



The voice of those affected by cancer in Yorkshire and The Humber

www.yorkshirecancercommunity.co.uk

Welcome to our autumn newsletter. We are a support and information network for people affected by cancer and those who support cancer patients and carers in Yorkshire and the Humber area.

Our aim is to enable the views and experiences of cancer patients and carers to be heard and used to improve the quality of cancer care in our region.

I hope you will enjoy reading patient stories and learning about new opportunities within the Yorkshire and Humber Cancer Community. If you would like to tell your story, please get in touch. Always look forward to hearing from you.

**Best wishes** 

Jill

### SOME NEW FACES – MEET THE BOARD 2021

2021 brings some changes to our board of Trustees. We said farewell and a big thank you to Zoe Bounds and Phil Gleeson, for all their efforts over the years and wish them well for the future. Zoe, a founding member of Best Friends York, joined us in 2017, and was instrumental along with the late Sheila Smith, in coming up with the project that is now Cancer SMART. Phil, who now chairs Leeds Involving People, has championed the cause of carers and people with disabilities and has always taken a keen interest in patient involvement in research.

Our chair, Sara Williamson, also decided that with the recruitment of new trustees, the time was right to step down, to be able to give her more time for her many other commitments. She is a research advisory panel member for Yorkshire Cancer Research, Community Panel Member, Planned Care Citizens' panel member, Chair of MY (Mid Yorkshire) Breast Cancer Support Group, works on various Cancer Alliance and Living with and Beyond workstreams in Leeds and Mid Yorkshire.

We welcome new trustees:

Our new chair, Dr Stewart Manning served as a GP in a South Leeds practice from 1976 until retirement in 2012. He is excited about achieving our goals to improve patient pathways and experiences, and bolster joined up services with staff, particularly at times when the NHS has been stretched during Covid.

Emily Gill joins with a background in residential care and administration. She brings a wealth of experience in policies, procedures and accountancy. She is a huge support to our Treasurer Paul Vose and is bringing new systems to improve our efficiency.

Rob Husband worked in the construction industry. After being diagnosed with a tumour on his vocal cord and coming out of treatment, Rob worked with Macmillan at Calderdale and Huddersfield hospitals in developing the "First Steps" programme for those newly diagnosed. He is also a Cancer SMART volunteer developing podcasts that help raise awareness and make cancer an every day conversation topic, in line with the Cancer SMART objectives.

Richard Midgley (pictured) joins the Board after holding a number of senior roles during a career in the IT industry. He is looking to bring his experience of business, governance and strategy to support the next steps of the YCC journey.

Deborah Adams continues as a Trustee and is our newly elected Secretary. She brings a wealth of experience in strategic planning and training with various local and national charities, with over 25 years as a fundraising manager. She sits on various governing bodies, and is a volunteer for the Cancer SMART project. Her connection with YCC is through having had breast cancer. She is also a fundraising consultant for the Foundation for Social Improvement and has excellent volunteer management experience.





Dr. Christina Dobson (pictured left) is a cancer researcher, specialising in research into colorectal cancer and early diagnosis. She is looking forward to working with Yorkshire Cancer Community to develop, and secure funding for, new initiatives to support those affected by cancer in Yorkshire and beyond.

Beverley Forkes (pictured right) continues as a Trustee, volunteers as a Macmillan befriender at Pinderfields Hospital, and sits on the Mid Yorkshire Cancer Patient Partnership Group and West Yorkshire & Harrogate Cancer Alliance Community Panel. She brings patient experience having survived breast cancer and is also a patient advocate for Breast Cancer Now.



Paul Vose continues as Treasurer, sits on the Mid Yorkshire Cancer Patient Partnership Group, Alliance Community Panel and is a lay member of both the West Yorkshire and

Harrogate Cancer Alliance board and Mid Yorkshire Cancer Board. He is a Macmillan Cancer Voice and is a patient advisor for NHS England. Following early retirement after a head and neck cancer diagnosis, Paul's focus has been on working with support groups, charities and hospitals to improve cancer care and support for patients and carers.



Back row, from left to right: Paul Vose (Treasurer), Dr Stewart Manning (new chair), Rob Husband, Helen Moss (Healthwatch administrator) Front row, from left to right: Sara Williamson (retired chair), Debs Adams (Secretary), Emily Gill and Jill Long (YCC Engagement & Communications Officer).

## **Breast Pain Survey**

South Yorkshire and Bassetlaw ICS Cancer Alliance is running a short survey about breast pain, to gain insight on what a breast pain service within the community should look like for their population.

The survey asks people of any gender, whether they have experienced breast pain or breast cancer or not, about their current knowledge around breast pain, breast examinations, and what their expectations would be of high quality breast education service provision both online and in the



community. Survey results will influence new breast pain service specifications within South Yorkshire and Bassetlaw, alongside the data and feedback from patients who have been involved the pilot of a community-based breast pain service in North Derbyshire. This pilot was set up after Mid-Nottingham ICP shared their insight from brand new one-stop clinics treating women with breast pain in the community, which started running last year.



The team are also running focus groups to gather further insight on this topic, which you can sign up to be involved in via the questionnaire if you wish.

To have your say, click here: <u>https://re-url.uk/WW8U</u>

## **Membership Survey**

Could you spare us five minutes of your time please and help improve the service offered by the Yorkshire Cancer Community. We are carrying out a survey to learn more about what people find helpful about YCC and how we could improve our offer.

Everyone's answers to the survey questions will be anonymous.

We will be holding a prize draw for a £25 voucher for people who have completed the survey by 31 October. If you would like to be considered for the voucher draw please leave your email address in the final survey question. Your email address will not be linked to your survey answers and will only be used for the purposes of the prize draw.

The link to the survey is below: https://www.smartsurvey.co.uk/s/8TIN6T/

Thank you in advance for all of your help and support, which will enable us to grow YCC in the vision of our entire community.

Dr Stewart Manning Chair Yorkshire Cancer Community

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### **BRIC - On line Research and Community Support Centre**

Sara Williamson, founder of the MY (Mid Yorkshire) Breast Cancer Support Group, chats with great friend Professor Naz Derakshan, founder of BRIC (Building Resilience in Breast Cancer Centre) and Professor of experimental psychopathology at Birkbeck University of London.

"BRIC currently has 2,000 breast cancer patients in a private Facebook group, and 5,000 in its public group. Members are from all over the UK. BRIC's aim is to reduce the psychological impact of breast cancer, reduce anxiety and depression and improve quality of life. Cognitive health is vital for emotional health. We hold interactive and guided discussions and feature award winning blogs, one of which has had over 100K readers. The pandemic has brought increased psychological trauma where treatments have been delayed, and job security has been impacted.

Our online presence has shown a great uplift in numbers. We have heard that sadly, many support groups have folded and indeed it has been a trying time for charities. Many ladies have had to shield, so communication and staying connected has been a lifeline for many. We conduct evidenced based research to reduce anxiety and depression to improve resilience in both primary and secondary breast cancer patients. In times where our



wonderful NHS is stretched, we are there to help with the psychological support.

People contact is vital for mental wellbeing so we have been holding meet ups around the UK as we open up to the new norm. Sara recently attended one in Manchester, and reports that it was wonderful to meet others with similar mind sets, and compare how care plans and cancer services differ so much around the country.

You are welcome to view the BRIC public page at <u>www.briccentre.bbk.ac.uk</u> or if you are a female, having had a breast cancer diagnosis you can join our closed fb group "BRiC private group (building resilience in breast cancer)".

## Portobello Centenary Garden Party – the first live event we have attended since the pandemic

It was good to be back and meeting people face to face again instead of through the medium of online platforms such as Zoom and Teams.

We took part in Portobello Garden Party, celebrating 100 years of this vibrant community outside Wakefield.

We had a stall to promote Cancer SMART – our project which we run in partnership with West Yorkshire & Harrogate Cancer Alliance – to raise awareness of cancer and promote the uptake of screening.

Thanks to Cancer Champion Bob Clayden, who also helps to run Portobello Craft & Camera Group, we had gazebos and tables and were able to offer outdoor crafts to visitors.

While children got to grips with ink printing on bags bearing our Cancer SMART logo (pictured), we were able to talk to their parents and carers about the project.

We saw brisk business with children decorating more than 24 bags, which used up all our supplies well before the day was over. Luckily, Bob and his team were on hand offering sunprinting on scarves.

> Cancer Champion Ric Myers (pictured left) volunteered all day, sustained by coffee and

biscuits, and proved a dab hand at demonstrating printing while talking about his experience of a lung cancer diagnosis.

See his story on page 12 of this newsletter.

Visitors to the stall seemed genuinely interested in hearing the Cancer SMART message – one of our aims is to make cancer an everyday conversation.

Thank you to everyone who visited us on the day.

Wakefield Council Community Ambassadors Liam (left) and Danny were interested in Ric's story















### Teledermatology: Supporting earlier diagnosis of skin cancer

To support more patients, manage NHS waiting lists safely, and help cancer services recover from Covid-19, the Cancer Alliance has worked alongside its partners to support the use of specialised images alongside urgent skin cancer referrals.

Skin cancer is one of the most common cancers in Humber, Coast and Vale. To help transform skin cancer pathways and increase early diagnosis in the area, the Alliance has provided 60 new iPhones and dermatoscopes to GP Practices across Hull and East Riding. The new equipment will mean healthcare professionals are able to rule out or diagnose skin cancer earlier, when treatment is often more successful.

The dermatoscopes, which are handheld instruments similar to a magnifying glass, enable specially trained GPs to capture and share microscopic images as Dr Dan Roper, Clinical Lead for Primary Care at HCV Health and Care Partnership explains, "In line with similar work that is taking place across the Alliance, Hull University Teaching Hospitals NHS Trust has changed the management of urgent cancer referrals to support image submission. Including images with referrals assists in effective triaging can often lead to a reduced number of appointments and anxiety for patients." The dermatoscope and iPhone combination can also be used to help GPs take a closer look at any moles or skin lesions than they would be able to normally, meaning they can reassure or refer patients to secondary care sooner.

A local patient who benefited from use of the technology said: "I developed a concerning lump on my neck and my GP took a photo that showed the minute detail of the lump. I thought here is a technology that is making it very clear what the problem is. Within 10 days, I saw a consultant who appreciated the information that was available and, within six days, I was in surgery. I was so pleased to get it sorted so quickly."

"In my experience it felt like the dots were very clearly joined up, from speaking to the receptionist, GP, senior practitioner, consultant and finally the registrar who did the surgery. All the dots lined up and I benefited enormously from that. I was really pleased that throughout the process, everybody seemed to be talking to each other which felt extremely important."

More information about the changes to skin pathways in the area can be found in this video: <u>https://youtu.be/1P3-o7hpjdg</u>



## An excellent training opportunity for carers and volunteers: First Steps into Research Programme

The Yorkshire and Humber Clinical Research Network has launched their 'First Steps into Research Programme', which seeks to ignite an interest in and increase knowledge of research to enable those who take part to have a career in health and social care research.

The programme is aimed at anyone working in a care home, domiciliary care, voluntary/charitable sector or local government in Yorkshire and Humber. There are more details about who is eligible on their website.

## WHAT WILL THIS PROGRAMME GIVE YOU?

It will give you the skills, knowledge and confidence to pursue a research career; either as a champion, a research practitioner, a Principal Investigator, or indeed by undertaking further higher Masters/Doctoral level study. At a very minimum, you will be more research aware and able to talk about research in your area.

#### If you would like

more information please contact Gail Creswick on <u>Gail.creswick@nihr.ac.uk</u> or 07789 746415.

Deadline: 18th October 2021. To apply/find out more information please visit <u>https://bit.ly/FirstStepsinResearch</u>



#### How do I sign up?

Go to <u>https://bit.ly/FirstStepsinRe</u> <u>search</u> or scan →



### Where do I get more information?

Speak to Gail Creswick on Gail.creswick@nihr.ac.uk 07789 746415

## First Steps in Research Programme

#### What is the programme

The aim of this programme is to ignite your passion and interest in research and give you the motivation, skills and knowledge (about research).

#### Who can take part?

Anyone working in a care home, domiciliary care, voluntary/charitable sector or local government in Yorkshire and Humber.



## Hot off the press

Please see these links for useful information:

Local services for Barnsley Cancer Patients: <u>https://best.barnsleyccg.nhs.uk/clinical-support/services/barnsley-cancer-patients-local-services/95921</u>

Cancer Services offered in the Mid Yorkshire Hospitals area, which includes Pinderfields, Pontefract and Dewsbury hospitals: <u>https://midyorks.nhs.uk/cancer-services</u>

07715 217845

## Leeds charity launches wellbeing walks for brain tumour patients and carers across Yorkshire

Yorkshire's Brain Tumour Charity (YBTC), based in Headingley, has partnered with social enterprise Good Footing to offer free mental health-boosting walks at local nature spots. The first walks will be in Leeds, Birstall and Barnsley, with more to follow.

Guided by a trained volunteer and open to all adults affected by a brain tumour including patients, carers and loved ones, the walks are a chance to socialise with people who understand while experiencing the calming benefits of the outdoors. A member of staff from YBTC will remain at the venue's café throughout, so that any family members physically unable to take part can enjoy a drink and a chat.



The first walk took place on Saturday 14 August at St Aidan's Nature Reserve in Leeds to great success. One participant said: "It was great being side by side, it really helped me to talk and feel more relaxed." Another said: "I enjoyed the discussions I had and hearing how other people have overcome the difficulties they've faced." Another commented: "Being outside felt great, and taking a little time for me was just what I needed."

Other walks are planned at Oakwell Hall, Birstall, Wentworth Woodhouse, Barnsley and at Temple Newsam, Leeds, with more dates to follow.

Yorkshire's Brain Tumour Charity CEO Marie Peacock said: "This was our first group wellbeing walk and I was delighted with how much everyone enjoyed it. As a charity, we want to ensure we are providing support in different ways to ensure there is something suitable and accessible for everyone. This is definitely something we will continue to organise each month across the region."



Good Footing founder Danny Bulmer (pictured left) said: "Good Footing is very excited to be working in partnership with YBTC. We wanted to create a space for people to feel comfortable in opening up and sharing their experiences, as well as a space to 'switch off' and enjoy the benefits of walking in nature.

"Our first walk at St. Aidan's couldn't have gone better. It was so good to see people who had not met previously sharing their relative experiences, hearing each other out and supporting one another. The walk also created space for carers to take some muchneeded time out for themselves. We're really looking forward to the upcoming walks at Birstall, Barnsley and Leeds and hope we can continue to make a positive difference to people's lives."

The walks are part of YBTC's ongoing project to expand their range of support, to provide an alternative for those who are wary of traditional support groups. Other alternatives include art and craft sessions, hypnotherapy and a peer support scheme.

There is also the opportunity to book a series of six one-on-one walks with Good Footing through the charity, arranged at a time and location to suit you.

Good Footing founder Danny started out in account management for creative agencies, before setting up a coworking space and a snack brand, and now works as a brand strategist. After struggling for several years with anxiety and depression, he launched Good Footing, running "outdoor workshops" including walks and wild swims, which aim to boost mental and physical wellbeing.

Yorkshire's Brain Tumour Charity is Yorkshire's leading brain tumour charity dedicated to raising funds for lifechanging research and patient support. They support brain tumour patients of all ages as well as their families, with services ranging from counselling and emergency grants to support groups and family events.

To find out more, visit <u>vorksbtc.org.uk/wellbeing-walks</u> Photographs courtesy of Rais Hasan

## THE POWER OF 10 – tackling Leeds 10k the MY way

It's usual to make friends of a similar age whilst going through shared experiences like university, careers and family connections, but it's not always easy to bond with others of different ages. The MY (Mid Yorkshire) Breast Cancer Support Group stick together like glue. There are over 210 members with the youngest being 23 and the oldest 85, all are women bar one (as even men get breast cancer too).

Regardless of the pandemic they have found innovative ways to stay connected. This includes: teleconferencing facilities for group Tea and Talks, bi weekly Crocodile Walks (socially distanced) doing 5k their way bi weekly, online forums and chats, a closed Facebook group, sewing scrubs and wash bags for the NHS, telephone calls, dance classes and helping friends with gardening or food/pharmacy deliveries, creative writing and more recently luncheon/evening meals out.

The mixed generations and ethnic diversity bring the richest connections, with different perspectives and ways of managing life with a breast cancer diagnosis. The age range brings nurturing and supportive bonds and valuable learning experiences. Members meet at various locations around West Yorkshire and demographics cover Harrogate, Huddersfield, Wakefield, Leeds, Kirklees to name a few. Throughout lockdown, ladies have worked tirelessly at supporting not only group members, but charities via fundraising activities. They feel it important to support all cancer patients and cancer charities, as it affects one in two of us in our life time. They share the love and pay the way forward for future patients and engage with their communities safely.

Founder and Chair Sara Williamson asked for 10 volunteers to take part in the Leeds 10K in support of Jacqui's Million. Sara met Jacqui Drake whilst on treatment and volunteering in radiotherapy at Jimmys a few years ago. Both are pretty hot at fundraising and an amazing friendship ensued. They are both well known for fundraising and networking, improving cancer pathways, and raising awareness of symptoms via various media platforms.

Jacqui is a terminal melanoma patient who pledged to raise one million pounds for valuable equipment for cancer patients at the Bexley, Leeds Cancer Centre. She oozes positivity just like these local inspirational women. Jacqui's Million is currently smashing the 260k mark. With the help of these ladies, they have contributed just under £5k and are grateful to those sponsorships. Should any one wish to still support the cause, donations can be made at <u>www.justgiving.com/Jacquismillion</u> quoting your NAME & STEP UP.



Sara liaised closely with the event organisers to ensure safety was paramount particularly for those on active treatment. They started out at the very back of the start line, and still beat their expected time by 20 minutes. Sara said "I am most grateful to ladies in the MY group who all work with abilities rather than disabilities. If one person is at a disadvantage, others step up. One of the side effects of my treatment is neuropathy, so breaking my foot after training, wasn't going to put a dampener on things. The lovely charity Experience Community stepped up with a trike, and tips to be able to complete this bucket list challenge in a wheelchair, with the aid of these merry "MY" women. Using your upper body and arms to propel yourself is hard when surgery restricts certain movement, so learning how to reengage different muscles was a tough call. I could not have done it without team "MY" and am humbled by their everlasting support of each other. What really hit us all was that this was the ultimate test. It was not about winning a marathon. It was about the distance itself being an accomplishment, be that in our care plans, cancer journey or actual kilometres. We felt the salt on our skin, cramping, high emotions for those that we have lost, a reality check for how far we have come, and a great sense of humility to be alive. All of us are wowed by the support of our donors".

Sara has marshalled at the Leeds 10k previously, but has never seen such excitement, respect and patience by all involved. "It seemed to mean more this year, what with the pandemic. Hats go off to the organisers. It was so wonderful to shout out to so many friends or families supporting different charities, particularly as it has been a tough time for charities losing many of their funding streams".

Ladies wanted to send out the message that life is not over with a breast cancer diagnosis and that exercise is paramount in reducing the risk of recurrence. It doesn't have to all be full pelt. You can do three lots of ten minutes per day, three or four times a week and it's great for the soul and mental health.

## The Faces behind the Cancer Information and Support Services at Scarborough and York Hospitals

During the Covid-19 pandemic, most cancer support services could no longer open their doors. Patients who had been used to calling into venues such as the Cancer Care Centre at York for complementary therapies, or just for a coffee while waiting for a medical appointment found themselves shielding at home.

While the support services were unable to offer their usual programme, nursing staff had never been busier, answering patient calls.

At Scarborough and York hospitals, Macmillan Lead Cancer Nurse Jackie Frazer, saw this as an opportunity to reorganise the support offered from both places to provide a more joined up service.

Michelle Kirkman in York and Gemma Kellerman in Scarborough now offer wellbeing calls to people affected by cancer and their families and carers, sharing the workload between them.



"There's no pattern to the calls," explained Gemma, pictured above. "Some people can't get hold of their GP, others just want a chat. Some are unsure of the terminology and don't know if it's the palliative team or a clinical nurse specialist (CNS) they need."

Michelle said patients have been reluctant to call their CNS (essentially their key worker) as they felt the

hospital was too busy with nurses too busy to take calls.

"We've given out the numbers and reassured them they can make that call.

"We've listened, and signposted and chased up the information they needed," she added.

As a complementary therapist, Michelle, pictured below, has also been able to offer simple breathing exercises over the phone to anxious patients.

The doors are still closed at the York Cancer Care Centre, although many of their services are offered online. Denise from the City of York Benefits Service works online from home and financial queries are dealt with by the Macmillan Financial Team.

In Scarborough, the small Macmillan office is next to the reception area, so



patients are able to call in, but financial advice is offered by Tracy from CAB, who is home-based. Even the Boots and Macmillan service which offered face to face appointments is still able to offer skin and beauty sessions via zoom calls.

Gemma, who has a background in healthcare, started working at Scarborough Hospital in 2019, and enjoys being part of the Cancer Information and Support team,.

Michelle started volunteering at a support group before landing her 'dream job' at the Cancer Care Centre York, 12 years ago.

Contact Monday – Friday: 8 am – 4pm

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Gemma (Scarborough) 01723 342606 Michelle (York) 01904 721166

## We bring the Support Group to you - Yorkshire Cancer Community Online Support Group

Our monthly online support group has just celebrated its first birthday. We started the group in response to so many groups having to close their doors during the pandemic, and to provide a listening ear for anyone who wanted to join in.

The group is open to any patient, carer or family member affected by cancer living anywhere in Yorkshire and the Humber. We don't have regular speakers, but chat about the topics of the day. During Covid we were particularly interested in how easy it was to access services, whether in person or remotely.

We're very fortunate to have a member of the Mid Yorkshire Macmillan Support and Information Team joining us each meeting. Kim, Laura or Amanda bring us an insight from Pinderfields Hospital and keep us updated on news from Mid Yorkshire Hospital Trust, including visiting restrictions or the launch of their new website.

One support group member said despite having cancer treatment, she had never been aware of what Macmillan could offer, until she attended the group. As a result she was able to apply for benefits, a blue badge and was helped get the information she needed for a pain clinic.

We've also been able to help attendees find out about other services such as Maggie's in Leeds or Cancer Support Yorkshire in Bradford. On one occasion, Community Artist Bob, led us in a mindfulness exercise to create patterns using just the resources we had to hand.

Since participants come from all over the region and meeting in person wouldn't be feasible, we've decided to carry on with the online format while there is still a need for the group.

We meet the second Tuesday of every month from 11 am – 12 noon. We would love you to join us. Contact <u>jill@yorkshirecancercommunity.co.uk</u> to receive a zoom invite and we can talk you through how to log on from your computer or laptop.



## Yorkshire Cancer Community Cancer Champion stars in NHS campaign to raise awareness that not every cough is Covid.

Retired welding engineer Ric Myers (69) from Leeds is passionate about raising awareness of lung cancer. Ric, who is a Champion with the Cancer SMART initiative, which we run in partnership with the West Yorkshire & Harrogate Cancer Alliance, was keen to be interviewed by Dr Amir Khan as part of a recent awareness raising campaign #DOITFORYOURSELF

"I was lucky in that they caught my lung cancer early. I had a persistent cough which was quite different to the smoker's cough, I used to have when I smoked," said Ric who was diagnosed in 2016.

Although initially dismissed as a virus, two chest X-rays confirmed that Ric had cancer, and he was scheduled for surgery at the Bexley Wing, Leeds, to remove a lump. Unfortunately, he had a reaction to the morphine and spent five days in Intensive Care.

He was due to have three courses of chemotherapy, but he developed sepsis, and his treatment was halted. Scans remained clear for nearly two years until in 2108, when black marks were detected on his left lung.

NICE (National Institute for Health and Care Excellence) had just approved a combination of chemotherapy and immunotherapy to be given to lung cancer patients and Ric was the first patient in Harrogate District Hospital, to be offered this treatment.

The regime continued until recently, when due to the number of infections he was contracting, the treatment was paused. Scans show the cancer is static. Ric has diabetes, COPD and Addison's Disease, which is a rare disorder of the adrenal gland.

Looking back, Ric confesses he has been a prodigious smoker and not looked after his diet or exercised. He was a very fit cyclist as a schoolboy, training daily, but when he started work, the welding shops of those times were thick with smoke. "You couldn't see your hand in front of your face. It was the norm and there was no awareness that it was an unhealthy thing to do," he recalls.

Ric was smoking as many as 40 cigarettes a day, and developed a bad smoker's cough. It was when he had frequent bouts of shortness of breath, he realized he needed to stop, so he could be well enough to be around for any grandchildren that might come along.

He stopped in 2014, using a smoking cessation clinic, which he found gave him the support he needed. "It's a bit like fighting cancer; you need the right mental approach to give up smoking. Being there for my grandchildren was all the motivation I needed."

Ric joined a Support Group set up at Sir Robert Ogden Macmillan Centre, Harrogate for lung cancer patients and their families. He found meeting with other patients and their loved ones to be reassuring, knowing he was not alone.

He knows the last 18 months must have been difficult for anyone with a smoker's cough. "Any cough has assumed to be Covid, but if you've had it for three weeks, it's time to get it checked out," he advised.

Ric's tip is to make a list of your symptoms when you go and visit the GP for the first time. That way you are equipped to answer any questions. "Don't be afraid. The sooner you get diagnosed, the better the outcome. The staff at Harrogate and Bexley were so kind, so supportive and with me every step of the way. You need the right mental approach. Take small steps and set small goals which can be easily measured."



www.yorkshirecancercommunity.co.uk

## Supporting cancer patients and their families from coastal communities

Hello, my name is Rebecca Price. I am a PhD researcher at Hull York Medical School, and I am funded by Yorkshire Cancer Research. I am exploring how we can best support cancer patients and their families in coastal communities during their cancer treatment.

The main focus of this study is to explore the following:

- To explore access and availability of support services available during cancer treatment and personal support
- Geographical comparisons of coastal and non-coastal areas in terms of deprivation and cancer outcomes
- To explore people's experiences of accessing cancer care from both coastal and noncoastal areas, specifically experiences of travel, and the impact this has on their everyday life and wellbeing.

We understand the importance of support services and personal support during cancer treatment. This can improve both physical and mental health and reduce distress. However, we do not fully understand the difference in these experiences and outcomes for patients and families in coastal communities.

The proposed study will involve multiple stages looking at both healthcare data and personal experiences. We will interview lung cancer patients who are currently accessing cancer treatment, or who have recently completed their treatment at Castle Hill Hospital in Cottingham, near Hull. This will include access to support, analysis of cancer outcomes and personal experiences, to understand how to best support patients and families in coastal communities.

#### Your involvement

We want to invite cancer patients or friends and family members with experiences of cancer to help us work out how to carry out this study. We are looking for people who live in coastal towns and villages in North Yorkshire, East Yorkshire and North East Lincolnshire. You do not need to have previous experience of research, just a willingness to give your perspective through either online meetings, email or telephone. With your help we can adapt this study in a collaborative fashion, creating a focus on what matters to people. There are five main aspects of this study that I am seeking your guidance on at different stages of this project.

#### Payment

We want to make sure that you are not out of pocket because of getting involved in our research. We also want to thank you for your time and contribution. For this reason, we offer a fee for each online meeting that you attend with us, an allowance of £5 to cover any related costs of online meetings (e.g. broadband or printing), and an additional fee if we ask you to review written information about the study.

SUPPORTING

WITH CANCER

WHO ARE WE LOOKING FOR?

We are looking for people who

and who live in a coastal area

orkshire cance

have experience of cancer, either

themselves, or within their family,

PEOPLE IN

COASTAL

Please let us know whether you wish to receive any of these payments. You can contribute to our work without payment if you prefer. If you receive state benefits or a pension, or pay income tax, we advise you to seek advice about how receiving payments from us might affect you.

#### Contact

Rebecca Price, PhD researcher Email hyrp26@hyms.ac.uk or Helen Roberts, Patient and Public Involvement Coordinator Email helen.roberts@hyms.ac.uk Tel 01482 463273.

If you would like to get involved please email Rebecca Price at: hyrp26@hyms.ac.uk or Helen Roberts by phone: 01482463273 COMMUNITIES

#### WHAT ARE WE LOOKING AT?

We want to learn more about what it's like to access cancer service and support if you live in a coastal community and how any inequalities can be addressed



We need your help to design our research study. We want to explore your experiences to help us focus on what matters to people living in coastal communities We would like to hold an online meeting to discuss our ideas and get your feedback. Alternatively you can contribute by email or telephone. We cover expenses and offer a fee to

thank you for your contribution.





## Blood in urine - I was a typical man – I ignored the early signs

When retired senior manager David Blunt spotted blood in his urine, he said he was a 'typical man' and ignored the signs. David, who lives outside Huddersfield in rural South Kirklees, first noticed the signs in February last year, but dismissed them as 'just a drop of blood'. It was only when talking with one of his daughters later that year, that somehow the conversation got round to worrying health conditions.

His daughter told him to make a GP appointment the next day. In fact if he wouldn't make it, she would. David worried it was an over-reaction, but got an appointment with a nurse practitioner at his local GP Surgery the next day, taking along a urine sample. He tested the sample for blood, confirmed there was blood present and asked him to return in a week's time. The next week, the sample again confirmed the presence of blood and David was offered an appointment at the Urology department at Huddersfield Royal Infirmary within 10 days. They performed an ultrasound scan and a cystoscopy – a procedure to look inside the bladder – a procedure David found to his surprise to be painless. The tests confirmed his prostate and bladder were clear but there was a lump on his right kidney they wanted to investigate.

The next week David was booked for a CT scan and was quickly contacted to say the consultant urologist would like to see him. Within the week, David was back at HRI, waiting to see the urologist. They told him his right kidney was twice the size it should be, and would need to be removed. They planned to use keyhole surgery which meant a quicker recovery for David. There was also a small lump on his left kidney, but it was so small, as not to be a major concern.

The pandemic was at its peak, and David suspected there could be delays before his surgery was scheduled but within two weeks, he was in hospital, with an expectation that surgery would take two hours. Unfortunately, his kidney was so large; they couldn't remove using keyhole surgery, so surgeons had to cut out the kidney, and also removed the adrenal gland too. He was later told that this procedure had probably saved his life.



He spent seven hours in surgery, and complications with his blood pressure meant his stay was extended to five nights.

"I'd only ever been in hospital once, and that was for a knee operation, so it was a shock to the system," he explained. He couldn't wait to get home, and once his bloods and blood pressure were deemed to be normal, he asked to be discharged.

That evening he woke in agony, and later passed out with pain. He ended up being readmitted into hospital, where after a short stay on a general ward, was moved back to Urology where he stayed for a further four days. David was told he would have follow up scans every three months to keep an eye on the remaining kidney. The plan being to remove the lesion by robotic surgery at Bradford Royal Infirmary. However, by the next scan the tumour had grown from 17 mm to 28 mm and David was referred to St James's Hospital Leeds for cryotherapy (the use of extreme cold to freeze and remove abnormal tissue).

Up until this point, David's treatment had been second to none. Any problems or concerns were promptly addressed by his two Clinical Nurse Specialists. He felt reassured he was treated as a person and not just as a number. He was so impressed by the care given to him at HRI; he wanted to give back and became involved with the Macmillan Information and Support Service at Calderdale and Huddersfield Hospitals. Along with another patient Rob (now a YCC trustee and Cancer Champion) he helped the Macmillan team of Helen, Mandy and Holly, work on digital services for patients during lockdown, which are now in line for national awards. He also volunteers for the West Yorkshire & Harrogate Cancer Alliance Community Panel, and enjoys looking at topics, which could improve patient experience. Now to his frustration, he has had no further news about his cryotherapy at St James, which leaves him in limbo, aware his tumour may still be growing.

"It's frustrating, but I do understand that with only three consultants and one who has been self-isolating due to Covid that the staff team are stretched. I do appreciate that but it's frightening because this is my life and I feel like everything is on hold."

## 5k Your Way - a support group with a difference

5k Your Way returned in September for the first time since the pandemic.

This is a community-based initiative to encourage those living with and beyond cancer, and their families, friends and anyone working in cancer services, to walk, jog, run, cheer or volunteer at a parkrun on the last Saturday of the month.

In West Yorkshire, 5k Your Way is held at Woodhouse Moor, Leeds, just one mile from the city centre. I went along to meet with ambassadors Lynn de Dombal and Vicki Gilbert (pictured below), who were there to welcome participants.

Lynn, a specialist physiotherapist explained the event was not about running. Anyone coming along could choose

to walk, jog, run or cheer on other participants. Afterwards ambassadors gather up participants for socialising over a much needed cake and drink nearby.

5kYour Way takes place on the last Saturday of the month at 9am meeting at a tarmac area near to Akmal's Tandoori Bistro, near to A660 Woodhouse Lane. Woodhouse Moor offers good access with completely paved routes.

Further information about the event and access to public transport can be found at <a href="http://www.parkrun.org.uk/woodhousemoor/course">www.parkrun.org.uk/woodhousemoor/course</a>

5k Your Way is held at other Yorkshire locations including Hull, Sheffield, York and Harrogate. For more details see: <u>www.5kyourway.org</u>



## A Yorkshire-wide network of Support Group Leaders

Support Group Leaders from across Yorkshire and the Humber have been meeting together online every two months to discuss the impact Covid has had on their groups.

The meetings were initiated by Ian Margerison, Macmillan Engagement Lead and have also included ourselves and Cancer Support Yorkshire.

They have been a useful forum to learn from groups who have successfully made the transition from face to face meetings to zoom calls. And now to learn from those groups who are hosting hybrid meetings featuring face to face with a zoom link for those who prefer to log in from home.

Groups have been inventive during the pandemic using WhatsApp, text, telephone conferencing, letters as well as emails to keep in touch with members. Others have met in smaller numbers outside or gone for socially distanced walks.

Many groups have met on hospital or charitable premises, and most hospital trusts are not confident to open their doors to support groups yet. In some cases, rooms that used to be available for support groups are now being used for vaccinations. Meetings have also discussed how to recruit new members and how to set up closed Facebook groups.

There is still a small amount of funding left from Macmillan to help support groups to continue, although the budget has almost been spent until the next financial year. For more information, contact Ian Margerison <u>IMargerison@macmillan.org.uk</u>. If you would like any of the notes from previous meetings or would like adding to the invitation list, please contact <u>jill@yorkshirecancercommunity.co.uk</u>



Breast Friends York have managed to stay in touch using Zoom

#### 07715 217845

## Help us beat cancer pain – we need your help!

Hello, I'm Dr Andy Page, a palliative care doctor, working at Leeds Teaching Hospital. I am interested in learning about the experience of patients, their friends or relatives who have lived with pain due to cancer.

#### We need you:

We need your help in the fight against cancer pain! Have you or one of your loved ones had cancer which caused pain? Would you like to be involved with scientific research to help others with cancer pain? Cancer affects 1 in 2 of us in our lifetimes – lets beat it together!

\* \* \* Volunteers NEEDED – only 1 to 2 hours of your time is required \* \* \*

We are planning research to help people with pain as a consequence of a cancer or cancer treatment. We need your help when planning this research, to ensure it tackles the issues important to those who have experienced cancer pain.

We plan to run a 90 minute focus group on Zoom to discuss your experiences of living with cancer pain and our research plans. Dates can be decided based on your availability.

Please get in touch – Email: <u>a.j.page@leeds.ac.uk</u>; Tel/ Text: 07392692675

\* \* \* A £25 gift voucher will be given as a thank you for your time \* \* \*

#### The problem:

Pain has a huge impact on those with cancer. It can affect over half of people receiving chemotherapy for cancer, rising to at least two in every three people with more advanced cancer.

Uncontrolled pain impacts on everyday life, making previously normal daily tasks (such as washing, dressing) and hobbies more difficult

or sometimes impossible. In turn, it can have a wide variety of knock-on effects, sometimes affecting an individual's mood, appetite, and energy levels.

For loved ones, it can be equally challenging, particularly if they feel powerless to help. Its impacts cannot be overstated!

Despite the use of current pain treatments, uncontrolled pain remains a significant burden for people with cancer. Even in those who achieve some degree of pain control, side effects from pain medication can be significantly burdensome; for some, more so than the pain itself.

It is important that doctors understand which drugs are helpful for people with cancer pain to ensure that pain can be well controlled. Despite advances in modern medicine, we shamefully do not still understand how to best use certain pain medication for cancer pain. Help us change this!

**NIHR** Research Design Service Yorkshire and Humber

Working with:

The Leeds Teaching Hospitals

Funded by:







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UNIVERSITY OF LEEDS

## Guts UK – the UK's charity for the digestive system

Guts UK is the only UK charity funding research into the digestive system from top to tail; which includes several conditions such as Crohn's disease, Irritable Bowel Syndrome

(IBS) and diverticular disease. Guts UK also cover cancers including:

- pancreatic
- liver
- bowel
- oesophageal
- stomach cancer



We all have guts – around 25 feet of them – and we don't really know a huge amount about why things go wrong.

Jenny Holdsworth, Community and Fundraising manager explained: "Our guts have been underfunded, understaffed and undervalued for decades. Together, we will join forces and bring about important change in this misunderstood area of health."

Jenny was speaking to me from the charity's office in

central Huddersfield. Some members of the team are based in London. The West Yorkshire location came about because gastroenterologists based in the North, used to come together nearby, as a convenient meeting point for what was known as the M62 Gut Club.

The charity used to be known as the much less memorable, Core. Since 1971, they have funded almost 300 projects and invested nearly £16 million pounds into medical research that leads to earlier diagnoses and kinder treatments for the millions of people who don't have the luxury of taking our guts for granted.

**Guts UK aims:** 

- To provide expert information information is power. When armed with information, patients can take control of their health and make informed decisions
- Raise public awareness their research shows 58% of people are embarrassed to talk about their digestive condition or symptoms. 51% of people delay seeking advice for their symptoms for over six months
- Fund life-changing and life-saving research: Guts UK is the only UK charity funding research into the digestive system from top to tail.

Guts UK is a founding member of the Less Survivable Cancers Taskforce, a partnership of six charities targeting six overlooked and underfunded cancers with the lowest survival rates: lung, brain, liver, stomach, pancreatic and oesophageal. Four of these six are digestive cancers.

The Taskforce campaigns to double the five year survival for these cancers. These cancers have a collective five year survival of only 14% and the campaign wants the Government and NHS England to commit to doubling survival to 28% by 2029.

"The trouble is the digestive cancers very often don't have recognizable symptoms. If it's indigestion or heartburn, patients feel they shouldn't bother their GP. The LSCT raise these issues with Parliament and has made headlines. "We are a small but mighty charity. We're dedicated to getting to grips with guts, once and for all," added Jenny.

To find out more about the Less Survival Cancers Taskforce see: <u>https://lesssurvivablecancers.org.uk</u>

To read about Guts UK and the research they fund to fight digestive diseases see: <u>https://gutscharity.org.uk</u>





## **Inspirational Campaigner Jo Taylor**

Sara Williamson founder and Chair of MY (Mid Yorkshire) Breast Cancer Support Group talks with Jo Taylor a mother of two, cancer patient and founder of the UK's only patient advocacy group for metastatic breast cancer known as "METUP UK".

Some people will say that breast cancer is the most common cancer in women due to the numbers diagnosed. Nearly a third of women diagnosed with early stage breast cancer will develop metastatic disease. Thirty-one women die daily and it's the biggest cancer killer of women under fifty.

Both women compare notes on how essential online platforms have been, particularly during lockdown. The voluntary and advocacy sector are picking up the pieces of the rather stretched NHS, and higher than normal

numbers of referrals are being made. Jo feels strongly that more needs to be done by our policy makers and health care professionals to widen the scope of clinical trials to elevate survival rates. Some patients may not have attended screenings or ignored body changes for fear of Covid, and Cancer will be around long after the pandemic.

What is frustrating is that somehow metastatic breast cancer gets lost in the hype of pink campaigns. Obviously, branding is important but there's nothing pretty, sexy or feminine about this incurable disease. Jo's hope is to gain access to the best medicines to prolong life, more so having lived with the disease for over seven years. It's important that primary breast cancer patients understand and recognise symptoms of MBC so that they can receive treatments sooner rather than later.

Jo is a great advocate of healthy lifestyle options and set up "abcd retreat" (<u>www.abcdiagnosis.co.uk</u>). This offers a fabulous weekend wellbeing experience. Sara said her experience was amazing being outdoors in the beautiful



be amongst like minded patients. Jo created the MBC infographic for red flag symptoms, which is used by NHS England for use throughout England for awareness of signs, and symptoms. Her Consultant, Medical Oncologist Dr Greg Wilson of the Christie, is happy to support Jo's formidable drive and commitment in improving treatment options.

If you would like to know more about the retreats check out the websites. With news reports showing that many people have put on lockdown weight, it's important to stay active to reduce the risk of recurrence.

METUPUK will be launching their interactive engagement campaign for Metastatic Breast Cancer during the month of October to coincide with Breast Cancer Awareness Month. Their campaign focuses on the darker side of cancer instead of the fluffy pink narrative. They are not sugar coating a disease that kills 31 women every day. Consisting of 31 individual female figures, a short video reveals the thoughts and frustrations of living with Metastatic Breast Cancer. This awareness campaign wants to change the statistics around this disease and we need everyone to be included in the conversation. The display will travel around various shopping centres, appearing in a selection of cities across the UK, supported by an online and social media presence.



## How can we improve breast screening uptake amongst women living in less privileged areas?

Hello, my name is Emily Lunn. I'm a researcher at Hull York Medical School. I am funded by Yorkshire Cancer Research, and I am exploring how day-to-day life for women living in less privileged areas affects their attitudes to breast screening.

We know that women from less well-off areas are less like to attend breast screening appointments. They are more likely to be diagnosed with breast cancer at a later stage and this means more intensive treatment and a lower chance of survival. My research aims to explore day to day life for women living in less privileged neighbourhoods across Yorkshire and how this affects their understanding and acceptance of breast screening.



The main focus of my study is to explore:

- What information and experiences shape women's ideas and attitudes about breast screening?
- How does breast screening fit into the pressures of everyday life for such women?

We will carry out focus groups with women who are of breast screening age (50-70) and live in less well-off neighbourhoods. We want to talk to all women, regardless of whether they have attended breast screening. We will discuss their everyday lives, including family, friendships, work, and social lives.

We know that there are many reasons why women are unable to go to breast screening. For some women, it may be difficult getting time off work. They may have caring responsibilities meaning there isn't enough time in the day to attend a screening appointment. For others, the fear or embarrassment of having a mammogram can be overwhelming. I want to talk to women about these kinds of issues so that we can understand how to make breast screening easier for women.



#### Why do we want you to be involved?

We want to talk to a small group of women from different parts of Yorkshire who have relevant personal experience, to help us to develop this study. You do not need to have previous experience of research, just a willingness to give your perspective through either online meetings, email, or telephone. With your help, we can carry out this study in a collaborative way, with a focus on what matters to women.

#### What do we need help with?

- There are 4 key areas we need your guidance on:
- 1. The research topic
  - Do you think this is an important area to research?
  - Do you think this research will benefit women?
- 2. Carrying out the research
  - What do you think about using focus groups?
  - Do you have any ideas about ways to work with women?
- 3. Finding women to take part in the study
  - We want to talk with women who do and don't attend breast screening. Do you have ideas about how best to reach women of screening age from less well-off communities?
  - Do you think we should approach this from a broader women's health point of view rather than focusing on cancer awareness?
  - What do you think is the best way of describing less well-off communities without being disrespectful to the people that live there?
  - Do you think we should offer women an incentive, like a shopping voucher, to take part in this study?
    - Can you share our recruitment advert within your networks?
- 4. Further involvement
  - Do you want to be involved with other stages of this study? For example, helping to review our findings, or helping to promote our findings in a clear way?

#### Payment

We want to make sure that you are not out of pocket because of getting involved in our research. We also want to thank you for your time and contribution. For this reason, we offer a fee for each online meeting that you attend with us, an allowance of £5 to cover any related costs of online meetings (e.g., broadband or printing), and an additional fee if we ask you to review written information about the study. Please let us know whether you wish to receive any of these payments. You can contribute to our work without payment if you prefer. If you receive state benefits or a pension or pay income tax, we advise you to seek advice about how receiving payments from us might affect you.

#### Contact

Emily Lunn, Postgraduate Researcher Email: emily.lunn@hyms.ac.uk or Helen Roberts, Patient and Public Involvement Coordinator Email: helen.roberts@hyms.ac.uk Tel: 01482 463273



# YOU CANcervive – Let's talk about cancer – our new podcast made in partnership with the West Yorkshire and Harrogate Cancer Alliance

It's been an exciting few months for our podcast – which was launched in August as part of the Cancer SMART initiative. Cancer SMART is a project to help tackle cancer, with the potential to save lives through more effective prevention advice and early diagnosis. To help steer the direction and design of the project, we involve Cancer Champions, a group of volunteers who have already been affected by cancer.

**News** 



Two of this group, cancer survivors Arzoo Dar and Rob Husband, came up with the idea of creating a podcast as being a Covid - safe way to reach more people with our Cancer SMART message. They have based episodes on the key messages contained in the SMART acronym using patient stories to illustrate.

We wanted to make a podcast for everyone, not just those who have survived or experienced cancer themselves – but for those who could potentially find themselves touched by cancer in their lifetime.

Said Rob, who was diagnosed with a head and neck cancer: "We want to make cancer an everyday conversation and get people talking, while focusing on the fundamentals of the Cancer SMART initiative." Arzoo, who experienced bone cancer as a teenager said: "We are passionate about raising awareness of cancer throughout the whole journey, from prevention, screening and early diagnosis through to survival and end of life."

You can access the podcast by scanning the QR code on the schedule on this page, or by going to our website:

https://yorkshirecancercommunity.co.uk/youcancervive-podcast/



## From Me To You

Who doesn't love receiving a letter? The chatty, informal sort, packed full of everyday juicy titbits with glimpses into someone else's life. And even better, with no obligation to respond.

When Alison Hitchcock's friend, Brian Greenley was diagnosed with bowel cancer in 2010, she offered to write letters to cheer him up. "I felt quite helpless. What could I offer? I didn't have any medical expertise. I didn't know him particularly well. Writing a letter seemed a simple thing to do," she explained.

Over the next two years, as Brian's cancer moved from stage III to IV, Alison continued to write letters. She told him about her daily life, the mundane happenings, the things that made her laugh. Although he had family and friends, he had been feeling disconnected from the world. Little did she know what an impact she was making. "He told me he saved the letters to take with him when he was having chemo. That way he could feel that I was there alongside him. He liked to re read a letter when he was feeling grim and it helped him to think that someone had been thinking of him," said Alison.

Brian who has now been clear of cancer for nine years comments: "I never appreciated how a letter could change my outlook on the day. Instead of seeing the world through my eyes, I saw it through Alison's eyes. People diagnosed with cancer often feel isolated. Alison writing a letter felt like a wonderful gift."

The pair of friends were urged to turn their idea into an organisation so that others could benefit. This led to the creation of From Me to You – a charity inspiring people to write letters to those living with cancer. From Me to You now offers a website with helpful tips on how to write a letter and letter writing workshops. Writers can donate a letter to a stranger, helping to reduce the social isolation and loneliness so often associated with cancer. Recipients can dip into the 'Happy Box' to receive a letter just the once or on a regular basis.

From Me to You works with 18 cancer centres and partner charities across the country including Maggie's Leeds, who help to distribute the letters to people undergoing treatment or living with a cancer diagnosis. Many cancer patients having benefited themselves decide they would like to write letters to others with a diagnosis.

"Living with cancer takes away so much of your independence, and this is a way they can give back," added Alison. Letter writers are given guidelines and asked to fill out an agreement not to disclose personal information, which could identify them. Letters can be handwritten or typed, and can even be emailed to the charity, if that makes life easier for the donor.



Alison and Brian cofounders of From Me to You

#### Why It's Good to Write - an excerpt from the From Me to You website

There are several reasons why it's good to write both for yourself and the reader.

- Letters are rarely misinterpreted, unlike texts and emails. A letter can't be rushed so the intent and voice are stronger.
- Research shows that a routine of letter writing can increase levels of contentedness and lower instances of depression.
- The reader has a choice about when to open your letter. It can lift a mood, provide comfort or be a special moment.
- You can fill a letter full of positivity, unlike the other things that come through the letterbox bills.
- You can express emotions and feelings in letters that you might struggle to articulate face to face.
- Holding a letter engages the senses of touch and smell two senses excluded from the digital age

"Cancer has left me feeling isolated and cut off from normal life. A letter arriving can change everything about my day." Dawn

"When my friend said my letters made him laugh out loud in the chemo ward, I knew I was making a difference." Anthony

There are now 3,000 writers signed up to From Me to You with around 1,000 active at any one time. Writers are sent thank you emails and newsletters, and Alison gets to know many of them personally.

If you are interested in being a writer, or receiving a letter, please go to https://frommetoyouletters.co.uk

I'd just like to say thankyou to you and everyone who writes letters to people like me who have been stuck in the house for most of this year. It's really helped to know that we are not alone and some special people are thinking of us

**Tracey, Letter Recipient** 

I hope you enjoyed this edition. If you would like your story to feature in the next edition, please contact me <u>jill@yorkshirecancercommunity.co.uk</u> or telephone 07715 217845. Please find more information, <u>including updates on all our projects on the website</u>: <u>www.yorkshirecancercommunity.co.uk</u>

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