

# ONE YEAR OF SCOTLAND'S FIRST EARLY CANCER DIAGNOSTIC CENTRES

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## BACKGROUND

Patients that do not meet the Scottish Referral Guidelines for Suspected Cancer criteria, or who present with non-specific but concerning symptoms, can cause GPs concern, especially if their 'gut instinct' is of a malignancy. In this instance, primary care would have to coordinate numerous tests while having full clinical responsibility, or choose a single speciality to refer to which may not be most appropriate. This can result in delayed diagnosis and unnecessary examinations being performed with poor patient experience and outcomes.

In NHS Scotland, around 60% of cancers are diagnosed through an urgent suspicion of cancer (USC) route, therefore around 40% of all cancers come through alternative routes (for example, routine or urgent referrals from primary care). Waits remain challenged, as a result of the Covid-19 pandemic, for many of these specialties. Meanwhile, cancer diagnoses via emergency routes are often associated with late stage disease and poorer clinical outcomes, therefore earlier detection is vital.

Compelling evidence has emerged from Rapid Diagnostic Centres (RDCs), based on the Danish model, that continue to be embedded across NHS England and NHS Wales. The Centres offer a timely, often one-stop environment for clinically complex patients with potentially serious non-specific symptoms such as weight loss, fatigue, nausea and abdominal pain.

The formation of Early Cancer Diagnostic Centres (ECDCs), within existing NHS Scotland infrastructure, similarly aims to provide primary care with access to a new fast-track diagnostic pathway for patients with non-specific symptoms suspicious of cancer. This marks a radical change to the patient experience of being tested for a suspicion of cancer and will be a new powerful asset in improving the detection of cancers earlier.

The Scottish Government's Cancer Recovery Plan – Recovery & Redesign: An Action Plan for Cancer Services – included a commitment to establish at least two ECDCs in Spring 2021, within existing NHS infrastructure. This was achieved with three Centres established by June 2021 in NHS Fife, NHS Dumfries & Galloway and NHS Ayrshire & Arran. The Scottish Government's NHS Recovery Plan, published August 2021, further commits to the evaluation of these early adopter sites to inform wider roll-out across Scotland.

A multi-disciplinary ECDC Oversight Group, chaired by an NHS Chief Executive, oversees the establishment of the Centres and their evolution. The group meets on a quarterly basis and enables Centres to share best practice and explore common challenges.

## METHOD

While all three early adopter Centres have a navigator at the centre of their service, to support the patient throughout the pathway, their models differ. This variation was welcomed to better inform the optimal ECDC model for NHS Scotland.

**NHS Ayrshire & Arran:** 21-day\* virtual model (no physical clinic in secondary care) open to referrals from both primary and secondary care (Combined Assessment Unit). Haematologist as Clinical Lead.

**NHS Dumfries & Galloway:** 7-day\* pathway with hot clinics and hot reporting. Haematologist as Clinical Lead.

**NHS Fife:** 21-day\* model that has moved towards a nurse-led service (Consultant Colorectal Surgeon as Clinical Lead) with GP embedded in the Centre.

\*this is the desired timescale that the Board is working to based on the time from the point of referral to diagnosis (cancer or not).

NHS Ayrshire & Arran and NHS Dumfries & Galloway opted for a phased launch – opening referrals by GP cluster to test the pathway and ensure effective management of demand and available capacity. NHS Fife launched the referral pathway across the region at one time.

Filter-function tests are undertaken in primary care at the point of referral, to help ensure the patients are on the right pathway.

A patient information resource was developed nationally, with patient and third sector representatives, to ensure quality, consistent information is available in regards to the ECDC from the point of referral.

A nationally agreed data set was also established early on to ensure all Centres were collecting the same data points and time milestones. This has been updated over time to help quantify the weight loss patients are presenting with and to include the GP practice code of the referrer, to determine where referrals are coming from.

### Results

While independent evaluation of the ECDCs will be undertaken by the University of Strathclyde over a two year period – and will include quantitative and qualitative analysis – some initial findings using aggregated data are below. This data covers the first nine months of the ECDCs being operational (the last quarterly report from the Centres for Year 1 is due after this publication).

- Over 720 referrals have been received (over 500 accepted).
- 16% conversion rate to cancer.
- 20% conversion to significant but non-cancer conditions.
- The most common symptoms at the point of referral is unexplained weight loss (58%).
- 64.5% of patients present with two or more non-specific symptoms at the point of referral.

### Patient information & experience

The Scottish Cancer Coalition and patient representatives worked collaboratively, through the ECDC Oversight Group, to ensure that quality resources are available to patients from the point of referral, to support informed decisions about their care.

A national survey system was procured and a patient questionnaire was developed to capture feedback and experience from everyone that moves through the ECDC – this will be used to help the Centres adapt and evolve over time to ensure their offering is truly person-centred.

"The experience was very professional with compassion and understanding from all staff."  
Patient 1

"My experience was very good, and I had a favourable diagnosis. I found it to be a speedy, very helpful service and I am grateful it exists. All the staff I dealt with were most helpful, courteous and efficient."  
Patient 2

"I received a very speedy referral which was ideal for peace of mind and convenient for my family to be with me... My doctor's practice were totally confused by my blood test results over the past 6 weeks and desperately needed answers to their concerns and ECDC was able to do this, therefore an excellent service that will benefit all people unfortunate enough to have cancer."  
Patient 3

### Primary Care experience

A questionnaire was developed to capture feedback and experiences from Primary Care colleagues across the three Health Boards. This helps monitor awareness of the pathway and identify areas for further improvement.

When prompted about how the primary care clinician would have managed the patient without an ECDC, responses so far include:

"I would have struggled – I had already referred to several specialties."  
GP, NHS Fife

"The diagnosis turned out to be rare. There is no way that I could have figured out which department to send him to without lots of trial and error."  
GP, NHS D&G

"I have had fantastic feedback from my patients who have been through the ECDC and this is always very welcome as a GP to hear that your patient's journey has been a positive one."  
GP, NHS Fife

"This might have been tricky – some ref Care of elderly or a medical speciality – this service is brilliant though and really appreciated. I have referred five patients and three had cancer – one not but she needed that wider investigation, and one pending."  
GP, NHS Fife

### Early Cancer Diagnostic Centre (ECDC) Key Principles

- Excellent patient coordination and support with patients having an assigned 'navigator' throughout their diagnostic pathway alongside access to accurate resources, to inform decision-making.
- Early identification of patients that meet ECDC referral criteria (in keeping with the principles of Realistic Medicine), with timely referral to the Centre and suite of preliminary tests completed.
- Prompt Active Clinical Referral Triage (ACRT) undertaken.
- Coordinated testing, based on the patient's needs in a 'one-stop' environment where possible, with live or rapid reporting, shortening the diagnostic pathway.
- Earlier diagnosis of cancer, or other condition(s), shared appropriately with the patient, and the outcome speedily communicated back to primary care along with next steps.
- Appropriate onward referral for further support, treatment or care.
- Adopt principles of realistic medicine.

Chart 1: cancers detected through the 3 ECDCs by tumour type

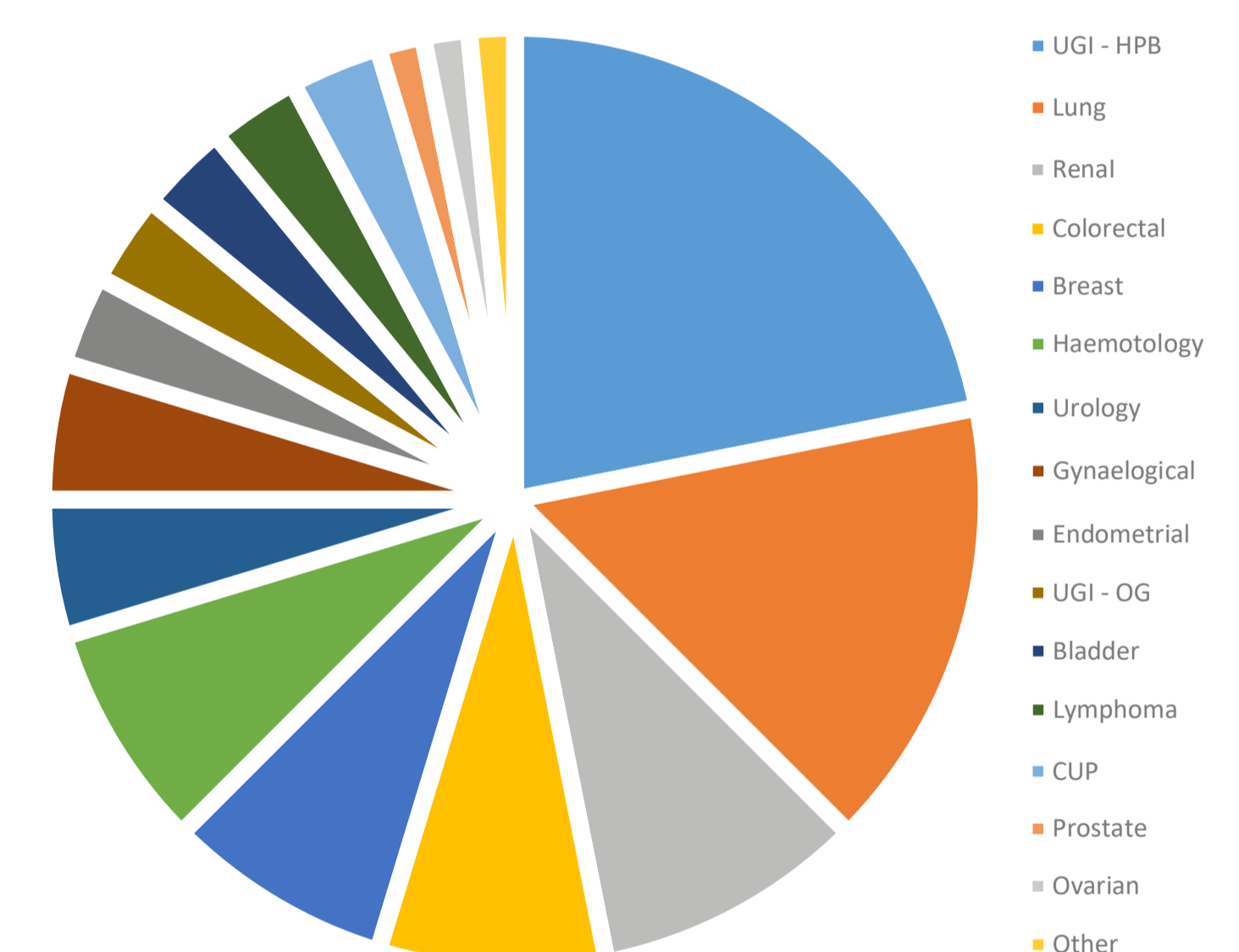
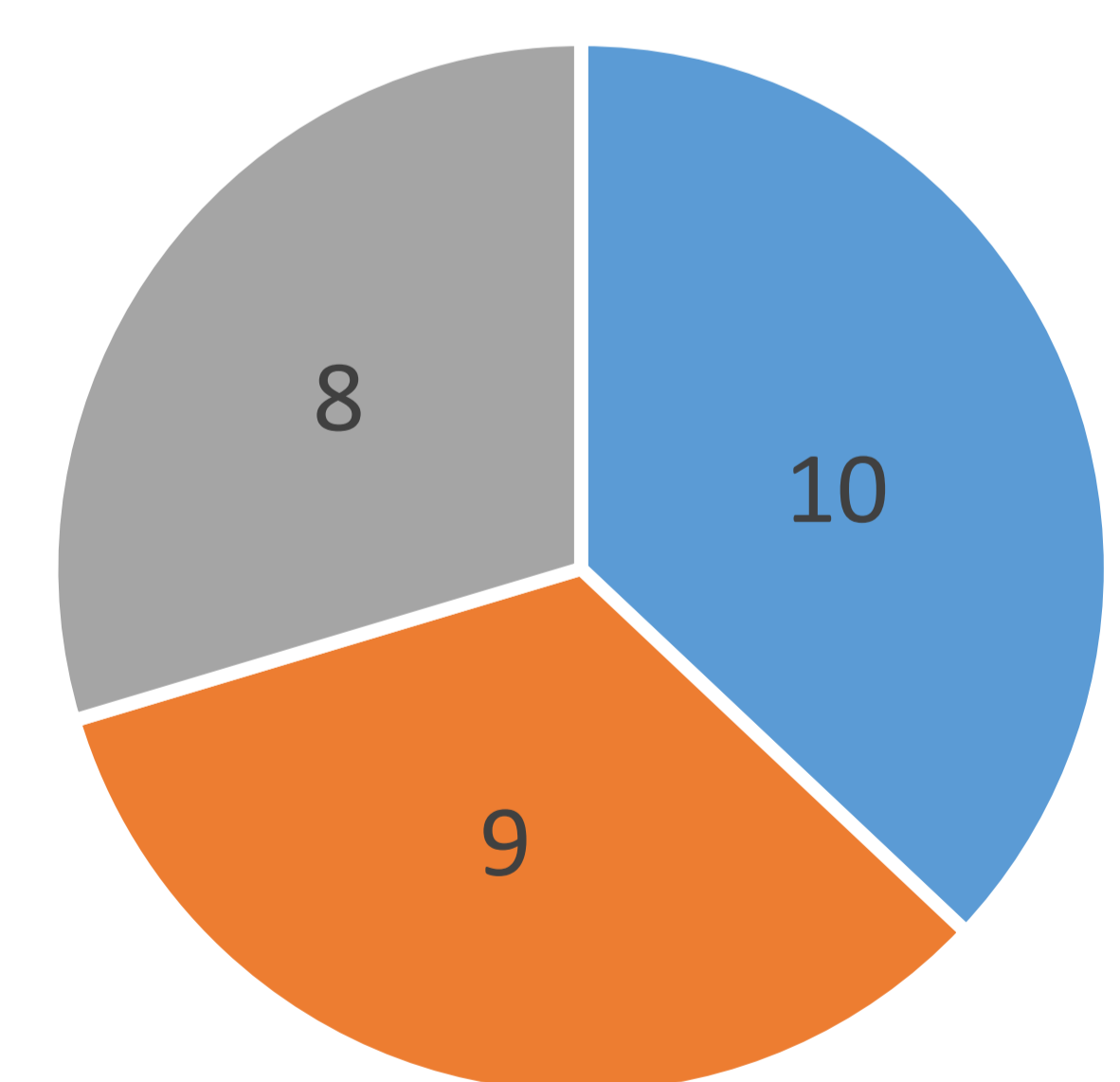


Chart 2: How patients rated overall experience  
1=very bad, 10=excellent



## DISCUSSION

While full evaluation will take two years to complete, at the time of publication, 'expressions of interest' are being sought from wider teams across NHS Scotland, to start establishing additional Centres and embedding the learnings that have emerged thus far. This may see the expansion of the ECDC model into site-specific pathways.

Patient information resources are in the process of being reviewed, based on patient feedback. More visual, video content will also be explored to ensure those with lower literacy levels are fully informed from the point of referral – patient and third sector input will be key to this.

The name of the Centres is being explored with patients to ensure the inclusion of 'cancer' isn't causing anxiety and to avoid confusion that they are being sent to a new physical 'Centre'. A name change may have to be considered in the future, depending on findings.

Primary care education has been key and required resource from the three Centres, to help ensure teams are aware of the new pathway and are familiar with the referral criteria. It's key that this engagement continues on an ongoing basis to ensure learnings are embedded and patient experience further improved.

While those that are diagnosed with cancer through an ECDC will trigger a 31-day pathway (and expect to receive their first treatment within 31 days from a decision to treat), consideration may have to be given to a new cancer waiting times standard (from the point of referral to diagnosis) or, for this patient cohort, to trigger the existing urgent suspicion of cancer (USC) 62-day standard.

## FURTHER DETAILS

For any questions/queries or further information please contact the Early Diagnosis & Cancer Performance Team via [cfsdcancerandedteam@nhs.scot](mailto:cfsdcancerandedteam@nhs.scot)