

Thames Valley Cancer Alliance Spring 2018 Newsletter



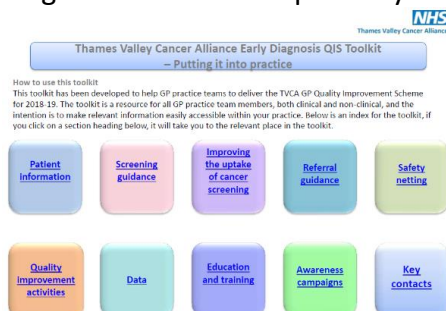
Welcome to the Spring edition of the Thames Valley Cancer Alliance newsletter - keeping you up-to-date with local, regional and national cancer developments and some of the important work that is being progressed across Thames Valley. **Let us know about what is happening in your area by contacting a member of the team and you could be in our next newsletter!**

Transformation Programme Update

QIS Project

The Quality Improvement Scheme (QIS) project team has developed a toolkit to help GP practice teams deliver the TVCA GP Quality Improvement Scheme for 2018/19.

The toolkit is a resource for all GP practice team members, both clinical and non-clinical, and the intention is to make relevant information easily accessible within practices. The toolkit includes best practice guidance and interventions which can be applied within practices to help increase screening uptake (for breast, bowel and cervical) and support improvements in cancer diagnosis via the 2ww pathway.



<http://tvscn.nhs.uk/networks/cancer/quality-improvement-scheme-qis-toolkit-for-primary-care/>

Contact Us: peiying.lo@nhs.net Alliance Team Administrator, Thames Valley Cancer Alliance

Anant Sachdev/Alison Burton – Joint Project SROs

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LWBC Project

TVCA Living With and Beyond Cancer Stakeholder Event

One of the Cancer Alliances' key priorities is implementing the recovery package – a series of interventions designed to support patients (and carers) to self-manage and receive holistic care following a cancer diagnosis and treatment (or those 'Living With and Beyond Cancer'). This project aims to build current best practice ensuring that all patients across Thames Valley have access to the same standard of support for Living With and Beyond Cancer.

This project was positively kick-started at an event held on 30 January 2018. Great representation from various organisations across the alliance came together to discuss and to share best practice. Attendees unanimously expressed their desire to work to improve the quality and uptake of the recovery package, and were able to identify what needs to happen locally and at a wider system level to make

this happen. The clinical leads of the project, Shelley Orton (Deputy Lead Cancer Nurse, Oxford University Hospitals) and Kate Rawlings (Macmillan Berkshire Cancer Rehabilitation Lead) presented the current picture across Thames Valley, before sharing best practice (and the minimum standards to achieve this) and providing some practical guidance and tools to support this.

Shairoz Claridge, (Director of Operations for Newbury & District CCG) the project SRO, was very pleased to see various sectors come together and share their learning, reiterating the need for system wide change in order to improve support and outcomes for cancer patients. The project team left the room, enthused with the desire for transformation that came from this event. The project team have subsequently been working with GPs to further discussions about Cancer Care reviews in Primary Care.

The planned next steps include working with organisations to help implement minimum standards and supporting them with education needs. We are continuing to link with other

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workstreams as part of the joined up wider approach to cancer transformation in Thames Valley. For further information please contact:

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Shelley Orton – Clinical Lead

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Kate Rawlings – Clinical Lead

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Cancer Pathway Redesign Project

Good cancer care begins with good pathways. The NICE guidelines (NG12 2015) moved a few of the goal posts to try and improve referral rates and referral contents.

Following publication of the NICE guidance, 2 week wait referral forms were made mandatory in Oxford. Educational points were added to help GPs decide who and when to refer. In collaboration with secondary care specialties, the NG12 criteria were adapted to fit the local services and allow 'right slot, first time' to be attained.

By studying the complete pathways where targets were often missed (Urology, Gastro, Gynaecology and Lung), we were able to move some of the diagnostics ahead of the first outpatient appointment (OPA) to achieve a more streamlined course of care and better outcomes.

By working together across primary and secondary care, on the four pathways where performance is currently poor, the Cancer Alliance Redesign project aims to achieve a more effective outcome for patients across Thames Valley, even if test results is negative. By referring early into an efficient pathway it is anticipated to reduce the cancer pick up rate to 3% and detect cancers earlier, with all the benefits that these sequelae allow.

Dr Shelley Hayles

Project Clinical Lead

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David's Blog



Since being asked to write a blog for the TVCA I have asked myself what qualifies me to be a patient representative. After all, I'm no different from anyone else who has been diagnosed and treated for cancer.

It's been just over three years now since my cancer pathway started, and I count myself fortunate with the outcome, so far.

My pathway didn't follow the designated pathway of the time, I say of the time because cancer pathways are changing, and hopefully for the better.

Let me reassure anyone who is reading this blog, I am not from a healthcare background, so I am impartial and want to see the best outcome for everyone diagnosed with cancer.

Managing cancer is extremely expensive, and that's probably an understatement. I've no facts or figures to substantiate this, but as a specific area of the healthcare budget, cancer, taken as a whole (research, diagnosis, treatment and aftercare at home or hospital/clinics etc.) must account for a large percentage.

The reason I'm writing about this is because changes are having to be made as resources allocated to cancer are finite and decisions made now will impact on how we manage cancer over the next decade or so. Due to increasing costs, the way forward in diagnostic, treatment and aftercare pathways are being revised with the best outcome for patient survival being the central outcome. It is not about dealing with future higher numbers being treated so that they live for five, ten or more years; it's about people living for five, ten or more years with the best quality of life possible.

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Initially, being diagnosed with cancer and then being informed that it is treatable is probably enough, but actually there is more to it. Imagine that there are three categories of treatment outcomes. The first, where life is prolonged (where diagnostics have been too late and certain treatments are no longer options). The second, where life is extended (where diagnostics have been good, but the treatment plan is cost related) and allows for larger numbers to be treated but doesn't fully take into account post quality of life issues. The third is where life is extended with quality. This outcome is the same as the second regarding diagnostics, but the treatments available are not cost capped, allowing for the same recovery, but with a better quality of life.

Any new pathway must be robust regarding the incorporation of new treatments as and when they become available. This will be a big factor when patient outcomes and available budgets have to be balanced; the logistics of buildings, equipment and staff required to underpin any new pathway is considerable. The new pathway will need to be designed to accommodate improvements in all areas of cancer (diagnostic, treatment and aftercare) and have the capacity to implement them quickly whilst minimising the impact on the ongoing service.

Maybe, modular pathways, where staff and logistics are based strategically as dedicated teams around the country, ensuring standardisation of care, which hopefully will enable outcome three to be delivered to all future cancer patients, is a possible way forward.

Cancer is specialised and requires specialist staff and specialist facilities in order to operate at the highest level. There is a caveat to achieve the best outcome for patients, which can unfortunately put a burden on patients who are required to travel to the new specialist pathway centres in order to receive the best possible treatment and quality of life outcome. A priority consideration to any new pathway must be to minimise the stresses placed upon patients and their personal support team who will be travelling, in some cases long distances to the new centres. This means providing adequate free parking and ensuring that short-term accommodation is available, close by, for one or two-night stays.

The above adequate free parking requirement shouldn't be limited to the patient, but must be extended to medical and support staff. We have made the car the primary means of transport, and therefore, we must build facilities to accommodate this at the planning stage of any future long-

term project, including the new cancer pathways.

Being able to park free at the point of work or treatment should not be considered a perk. It is about looking after the workforce and patients by reducing stress. I doubt if loss of income from parking fees comes close to loss of working hours due to accumulated stress or the impact of stress on patient recovery.

Food for thought.

David Manthorpe
Patient Representative for the Thames Valley Cancer Alliance & Chair of the Compass prostate Cancer Support Group
<mailto:pca.group.members@gmail.com>

I'd welcome your thoughts on the above.

Why Patient-Led Partnerships are Key in Success for Meaningful Cancer Patient Engagement

By Suzan St Maur
Milton Keynes Cancer Patient Partnership (MKCPP)

Cancer patient groups come and go, as we have seen in the Thames Valley region – and others – over time. Various reasons are given

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<https://tvscn.nhs.uk>

but invariably the demise of such groups has its roots in an imbalance between the need for independent discussion, and the fact that in the main, such groups have been hosted not by patients, but by an NHS region/STP, Trust, CCG, charity, etc.

Now that the patient voice is being recognised for its value not only in terms of medical PR, but also in terms of insightful, relevant and co-operative input, such an imbalance is even less likely to work than it did before.

Today's cancer patients and carers: articulate, constructive and caring.

It's worth remembering that cancer patients and carers are also human beings, most of whom are intelligent community members who are more than capable of leading and contributing to such groups in a very positive manner.

We patients are not out to nitpick over trivia with the HCPs, NHS admin staffers, Macmillan staffers etc. If we have complaints there are (or should be) well marked, *separate* pathways for those to be shared and discussed. Patients joining engagement groups have as much interest in constructive criticism and its practical and affordable resolution, as the paid professionals and staffers do.

Patients are the only common denominator across the entire cancer journey. This is another

factor that seems to have escaped even NHS strategists. Due to the unfortunately vertical structure of cancer care in the UK (and elsewhere), cancer journeys tend to be chopped up and shoved into various silos – e.g. primary care, acute care, oncology, palliative care, hospice service, etc. Large cancer charities support various elements within these areas but are unable to homogenise them. First, the bad news; patients and carers find this issue - of left hands not knowing what right hands are doing - very worrying, usually at a time when they need extra worry like a third eyebrow. The good news, however, is that because patients are obliged to view the big picture whether they like it or not, they can provide a wider and more holistic impression of the cancer journey in their locality than the other factions have time to consider.

This common denominator leads to a truly balanced partnership.

Considering that the longevity of most cancer patient groups in this region and elsewhere is five years or less, it's interesting to note that the MKCPP was first established in 2002 and is still going strong today. It was important even back then to the founders of the group, to set the criteria that would create a productive and harmonious partnership of cancer patients, carers, HCPs and others involved in the cancer journey. And that's what happened. The

group, started by our current Secretary Jaff Newton and a handful of other cancer patients and carers, led from the front in creating a partnership with all concerned.

Because of our neutral and all-encompassing stance in among the various, vertically structured factions at local, regional and national level ... we are well placed to offer these key resources:

- Unbiased signposting for cancer patients and carers on our patch and beyond
- A continually updated stream of information and feedback to all cancer care factions
- A patient-led forum in which all local cancer stakeholders work together as equals
- Workshops for GP practices bringing primary, hospital, Macmillan, plus dozens of local patients together for learning, sharing and networking.



For more information about the MKCPP please visit <http://mkcpp.org> or email info@mkcpp.org



Spotlight Feature - The 'Spotlight' feature aims to share information and highlight key developments in specific areas of cancer.

Spotlight

CANCER SCREENING

The Benefits and Risks of Screening

The benefits of having a screening test include:

- Screening can detect a problem early, before you have any symptoms.
- Finding out about a problem early can mean that treatment is more effective.
- Finding out you have a health problem or an increased risk of a health problem can help people make better informed decisions about their health.
- Screening can reduce the risk of developing a condition or its complications.
- Screening can save lives.

The risks and limitations of screening include:

- Screening tests are not 100% accurate. You could be told you have a problem when you don't – this is called a "false positive" and may lead to some people having unnecessary further tests or treatment as a result of screening. A screening test could also miss a problem – this is called a "false negative" and could lead to people ignoring symptoms in the future.
- Some screening tests can lead to difficult decisions.
- Finding out you may have a health problem can cause considerable anxiety.
- Even if your screening test result is normal or negative (i.e. you are not at high risk), you could still go on to develop the condition.

Bowel, Breast and Cervical Screening

NHS England is responsible for commissioning NHS Screening programmes including bowel, breast and cervical.

Bowel Screening

The NHS Bowel Cancer Screening programme offers screening every 2 years to all men and women aged 60 to 74. Over 75s can request a home testing kit every 2 years by calling the free bowel cancer screening helpline on **0800 707 60 60**.

Bowel cancer is the third most common cancer in the UK, and the second leading cause of cancer deaths, with over 16,000 people dying from it each year. Regular screening has been shown to reduce the risk of dying from bowel cancer by 16% and can save up to 20,000 deaths from bowel cancer over the next 20 years if just 60% of those eligible take up the invitation for bowel screening.

Bowel scope screening (also called flexible sigmoidoscopy or 'flexisig') is being rolled out to all men and women in England aged 55. This is a one-off test. If a patient decides not to have the test straight away, they can ask to have it at any point up their 60th birthday.

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Breast Screening

The NHS Breast Screening Programme is offered to all women aged 50 to 70 years every three years. There is also a national randomized control trial of age extension which involves women aged 47 to 49 years and 71 to 73 years being invited for screening.

Breast cancer is the most common type of cancer in women in the UK, and causes around 12,000 deaths each year. Regular screening can lead to a 20% reduction in mortality with 1300 deaths prevented annually.

Cervical Screening

The NHS Cervical Screening programme offers screening at different intervals depending on age.

- aged 25 to 49 – every 3 years
- aged 50 to 64 – every 5 years
- over 65 – for women who haven't been screened since age 50 or those who have recently had abnormal tests.

Cervical cancer is the most common cancer in women under 35 years of age, and mainly affects sexually active women aged between 30 and 45 years; with around 3,100 women diagnosed each year. Cervical screening can prevent around 45% of cases in women in their 30s rising to 75% women in their 50s & 60s. The national screening programme has saved over 8000 lives in the last decade.

Further information and useful links can be found in the Resources section below.

Bowel Cancer Awareness Month April 2018

Get ready to support Bowel Cancer Awareness Month here in the UK which this year focuses on raising awareness of bowel cancer symptoms.

The symptoms of bowel cancer include:



- Bleeding from your bottom and/or blood in your poo
- A persistent and unexplained change in bowel habit
- Unexplained weight loss
- Extreme tiredness for no obvious reason
- A pain or lump in your tummy

If you have any concerns or if things just don't feel right, go and see your doctor

<https://www.bowelcanceruk.org.uk/bowel-cancer-awareness-month/>

TVCA Resources

SoE Dashboard

South of England Cancer Alliances Dashboard

<http://tvscn.nhs.uk/networks/cancer/resources/>

QIS Toolkit

<http://tvscn.nhs.uk/networks/cancer/quality-improvement-scheme-qis-toolkit-for-primary-care/>

Resources

Screening

Information for patients and public

NHS Choices

<https://www.nhs.uk/Livewell/preventing-cancer/Pages/cancer-screening.aspx>

Public Health Matters is the official blog of Public Health England, providing expert insight on the organisation's work and all aspects of public health.

<https://publichealthmatters.blog.gov.uk/category/hwb/screening/>

Cancer Research UK

<http://www.cancerresearchuk.org/about-cancer/screening>

Information for professionals

Public Health England Screening helpdesk

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<https://tvscn.nhs.uk>

https://legacyscreening.phe.org.uk/email_us_form.php

Public Health England Screening blog

<https://phescreening.blog.gov.uk/about/>

Health Matters - a resource for public health professionals and LAs

<https://www.gov.uk/government/publications/health-matters-making-cervical-screening-more-accessible/health-matters-making-cervical-screening-more-accessible--2>

<https://www.gov.uk/government/publications/health-matters-preventing-bowel-cancer/health-matters-improving-the-prevention-and-detection-of-bowel-cancer>

<https://publichealthmatters.blog.gov.uk/2016/07/11/health-matters-bowel-cancer-behind-the-data/>

OXCHOCS (Oxford Churchill Hospital Ovarian Cancer Support) **OXCHOCS** aims to provide a safe, confidential space where ladies with ovarian cancer can meet to share experiences and receive support, as much or as little as they feel appropriate. OXCHOCS provide telephone support to enable ladies with ovarian cancer to live well with their disease and encourage fund-raising to support gynaecology cancer services at the Churchill Hospital and gynaecology cancer research within Oxford University.

OXCHOCS also represent ovarian cancer patients' views within the Thames Valley Gynaecology Cancer Alliance Group.

The next OXCHOCS meeting is at the Maggie's Centre, Churchill Hospital, on Tuesday 5th June 3-5pm. All ovarian cancer patients are welcome at this meeting.

<http://www.oxchocs.org.uk>



Cancer Research UK Facilitator Programme

The Cancer Research UK (CRUK) Facilitator Programme works in partnership with the NHS to provide face to face tailored support to GP practices and health professionals to help improve the prevention and early diagnosis of cancer.

How can your local CRUK Facilitator help you?

Facilitators can offer a range of support depending on your needs and priorities. This can include:

- A facilitated discussion of your practice cancer profiles
<https://fingertips.phe.org.uk/profile/cancerservices>
- Support to help you increase your screening uptake, particularly bowel screening. Providing information on best practice and

evidence based strategies along with patient information and resources to help you to raise awareness.

- Providing and introducing you to a range of early diagnosis tools and resources including a wide range of patient information
<https://publications.cancerresearchuk.org/>

- Facilitate a one hour safety netting workshop to help you to review and reflect on your current safety netting processes and systems.

- Deliver a one hour cancer awareness and screening workshop for your non-clinical staff (these have proved extremely popular and effective with practices in other parts of the Thames Valley).

A practice visit or workshop can be scheduled in to a practice meeting, or as part of your protected learning time. Contact your area Facilitator to arrange a practice visit or a training session.

Berkshire West: Bridget England
bridget.england@cancer.org.uk

Tel: 07500 881933

Berkshire East and Buckinghamshire: Louise Forster
louise.forster@cancer.org.uk

Tel: 07785 441814

Oxfordshire and Swindon: Hannah Williams
hannah.williams1@cancer.org.uk

Tel: 07770 866050

Contact Us: peiyang.io@nhs.net Alliance Team Administrator, Thames Valley Cancer Alliance

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A Big Thank You to Lis Pickles - Clinical Groups Administrator

We would like to say a **BIG** thank you to Lis Pickles who has now sadly left the Alliance and has joined the Ludwig Institute for Cancer Research as a Data Assistant. We would like to thank Lis for her exceptional support to the Alliance and the Clinical Groups and wish her all the best in her new role!

New Cancer Alliance Team Members

It is an exciting time for the Alliance and we are pleased to inform you that we will shortly be welcoming four new members to the team! We have successfully recruited a Programme Manager who will oversee the TVCA Transformation Programme and we have also recruited 3 new project managers for the LWBC and Early Diagnosis transformation project streams.

Find out more about our new members in our Summer newsletter!

Cancer Alliance Team Contact Details

Cancer Alliance Clinical Lead	Dr Bernadette Lavery	Bernadette.lavery@nhs.net
Prevention & Early Diagnosis Clinical Lead	Dr Anant Sachdev	Anant.sachdev@nhs.net
Cancer Alliance Manager	Monique Audifferen	Monique.audifferen@nhs.net
Quality Improvement Lead, Prevention & Early Diagnosis	Lally Widelska	Alexandra.widelska@nhs.net
Cancer Alliance Administrator	Pei Lo	Peiying.lo@nhs.net
Clinical Groups Administrator	Recruiting	tvscnadmin@nhs.net

Upcoming Meetings

Meeting	Date	Time	Venue
TVCA Delivery Group	10 th April 2018	09:30-11:30	The Oxford Science Park
Transformation Programme Leads	10 th April 2018	11:30-12:30	The Oxford Science Park
Lung Cancer Alliance Group	12 th April 2018	14:00-16:00	The Oxford Science Park
Urology Working Group	19 th April 2018	09:30-11:30	The Oxford Science Park
QIS Working Group	26 th April 2018	14:30-1600	TBC
Upper GI Cancer Alliance Group	9 th May 2018	10:00-12:00	TBC
Urology Working Group	10 th May 2018	09:30-11:30	TBC
Acute Oncology Cancer Alliance Group	10 th May 2018	10:00-12:00	TBC
Urology Cancer Alliance Group	15 th May 2018	10:00-12:00	TBC
Skin Cancer Alliance Group	16 th May 2018	09:30-11:30	The Churchill Hospital, Oxford
Head and Neck Cancer Alliance Group	18 th May 2018	09:00-10:00	The Churchill Hospital, Oxford
Breast Cancer Alliance Group	23 rd May 2018	14:00-16:00	TBC
Colorectal Cancer Alliance Group	6 th June 2018	14:00-16:00	TBC
Radiotherapy Cancer Alliance Group	18 th June 2018	10:00-12:00	TBC
TVCA Delivery Group	7 th June 2018	10:00-12:00	TBC
TVCA Executive Board	26 th June 2018	09:30-11:30	TBC