereavement).

That's why I joined MCIP's User Involvement Group in June 2014 and joined its Board, Branding and Communications groups and the Exec Management Committee.

The thing that I enjoyed is the co-production with everyone from patients and carers to clinicians and commissioners at different levels. Everyone was equal and brought their voice to the table.

There was good engagement throughout, which is a good example for other health areas. No question or answer was stupid, or disregarded. I felt my voice was heard.

I hope that others will now not have to face the challenges that my partner and I went through, and that cancer pathways become smoother.

It is a way of giving something back. It helped me personally after the death of my partner, as it kept me busy, but more importantly my partner's cancer and death had meaning in helping others.

I am so proud of what has been accomplished for the people of Manchester.

Everyone has been so supportive, understanding. It has been a pleasure being involved and working with you all, thank you.

Doreen Hylton



I first contacted Macmillan for support because I was a carer for my mother, who had been diagnosed with bowel cancer and was also deaf and blind.

I attended a Macmillan workshop in Manchester after seeing it advertised in a council newsletter. I learned that Macmillan was looking for people who could talk to health professionals and cancer pathway managers about their experience of palliative care.

From day one, the support from Macmillan was regular and consistent and, more importantly, genuine. I became involved with MCIP as a User Involvement Volunteer and was given much freedom to share my opinions and suggestions on cancer care.

I felt that I was being listened to and that some of my suggestions were followed up and considered, which was so important. There was good written communication, in addition to verbal and one-to-one meetings, where needed. Any concerns I had, the Macmillan staff were there to listen and provide support. There was always a 'thank you' from the Macmillan staff, especially to their volunteers. I always felt that my time and contribution were appreciated and counted for something.

There was no hierarchy behaviour; everyone in meetings was there to make a contribution and share their own experience and suggestions. That was the beauty of it.

My mother has since passed away and I feel like something good has come out of, what was on some occasions, a poor experience for the things that she went through on her cancer life journey.

The icing on the cake was being invited on behalf of the MCIP volunteers, to accept a 'Thank You' at Buckingham Palace.

I feel it's important to give in some way. There are many ways to give and for me, moving forward, I want to continue to volunteer. I'm considering spending time with those in hospital who have no one to visit them.

We all have something to offer in life and what better way than to share by volunteering?

Nina Jackson



I joined MCIP in the autumn of 2013, when I became a member of the Primary, Palliative and End of life workstream in phase one. After this I was a member of the Breast Steering Group in phase three. Throughout my time with MCIP I have also been involved in commenting on leaflets and letters, attended focus groups, appeared on posters and given presentations and talks at events and training working shops.

At my first MCIP workshop I met Jonathan Lewis, a volunteer, who was already involved in the programme. He made a huge impression on me. I was struck by his openness, enthusiasm and absolute passion about making sure patients' voices were heard and, more importantly, listened to.

When I joined the programme, I had no idea that my involvement would last so long or be as significant as it turned out to be. I had a relatively positive experience of cancer care so wanted to highlight this as well as giving feedback on things that hadn't worked so well or that I wished had happened. It was a way of giving something back after the treatment and care I had received.

I have found that I have benefitted greatly from my involvement in ways I hadn't expected. I understand the system better, have more empathy for people in different and difficult situations, and have increased my confidence. I have also had the opportunity to do things I would never have done otherwise such as giving a presentation to over 100 professionals.

I feel that by sharing my own experiences I have been able to make a difference for other people affected by cancer. I have felt listened to. It has been an honour and privilege to be able to help influence future care. I feel very proud of what we have achieved by working together.

I would recommend volunteering on such a programme. I always say that unless you have had cancer you do not know what it feels like from the patient's point of view. Through this programme I have realised how vital it is to involve people affected by cancer when planning changes and improvements. I have come away with enthusiasm for user involvement and satisfaction of hopefully having made a difference.

Pat Scappaticci



As a person affected by cancer I was interested in MCIP from the start of the programme in 2014, but due to other volunteering commitments didn't follow through until 2015. I was already volunteering with a Manchester Macmillan project and had a very positive volunteering experience. I was sure this ethos would follow through with MCIP and it did.

I was very interested in MCIP as it represents collaborative working with a strong focus on User Involvement. It focused on key priorities relating to cancer in Manchester and ultimately it delivered. Improving services for local people interested me through the opportunity to share my experience of cancer care in Manchester. Being part of MCIP has made me feel very proud. I feel I've had the opportunity to influence decisions through my experience and I'm sure influenced change in breast cancer care pathway.

My confidence was boosted by doing things such as co-facilitating a workshop at the MCIP Showcase event in February 2017. I valued the fact that MCIP recognised my skills from my working career and asked me to join an interview panel. I thoroughly enjoyed a number of different focus groups where I met with patients and carers, and respected their views and opinions relating to potential service improvements. I think that my main achievement has been fully understanding and seeing UI in action, through co-production on a range of service improvements for Manchester residents.

Being part of MCIP has made me feel valued and rewarded. We recently received a Macmillan award for our achievements. I valued and enjoyed the welcome into the project by Mel Atack, MCIP's UI Manager. She did a great job ensuring I felt comfortable, informed and involved.

I also met some amazing volunteers. People truly committed to supporting service improvement through their experiences, skills and resilienceNina Jackson, Jan Floyd, Ruth Flanagan to name a few. My advice to those thinking of volunteering is: "Go for it...you'll gain more than you could ever give!" Volunteering with peers is cathartic. Macmillan has a wealth of experience in valuing, nurturing and supporting volunteers. Be it through support, learning and development to lovely reward and recognition events...you're looked after well.

Come on - you're needed to bring patient experience to help develop and improve cancer services.

Mike Thorpe



I joined MCIP in 2015. I first heard about it the year before just as I was starting cancer treatment. I'd read a news report about the launch event, which Caroline Aherne spoke at and asked patients and carers to become involved in it.

As a User Involvement Volunteer, I took part in various workshops, joined a steering group and appeared in a video. I also helped out raising awareness of the programme at places like the South Manchester Community Games, North

Manchester General Hospital and as part of the very successful Lung Health Checks in shopping area car parks in some of Manchester's most deprived communities.

All of this involved meeting people as well as the fantastic volunteers working with us which I really enjoy.

We also had some larger events like the North Manchester Macmillan Palliative Care Support Service launch and the primary care event at Manchester Town Hall. The primary care event was probably my favourite. I was one of four patients taking part in different parts of the event. I was asked a few questions on stage. We were also involved in the table sessions to be part of the discussions with GPs and other practice staff. At the end of that event, we all felt that we'd been part of something special and that we were helping to make a difference.

My experience of working with MCIP has been fantastic. I've met wonderful people who are now friends. Together we've been involved in some marvellous work like the Lung Health Checks, the breast cancer aftercare pathway, the palliative care initiative and the primary care work. All of these are making vast improvements to cancer care and the learnings are being shared with other areas.

The friendships and sense of achievement are reasons I would give to a patient or carer thinking of joining something similar in their local area.

You really can make a difference in your own community. Our voices are so important and are listened to and have a genuine impact on redesigning cancer services.

Thank you to you all



Receiving the Macmillan Richard Hambro Volunteer Award from Andy Crane at the Manchester Hilton in recognition of this team's dedication and commitment to the Macmillan Cancer Improvement Partnership in Manchester



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