

**Awareness & Early Diagnosis Clinical  
Advisory Group (CAG)  
FINAL MEETING  
Output from Workshop Discussions on  
Implementing the Cancer Strategy:  
Summary Report & Suggested Actions for  
Cancer Alliances**

**South East Cancer Clinical Network  
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## Background

The Awareness and Early Diagnosis Clinical Advisory Group (CAG) comprises representation from provider and commissioning organisations across Kent, Surrey and Sussex alongside patient, carer and third sector members. Meetings of the Clinical Advisory Group (CAG) provide a forum for bringing together and agreeing the Awareness and Early Diagnosis component of the overarching South East Cancer Clinical Network strategic work programme.

## Purpose of the meeting

The final meeting of the CAG took place on 12<sup>th</sup> July 2017 and its purpose was to facilitate a smooth transition to Cancer Alliances later in the year. The meeting provided an opportunity for stakeholders to contribute to the development of the Early Diagnosis delivery plans within each of the Cancer Alliances. Delegates were invited to take part in up to 4 workshops, each of which focussed on separate elements of the Early Diagnosis agenda, namely;

1. Screening
2. Implementation of NG12
3. Introducing Rapid Access Diagnostic Centres and
4. Delivering the 28 and 62 day standards.

A key function of the Cancer Alliances is to deliver on the recommendations of the Independent Cancer Taskforce (2015-2020). An objective of the workshop discussions was therefore to provide Cancer Alliances with suggestions on how to progress their Delivery Plans for each topic, with particular reference to the relevant Cancer Taskforce recommendations.

This report summarises the outputs of the discussions which took place.



## Screening

The Independent Cancer Taskforce focusses on the benefits of screening in its report, 'Achieving World Class Cancer Outcomes: A Strategy for England (2015-2020)'. Screening not only reduces the incidence of cancer but it also improves outcomes for those patients whose cancers are diagnosed at an earlier stage. England's existing cancer screening programmes save thousands of lives. However, ongoing research shows there is the potential to do more, both by improving screening participation and by introducing new tests where applicable.

### 1. Discussion Points from the Screening Workshop

#### General Discussion Points:

- The overwhelming majority of participants felt screening should feature in both prevention and early diagnosis (ED) work streams within the Cancer Alliances.
- The PHE Screening & Imms teams (both Kent/Medway and Surrey/Sussex) advocate screening inclusion in prevention and ED work streams
- Significant concerns were raised that screening will 'get lost' if solely in ED work stream
- Is there sufficient prioritisation of screening?
- There was an emphasis that screening is for 'well people,' not the symptomatic
- It is helpful to refer to 'increased participation in screening' rather than 'increased screening uptake', as this avoids confusion with the 'uptake and coverage' performance measures.
- Bowel screening results come from the hub electronically and are automatically Read coded onto practice systems. Can the same be done for breast screening results? This would make following up breast screening non responders/attenders much easier.



- There is currently inconsistency in Read coding between GP practices. Ensuring some consistency would make follow up and auditing processes easier.
- It is important for those who have been screened to communicate the improved outcomes which occur as a result of participation in screening.

### **Working with PHE and other key stakeholders:**

- Colleagues from PHE were recognised as being key contacts in screening work but sole responsibility does not sit with them
- The group felt everyone with an interest in screening should be involved and, as above, there should be a dedicated sub group for screening which has representation from both prevention and ED work streams. Please see the 'Recommended next steps' section for suggested membership of this sub-group.

### **How can vulnerable patient groups be supported to participate in screening?**

- It was noted that there is better participation from people with learning disabilities in bowel cancer screening, compared with the cervical and breast screening programmes.
- Have we corrected identified vulnerable groups are and what is informing decisions regarding these groups? Data is not always recorded
- Due to a number of GP practices closing, a concern was raised that an increasing number of people may not be invited for screening.
- Some areas have done health equity audits and action plans but there was an issue with accessing the correct information and demographics.



## 2. Shared Learning from across the KSS Geography

Please see below for details regarding the local strategies that have been employed to increase screening participation across our locality:

Area	Initiative	Contact details
Surrey	<p>Surrey Screening toolkit</p> <ul style="list-style-type: none"> <li>• For GP practices and CCGs</li> <li>• Evidence based interventions to increase cancer screening uptake</li> <li>• Training for GP practice staff (clinical &amp; non-clinical) by CRUK</li> <li>• Generic version available for other areas</li> <li>• Hosted on SE Clinical Network website</li> </ul> <p>Surrey teaching resource PHSE for secondary schools</p> <p>Surrey Heath CCG</p> <ul style="list-style-type: none"> <li>• Survey of GP practice's follow up of screening non-responders/attenders</li> </ul> <p>East Surrey</p> <ul style="list-style-type: none"> <li>• Research into cervical screening uptake</li> </ul>	<p>Debbie Bell CRUK</p> <p>Sarah Tomkinson PHE</p> <p>Elaine Dunlop PH SCC</p> <p>Jenni Thomas PHE</p> <p>Dr Tina George</p> <p>Cyane Sullivan</p> <p>Raheel Anwar</p>
H&R CCG	<p>Hastings and Rother had a LCS for GPs to send letter to all non-responders. All GPs took part. The LSC came to an end at the end of March 2017, there are plans to evaluate</p>	<p>Sarah Spencer-Bowdage CRUK</p> <p>Emma Cuppini</p>
Kent	<ul style="list-style-type: none"> <li>• Screening work in prisons</li> <li>• The majority of CCG's in Kent and Medway are focusing on targeting practices that have low bowel screening uptakes, and providing trainings and assisting in supporting audits to increase uptakes.</li> </ul>	<p>Lisa Abangma CRUK</p> <p>Sarah Murphy PHE</p> <p>Pam Njawe PHE</p>



Area	Initiative	Contact details
	<ul style="list-style-type: none"> <li>In Dartford, Gravesham and Swanley, they are piloting clinical systems in practices to help identify patients at risk of bowel cancer. They are supporting the uptake of GP endorsed letters in practices</li> <li>Thanet cancer community champions project providing a volunteer coordinator to recruit volunteers from key communities utilising an asset based approach to increase awareness of signs &amp; symptoms of cancer, screening, prevention messages, smoking cessation and healthy weight).</li> </ul>	Sharon Middleton
NEH&F CCG	<p>Improving quality in cancer – primary care pilot</p> <ul style="list-style-type: none"> <li>The pilot for bowel cancer screening (and cancer care reviews) commenced October 2016 – March 2017. 14 GP practices participating. The evaluation will inform future roll out of the projects with the aim to extend across all three cancer screening programmes &amp; all GPs</li> <li>Personalised letters sent to non-responders to the initial bowel screening invitation.</li> <li>An easy read letter with pictures developed for patients with learning disabilities.</li> <li>Letter translated for Nepali patients</li> <li>Evaluate and roll out in April 2017.</li> </ul> <p><b>Cancer improvement plan 2017/18</b>                      NHS England – South (Wessex) Public Health developing a Hampshire and Isle of Wight STP screening plan to improve the coverage of the screening programmes across STP footprint. Focus for 2017/18 element of the screening plan will be on cervical cancer screening.</p> <p>The GP practices will be required to:</p> <ul style="list-style-type: none"> <li>Send personalised letters to non-responders of the bowel cancer screening programme and those approaching their 60<sup>th</sup> birthday. Improve coding</li> <li>Improve coding of women participating in the breast screening programme &amp; non-responders. Opportunistic promotion of the breast screening</li> </ul>	Alex Greenway/ Dr Nelly King



Area	Initiative	Contact details
	programme. • Develop a process to actively engage with hard to reach groups	
Kent/Surrey/Sussex	Improving participation in NHS screening programmes for people with learning disabilities in Kent and Medway and Surrey and Sussex	Sarah Tomkinson Pam Njawe
	<b>RCGP/CRUK primary care cancer toolkit</b> <a href="http://www.rcgp.org.uk/clinical-and-research/toolkits/primary-care-cancer-toolkit.aspx">http://www.rcgp.org.uk/clinical-and-research/toolkits/primary-care-cancer-toolkit.aspx</a>	





### 3. Screening: Recommendations on next steps for the Cancer Alliances

- There needs to be a dedicated sub-group for screening which should have representation from both the prevention and ED Alliance work streams. There also needs to be greater communication between stakeholders and clarity regarding responsibilities.

- Membership of the Cancer Alliance screening sub-group should include:

Local authority PHE	NHSE	CCGs
Providers Primary care	Health Watch	Cancer charities
Patients	Communities	Sexual health clinics

- Education and awareness of screening programmes should extend to health professionals as well as patients
- Communication of improved outcomes as a result of screening from participants themselves could be very powerful
- Any demand and capacity planning which is undertaken for diagnostic services needs to factor in screening services too
- There needs to be some recognition of cross-boundary issues where CCGs work within 2 different Screening and Imms teams (e.g. North East Hants and Farnham CCG)
- People who are not registered with GPs are a vulnerable group, as they will not be invited for screening
- Please refer to ‘increased participation in screening’ rather than ‘increasing screening uptake’ in documents (to avoid confusion with screening ‘uptake’ and ‘coverage’).
- As bowel screening results are sent to GP surgeries electronically (and are therefore read coded onto practice systems), can the same be done for the breast screening programme to assist in follow-up of non-attenders?
- Encourage greater consistency in read coding within GP surgeries



## Implementing NG12

In order to ensure earlier diagnosis of cancer, NICE updated its guidelines on referrals for suspected cancer from Primary Care (NG12) in June 2015. This guidance was based on evidence taken from large-scale Primary Care studies and the threshold for referrals was lowered to include symptoms corresponding to a 3% positive predictive value of having cancer (reduced from 5% previously). This means that more patients will be referred for suspected cancer from Primary Care, hopefully leading to increased detection of cancers at an earlier stage.

### 1. Discussion Points from the NG12 Workshop

#### General points:

- NG12 should not be approached in isolation (it is also important to be mindful of other considerations, as outlined below)
- Diagnostic and workforce capacity is essential for successful implementation
- There is much variation in the availability of direct access diagnostic tests
- Having the referral proformas in place does not necessarily mean that the guidelines have been implemented
- Greater education is needed for secondary care colleagues regarding NG12 and its purpose
- Surrey TSSGs are better developed compared with Sussex TSSGs

#### Points relating to referral pathways:

- It is difficult to know when the pathway begins from a GP perspective
- Some GPs (and Trusts) are still using fax for suspected cancer referrals



- There is a lack of clarity regarding who is responsible for managing steps in the process (i.e. primary or secondary care), including communication with patients
- Telephone assessments / triage may be helpful prior to attending clinic appointments
- Patients need to be seen soon after their initial triage and subsequently after their diagnosis
- There are issues with diagnostic reports coming back from secondary care and support is needed for GPs to interpret them (quality of reports is often an issue)

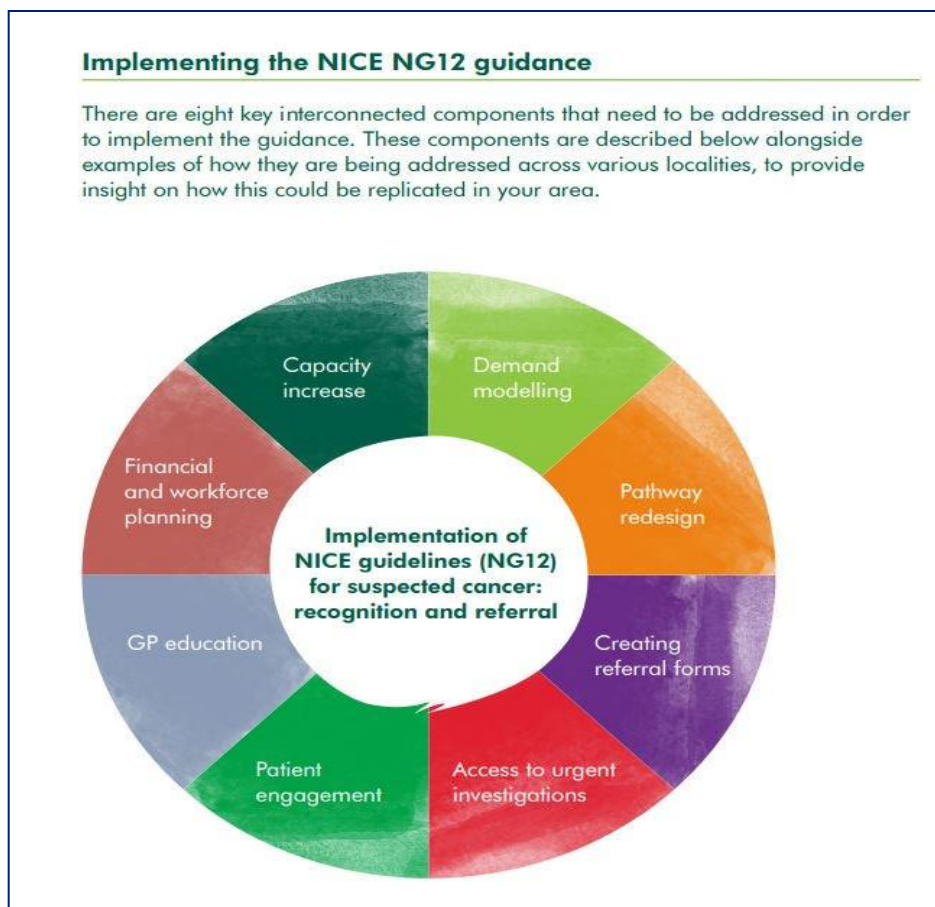
## 2. Shared Learning from across the KSS Geography

- Guildford & Waverley CCG and North East Surrey CCG have had their NG12 referral proformas reviewed by the TSSG. The CCGs are agreeing the final versions of the forms.
- Difficulties have been noted with regards to GP IT systems and referral routes into London
- Surrey GPs appear to be adopting the NG12 referral forms at different times
- East Sussex NHS Hospitals Trust (ESHT) report the main challenge in implementing NG12 is ensuring sufficient capacity in Secondary Care. Additional mobile clinics have been arranged to meet targets and build capacity



### 3. NG12: Recommendations on next steps for the Cancer Alliances

- The Macmillan Infographic (below) may be useful to for Alliances to measure and map NG12 implementation across their locality.



- Referral pathways need to be refined (i.e. clarifying when the pathway starts, ensuring consistency in the quality of diagnostic reports and achieving a shared understanding of where responsibilities lie at each step).
- Patient engagement and awareness is essential



## Multidisciplinary Diagnostic Centres / MDCs

In its report, the Independent Cancer Taskforce noted “there is no optimal referral pathway for patients with non-specific but persistent, concerning symptoms. These patients often fall through gaps, resulting in delays to diagnosis. Others may end up shuttling between primary and secondary care if the first or second test ordered is uninformative.”

A proposed solution for supporting these patients is through the 'Multidisciplinary Diagnostic Centre (MDC)' model, which is a single testing location where a patient can undergo several investigations relevant to their symptoms, on the same day. An MDC could be based in a community or a hospital setting, addressing symptoms for which GPs find it hard to determine the appropriate referral pathway (including “low risk but not no risk” groups). According to the recently published 'Next Steps on the NHS Five Year Forward View,' by March 2019, there should be at least 1 new MDC in each of the 16 cancer alliances.

### 1. Discussion Points from the MDC Workshop

The following themes emerged during the discussions at the MDC workshop:

#### **Which patients to refer & symptomatology:**

- Vague symptoms, when GPs are not clear which NG12 pathway to use.
- Unexplained tiredness / generally unwell
- Vague abdominal symptoms
- Weight loss of uncertain cause
- GP concern persists when initial diagnostic tests have not revealed an abnormality

#### **Work-up prior referral:**

- Basic, baseline blood tests
- Clear patient communication about the referral (including an information leaflet)



## **Triage**

It was decided that patient triage would be required prior to entering the MDC pathway, which might include a patient fitness assessment, a mental health and holistic needs assessment. These could be carried out by a GP or by secondary care.

## **Which diagnostic tests should be available at the MDC?**

It was agreed that MDC staff should decide which of the following tests are required;

- Bloods
- USS
- CT & MRI
- Endoscopy & colonoscopy

## **Proposed timescales for MDC diagnostic tests**

- Tests should be performed within 48 hours of referral
- Results should be reported and available within 24-48 hours
- This should be a 24/7 service (not necessarily with regards to patient-facing appointments but for reporting purposes)

## **MDC resourcing:**

- Development of staffing was thought to be an important issue which would need to be addressed imminently in order to ensure MDC roll-out by 2019 (to include radiology staff).
- Scoping of equipment requirements must also commence quickly



## 2. MDCs: Recommendations on next steps for the Cancer Alliances

- It was agreed that all patients referred to MDCs would need to be entered onto a single diagnostic pathway comprising the following steps;



- The suggestions in this document should be shared with patients, who must be fully engaged in co-developing the MDC model.
- Patients who are referred to MDCs should receive clear and if appropriate, written communication about the referral (easy read and standard versions should be available)



## Achieving the 28 and 62-day standards

This year, NHS England has renewed its focus on achieving the 62 day standard (i.e. patients should expect a maximum 62-day wait from urgent referral for suspected cancer to the first definitive treatment). The publication, 'Next Steps on the NHS Five Year Forward View,' states **“We will focus specifically on the cancer 62-day standard ahead of the introduction of the new standard to give patients a definitive diagnosis within 28 days by 2020.”** Performance incentives for attainment of the 62-day standard will be applied to funding available to the cancer alliances.

Compliance with the 62 day standard will undoubtedly support successful implementation of the 28 day standard, which was described in the Independent Cancer Taskforce report as follows; **“Patients referred for testing by a GP, because of symptoms or clinical judgement, should either be definitively diagnosed with cancer or cancer excluded and this result should be communicated to the patient within four weeks.** The ambition should be that CCGs achieve this target for 95% of patients by 2020, with 50% definitively diagnosed or cancer excluded within 2 weeks. Once this new metric is embedded, CCGs and providers should be permitted to phase out the urgent referral (2-week) pathway” [recommendation 24].

### 1. Discussion Points from the 28 and 62-day standards workshop

The following themes emerged during the discussions at this workshop:

#### Challenges identified by Providers:

- Problems with diagnostic capacity (though not necessarily across all pathways)
- Multiple diagnostic testing and reporting can be a challenge





- Workforce capacity issues – it is difficult to recruit radiologists
- Patient choice can cause breaches
- Ongoing issue of breach allocations

#### **Patient considerations:**

- Diagnostic tests need to be accessible to patients (geographically)
- Are patients well enough for treatment? Consider making an initial assessment of the patient's physical and mental health needs (e.g. via HNAs)
- Currently, the only person who supports the patient to the point of diagnosis is the GP – could CNSs or others also have a role?
- Give more information to patients about timed pathways

#### **Pathway considerations:**

- Ensure better sharing of records between Primary and Secondary Care. Consider the role of handheld documents
- Look at different ways of working (e.g. the lung cancer pathway)
- Direct access test reports should include advice on 'next steps' for GPs
- AQP excludes cancer pathways currently – consider diverting non cancer cases to AQPs leaving extra capacity for cancer at the Acute Trusts?
- Development of local KPIs vs National Standards
- Patients need to be allocated a key worker

## **2. Shared Learning from across the KSS Geography**

The following arrangements are currently working well;

- Daily patient timeline meetings
- Sharing learning between Trusts, including having a 'Waiting Times Performance Group' to disseminate good practice



### 3. The 28 & 62 day standards: Next Steps Suggested for Cancer Alliances

Based on these discussions, a number of actions were identified for Alliances to take forward;

- The emergence of new Cancer Alliances provides a fresh opportunity to look at these standards in a different way – what does true transformation look like?
- Clarify how the 28 day standard interacts with the 62 day standard
- Please ensure that direct access reports are tailored to the needs of GPs, providing clear advice on ‘next steps’
- Consider extra support for patients up to the point of diagnosis (e.g. with a key worker)
- Explore use of AQP services
- Provide guidance on the local use of KPIs vs National Standards
- An analysis of capacity and demand (for diagnostic availability and workforce) is needed
- Work alongside the Providers to perform activity analysis
- Remove unwarranted variation on waiting times performance
- Ensure there is no ‘game playing’ on targets
- Act as a vehicle to promote the sharing of good practice across the patch (e.g. using a Waiting Times Performance Group)

