NHS
Wessex
Cancer Alliance

APPENDIX 1: CANCER CARE COORDINATOR RESOURCE PACK

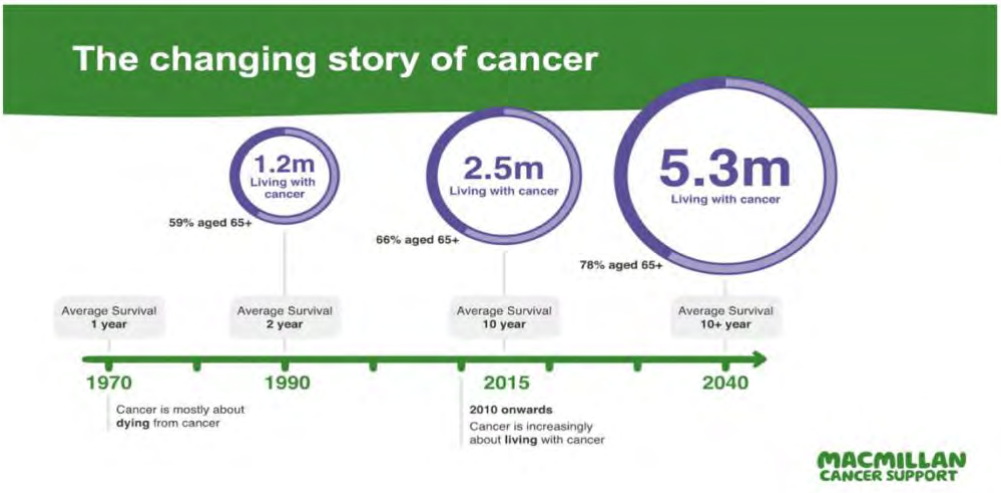
Wessex Cancer Alliance
Induction and Training Package for Cancer Care Coordinator

One in two people will have a cancer diagnosis in their lifetime.

We want to work with you to make sure that you have the confidence, knowledge, and resources to support people at risk of and living with cancer.

Please choose from the topics below for information, tools, resources, and relevant training.

For additional information, please also see our Toolkit for Primary Care.



CANCER CARE COORDINATOR ROLE

You have many skills that can be utilised to support cancer patients and improve standards of care in your Primary Care Network (PCN)

Your role can be used throughout the patient pathway but is most likely to be utilised in the prevention, screening, and the early diagnosis part of the pathway.

Your PCN may have a specific idea of how your skills can be utilised, and other PCNs may look to you to develop the service. Either way, you can use this Wessex Cancer Alliance Training and Induction Package to help you understand potential for your role and how to access the relevant training and development to support you in this role.

Key Strengths of your role:

- **Promoting prevention** through maintaining registers, contacting at risk patient groups, onward referral and lead on poster and leaflet promotion within the PCN

- **Administrative and quality improvement support in gathering and interpreting data** to improve coding, screening, faster diagnoses, and health inequalities.

- **Co-ordinating referrals and managing safety netting** ensuring symptoms and referrals are not missed and 2-week waits (2WW) are achieved.

- **Patient information, support and education** including contacting non-responders and targeting populations.

- **Care Navigation –** supporting patients through the process off 2WW referrals linking in with care navigator roles in secondary care.

- **Personalised Care** - driving up standards of personalised patient care by involvement in the early phases after diagnosis, ensuring referral to other key healthcare providers such as social prescribers, health and well-being coaches and other members of the practice team, providing access and early support to:
    1. change current patient behaviours
    2. give universal Prehabilitation advice
    3. Access emotional, psychological, social, and financial support

There are also points within the pathway where it maybe opportune to be involved, shortly after diagnosis, when treatment ends and if there is a palliative diagnosis.

As a cancer care coordinator, you can support completion of the holistic needs assessment prior to cancer care reviews, this helps patients to prepare for these discussions and help to refer onto appropriate professions in community and third sector teams.

As more Cancer Care Coordinators are employed and promoted, we expect that you will be the point of contact for additional services outside of primary care, increasing efficiency and communication between sectors, patient access and improving the patient experience.

Other potential responsibilities:

As a cancer care coordinator, you could play a key role in following up on early diagnosis safety netting objectives by:

- ensuring 2-week wait achieved. This will include following up with patients that they have been seen and diagnostics and referrals sent.
- Support patients with appropriate information so they are aware of what to expect when referred (e.g., info available on WCA website/Macmillan)
- You could also follow up on 'watch and wait scenarios' when patients' symptoms do not meet the criteria for referral. This could be very beneficial in high-risk patient groups who may not self-refer (i.e., learning disability/Dementia/mental health.
- Ensure FIT testing/full results for suspected gastrointestinal cancer referrals are completed.

WESSEX CANCER ALLIANCE SUPPORT

As the Wessex Cancer Alliance, we want to support your role as a cancer care coordinator in the following ways:

- Provision of this Induction Package
- Training and Education
- Tools to help your practice
- Engagement in a Community of Practice
- Peer shadowing opportunities

We currently provide wider workforce webinars to help share knowledge and provide cancer specific training. These can be found here: Cancer and the wider workforce webinar series - Welcome to Wessex Cancer Alliance

We welcome new members to our Community of Practice. This is a group where you can meet other Care Coordinators to share knowledge and support each other. Please contact tamzen.hogben@nhs.net to join this group.

Wessex Cancer Alliance provides a Primary Care Newsletter which provides up to date information and education offers. Please contact england.wessexcanceralliance@nhs.net if you would like to subscribe.

Macmillan also provide a Primary Care Update which includes latest developments, learning and case studies relating to cancer across primary care, to sign up please access the following link: Sign up for Primary Care Update - Macmillan Cancer Support

If you are new to this role, you may also find the following helpful.

NHS England Welcome pack: care-coordinator-welcome-pack.pdf (england.nhs.uk)

HEE Care Navigation: A Competency Framework: Care Navigation Competency Framework_Final.pdf (hee.nhs.uk)

Support can also be provided by your primary care training hubs in your region. This does include community of practice to offer peer support and mentor opportunities.

Dorset: Dorset Primary Care Training Hub (primarycaredorset.co.uk)

Hampshire and Isle of Wight: Thames Valley and Wessex Primary Care School Working across Wessex (hee.nhs.uk)

We know that the biggest action we can take to improve cancer survival is to diagnose it earlier; patients diagnosed at stage 1 or 2 have the best chance of curative treatment and long-term survival.

The NHS Long Term Plan aims to achieve diagnosis of 75% of all cancers, at stage 1 or 2, by 2028; this will save an estimated additional 55,000 lives per year and increase survival rates to more than 70%.

We can only achieve this by **working together across primary and secondary care and in communities** to improve the awareness of symptoms of cancer, screening programmes and cancer prevention.

CANCER PREVENTION

Evidence shows that up to 40% of cancers can be prevented.

Smoking

Smoking is the single most avoidable risk factor for cancer.
Approximately 300,000 people across Wessex still smoke, which is around the national average of 14%.

Obesity

Across Wessex nearly two thirds of the population are overweight or obese and at an increased risk of developing cancer. This equates to around **one million people**. More than one in 20 (5%) cancer cases are caused by excess weight.

Alcohol

Alcohol is classified as a Class 1 carcinogen and is a major risk factor for breast and bowel cancers, the second and third most prevalent cancers in Wessex.

As a Cancer Care Coordinator, you can help to promote healthy lifestyles within the practices in your PCN by:

- Ensuring patient information is visible
- Think of innovative ways to promote health lifestyles through social media, waiting room TVs and PCN websites
- Sharing knowledge and patient information with other members of the PCN team
- Promoting referral into healthy checks, smoking cessation, health and well-being coaches and external services

Resources for your patients

- NHS Better health
  Free tools and support to help people lose weight, get active or stop smoking. Includes a range of apps - Quit Smoking, Couch to 5k and Drink Free Days

- Wellbeing Services in Wessex – Cancer Matters Wessex provides links to local services
- Active Dorset Videos

Survival rates have improved significantly over the last 10 years and today more than 50% of people will survive cancer for 10 or more years.

By 2040 it is estimated that a total of 5.3 million adults in the United Kingdom will be living with or beyond a cancer diagnosis. This is due to a combination of factors including more effective cancer treatments, and a growing and ageing population.

CANCER SCREENING

What is screening?

- A way of detecting cancer or pre-cancerous changes
- Targets a particular group of people
- Aimed at people without symptoms
- Most people screened won't have cancer

Some common cancers are detected early by screening which makes it more likely they will be curable**.** National screening programmes are in place for three of the most common cancers: **bowel, cervical and breast cancer.** Screening can also identify early abnormalities **before** they become cancerous.

There is wide variation in participation in screening programmes across Wessex however coverage rates are particularly low in the more deprived urban areas of Portsmouth and Southampton, Bournemouth, and Poole.

National cancer screening programmes (CRUK)

Screening is for people without symptoms.
Where new symptoms develop, even if a patient has had their screening tests, discussion with a healthcare professional is advised.

Breast Screening

- Women aged 50-70 invited every 3 years
- Mammogram in mobile screening unit
- Results by letter
- Those over 70 can request a test every three years

Bowel Screening

- Men and women aged 56-74, invited every two years
- Test kit comes by post, returned by post
- Results by letter
- Those 75 and above can request a kit every two years

Cervical Screening

- Women aged 24-49 every 3 years
- Women aged 50-64 every 5 years
- Invite by post
- Test carried out in GP surgery
- Results by letter

It is estimated that cervical screening saves approximately 4,500 lives per year in England.
Cervical cancer rates are highest in females aged 30-34.

99.8% of cervical cancer cases are caused by the HPV infection. In England, girls and boys aged 12 and 13 are routinely offered the HPV vaccination in school Year 8. If the vaccine is missed, people are eligible to have it free on the NHS until they are 25.

Research suggests that endorsement from practice teams can lead to increased uptake in screening, and therefore discussions with patients who are overdue for their screening tests can be helpful.

Possibly link to suggested "script" for discussing overdue smear from CRUK.

Reaching out to specific groups / reducing inequalities

There are significant health inequalities across Wessex in relation to uptake of screening programmes, awareness of cancer signs and symptoms and access to healthcare. This can be influenced by several factors and is greater in harder to reach communities e.g., those with learning disabilities, BME populations, and older people.

Many organisations produce information in easy read formats or in different languages, and there are an increasing number of videos available to prepare people for what to expect at appointments. For more details on these resources please see the Toolkit for Primary Care.

Black men are twice as likely to get prostate cancer than white men. One in 4 black men will get prostate cancer in their lifetime and their risk is increased if they are over 45 and/or have a family member, particularly father or brother, who has been diagnosed. If concerned they are at increased risk men can make an appointment to discuss this with the GP and may be offered a PSA blood test.

Further examples e.g., Learning Disabilities, SMI and homeless populations.

Your Primary Care Network is likely to want you to be involved in improving screening rates in your PCN.

Please access the Primary Care Toolkit here: Cancer Screening Programmes - Welcome to Wessex Cancer Alliance here you will find links to:

- National guidance for each screening programme
- QI toolkit
- Patient information leaflets and tutorials
- How to improve screening uptake

For assistance with how to run reports to aid with gathering data, Ardens provide on-line tutorials which you can access here: Cancer Resources Overview : Ardens

EARLY DIAGNOSIS

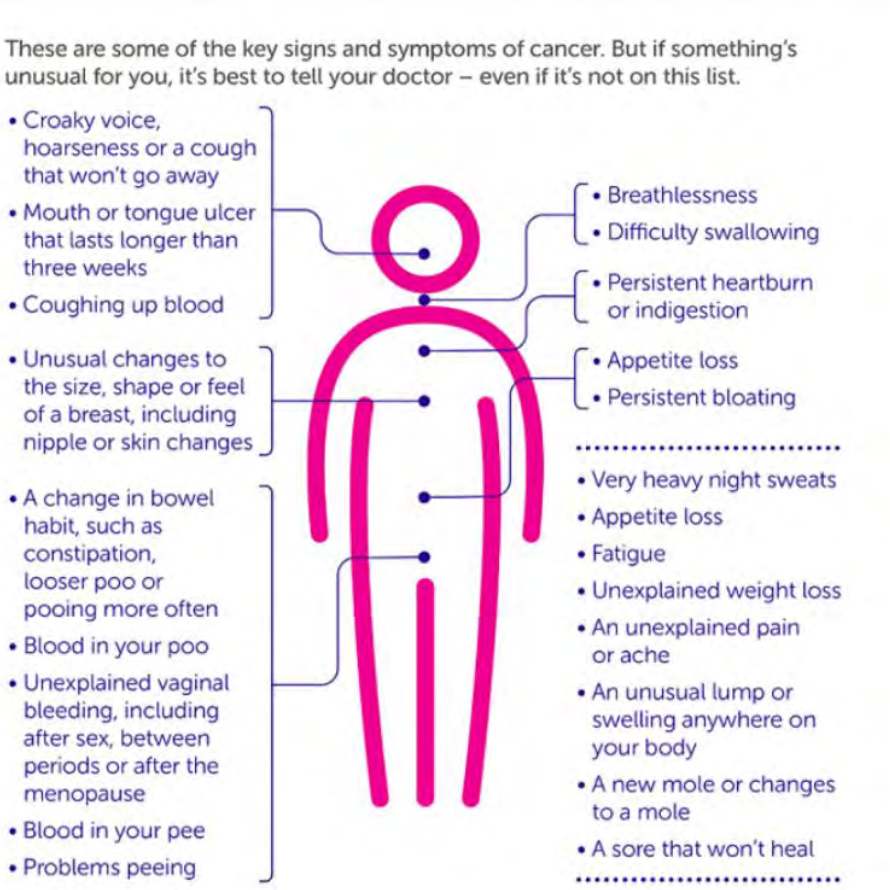
Recognising signs and symptoms

There are approximately 363,000 new cases of cancer per year in the UK.
When cancer is spotted at an early stage, treatment is more likely to be successful.
For example, when diagnosed at stage 1, more than 90% people will survive bowel cancer for five years or more, compared to less than 10% when diagnosed at stage 4.

As a Cancer Care Coordinator, you can also help by promoting symptom awareness resources and awareness campaigns which are available here: Awareness Campaigns - Welcome to Wessex Cancer Alliance

Other Useful Resources

- CRUK GP surgery slides on cancer prevention
- CRUK awareness and prevention resources
- PHE Campaign Resource Centre includes the Help Us Help You Cancer Symptom Awareness campaigns
- Be Clear on Cancer – Information on previous campaigns, resources, and evaluation
- Coppafeel: https://coppafeel.org/
- Breast Cancer Now https://breastcancernow.org/
- know your lemons https://knowyourlemons.org/



WCA ALLIANCE PCN DES – Early Diagnosis support pack

This support pack is intended to assist with the implementation and delivery of the Network Contract DES requirements for Supporting Early Cancer Diagnosis. The additional supporting information in this document is purely advisory and to be read alongside the Network Contract DES Guidance.

SUPPORTING PEOPLE AFTER DIAGNOSIS

A cancer diagnosis can obviously be a difficult time for people. They may have physical, emotional, practical, or social concerns and the impact of these can vary at different points in their cancer experience. Receiving care that is tailored to a person's particular needs can have a significant impact on their experience and quality of life.

Personalised Care and Support Planning (PCSP) helps people living with cancer to take an active and empowered role in the way their care is planned and delivered, with interventions and care tailored around the things that matter most to them.

It is achieved through a series of supportive conversations in which the patient, or someone who knows them well, actively participates to explore the management of their own health and well-being in the context of their life and family situation.

For more information see:

NHS Personalised Care

Macmillan Personalised care for people living with cancer

Right By You Wessex

Prehabilitation

Prehabilitation enables people with cancer to prepare for treatment through promoting healthy behaviours and through needs-based prescribing of exercise, nutrition, and psychological interventions. The aims of Prehabilitation are to empower patients to maximise resilience to treatment and improve long-term health.

Useful information

- Physical Activity and Cancer – Guidance for healthcare professionals, Macmillan Cancer Support
- Prehabilitation resources for healthcare professionals, Macmillan Cancer Support
- PRosPer - Cancer Prehabilitation and Rehabilitation - eLearning for healthcare (e-lfh.org.uk)
- MAC14531_Ten_top_tips_2019_Prehabilitation.indd (macmillan.org.uk)
- Physical activity and cancer | Booklet - Macmillan Cancer Support
- Move more (macmillan.org.uk)
- Benefits of exercise - NHS (www.nhs.uk)

The importance of physical activity before, during and after cancer treatment

Not only does moving more help improve clinical outcomes, but it can also help people take control of their lives, reduce social isolation, and enable people to live independently.

A cancer referral or diagnosis provides a 'teachable moment': a time when an individual is more inclined to change their behaviour. Cancer patients have been shown to demonstrate an enhanced motivation to change lifestyle behaviours, especially within the year after diagnosis.

As a Cancer Care Coordinator, you can support someone with a diagnosis of Cancer in many ways. Administratively you can be monitoring any new diagnosis and start supportive interventions earlier in the pathway.

Examples of how you can be involved:

- After liaising with a patient's secondary care team (CNS), a Follow-up call within a couple of weeks after diagnosis may enable more proactive and timely support to cancer patients
- Referral to Social Prescribing Team for those that are likely to need more support and help – think learning disability, Frailty scores, High Deprivation Score, more than 2 long term conditions, over 70 years.
- Prehabilitation – Universal advice can be given by CCC introducing to patient information on-line, patient information leaflets and referral to any prehab services if available.
- Referral to other therapy Additional reimbursement roles if available in the PCN such as Dietitians and Occupational Therapists
- Referral to Health and Wellbeing coaches for further support on changing behaviour
- Signposting to Cancer Map and Macmillan which offer a lot of advice and support services.

ARDENS RESOURCES

Ardens are a primary care resource that you will find invaluable as a Cancer Care Coordinator. They have searches, templates and information build into both EMIS and System 1 clinical systems that you can use and share with your wider team.

Overview to the latest PCN DES: Network Contract DES 22-23 Overview on Vimeo

Additional roles resources: ARRS Resources Webinar: Ardens

System 1 (TPP) resources :Ardens SystmOne - Cancer Resources Webinar - May 2022 : Ardens

EMIS WEB resources: Ardens EMIS Cancer Resources Webinar - Bing video

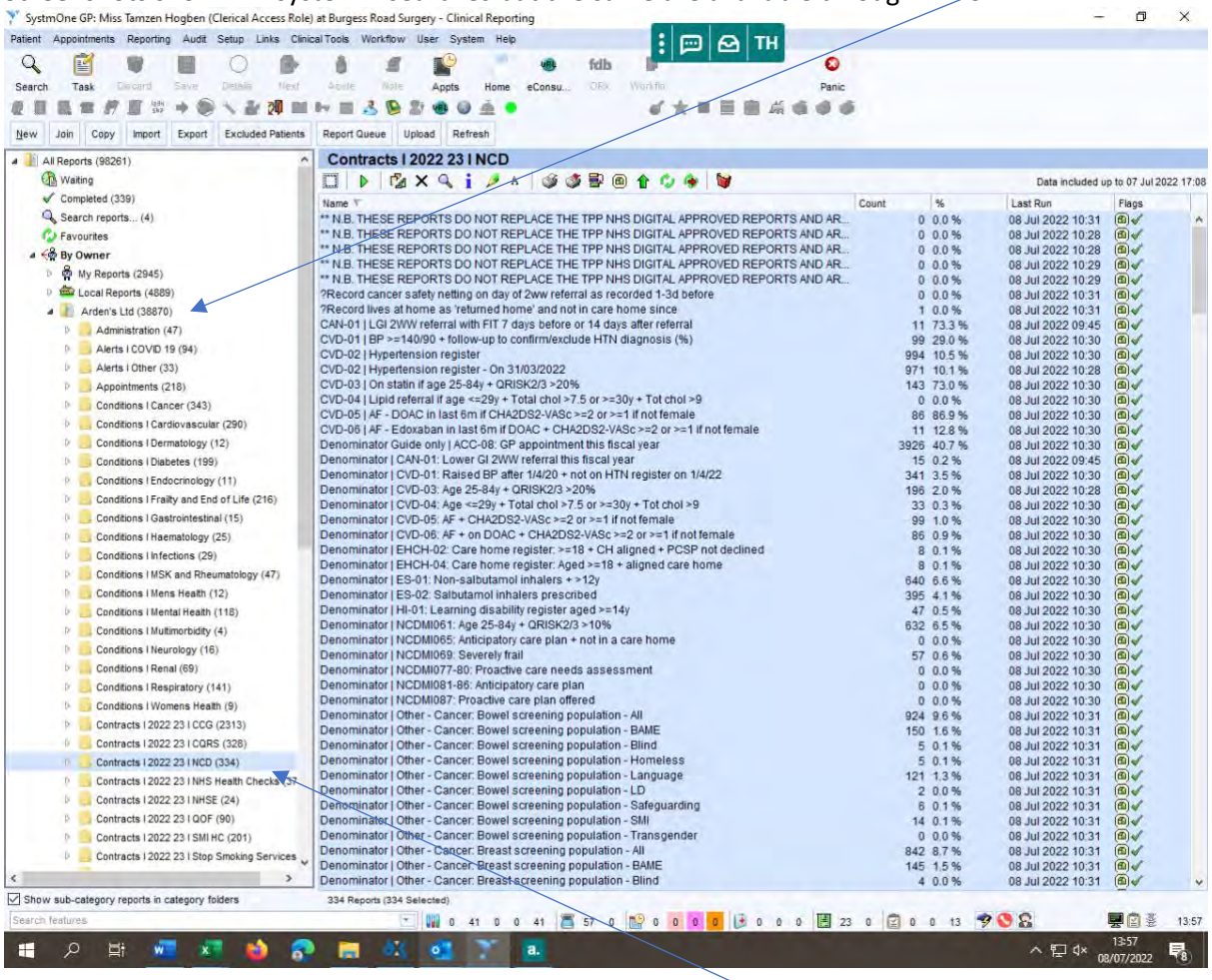
Wessex Cancer Alliance PCN DES webinar - https://youtu.be/157NGG9FLj4

Safety Netting: Cancer 2ww Referrals & Safety Netting: Ardens

Qof and Ardens: QOF - Cancer: Ardens
ARDENS MANAGER VIDEO LINK: Network Contract DES 22-23 Overview on Vimeo

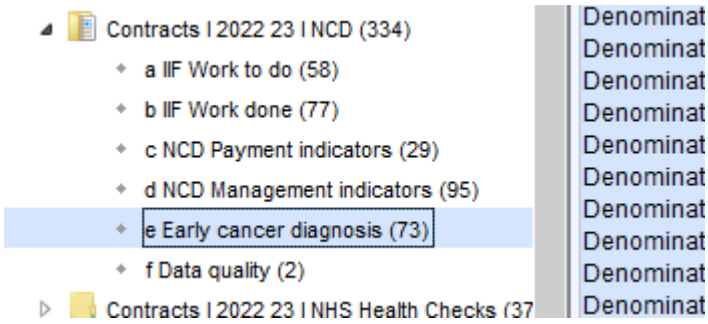
CLINICAL SYSTEM SEARCHES

Screenshots show TPP system 1 searches but the same are available through EMIS.

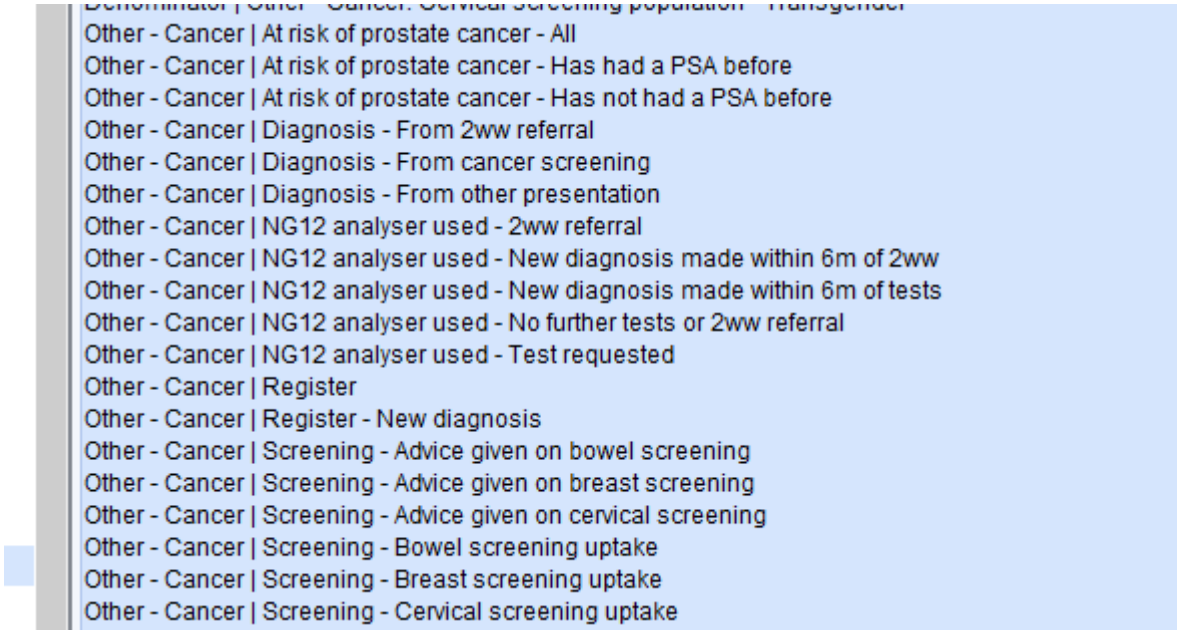


Select ARDENS REPORTS – Contracts – 2022-2023 NCD

Within that you will need to select the EARLY DIAGNOSIS SECTION



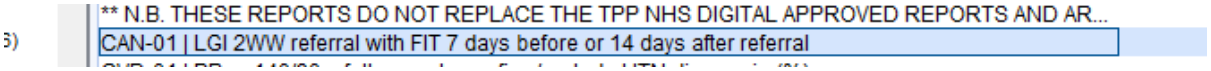
You will see 73 Reports. The ones that are useful are.

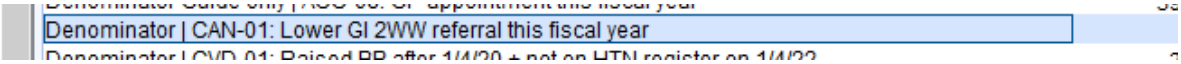


As you will see there are searches to enable you to see specific screening groups such as BAME/Transgender etc. Which are also handy should you wish to focus on a specific cohort of patients for audit purposes.

<u>IIF CAN-01 SEARCHES</u>

In the same section (CONTRACTS NCD) You will see a folder called IIF – WORK DONE. In there are the following searches which will help you find the necessary information for this indicator.





CANCER CARE REVIEWS

Cancer Care Reviews (CCR)

A Cancer Care Review is a holistic conversation between a patient and primary care professional about their cancer experience and concerns. It is designed to help people understand what support is available to them and enable them to begin supported self-management where appropriate.

The Quality and Outcomes Framework (QOF) requires primary care professionals to carry out a CCR at the time of a patient's diagnosis (within 3 months) and after a patient has received acute treatment (within 12 months).

Macmillan have produced a template to guide this conversation which is available in all the main GP systems.

The clinical template software Ardens also has a cancer care review template, including under the social prescriber's tab (double check this).

Cancer care coordinators can prepare patients for cancer care reviews by supporting completion of holistic needs assessment, this may also guide the best professional to conduct the cancer care review dependent on the patient's areas of need.

There is potential for various non-clinical roles to be involved in delivering the 3-month cancer care reviews. However, this should only be encouraged in experienced cancer care coordinators that have had support and training to develop in this area. You can also support the registered healthcare professionals in your practice/PCN to deliver the 12-month cancer care review.

Resources

- Macmillan CCR Information includes guidance on accessing the CCR templates in different systems, template patient letters and text messages
- Holistic Needs Assessment Concerns Checklist, available in different languages and in easy read format.
- Top tips for carrying out a CCR
- Social prescribing for cancer patients: A guide for PCNs
- Cancer Matters Wessex
- Cancer Care Map – Directory of cancer support services across the UK
- Macmillan In Your Area – Online search tool for local Macmillan services including information and support, wellbeing services and rehabilitation groups.

PALLIATIVE/END OF LIFE CARE

As a Cancer care Coordinator, you may be asked to:

- coordinate palliative gold standard framework meetings within your PCN,
- be involved in the administrative management of palliative register,
- follow-up on actions completing signposting and referral activities.

As a member of the team your knowledge of cancer support groups and rehabilitation teams will be invaluable in promoting rehabilitative care earlier in the palliative process and provide opportunities for self-referral when patients start to deteriorate.

Training and education

End of Life Care for All (e-ELCA)

Interactive e-learning sessions which are grouped into nine modules including: Advance care planning, Communication skills and Bereavement care. It also includes a training needs analysis tool to you assess your strengths and areas to focus on.

Difficult conversations

Macmillan **difficult conversations** resources including Leading difficult conversations, key principles, using technology to communicate, delivering bad news, talking about death, and dying, communicating with people who are recently bereaved.

Communicating with empathy

e-LfH programme with 6 sessions developed to promote sensitive and effective communication in end-of-life care.

Bereavement Support

Some PCNs are leading in supporting someone who has recently been bereaved and developing bereavement groups.
If you are involved in contacting recently bereaved relatives, please read the Macmillan document Primary Care 10 Top Tips:
MAC14531_Ten_top_tips_BEREAVEMENT_2.indd (macmillan.org.uk)

If you would like an introduction to palliative and end of life care, please access the following training.

https://macmillan.fuseuniversal.com/communities/397/contents/200299

Macmillan provide information for people coping with bereavement including practicalities and emotional support:
Coping with bereavement - Macmillan Cancer Support

How to claim bereavement benefits:

Claiming bereavement benefits - Macmillan Cancer Support

Useful resources/organisations
cruse.org.uk

AtaLoss.org is the UK's signposting and information website for bereaved people

Home – The Good Grief Trust

Good Life, Good Death, Good Grief: Welcome (goodlifedeathgrief.org.uk)

Hope Again (for Young People)

Childhood Bereavement Network

HSCNI Bereavement Network – To work towards continuous improvement in bereavement care

TRAINING AND EDUCATION

The training sessions below provide useful introductions to cancer and cancer care.

Talk Cancer online workshops – Cancer Research UK
Free interactive session suitable for anyone wanting to build their confidence and skills to have supportive conversations with others about reducing their risk of cancer, the importance of spotting cancer early and making healthy changes. Also available as a self-directed online course.

Cancer Awareness - Macmillan Cancer Support
E-learning course providing an overview and introduction to cancer awareness, living with and beyond cancer and End of Life and Palliative Care.

E-learning for health – Cancer in the Community

Communities against cancer - Action Hampshire
Free interactive online workshops for people working or volunteering in the voluntary and community sector across Wessex. Covers cancer risk factors, symptom awareness, cancer screening, early diagnosis, and health inequalities.

Cancer Awareness webinars – Macmillan & Dorset CCG
Led by secondary care clinicians and aimed at NHS workers, carers and volunteers, this series of webinars cover different cancer types and treatments.

- 30 seconds to save a life NCSCT
  Very Brief Advice training for smoking cessation.

- Behaviour Change and Cancer Prevention online course – RCGP
  Free 30 min online module to promote behaviour change around smoking, obesity, and alcohol consumption to reduce cancer risk. Requires registration but is open to all.

- Making Every Contact Count – Directory of MECC e-learning resources

- Physical Activity and Health – e-learning for health
  Online course for healthcare professionals to champion the benefits of physical activity.

- Energise Me Social Prescribing Training (Hants)
  Designed to help anyone undertaking any form of social prescribing activity to have better conversations around physical activity.

- CRUK Cancer Awareness and Prevention – Resources for Health Professionals

OTHER USEFUL RESOURCES

Sources of Information

NHS - Cancer

Cancer Research UK provide a wide range of information and support around cancer prevention, diagnosis and treatments, and the latest research and evidence.

Macmillan Cancer Support provide information on all cancer types and offer many other services for your patients including: telephone support line, online community, information booklets, benefits and work advice and access to financial support.

Tumour site specific charities can offer focused support for people who want to find out more about their cancer, and other people's experiences after being diagnosed.
Bowel Cancer UK
Breast Cancer Now
Jo's Cervical Cancer Trust
Prostate Cancer UK
CoppaFeel! | Check Your Boobs or Pecs | Breast Cancer Awareness
Roy Castle Lung Cancer Foundation
Target Ovarian Cancer
https://ruthstraussfoundation.com/

Wessex Local Information

Cancer Matters Wessex
Cancer Matters Wessex is a dedicated website for patients in Hampshire, the Isle of Wight and Dorset, who need support or advice about cancer. The site provides information about the referral process, what happens if you have been diagnosed, and support groups and wellbeing services available for people living with cancer.

Cancer Care Map
Online directory to help people living with cancer find care and support services in their local area, anywhere in the UK.

Macmillan In Your Area
Online search tool for local Macmillan services including information and support, wellbeing services and rehabilitation groups.