



Leeds Cancer Programme



Transforming
cancer care
together

Welcome to the seventh edition of the Leeds Cancer Programme Stakeholder Newsletter. During this edition we will be saying goodbye to Professor Duffy, introducing our new programme manager, focussing on targeted work to address access to cervical screening, and highlighting rapid changes made due to the impact of COVID-19.

As Joanna Bayton-Smith moves into her new role as Head of Pathway Integration (Episodic Care), we introduce Tom Daniels, the new Macmillan Leeds Cancer Programme Project Manager.

I first joined the NHS as a management trainee in 2007, and since then have worked in range of operational and commissioning roles at both local and national level. I also took some time away from the service researching approaches to decision making on health spending and the role that the public should play in these types of decisions, completing my PhD in 2016.

Having grown up in Leeds, I returned to my home city for my last job which was Senior Commissioning Manager for Community Care Beds and End of Life Care. I am proud to continue to work for the CCG and Macmillan now as the Leeds Cancer Programme Manager for the city and I look forward to continuing to build on the relationships that I have developed locally.

My vision for the project is that when it comes to an end the developments made across the



Tom and daughter Phoebe

city will become business as usual. Leeds will continue to lead the way in cancer diagnosis and care, screening uptake will continue to rise and cutting edge diagnostics will enable more cancers to be detected at an earlier stage, people living with cancer will be more supported, empowered and informed to make decisions about their care and health inequalities will be identified more quickly and tackled more effectively.

Away from work I enjoy spending time with my wife Lindsey and our daughter Phoebe who was born last September and who kept us entertained during lockdown!



Professor Sean Duffy

Professor Dean Duffy

As the **Leeds Cancer Programme Joint Lead and Clinical Chair**, Professor Sean Duffy looks forward to his imminent retirement; we take a quick look at his immense achievements both locally, regionally and nationally.

Professor Duffy has always been a strong advocate, champion and clinician for cancer patients and their services. For many years over his extensive career he has held strategic positions which allow organisations to work better together to create improved services and patient experience. Before returning to Leeds in 2016 Professor Duffy was the **NHS England National Clinical Director for Cancer**; during this three year period he was responsible for overseeing all aspects of cancer care for England.

Prior to that role he was the Chair of the Cancer and Blood Programme of Care, NHS England and Chair of the Specialised Cancer Clinical Reference Group, NHS England. Before taking up these roles he already had extensive understanding of the Leeds and regional Health and Care systems in his roles as Clinical Director, Leeds Teaching Hospitals Trust; Director of Learning and Teaching, University of Leeds, School of Medicine; and Director and Medical Director, Yorkshire Cancer Network.

Professor Duffy has extensive published research and a strong platform of research work encompassing **Heath Services Research (HSR)**, endometrial function and dysfunction, and medical education. He is currently Chief investigator for Machine Learning for Cancer Risk, University of Leeds and an advisor for the Prolaris project to predict high risk prostate cancer. Alongside these roles, Professor Duffy also provides a full range of gynaecology out-

patient services (diagnostic and treatment) and holds a regular operating session.

Professor Duffy has also received prestigious awards: Ethicon Travelling Fellowship (RCOG), William Blair-Bell Lectureship (RCOG) and Bernard Baron Travelling Fellowship (RCOG). He will retire to spend time in Cork with his family.

Reducing Health Inequalities in Cervical Screening for people with Learning Disabilities

Tom Daniels, Louise Cresswell and Rachel Bethell

The last Leeds Cancer Programme Stakeholder Newsletter published in March 2021 focused on our ambition to reduce health inequalities across the city and set out a range of approaches and actions being taken by colleagues to support this. In this article we highlight the specific inequalities experienced by people with **Learning Disabilities** in accessing cervical screening and identify next steps to help to reduce these.

The impact of cervical screening on cancer mortality is well known, with research suggesting that screening currently prevents 70% of deaths from cervical cancer. However, if uptake was increased and screening was carried out for all those eligible, then it is estimated that this figure could rise to 83%. This makes it all the more important that as many people as possible who are able to benefit from screening are given the opportunity to do so.

Across Leeds the current uptake rate for cervical screening (all ages) is 68.4%, but amongst the population registered with learning disabilities it is just 36.3%. In total there are 1036 people in Leeds with learning disabilities who are eligible for cervical screening but data extracted in March 2021 showed that fewer than 400 of these people were actually screened.

Quality Outcomes Framework (QOF) data suggests that the inequalities experienced by people with learning difficulties accessing cervical screening are less profound than those previously described, however this does not take account of QOF PCA (personalised care adjustment) exception reporting (i.e. individuals who were identified on the system as having reason not to be included in the figures). Reasons for personalised care adjustment exception reporting include patient choice, patient did not respond to three invites and cervical screening was deemed to be unsuitable for the patient. Research has shown that people with learning disabilities were four times more likely to be exception reported than the eligible

population as a whole, and so despite the QOF data suggesting that the uptake for these communities is 63.6%, there is still significant work to do.

Inequalities in accessing screening for individuals with learning disabilities seem to be greater for older people, with uptake of cervical screening at 29.1% for 50-64 year olds against 40.1% for people aged 25-49. This may suggest that inequalities will reduce over time, but it also suggests that focused work needs to be done to understand levels of uptake amongst older people with learning disabilities if we are to tackle a growing inequality within this population itself.

We have a range of structures and programmes in Leeds designed to increase screening uptake amongst people with Learning Disabilities. In November 2020 a **Cancer and Learning Disabilities task group** was established as a sub-group of the Leeds Cancer Prevention, Awareness and Increasing Screening Uptake steering group. The group is driving forward a range of targeted local level activity aimed at better understanding and overcoming the barriers to screening in order to support increased uptake.

There is also specific targeted activity, for example, the **Leeds Community Cancer Awareness Service** which has been commissioned by Public Health, Leeds City Council to raise awareness of the signs and symptoms of cancer and to encourage uptake of screening in areas of highest deprivation and with groups where uptake of screening programmes are lower, which includes with people with lived experience of LD.

Alongside this, colleagues from **Cancer Wise Leeds**, funded by **Yorkshire Cancer Research**, are carrying out an in-depth audit with one Primary Care Network (PCN) to better understand the exemptions. The findings from this audit will then be used to support practices in reducing inappropriate exemptions within the learning difficulties population and key learning will be shared across the city to reduce the deep-seated inequalities experienced by people with learning disabilities in Leeds.

Covid Impact Case Study – moving patient education programmes on-line

Judy Turley

Covid-19 brought Leeds Teaching Hospital's NHS Trust patient education programmes (PEP) to a halt in March 2020. They had

initially been introduced in 2017 for patients during or at the end of their treatment, giving clinical information and general health and wellbeing advice to enable patients to live their lives as well as they could. It was also a great opportunity for people to come together having faced a similar cancer and share their experiences. Out of this network new friendship groups, golf matches, walking groups etc. were formed.

Each session was usually delivered by a **Cancer Nurse Specialist** alongside trained facilitators as a face to face, day long, group session. By March 2020 we had introduced these regular sessions for 10 different cancer tumour sites with possible expansion to more.

In September 2020, patients who had been scheduled to attend when Covid-19 lockdown affected services were invited to our initial virtual PEPs. As there was a high quantity of breast patients waiting for a PEP, we trialled our new approach with them and feedback on the whole was positive. Without a budget (or professional film makers) we made a series of information films for our patients covering the generic topics the majority of cancer patients ask about. These are available on our website [here](#). Our hospital charity provided subtitles and making these videos available on our website also enabled those patients whose first language is not English to listen to or read them with their families and/or friends.

For further information please email leedsth-tr.leadcancerteam@nhs.net

Macmillan's Get Support Campaign

Our key partner, **Macmillan Cancer Support**, is encouraging more people to make use of the charity's round-the-clock support. Patients and their loved ones can contact Macmillan's phoneline, where specially trained cancer nurses and advisors are there for anyone affected by or worried about cancer, every day of the week on **0808 808 00 00 (8am-8pm)**. Additional emotional support is available through the charity's 'Telephone Buddies' scheme – an 8-week support system for people with cancer who may be isolated from loved ones. Peer-to-peer support is available 24 hours a day on its Online Community, an online forum with over 90,000 members. The charity is also reminding anyone worried about cancer symptoms to contact their GP as an absolute priority.

FIT Test Update

Re-launch of 2ww Suspected Colorectal Cancer Pathway and FIT Testing – ensuring smoother patient pathway experience.

In January 2021 Leeds re-launched the **2ww Suspected Colorectal Cancer Pathway and FIT** testing across primary care. Due to the success of the FIT test in triaging patients, the pathway has been split into two patient groups. The modified referral criteria will determine if a patient should continue on the pathway as "Straight to 2WW Referral" or "Straight to a FIT test".

To support the pathway across primary care, endoscopy and pathology, two FIT Patient Navigators have been appointed at LTHT. The 'Navigator' role is vital in safety netting patients referred for a FIT test; they are responsible for monitoring ICE FIT test requests, overseeing practice stock control, contacting patients who have not returned a sample, and supporting the patient through the pathway. Since the launch of the new pathway there have been:

- **3803 patients referred for a FIT test**
- **532 positive FIT results and 2585 negative FIT results.**
- **24/532 positive FIT patients have gone onto have cancer.**

For more information please contact:
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Leeds Awarded £340,000 for Cancer Recovery Fund

An additional £20m has been made available nationally for Cancer Alliances to accelerate and support cancer services recovery and aid earlier diagnosis following on from the increase of later diagnosis due to the pandemic.

Bids were invited from across the **West Yorkshire and Harrogate Cancer Alliance** in June to apply for the funding. Schemes which accelerated implementation of service models that streamlined the front end of the pathway, identified 'missing' cancer diagnoses and enabled management of high referral volumes were requested to be put forward for consideration.

A local prioritisation exercise took place and Leeds was awarded revenue funding amounting to **£340k to support head and neck, skin and breast cancer pathways**. In total WY&H Alliance was allocated £996k to fund 35 individual schemes.

To get in touch, or to find out more, please contact:

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