



Transforming cancer care **together**

Welcome to the third edition of our briefing. It's been a busy time as we have passed the halfway mark of our Cancer Programme and we can see the transformation and change really making a difference to cancer prevention and diagnosis, and to people living with, or affected by cancer. In this edition we focus on working with partners, collaboration and patient and public involvement to give you an insight to the relationships being forged and the importance of working across the health and care system.

A New Partnership

We are delighted to begin a new partnership with **Yorkshire Cancer Research** who has generously funded a £2m campaign to increase the take up of Bowel, Breast and Cervical cancer screening in Leeds. Delivered with Leeds City Council's Public Health team, the three-year project aims to improve cancer screening rates in Leeds which currently vary across the many diverse communities, as well as improving awareness of the signs and symptoms of the disease.

The funding from Yorkshire Cancer Research will enable a city-wide infrastructure to ensure that people who do not take up their screening invitation, or find it hard to engage in traditional cancer services, are targeted and followed-up.



Dr Stuart Griffiths, Director of Research and Services at Yorkshire Cancer Research, said:

"We are delighted to be working in partnership with the Leeds Cancer Programme to increase

participation in the three national cancer screening programmes and raise awareness



of signs and symptoms of cancer and risk factors. Early diagnosis saves lives. It's vital that we work in local communities to support people in completing their

tests. We'd like to

Dr Kathryn Scott, Chief Executive, Yorkshire Cancer Research in completing their

thank the charity's supporters for making this unique initiative possible."

Cllr Rebecca Charlwood, Leeds City Council Executive Member for Health, Wellbeing and Health, said:

"This is welcome additional funding to support prevention, awareness and increased uptake of cancer screening in Leeds. It will play an important part in our commitment to increase the health of the poorest fastest and a city wide focus on addressing health inequalities which often result in poor cancer outcomes."

"Screening provides a vital role in detecting cancers early and we know there are many people who have been able to have prompt and effective treatment because of it." Involving the public and patients in Leeds Cancer Programme has been key to our work and we run our very active 'Engagement Hub' where we consult with our volunteers who represent the people of Leeds and its diverse communities. Here, we invited two active representatives who work with the programme to tell us their story of how and why they got involved with Leeds Cancer Programme.

Working with patients

Hazel Featherstone who is a Patient Representative, Living With & Beyond Cancer Workstream:



Hazel Featherstone

"In 2011, I was diagnosed with bowel cancer. I underwent chemotherapy and three major surgeries, including a 25% bowel resection and 75% liver resection. I know I wouldn't be here today without the skill of the oncology and surgical teams, and I can't begin to describe how grateful I am to them. The recovery from surgery and dealing with the diagnosis was mentally and physically tough, and I felt that I could really do with speaking to someone who had been through similar surgery so that I could compare notes on how I was doing and gain tips on moving forward. The nurses joked "there's nothing like that; perhaps you need to start something!"

"That conversation came to mind frequently, so when I retired from my work as a Chaplain at St Gemma's hospice I felt it was time to do something about it, and I started a support group to "put my money where my mouth was" and try to make a difference to those who were now on their cancer journey. Through running this group I was approached by a Macmillan GP to go and speak to a group of Leeds GPs and practice nurses to give them some insight from a patient's perspective what it is really like "living with and beyond cancer" as it is difficult for anyone who hasn't been through it to understand how life changing it is.

"Since then, I've been involved in lots of different things – I was invited to join the Leeds Cancer Programme Living With and Beyond Cancer Steering Group as a patient representative. I've been asked to attend and speak at other events and sit on peer review panels. I still run my support group, and feedback concerns they raise into the steering group; it keeps what I contribute fresh and means that I can make their experiences count and influence changes for future patients."

Our patient and public involvement:

Engagement Hub member **Phil Gleeson** talks about his volunteering:



"I'm Phil, 60yrs old and married with 3 children (all grown up, one still at home) I'm also a grandad too. I retired in 1995 through ill health; prior to that, my career started off when I trained in engineering straight from school and I was eventually a Director of Logistics in the North."

Phil Gleeson

Why did you get involved with the Leeds Cancer Programme?

I got involved in Patient Public Involvement (PPI) in 1996. I had been ill for a number of years, and in 1995 I had to retire with what is now known to be Fibromyalgia and Chronic Fatigue as I was unable to carry on in work. Back then it was very hard to get an actual diagnosis, and for a year I was actually treated for what was then believed as a mental health issue, as opposed to a physical health condition. In the end I was lucky - my GP was studying Fibromyalgia and I finally got a proper diagnosis. I wanted to get involved in PPI because I wanted to give something back and I enjoy helping people. I wanted to help advocate for people, and support them where I could with signposting and knowing where to get information that they need. I'm also an early member of the Access Committee for Leeds (an Independent Group), which helps to improve access to public facilities for people with disabilities – this can be physical access such as dropped kerbs, right through to signposting for

support, paperwork and helping people access benefits.

How has cancer affected you personally?

I haven't had cancer myself; however I lost one uncle to it when I was 7 or 8 years old. My uncle was only in his 30's; cancer wasn't talked about like it is now. We weren't even allowed to visit him then; and then I lost another uncle to it. Unfortunately cancer is one of those diseases that affects everybody. My experiences with cancer have been through friends and family members.

What do you think of cancer services and care in Leeds?

I think there's lots of cancer support available to people in Leeds, and there are brilliant facilities at the Leeds Cancer Centre at St James University Hospital.

How would you summarise your role as a Network Member at the Leeds Cancer Programme?

I would say that I'm an advocate of Leeds Cancer Programme. I want to learn as much about what's going on as possible. My main reason for getting involved is because I want people to find out about all the useful information that I pick up as I go along. I sit on a number of groups – it's important to make sure that people and patients have a say in decisions that are made. I'm able to challenge or question when decisions are made or if I think people need more information.

What are the benefits of being involved/what do you get out of it?

It helps me give back to people. It helps make services better for the future which I think is really important.

When you're not volunteering – what do you like to do in your spare time?

Volunteering is what I do! I do however like to keep up with politics and current affairs. It's why it's important to speak up!

Leeds Community Healthcare event, 14th May 2019

In May the Leeds Cancer Programme delivered a collaborative awareness raising workshop for staff members from the **Specialist and Adult Business Units at Leeds Community Healthcare NHS Trust**. Over 100 clinical staff members attended to hear speakers from each of the Leeds Cancer Programme work streams alongside partners from Leeds Teaching Hospitals NHS Trust, Public Health, NHS England, Cancer Research UK and Macmillan. The workshop aimed to increase awareness across the community workforce of the work the Leeds Cancer Programme is undertaking, provide insight into the impact the delegates role may have on the cancer journey, and enable patient facing staff to feel more confident when having conversations with patients about their cancer. Topics covered included:

- Prevention, awareness and screening uptake and barriers
- Early Diagnosis
- Cancer pathway and the Multi-Disciplinary Team
- Treatment, prognosis and side effects
- The Recovery Package
- Patient education and wellbeing events
- The national Macmillan service





Workshops and presentations with Leeds Community Healthcare

Delegates spent time considering what they could do within their own working environment to encourage participation in screening, and identified learning they would take away from the workshop to think about implementing in their own practice. Evaluation indicated that delegates felt the workshop had improved their knowledge of the Leeds Cancer Programme, national screening programmes, cancer pathways and treatments and side effects.

Caroline McNamara, Clinical Lead, Adult Business Unit, Leeds Community Healthcare NHS Trust:

"This was an excellent event bringing together the senior clinicians who work with adults in the community to understand what and how the Leeds Cancer Programme enables within the city and how we can all work together to improve the cancer care outcomes for our patients."

Teledermatology

The Leeds Teledermatology service for suspected skin cancer patients has now been in place for over one year. From project launch on 1st June 2018 – 11th June 2019 the outcomes have been extremely positive and the service continues to evolve with further refinements being made;

- 8,886 2 week-wait skin referrals have been received by Leeds Teaching Hospitals NHS Trust from across the city of Leeds;
- 5,810 patients (65%) have been appointed to a Teledermatology Triage Clinic;
- All patients appointed to triage are assessed with 48 working hours improving 'Cancer Waiting Time first seen performance';
- The confidence of the team is increasing as consultants become more experienced in image triage. In the first month of the project the rate of discharge back to the GP on image assessment was 9.5%. In May 2019 the rate was recorded at 29% of Teledermatology referrals.

One of the key benefits of the technology enabling this new service is that patients do not have to attend the hospital for this initial clinical assessment. We are currently conducting a patient experience survey to capture feedback from patients since implementation. Also, teledermatology will enable the use of images to be used as a training resource for GPs, to help them improve their diagnostic skills and quality and speed of referral in future.

Following implementation of the Leeds Teledermatology Model there has been local and national interest. The project team, led by Dr Walayat Hussain, Clinical Lead, has presented at the West Yorkshire and Harrogate Cancer Alliance event to other Trusts and is receiving an increasing number of calls from dermatology clinical leads throughout the UK to share the Leeds experience and model.

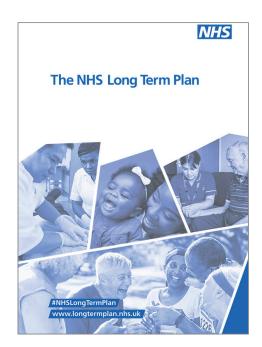
As word of the Leeds Teledermatology service is spreading there have been numerous enquiries resulting in tele-conference calls with interested Clinical Commissioning Groups across the country including, Wandsworth, Gloucestershire, South Yorkshire and Bassetlaw and Merseyside and Cheshire Cancer Alliances to name a few.

NHS Long Term Plan

Following the announcement of the **NHS Long Term Plan**, which sets out a number of national priorities to save thousands of lives more each year, Leeds Cancer Programme will reflect on the keys steers for Cancer:

- Create new **Rapid Diagnostic Centres** across the country so patients displaying symptoms of cancer can be assessed and diagnosed in as little as a day;
- Introduce a new, **faster diagnosis standard** which will ensure that patients receive a definitive diagnosis or ruling out of cancer within 28 days;
- Give people with cancer care that suits their needs with **personalised care packages**, giving patients more say over the care they receive.

Leeds is well placed to build on the delivery of these national NHS priorities including the ambition around Rapid Diagnostic **Centres (RDCs)**. We are using our learning and experience from the implementation of the Accelerate, Coordinate, Evaluate (ACE) pathway for patients with 'vague' but concerning symptoms to develop a model of RDCs that suits the needs of Leeds and its residents. Our next Stakeholder briefing will include an update on our progress. In addition, we will also provide an update on our Community Cancer Care Support Service, due to start late 2019, initially in two Primary Care Network areas of Leeds, and will provide personalised support to patients diagnosed with cancer.



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