



# Transforming cancer care together

Welcome to issue four of our stakeholder briefing where we aim to keep you up to date with the progress of Leeds Cancer Programme. Across this edition we focus on our our work with communities and to address to address health inequalities in Leeds.

This issue is the penultimate newsletter regarding the programme in its existing form, as we move towards the end of our current funding and structure and look towards a transition in the programme which is described below.

### Leeds Cancer Programme – our future and priorities

#### Joanna Bayton-Smith

#### Leeds Cancer Programme Manager

Over the next few months we will see a transition period for the Leeds Cancer Programme as we reach the end of generous funding from Macmillan Cancer Support. The three year investment has enabled us to make innovation and change across all aspects of cancer in Leeds and we now work towards sustaining cancer pathways and building on our achievements.

As we move into this period of change, we will ensure our continued focus is on the delivery of priority activities outlined within the **NHS Long Term Plan**. We will continue to develop our work to achieve earlier diagnosis and improve screening uptake across Primary Care Networks, focusing on the most vulnerable populations in Leeds, to address health inequalities. The core structure of the Cancer Programme will remain the same, focusing on work across the entire cancer journey, from prevention and awareness work, to diagnosing cancers earlier to maximise

treatment opportunities, as well as supporting people to live with and beyond cancer.

Driven by the NHS Long Term Plan and the needs within Leeds, we have new and emerging priorities for our work:

- Focus on the development of 'Rapid
   Diagnostic Centres' to ensure patients get the
   right test and diagnosis first time;
- Implementation of the 'Cancer Wise Leeds'
  project, funded by Yorkshire Cancer Research,
  with the ambition to support Primary Care
  Networks to increase uptake in national
  breast, bowel and cervical cancer screening
  programmes;
- The implementation of our 'Community Cancer Support Service', to be delivered with Leeds Community Healthcare Trust, which will focus on delivering personalised support in the community for people following their cancer diagnosis.

In early April 2020, we will be holding an event to celebrate the Programme's work, and to share with colleagues the ongoing vision to improve cancer outcomes for the people of Leeds.

## Working with vulnerable groups to help prevent cancer

#### Aveesha Lewis

#### Leeds City Council Public Health Team April 18 - Mar 19

The Public Health Team leads the Prevention, Screening and Awareness work of the Leeds Cancer Programme. To develop our prevention strategies we are working with **Leeds Cancer Awareness (LCA)**. LCA is a community based service which aims to reduce inequalities in cancer by contributing to an increase in awareness and uptake of screening/chest x-ray services in areas or communities with poorer cancer outcomes. LCA delivers community outreach which targets specific populations and communities across Leeds. The work they are undertaking is:

- To raise awareness of breast, bowel and lung cancer signs and symptoms;
- To promote and encourage uptake of NHS breast and bowel cancer screening services and the lung open access x-ray service in Leeds.

The service makes contact with the public through brief advice conversations and presents specific advice sessions at existing groups or networks. The service is a key partner with many local agencies or organisations contacting them directly for their expertise.

This year, working with the Leeds Cancer Programme, the service has exceeded their target and engaged a total of **5,291** people:

**4,611** new people have been involved in their cancer prevention messages;

**38%** of the total contacts have been men, a key target;

**3,802** have been from vulnerable groups (Adults with a Learning Disability, Adults with mental illness, Roma, Gypsy & Irish/Scottish/English traveller communities, Black & Minority Ethnic groups, Men).

We aim to continue this work for the next three years in our ambition to address cancer inequalities across Leeds.

"The Cancer Care Support Service could enable someone to take your burden, either by listening or advising."

Patient feedback on shaping the CCSS, Sept 2019.



Leeds Cancer Awareness Service at Kirkstall Festival, Summer 19

## **Community Cancer Support and reaching seldom heard communities**

#### Charlotte Guest and Toni Larter, Leeds Cancer Programme

We know that life for those affected by cancer can be challenging. We also know that more and more people are now living longer with cancer. In Leeds there are over 25,000 people currently living with or beyond a cancer diagnosis.

It is not uncommon for people to feel lost and struggle to come to terms with living with cancer, or going back to 'normal life' after cancer treatment has been completed. We want to help people affected by cancer find help in their local community easily, as and when they need it.

The aim of the Community Cancer Support Service (CCSS) is to improve the quality of life for patients and carers living with and beyond a cancer diagnosis; and to improve the access to local support services in order for them to lead as full and active life as possible. The service will be led by trained nurses to provide support to patients to navigate the system from the point of a cancer diagnosis and help with signposting and referral into existing community services. The CCSS service is being developed and delivered with partners Leeds Community Healthcare NHS Trust and will initially be delivered in Yeadon, Otley, Harehills, Richmond Hill and Burmantofts.

As part of the service design we embarked on public engagement with 60 people from seldom heard communities to find out what sort of things people who have a diagnosis of cancer (or their carers) would want help with, and how it would be best for them to access it. The feedback was required to develop a useful and accessible support service for people affected by cancer.

We know that some of the geographical areas this service will cover have high percentages of people from seldom heard communities. The term 'seldom-heard' refers to under-represented people might use this service, who are less likely to be heard by health professionals. Therefore we wanted to make sure that we engaged with these communities to make sure we take into account their needs when developing this service.

Many factors can contribute to people who use services being seldom-heard, including: Disability, Ethnicity, Sexuality, Communication impairments, Mental health problems, Homelessness and Geographical isolation

Responses from the engagement are helping to shape how we design the Community Cancer Support Service to make it as accessible as possible to all people in communities who have a cancer diagnosis.

#### Rapid Diagnostic Centres (RDC's)

#### Angie Craig, Deputy-Director of Operations Leeds Teaching Hospitals

RDC's will evolve from the successful work of the ACE (Accelerate Coordinate Evaluate) Vague Symptoms Multi-Disciplinary Diagnostic Centres (MDC's) work piloted over the last 2 years (of which Leeds is one).

Over the next 5 years RDC's will offer a single point of access to a diagnostic pathway for all NHS patients with symptoms that could be cancer. They will ensure that patients' receive co-ordinated testing with as few visits to hospital as possible, improving faster diagnosis and providing an appropriate onward referral for treatment, whether or not they have cancer.

Leeds has received non-recurrent funding for 2019/20 through the West Yorkshire & Harrogate Cancer Alliance to broaden and develop their ACE MDC Service in line with the national RDC specification requirements. This investment will support the delivery of an RDC for Leeds patients with vague symptoms and also new ways of working for site specific Upper GI and Lower GI symptoms across the Leeds GP population by the end of January 2020. The following principles will apply:

• Primary care led review of battery of blood tests

Early Identification Timely Referral Effective Triage Co-ordinated Timely Diagnosis Onward Testing

Model of Rapid Diagnostic Centres

- and chest x-ray prior to referral into secondary care;
- Delivery of CNS led holistic needs assessment;
- Co-ordinated testing and rapid re-discussion;
- Patient centred CNS support from referral and ensuring 'right test first time';
- Cost effective reduction in diagnostic testing compared to 2WW pathways;
- Collaborative working across the primary and secondary care system. A primary care champion will be appointed into the RDC model.

## Patient non-attendance at urgent referral appointments for suspected cancer

By Peter Knapp, Reader in Health Sciences, Department of Health Sciences, the University of York and York and Hull Medical School. e: peter.knapp@york.ac.uk t:01904 32 1675

If a patient has signs or symptoms of cancer, a GP would refer him or her on the Two-Week-Wait pathway. You might think every patient suspected of having cancer would be sure not to miss this visit to an oncologist, but our latest research (funded by Yorkshire Cancer Research) shows that more than 5% of patients cancel or don't attend these crucial appointments. In England there are now 1.9 million Two-Week-Wait referrals annually and 48% of all UK cancers are diagnosed through this route.

We found that patients who didn't attend these appointments were less likely than attending patients to be diagnosed with cancer. But non-attending patients who were eventually diagnosed with cancer were 12% more likely to die within a year of diagnosis.

Non-attending patients tended to have more advanced cancer at diagnosis, suggesting they had been slower to make the GP appointment that resulted in a referral.

Our statistical analysis showed that nonattendance was more likely in patients from poorer parts of Leeds, men, the youngest or oldest patients, patients with particular types of suspected cancer (especially gastro-intestinal cancer), and live further from the hospital.

We need to find solutions, such as GPs ensuring that patients understand the appointments system and the importance of attending, and reassuring patients about possible diagnostic tests. Contacting and re-booking non-attenders must be a priority. A greater challenge is ensuring that patients don't delay reporting symptoms to their GP.