

# **Clinical Review of Cancer Waiting Times (CWT) Standards in Scotland**

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**Scottish Government**  
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## 1. Foreword

As Chair of the Ministerial Cancer Performance Delivery Group, I welcome this independent clinically-led review of Cancer Waiting Times (CWT) Standards in Scotland and its recommendations.

With more people coming through our cancer pathways than ever before it's imperative that we ensure they're appropriately supported in doing so and receive the best, timely care possible.

I appreciate everyone's work and efforts across NHS Scotland every day to ensure cancer patients remain a priority however there's no denying that more needs to be done to improve current cancer waiting times performance.

The publication of this report marks a step change and I look forward to working with our delivery group, and wider networks to turn the Review's recommendations into reality to ultimately improve cancer outcomes for people in Scotland.

A handwritten signature in black ink that reads "Shona Robison".

Shona Robison  
Cabinet Secretary for Health & Sport

## 2. Comments from the Chair

Scotland's cancer strategy Beating Cancer: Ambition and Action, published in March 2016, included an aim to *'examine whether additional targets for treatment or diagnosis would improve outcomes for people with cancer.'*

The publication of this blueprint for cancer care in Scotland provided an ideal opportunity to review Cancer Waiting Times (CWT) Standards in Scotland to shape information that could significantly change and enhance the patient experience, while determining if any amendments to the standards would meet the needs of patients and the NHS for the future.

There is wide clinical agreement that the standards have been crucial in driving improvements in performance and patient care. However, while the introduction of new CWT standards in Scotland in April 2010 initially resulted in marked improvements in performance of cancer pathways, there has been deterioration in performance against the 62 day standard more recently. Latest statistics, at the point of publication (from October - December 2017), show performance for the 62 day standard at 87.1% and 94.5% for the 31 day standard.

I was asked to Chair a steering group to consider the current and future position of the CWT standards in Scotland. This multidisciplinary group comprised of NHS managers, ISD Scotland representatives, primary and secondary care clinicians and Scottish Government officials, reflecting a wide spread of geography and expertise.

A key milestone in the Review process was a large stakeholder event that took place in June 2017 to ensure the views of all interested parties were captured at an early stage. This was supported by a patient and public questionnaire and ongoing engagement with colleagues in the Scottish Cancer Coalition.

The Review process identified a significant challenge, especially to the 62 day standard with increasing numbers of patients going through the Urgent Suspicion of Cancer (USC) referral pathway and thus impacting on diagnostics and other high risk patient groups. Conversely only small proportions of these referrals result in cancers being diagnosed (3-5%).

The Review process demonstrated at an early stage that the introduction and maintenance of CWT standards in Scotland had improved the collection of cancer related data and the efficiency of cancer pathways, while allowing comparisons within Scotland over time as well as with other countries. Thus, the retention of CWT standards was agreed in principal from the outset.

A selection of recommendations reflecting the main themes explored during the Review, and contained in this report, were produced and agreed as a framework for change.

Post review the initial action should be to fine tune the process to ensure that only higher risk individuals come in to the USC pathway. This will involve refining the referral guidelines for primary care, making triage of referrals smarter in secondary

care, improving direct access to diagnostics from primary care and thus stratifying USC patients according to agreed clinical urgency.

There will of course be differences in the pace of adoption of these recommendations among NHS Boards. Progress may be monitored initially by the Ministerial Cancer Performance Delivery Group.

As Chair of this independent clinical review, I would like to thank everyone across the NHS, Scottish Government, public, third sector and beyond who has taken part and fed into this valuable piece of work to ultimately improve cancer outcomes for the people of Scotland. I would particularly like to thank the hard-working members of the steering group for all their enthusiasm and input.

If you have any comments in regards to the Review or this report please feel free to make contact via [cancerdeliveryteam@gov.scot](mailto:cancerdeliveryteam@gov.scot)



Dr Valerie Doherty  
Chair of Clinical Review of Cancer Waiting Times  
(CWT) Standards

### **3. Recommendations**

#### **3.1 Cancer Pathways**

- Re – evaluate inclusion/ exclusion criteria of cancer types subject to CWT standards while taking into account the level of resource available for any additional data collection requests.
- Review evidence for making CWT standards timings variable according to tumour biology.
- Review evidence of patient benefit from submitting additional time intervals within the cancer pathway to CWT standards scrutiny e.g. time to subsequent treatment(s).
- Ensure that existing agreed cancer pathways are reactive to new techniques and treatments with well-established processes to enable change to be introduced.
- Minimise variance in agreed pathways by regular cross comparison and dialogue with local, regional and national specialty services.
- Refine the selection of USC patients in both primary and secondary care.

#### **3.2 Primary Care**

- Undertake a review of Scottish Referral Guidelines for Suspected Cancer.
- Reduce variance in availability of protocol led direct access to diagnostics.
- Ensure patients are provided with adequate information and support at the time of their USC referral.

#### **3.3 Secondary Care**

- Embed smarter vetting/triage processes to ensure USC referred patients are managed in order of apparent risk, in terms of access to diagnostics/clinics and avoid variation by considering the use of triaging protocols.
- Regularly review availability of slots for USC patients in clinics, and diagnostics waiting lists (radiology, endoscopy etc.) and make these flexible to best meet pressures in real time.
- Encourage greater use of virtual clinics and advice services learning from Health Boards where these have been successfully trialled.
- Regularly review turnaround times for diagnostic laboratory tests and communicate these to both clinical and tracking staff.
- Ensure that consideration is given to including other higher risk patient groups into any planning for USC referral patients.

### 3.4 Patient Support

- Ensure appropriate information on the USC referral process, tests throughout and purpose is available at the point of referral from primary care.
- Ensure an appropriate and consistent level of information is available throughout the whole pathway and dovetails, if needed, with treatment pathways and explanation of results.
- Provide a key contact for all patients requiring additional support, while ensuring they are clearly signposted for patients to utilise.
- Ensure locally relevant details and timescales are incorporated into any patient information materials/documents.
- Review and act on the outcomes of patient experience QPIs and other relevant patient evaluation processes (e.g PROMs) as and when available.

### 3.5 Data

- Embed proven good practice of close tracking of USC referral patients by fully supported tracking, audit and MDT staff.
- Review any current variance in data collection e.g. in application of exclusion criteria and other adjustments.
- Liaise with ISD Scotland colleagues to maximise available data usage for patient and service benefits.
- Ensure that all clinically relevant data e.g. from MDTs is assimilated into cancer tracking/pathway information.
- Integrate CWT data with any additional available outcome data such as recurrence rates and PROMs as well as survival/mortality.

## 4. Defining Cancer Waiting Times (CWT) Standards in Scotland

The Scottish Government's current position has been to focus on 'whole cancer pathway' standards. The pathway to diagnosis and staging (and therefore to a decision-to-treat date) can be complex for cancer patients, involving several medical investigations and decision-making processes.

There are two waiting times standards which are applicable to adults (NHS Scotland patients over 16 at the date of diagnosis), with a newly diagnosed primary cancer against the ten major cancer types:

**31-day target** from decision to treat until first treatment, regardless of the route of referral.

**62-day target** from urgent referral with suspicion of cancer, including referrals from national cancer screening programmes, until first treatment.

There is currently a 5% tolerance on each standard in Scotland.

To ensure first treatment occurs within the 62 day timescales, an early first appointment for diagnostic investigations or clinic is advisable. For the CWT standards to be met, all steps included in the pathway require completion in a timely manner.

For patients with cancer, Scottish Government waiting times policy applies to first treatments. The first treatment standards provide assurance to patients that the immediate cancer control measures are being started as soon as possible and reduce the period of uncertainty whilst awaiting clarification of a diagnosis.

The 31-day standard was introduced as around 45% of all cancers diagnosed in Scotland are through non USC referral routes. A 31-day treatment standard is in place to ensure that access from decision-to-treat to first definitive treatment is equitable for all cancer patients, regardless of their flow into the system.

Patients are excluded from the standard who have died before treatment, refused all treatment or are regarded as clinically complex. On reflection of a whole patient pathway there may be some areas of delay not attributable to NHS Board performance. These pathways may be adjusted to discount periods of patient unavailability, for patient-induced delays and/or medical suspensions.

### 4.1 Comparing Scotland's definition to other UK nations

There are notable differences between the cancer standard definitions across the UK – these are outlined by the Government Statistical Service here (<https://gss.civilservice.gov.uk/health-waiting-time-statistics/>).



Below is a summary of latest published performance statistics across the four nations however caution should be exercised when comparing CWT performance in other UK countries to Scotland.

**Table 1: Latest published CWT performance across the UK (62 day standard)**

**62 day standard**

Quarter	Scotland (95%)	England (85%)	Wales (95%)	Northern Ireland (95%)
Q1 2017	88.1%	81.1%	87.8%	68.6%
Q2 2017	86.9%	81.5%	86.2%	68.4%
Q3 2017	87.2%	82.2%	87.1%	63.2%
Q4 2017	87.1%	82.2%	88.4%	66.7%

**Table 2: Latest published CWT performance across the UK (31 day standard)**

Quarter	Scotland (95%)	England (93%)	Wales (98%)	Northern Ireland (98%)
Q1 2017	94.9%	97.5%	97.1%	94.5%
Q2 2017	94.8%	97.5%	97.2%	93.9%
Q3 2017	94.5%	97.7%	98.1%	93.5%
Q4 2017	94.5%	97.0%	97.2%	97.2%

**Sources:**

England: <https://www.england.nhs.uk/statistics/statistical-work-areas/cancer-waiting-times/>

Scotland: <http://www.isdscotland.org/Health-Topics/Waiting-Times/Publications/>

Wales: <http://gov.wales/splash?orig=/statistics-and-research/nhs-cancer-waitingtimes/>

Northern Ireland: <https://www.health-ni.gov.uk/articles/cancer-waiting-times>

## **5. The Cancer Waiting Times (CWT) Review**

### **5.1 Scope and remit**

The Review should consider:

- What new measures along the cancer pathway(s) would give clinically meaningful information to inform planning and assess and enhance service quality;
- What measures (new or existing) are most valued by patients and why;
- Are the current cancer waiting times (CWT) standards clinically justified?
- Should additional specific cancer types be included or excluded from the standards?

And ensure that:

- The CWT standards remain patient-centred by engaging with patient groups about what they most value;
- Any revisions to CWT standards are achievable in terms of service delivery;
- Specific clinical issues identified within the treatment/diagnostic pathway for those cancers where additional options now require more patient thinking time including those with a 'watch and wait' recommendation are tackled;
- Consideration is given to the impact of any changes to the CWT standards on wider systems within local health economies.

The Review should:

- Review the literature covering the evidence for CWT standards and any relevant independent studies;
- Compare policies between the four devolved administrations, particularly the different approaches to implementing and monitoring any CWT standards and to share examples of best practice;
- Engage widely with third sector, NHS organisations and relevant social care teams in addition to key patient groups and clinical staff;
- Take account of other developing areas of health policy;
- Review relevant ministerial correspondence received during the Review period around cancer waiting times and;
- Ensure the information burden placed on NHS Scotland through the need to collect data, implement, manage and monitor any revised CWT standards is considered within the scope of the Review.

## **5.2 Steering group**

The Clinical Review of CWT Standards steering group, consisting of NHS primary and secondary care clinicians, NHS managers, Scottish Government cancer officials and ISD Scotland representatives, was formed in March 2017 to reflect geography and range of expertise (see Appendix A for the full membership list).

Each member agreed to act as a conduit for information between the Review steering group and relevant clinical colleagues, both locally and regionally.

The group initially agreed on the direction of the Review and the specific questions to be considered as part of this. While reviewing the available data and insight from NHS Boards on existing patient cancer pathways additional data was requested from Boards to help understand pathway complexities (see Appendix B). The data gathered helped shape the content for the large stakeholder event held in June 2017.

A further steering group meeting was held in September 2017 where the emerging themes for recommendations were fully discussed. Recommendations were derived after consideration of the inputs of all contributing stakeholder groups, the public and patient questionnaire and comments returned centrally to the steering group. Agreed recommendations were circulated in November 2017 for final agreement.

## **5.3 Stakeholder event**

A stakeholder event attended by over 80 people from the public, third sector, ISD Scotland data and audit staff, Cancer Managers, a range of clinicians and Scottish Government officials was held in June 2017. The event provided a platform for discussion, debate and dialogue around existing CWT standards while sharing best practice from NHS Boards and pathways.

Engagement with those in attendance on the day continued after the event to encourage further input to the Review.

Plenary sessions with invited speakers explored the impact of CWT standards on patient outcomes, Realistic Medicine, pathway complexity, background evidence and other key topics. Six parallel workshops ran on the day to allow maximal opportunity for dialogue and sharing of views amongst participants (see Appendix C for the full event programme).

## **5.4 Public and patient involvement**

Input from patients, carers and the wider public was recognised as critical at the outset of the Review to better understand attitudes and expectations around timings in cancer pathways. It was important to better understand the views of individuals who had been through a cancer pathway previously and those who had not – to compare their understanding of the process and experiences.

The questionnaire, developed with input from patient groups, was delivered by an independent research company - Kantar TNS. 1,018 members of the public were

questioned face-to-face while over 70 current/previous cancer patients completed it online. The full questionnaire is available in Appendix D.

In essence, the answers showed confidence and trust in the primary care team and secondary care clinicians. However public expectations of the speed within which investigations should be done, and results obtained, were impractically short e.g. a few days.

An area of increased concern was the lack of easily accessible practical information on tests, possible results, timings and on-going advice and support during the waiting process.

## 6. Review themes and recommendations

### 6.1 Cancer Pathways

Current pathways indicating steps from referral/other presentation through diagnostics to treatment were collected from NHS Boards for the Review. Tumour specific pathways apply most frequently at NHS Board level, occasionally at regional level and even less frequently at a national level. The reason for variation among these pathways requires more detailed evaluation.

#### 6.1.1 Tumour groups included in CWT standards

Scottish Cancer Waiting Times (CWT) Standards currently apply to ten major cancer types selected on their rates of incidence and mortality. This differs from other UK nations as outlined in section 4.

There is a rolling programme of annual audits of additional pathways undertaken by ISD Scotland to ensure cancer patients not included in existing CWT standards are not adversely affected by longer waiting times.

In light of perceived patient benefit, colleagues in the third sector and cancer patient groups regularly request consideration of additional new cancer types to CWT standards scrutiny.

**Recommendation:** Re-evaluate inclusion/exclusion criteria of cancer types subject to CWT standards while taking into account the level of resource available for any additional data collection requests.

#### 6.1.2 Time associated CWT standards

Third sector and patient groups have long expressed the view that existing standards are too long, citing patient anxiety as a main concern.

There is no clear clinical evidence to support the choice of 62 or 31 days as the standards. It is assumed that delay, either by providers or patients, will have an adverse effect on outcomes, as patients will present with later stage disease. Again evidence to support this is not clear cut. A meta-analysis found “only moderate consensus” as to an association with time intervals in the diagnostic process and outcomes (Neal et al 2015).

There is a recognised waiting-times paradox in that late stage disease may present rapidly due to alarm symptoms and conversely early stage disease may be diagnosed after many months. The conclusion, presented by an expert in this field at the Review’s stakeholder event, was that for most cancer cases a short delay was not clinically significant but clearly could have a major impact in terms of patient/carer anxiety.

Individual tumour biology also needs to be considered in any modification of standards’ duration. Patients with some tumours e.g. leukaemia’s and aggressive sub-types of lung cancer may require immediate treatment within a matter of days

whereas for others waiting for intervals of a few months has no discernible effect on clinical outcome.

It is of note that the public questionnaire undertaken as part of the Review showed that there was a desire for rapid diagnosis but also recognition that the capacity to undertake and report on tests was limited. The survey found that 49% of the public and 55% of the patient group trusted clinical staff to prioritise cases appropriately. Of these, 60% of the public and 57% of the patient group attributed this to an overall trust in doctors and health professionals. Full results from the public/patient questionnaire can be seen in Appendix D.

Information collected for the Review shows that some of the pathways for the ten current tumour groups already are, or are becoming, more complex and multi-stepped than others in their diagnostic or treatment phases. Those with lengthening diagnostic components are increasingly challenged by the 62 day standard while for those where treatment options have increased the 31 day standard may be more problematic.

Given the lack of evidence of clinical benefit derived from 62 and 31 day time intervals it would be more useful to clarify what CWT standard duration is appropriate for each tumour type, be that shorter or longer than current timings.

Considering adding the optimal time intervals between steps on pathways would strengthen links between cancer tracking and CWT data collection and better identify bottlenecks.

<b>Recommendation:</b> Review evidence for making CWT standards timings variable according to tumour biology.
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### **6.1.3 Considering additional CWT standards for Scotland**

Thus far there is no clear evidence of the benefit to patient outcomes from the additional application of the Two Week Wait (2WW) CWT standard as applies in England.

While there is no current evidence to support the introduction of the 2WW CWT standard in Scotland, the outcomes from the pilot of the 28 day faster diagnosis standard in England will require consideration when data on outcomes becomes available.

In NHS England, data is collected on the time intervals to subsequent treatments as well as to first treatment. Consideration of this as an additional standard in Scotland would require clear evidence of patient benefit and an evaluation of the existing data and audit capacity across NHS Scotland.

At this time however, there is no data to suggest the inclusion of additional standards would improve cancer patient outcomes in Scotland.

**Recommendation:** Review evidence of patient benefit from submitting additional time intervals within the cancer pathway to CWT standards scrutiny e.g. time to subsequent treatment.

#### 6.1.4 Getting the best out of CWT standards

The Review concluded that the introduction of CWT standards has improved data collection and efficiency of cancer pathways. It also recognised that there is no clear evidence that alternative time measurements are beneficial therefore, optimising the value of their measurement was agreed as a priority for the Review.

Scottish CWT data for the 31 day standard (from decision-to-treat to start of first treatment) suggests that this standard is largely being met and is acceptable to both public and clinical communities.

Additional risk stratification, according to tumour biology, could further improve the flow for the 31 day patient cohort and provide valuable decision making support information to clinical teams.

The Review recognises that the most challenging area is the 62 day standard (from urgent referral to first treatment) – where data reflects greater and increasing challenges in this standard being met.

Data analysed as part of the Review demonstrates that conversion rates from USC referrals to confirmed cancer diagnoses are generally low (3-5%) suggesting that there is scope to refine the selection of USC referral use. Data shows wide variation in overall conversion rates among Boards (6.2% to 25.2%) and by cancer type. It is recognised that some tumours e.g. pancreatic, colorectal and ovarian not infrequently present with vague rather than clear red flag symptoms and thus would be expected to have lower conversion rates.

Enhancing the selection of USC patients to better identify those at higher risk of a positive cancer diagnosis would likely reduce the number of patients going through this diagnostic pathway. This would allow more rapid throughput in diagnostics and ultimately earlier access to treatment options. In addition, this refinement of USC selection would avoid anxiety for those currently on an USC pathway unnecessarily.

It is essential that patients have immediate access to appropriate information and advice upon their USC referral, on its significance and possible outcomes.

An opportunity to refine and risk stratify USC patients occurs at two main points:

1. Primary care selection for USC referral and;
2. Secondary care optimal triage of received USC referrals.

#### **Recommendations:**

- Ensure that existing agreed cancer pathways are reactive to new techniques and treatments with well-established processes to enable change to be introduced.
- Minimise variance in agreed pathways by regular cross comparison and dialogue with local, regional and national specialty services.
- Refine the selection of USC patients in both primary and secondary care.

## 6.2 Primary Care

The existing [Scottish Referral Guidelines for Suspected Cancer \(2014\)](#) are well regarded within primary care to help guide USC referrals. However, adjustment/qualification of existing signs and symptoms would likely enhance their discriminating power while incorporating newer diagnostic techniques (e.g. qFIT, mpMRI) that have emerged since their publication. Newer decision making support tools like Q Cancer should also be considered alongside an update to give an improved degree of risk stratification at the time of referral.

For tumour types with characteristic sign/symptom constellations there is a clear next diagnostic step to diagnosis while those types with vague symptoms may require several investigative steps before a cancer diagnosis is delivered, or not. Allowing primary care colleagues direct access to diagnostics would speed up the diagnostic pathway in both of these tumour types. Review data from ISD Scotland/NHS Boards demonstrated variance in availability of direct access to diagnostics across NHS Scotland - this needs to be explored and rectified.

### Recommendations:

- Undertake a review of Scottish Referral Guidelines for Suspected Cancer.
- Reduce variance in availability of protocol led direct access to diagnostics.
- Ensure patients are provided with adequate information and support at the time of their USC referral.



## 6.3 Secondary Care

### 6.3.1 Triage

Receipt of an USC referral in secondary care provides a further opportunity to stratify patient flow according to risk. In the majority of cases this is carried out by consultants. The Review's data showed considerable variation in practice between NHS Boards and within groups of triage clinicians. From discussions with Boards, there appeared to be an acknowledgement that some non-urgent referrals were received through the USC pathway, but that the limited time available for triage restricted the option of returning the referral to primary care to request additional information or re-classification of the patient's referral.

Opportunities for enhancing referral quality and valuable information exchange opportunities between secondary and primary care, are being missed. Adequate time allowance, to reflect the value of triage within clinical staff job planning, needs to be universal across NHS Scotland.

In some Boards, enhancement of USC referrals had been achieved by the use of virtual clinics and electronic advice lines between secondary care and primary care prior to diagnostic referral. After discussion, and clarification of case history patients can then be booked directly to the appropriate USC diagnostics team or clinic, redirected to another service or referred in routinely.

#### **Recommendations:**

- Embed smarter vetting/triage processes to ensure USC referred patients are managed in order of apparent risk, in terms of access to diagnostics/clinics and avoid variation by considering the use of triaging protocols.
- Regularly review availability of slots for USC patients in clinics, and diagnostics waiting lists (radiology, endoscopy etc.) and make these flexible to best meet pressures in real time.
- Encourage greater use of virtual clinics and advice services learning from NHS Boards where these have been successfully trialled.

### 6.3.2 Tracking patient progress

Data collected through the Review showed, once the patient had entered the relevant fast track USC pathway, there was variation across NHS Boards in how tracking of progress continued. Post triage delays can be minimised by having readily available slots for USC patients in relevant clinics and diagnostics lists together with up to date turnaround times for laboratory investigations. On-going tracking means that any delay or disruption within the diagnostic pathway can be promptly identified to the relevant clinical teams and patient accordingly.

NHS Boards highlighted the difficulty in arranging urgent appointments for patients who were unaware of their USC status. It seems likely that this lack of awareness contributes to DNA numbers for urgent clinics and key diagnostics. If a patient is made fully aware of the USC pathway they are on from the outset it seems likely that they will better understand the significance and importance of each step, feel more in

control of the process and be better placed to make informed decisions about their care.

The Review data analysed showed that pressure in the USC pathway could sometimes impact on other high-risk groups such as patients under surveillance programmes due to a family history of cancer or previous clinical findings. Some of these groups may be at higher risk of cancer than the currently selected pool of USC referred patients.

**Recommendations:**

- Regularly review turnaround times for diagnostic laboratory tests and communicate to both clinical and tracking staff.
- Ensure that consideration is given to including other higher risk patient groups into any planning for USC referral patients.

## 6.4 Patient Support

Currently there are three Cancer Experience QPIs (Quality Performance Indicators) available although it is not clear how widespread the utilisation of these generic questions has been to date.

1. Communication: Patients should experience excellent communication from health care professionals throughout their cancer care.
2. Information Provision: Patients should experience excellent information provision from healthcare professionals throughout their cancer care.
3. Shared Decision-Making: Patients are empowered by healthcare professionals to share decisions about their care and treatment.

These are not subject to the type of regular scrutiny undertaken for tumour specific QPIs. Every effort should be made to encourage all NHS Boards to use the questions and review and act on the results accordingly.

The results from Scotland's first Cancer Patient Experience Survey were published in 2015/16, looking at the full care journey that a cancer patient experiences, from thinking that something might be wrong with them to the support they received after their treatment.

Interestingly, the majority of patients (82%) felt that they were seen by a hospital doctor as soon as they thought it was necessary.

**Table 3: Length of time before first appointment with hospital doctor**

How do you feel about the length of time you had to wait before your first appointment with a hospital doctor?	n	%
I was seen as soon as I thought was necessary	3,856	82%
I should have been seen a bit sooner	549	12%
I should have been seen a lot sooner	280	6%
Total	4,685	100%

**Source:** Scottish Cancer Patient Experience Survey 2015/16

Differences in patients' views about the wait before seeing a hospital doctor can partly be explained by the route that they took to hospital. Those that went to hospital following a screening appointment were most likely to be positive (95%) and unsurprisingly those who attended hospital after five or more visits to their GP practice were least likely to be positive (46%).

The Review's patient and public questionnaire and stakeholder input identified a need for better information and support for patients and their carers.

The Review's questionnaire reported that when asked about receiving information about the expected waiting time between having tests and receiving results, 31% of patients said that they received some information, but not enough while 17% said they didn't receive any.

When it came to receiving information about the time expected to wait from receiving their diagnosis to starting treatment, 29% said that they received some information but not enough while 15% said they didn't receive any information.

The end goal of the well informed patient is someone who is best placed to share in decisions regarding their cancer care. This begins with ensuring clear explanations of all steps of the pathway are available and understandable. For some patients a link worker, intermediary or key contact may be the solution for part or all of their cancer journey.

Given the increasing amount and variable quality of cancer related information on and offline it is important that patients are signposted to additional, trusted quality sources. The introduction of patient tailored accessible information at the time of their USC referral seems logical with additional information milestones highlighted at later points in their pathway.

There has been a notable recent increase in the use of Patient Reported Outcome Measures (PROMs) as a means of understanding the benefits of interventions such as surgery or for monitoring patients with long term conditions. These provide an added layer of information to the responsible clinician and can facilitate access to online advice between appointments.

In the USA there is now evidence that cancer survival is improved in cohorts of patients contributing to PROMs, compared to those on standard follow-up (Basch 2017). For cancer, incorporating PROMs into routine practice would provide an additional valuable measure to current survival and other outcome measures.

#### **Recommendations:**

- Ensure appropriate information on the USC referral process, tests throughout and purpose is available at the point of referral from primary care.
- Ensure an appropriate and consistent level of information is available throughout the whole pathway and dovetails, if needed, with treatment pathways and explanation of results.
- Provide a key contact for all patients requiring additional support, while ensuring they are clearly signposted for patients to utilise.
- Ensure locally relevant details and timescales are incorporated into any patient information materials/documents.
- Review and act on the outcomes of patient experience QPIs and other relevant patient evaluation processes (e.g PROMs) as and when available.

## 6.5 Data

The Review process demonstrated widespread agreement that the requirement to collect CWT data had resulted in improvements in methods of data collection and streamlined cancer pathways. Overall survival figures for cancer are improving but clearly this will reflect elements such as advances in treatments, effects of screening programmes, earlier stage diagnoses and possible changes in tumour biology, in addition to any effect of CWT data collection.

Data gathered by key personnel (trackers, Cancer Managers, MDT co-ordinators and audit staff) currently provides information for clinicians and planners although all these data sources are not fully integrated. The Review data analysed revealed wide variation across NHS Boards in the numbers and grades of staff involved in this data collection process and the ability to utilise the staff flexibly. All NHS Boards felt capacity was adequate for currently collected CWT data.

Further NHS Board variance was apparent in the application of exclusion criteria and other adjustments to CWT data - the reasons for this variance need to be identified. Consideration should be given to removing some exclusion criteria to align with other UK nations.

During the Review concerns were raised, from the steering group and via the stakeholder event, about the ease and immediacy of availability of CWT data for clinical use. Recent introduction of dashboards such as those provided by ISD Scotland should improve this but the consensus of the Review was that better signposting to dashboards is required.

### Recommendations:

- Embed proven good practice of close tracking of USC referral patients by fully supported tracking, audit and MDT staff.
- Review any current variance in data collection e.g. in application of exclusion criteria and other adjustments.
- Liaise with ISD Scotland colleagues to maximise available data usage for patient and service benefits.
- Ensure that all clinically relevant data e.g. from MDTs is assimilated into cancer tracking/pathway information.
- Integrate CWT data with any additional available outcome data such as recurrence rates and PROMs as well as survival/mortality.

## **7. Suggested next steps**

- Changes to referral and triage processes should be undertaken through regional cancer networks, tumour specific specialty groups and by a refresh of the Scottish Referral Guidelines for Suspected Cancer used in primary care.
- Modification of collection and access to cancer data, and integration of all available cancer data, should be led by regional and NHS Board Cancer Managers, audit staff and colleagues in ISD Scotland.
- An expert pathways group should assess available evidence for the inclusion/removal of tumour types from CWT standards, alignment of timescales according to tumour biology and consider the addition of times to subsequent treatments in the standards.
- A separate group should consider patient and carer information sources, optimal support from referral onwards and review the role of PROMs. This group would benefit from strong patient group and third sector leadership.
- Retaining a patient focus is clearly vital and key to any consideration of change is the need to ensure the patient voice is well heard.

## Appendix A

### Steering group membership

<b>Name</b>	<b>Role</b>	<b>Organisation</b>
Dr Valerie Doherty	Chair	Scottish Government
Nicola Barnstaple	Cancer Access Support	Scottish Government
Dr David Brewster	Former Director, Scottish Cancer Registry	NHS National Services Scotland
Dr Hugh Brown	Chair, Scottish Primary Care Cancer Group	NHS Ayrshire & Arran
Richard Copland	Former Head of Access Support	Scottish Government
Simon Jackson	Consultant Radiologist	NHS Lothian
Margaret Kelly	Cancer Services Manager	NHS Lanarkshire
Mr James Mander	Lead Cancer Clinician (SCAN)	NHS Lothian
Fiona McKenzie	Cancer Waiting Times Lead	ISD Scotland
Derick MacRae	Service Manager	NHS Highland
Gary Jenkins/Melanie McColgan	Director of Regional Services/General Manager	NHS Greater Glasgow & Clyde
Dr Ian Penman	Consultant Gastroenterologist	NHS Lothian
Mr Sami Shimi	NOSCAN Clinical Lead	NHS Tayside
Mr Seamus Teahan	Regional Lead Cancer Clinician (WOSCAN)	NHS Forth Valley
Jan Young	Senior Assistant Statistician	Scottish Government

## **Appendix B**

### **Data collection template**

#### **Resource**

There are concerns about the level of resource required at NHS Board level to track and record CWT data and whether existing collection methods are optimal.

How long is spent on average each month on collecting this data (in hours)?

How many and what type of people (e.g. tracker , audit , MDT) does this process involve? Please indicate AFC banding where possible.

Please detail any examples you have of permanent or flexible re-allocation of your tracking resource which has helped ensure CWT data collection.

In your Board, has the level of resource allocated to support CWT data collection changed since the standards were introduced in 2012? If so, in what way?



**Triage**

Variance in allocation of USC flag to referrals from primary care and in subsequent clinical triage of these in secondary care was reported by steering group . We are keen to understand this position. Please provide examples of vetting USC referral experiences, is there a triage protocol , are some retuned to GP or re-graded?

We are looking to obtain examples across different tumour types. Please provide details of numbers of USC referrals and conversion rates for each tumour type for the last three months (if available).

--

**Timed pathways**

We would like to obtain examples of timed pathways which have changed since 2012. Please provide examples (minimum two pathways) of 2012 and present day pathway.

--

**Diagnostics**

In several tumour types a USC referral will require imaging or scoping to reach a diagnosis. The extent of this was raised as a possible pressure by the steering group. We would like to obtain data around the number of USC requests for scope and imaging across different pathways to look at any variance. Please provide any detail below.

--

**High risk patients**

It is felt that current arrangements put some higher risk groups at a disadvantage, such as those with a strong family history of cancer, those under regular surveillance, those due repeat investigations, and those patients with significant but non-malignant conditions. This seems a particular issue in gastroenterology (Upper GI and colorectal services) gynaecology and breast.

Approximately how many people are considered to be under regular surveillance in your service at present in any/ all the above tumour types?

What are current waiting times like for these patients?

What 'safety netting' is in place for these patients to avoid them being lost to follow up or unduly delayed?

*Many thanks for completing, please return this to [cancerdeliveryteam@gov.scot](mailto:cancerdeliveryteam@gov.scot) before **26 May 2017**.*

## Appendix C

### CLINICAL REVIEW OF CANCER WAITING TIMES TARGETS STAKEHOLDER MEETING

Monday 19<sup>th</sup> June 2017 9:30 am – 4 pm

Scottish Health Service Centre (SHSC) Western General Hospital Edinburgh

### PROGRAMME

09:30	Welcome, introductions and purpose of meeting	V Doherty
09:45	Directorate of Performance & Delivery – priorities for 17/18	A Hunter
09:50	Cancer Access Standards Performance Overview	Cancer Access Team
10:15	Realistic Medicine & Cancer Care	D Dunlop
10:35	Q & A session	
10:45	MID MORNING BREAK	
11:00	Impact of Delay on Outcomes	P Murchie
11:20	Urgent Cancer Referrals and Conversion Rates	S Shimi
11:35	Q & A session	
11:40	PARALLEL WORKSHOPS <ul style="list-style-type: none"><li>Improving the primary/secondary care interface – referrals &amp; thresholds</li><li>Improving secondary care triage and vetting</li><li>How to maximise patient involvement on cancer pathways</li></ul>	P Hutchison  S Shimi D Dunlop
12:30	LUNCH	
13:15	Pathway Complexity	S Teahan
13:30	Patient Experience – TNS Survey Results	V Doherty
14:00	PARALLEL WORKSHOPS <ul style="list-style-type: none"><li>Optimizing the cancer pathway</li><li>Improving data collection and definitions</li><li>Identifying benefits and possible adverse effects of CWT</li></ul>	S Teahan R Black D MacRae
14:50	AFTERNOON BREAK	
15:05	Feedback from workshops, Q & A panel & Next Steps	V Doherty
15:45	CLOSE	

# Cancer Waiting Times Research

## Summary of Results

Prepared by Kantar TNS for Scottish Government



The research was carried out in compliance with our certification to ISO 9001 and ISO 20252 (International Service Standard for Market, Opinion and Social Research).

NOTE: Q005 to Q010 were asked as self-completion in the general public survey, with the remaining questions interviewer administered. All questions were self-completion in the patient groups survey

## Q005: FIRSTACT

Matrix

**Not back | Number of rows: 9 | Number of columns: 2**

If you spotted a persistent change in your health (such as unexpected weight loss, a change in your patterns of going to the loo or a general unusual change in your body), what would be the first thing you would do? What else?

*Please select only the first thing you would do in the first column, and then select anything else you might do in the second column.*

### Random

Base: All respondents: First thing you would do	Public (1018) %	Patient Groups (71) %
<b>Take any action (Net)</b>	<b>98</b>	<b>99</b>
Wait to see if it clears up on its own	6	11
Speak to a friend/family member	11	10
Go online for advice	5	10
Speak to a pharmacist	2	1
Visit my GP	70	61
Go to A&E	1	-
Call NHS24/other helpline	3	-
Other	1	6
Nothing	2	1

Base: All respondents: Total mentions of things you would do	Public (1018) %	Patient Groups (71) %
<b>Take any action (Net)</b>	<b>98</b>	<b>99</b>
Wait to see if it clears up on its own	13	27
Speak to a friend/family member	28	45
Go online for advice	18	42
Speak to a pharmacist	12	11
Visit my GP	88	87
Go to A&E	13	1
Call NHS24/other helpline	21	8
Other	2	8
Nothing	2	1

## Q006: GPWAIT

Single coded

**Not back**

How long would you wait before you visited your GP?

*Please select one answer only*

### Normal

Base: All respondents: Total mentions of things you would do	Public (1018) %	Patient Groups (71) %
<b>Three weeks or less (Net)</b>	<b>85</b>	<b>85</b>
A few days	45	31
A week or two	33	44
Three weeks	6	10
<b>Longer than three weeks (Net)</b>	<b>11</b>	<b>10</b>
A month	5	7
A few months	3	3
Longer than a few months	2	-
Don't know	4	6

**Q007: TESTWAIT2**

Single coded

**Not back**

If your GP felt it was **unlikely that there was anything serious wrong**, but still wanted you to have some tests at the hospital, to investigate your concern further, how long would you expect to wait before this happened?

*Please select one answer only*

**Normal**

Base: All respondents	Public (1018) %	Patient Groups (71) %
<b>Within a week (Net)</b>	<b>37</b>	<b>14</b>
Same day	9	-
A few days	14	7
A week	14	7
<b>Longer than a week but within a month (Net)</b>	<b>41</b>	<b>55</b>
One to two weeks	18	14
Three to four weeks	13	25
Around a month	9	15
Longer than a month	11	7
It depends on the severity of my symptoms / condition	7	24
Don't know	4	-

**Q008: TESTWAIT**

Single coded

**Not back**

If your GP wanted you to have some tests at the hospital, as it **might be something serious**, how long would you expect to wait before this happened?

*Please select one answer only*

**Normal**

Base: All respondents	Public (1018) %	Patient Groups (71) %
<b>Within a week (Net)</b>	<b>62</b>	<b>49</b>
Same day	19	7
A few days	26	23
A week	18	20
<b>Longer than a week but within a month (Net)</b>	<b>28</b>	<b>42</b>
One to two weeks	16	28
Three to four weeks	8	8
Around a month	4	6
Longer than a month	3	1
It depends on the severity of my symptoms / condition	4	7
Don't know	3	-

**Q009: WAITATTITUDES****Matrix****Not back | Number of rows: 6 | Number of columns: 7**

Here are some things people have said when waiting for the results of tests which have been carried out because cancer is suspected.

Please select one answer for each to show the extent to which you agree or disagree.

*Please select one answer only for each statement.*

**Random**

<b>Base: All Public (1018) / Patient Groups (71)</b>		<b>Total Agree</b>	Agree strongly	Agree	Agree slightly	Neither agree nor disagree	Disagree slightly	Disagree	Disagree strongly	<b>Total Disagree</b>
It would be good to know I could contact someone at my GP practice if I was worried or concerned about any further changes while waiting for my test results (%)	Public	<b>89</b>	34	47	9	8	*	1	1	<b>2</b>
	Patient Groups	<b>90</b>	45	42	3	4	3	3	-	<b>6</b>
It's better to wait until the results for ALL your tests are available, so the healthcare team is fully informed before talking to you about your diagnosis and treatment options (%)	Public	<b>82</b>	23	46	14	9	5	3	1	<b>9</b>
	Patient Groups	<b>79</b>	18	42	18	1	7	7	6	<b>20</b>
Due to the large number of tests being undertaken every day at the hospital, not everyone's results can be processed on the same day they have the tests. (%)	Public	<b>85</b>	20	53	12	10	1	3	1	<b>5</b>
	Patient Groups	<b>76</b>	20	46	10	6	8	8	1	<b>18</b>
Every case is looked at individually so the length of time you wait will depend on the urgency of your condition, as determined by a team of experienced health professionals. (%)	Public	<b>83</b>	21	49	13	11	2	3	1	<b>7</b>
	Patient Groups	<b>75</b>	18	48	8	3	10	10	3	<b>23</b>
It would be good to have a helpline to call to speak to someone about any worries or concerns – or about what may lie ahead - while you wait for your results (%)	Public	<b>79</b>	27	40	12	13	2	4	1	<b>7</b>
	Patient Groups	<b>75</b>	34	30	11	14	4	7	-	<b>11</b>
Nothing anyone could say or tell me would help reassure me while I've been left to wait for results (%)	Public	<b>53</b>	11	27	14	19	9	14	4	<b>28</b>
	Patient Groups	<b>52</b>	23	21	8	15	6	17	10	<b>32</b>

**Q010: CAPI OMNIBUS END OF SELF-COMPLETION****Text****Not back**

Thank you, please hand the computer back to the interviewer.

**Q011: WAIT TEST STATUS****Single coded****Not back**

Generally thinking about waiting for test results, that could lead to a cancer diagnosis, which of the following best applies to you?

*Please select one answer only.*

**Inverted**

<b>Base: All respondents</b>	<b>Public (1018) %</b>	<b>Patient Groups (71) %</b>
It could be good to have a little time between having the tests and receiving the results	8	-
I wouldn't want to spend any time waiting for the results	35	42
You simply have to trust the health professionals and assume that, if they think it is something serious, or that could get worse quickly, you'll be prioritised/processed sooner	49	55
Don't know	8	3

**Q012: REASONWAITSTATUS****Open****Not back**

You said at the previous question that: [INSERT TEXT SELECTED AT Q011].

Why do you say that?

*CAPI OMNIBUS: PROBE FULLY AND RECORD VERBATIM.  
 ONLINE: Please write in as much information as possible in the box below*

<b>Base: All respondents who stated it would be good to have a little time</b>	<b>Public (68) %</b>	<b>Patient Groups (-) %</b>
Would want (thinking) time/time to adjust	26	-
There is a process to follow/can't rush results	10	-
Would want peace of mind/put my mind at rest	9	-
Would want to know ASAP/immediately	7	-
Would want treatment asap/to start asap	3	-
Nothing	9	-
Others	9	-
Don't know	22	-

<b>Base: All respondents who stated wouldn't want to spend any time</b>	<b>Public (343) %</b>	<b>Patient Groups (30*) %</b>
Would want to know ASAP/immediately	39	63
Would want peace of mind/put my mind at rest	19	37
Would want treatment asap/to start asap	16	7
The sooner (it is tackled) the better	8	10
Previous (family) experience	5	17
No point in delaying/why waste time	4	-
Condition might deteriorate	3	3
There is a process to follow/can't rush results	*	20
Others may need to be seen sooner	*	3
Nothing	5	7
Others	1	3
Don't know	7	-



<b>Base: All who stated you have to trust the health professionals</b>	<b>Public (507) %</b>	<b>Patient Groups (39*) %</b>
Trust the NHS/them	32	26
They are the experts/professionals	24	31
They know best/better	19	3
There is a process to follow/can't rush results	4	13
If serious you would be prioritised	4	36
Previous (family) experience	4	18
Would want to know ASAP/immediately	3	10
Just have to accept it/deal with it/no choice	3	3
Would want treatment asap/to start asap	1	3
Would want peace of mind/put my mind at rest	1	5
The sooner (it is tackled) the better	*	5
Others may need to be seen sooner	2	5
No reason/that's just how I feel	*	5
Nothing	6	-
Others	1	3
Don't know	5	-

\*=caution: low base size

### Q013: TREATWAITSTATUS

Single coded

#### Not back

If you were to receive a cancer diagnosis, thinking about starting your treatment, which of the following best applies to you?

*Please select one answer only*

#### Inverted

<b>Base: All respondents</b>	<b>Public (1018) %</b>	<b>Patient Groups (71) %</b>
It could be good to have a little time between receiving a diagnosis and starting treatment	6	10
I wouldn't want to spend any time waiting for my treatment once my diagnosis was confirmed	44	61
You simply have to trust the health professionals and assume that you'll receive your treatment in an appropriate time-frame	39	30
Don't know	11	-

[Not back](#)

You said at previous question that: [INSERT TEXT SELECTED AT Q013].  
Why do you say that?

*CAPI OMNIBUS: PROBE FULLY AND RECORD VERBATIM.*  
*ONLINE: Please write in as much information as possible in the box below*

Base: All respondents who stated it would be good to have a little time	Public (59) %	Patient Groups (7*) %
Depends how serious it is	2	29
Trust doctors/professionals/they know what they are doing	2	14
Would want to consider other options/think it over	28	43
To help you come to terms with it/prepare you mentally	27	57
Would want to talk/prepare family/friends	7	14
Previous experience/family member had cancer	1	14
Would want treatment (right away)/can start treatment (immediately)	6	-
Sooner (treatment) starts the better	4	-
Cancer is life threatening/serious	3	-
Nothing	5	-
Other	15	-
Don't know	2	-

\*=caution: low base size

Base: All respondents who stated wouldn't want to spend any time	Public (445) %	Patient Groups (43*) %
Would want treatment (right away)/can start treatment (immediately)	31	42
Sooner (treatment) starts the better	25	23
Have a better chance of survival/improve chances/better outcome	17	16
Time is important/don't want to waste time	6	5
To prevent cancer spreading/can get worse (quickly)	5	12
Delaying can make it worse/you could die	3	5
Cancer is life threatening/serious	3	2
Trust doctors/professionals/they know what they are doing	*	5
Doctors/professionals need time to plan/treatment needs to be planned	-	5
Would like to/need to know (right away)	3	2
I don't like waiting/am impatient/wouldn't want to wait	5	7
Waiting would cause stress/worry/is horrible	5	26
Previous experience/family member had cancer	3	23
Nothing	5	-
Other	5	5
Don't know	*	-

Base: All who stated you have to trust the health professionals	Public (383) %	Patient Groups (21*) %
Trust doctors/professionals/they know what they are doing	60	57
Trust the NHS	12	5
Doctors/professionals need time to plan/treatment needs to be planned	1	14
Waiting would cause stress/worry/is horrible	-	5
Previous experience/family member had cancer	5	24
No other option/you have to/that's how it goes	4	5
Cannot be done instantly/other people needing treatment	3	-
Sooner (treatment starts) the better	*	5
Other	7	19
Nothing	9	-
Don't know	1	-

**Q015: CANCERHIST**

Single coded

[Not back](#)

Which of the following statements best describes you?

*Please select one answer only.*[Inverted](#)

Base: All respondents	Public (1018) %	Patient Groups (71) %
<b>Any experience of cancer</b>	<b>8</b>	<b>73</b>
I have been diagnosed with cancer at some point in my life	8	39
I am currently receiving treatment for cancer	1	34
I have never been diagnosed with cancer	87	23
Prefer not to answer	5	4

Ask only if **Q015,1,2****Q016: EXPWAIT**

Single coded

[Not back](#)

During your experience with cancer, do you feel you received enough information **about the time you were expected to wait** in between having tests and receiving results?

*Please select one answer only.*[Inverted](#)

Base: All respondents who have been diagnosed with or a receiving treatment for cancer	Patient Groups (52) %
I received too much information.	-
I received the right amount of information	50
I received some information, but not enough	31
I didn't receive any information	17
Not sure	2

Ask only if **Q015,1,2****Q017: EXPWAITTREAT**

Single coded

[Not back](#)

And do you feel you received enough information **about the time you were expected to wait** from receiving your diagnosis to starting treatment?

*Please select one answer only.*[Inverted](#)

Base: All respondents who have been diagnosed with or a receiving treatment for cancer	Patient Groups (52) %
I received too much information.	-
I received the right amount of information	54
I received some information, but not enough	29
I didn't receive any information	15
Not sure	2

**Q018: OTHERCOMMS****Open****Not back**

Please feel free to expand/leave any comments you have on this subject. What could have been done differently/better in your opinion? (max 300 words).

<b>Base: All respondents</b>	<b>Patient Groups (71) %</b>
Happy/satisfied with my treatment (include all references to hospitals, GPs etc.)	14
Wait is too long/should be much quicker (between diagnosis and treatment)	14
Errors/mistakes were made/I was over-looked/notes were lost	6
Had to persevere to get diagnosis/was not believed	8
Stressful/anxious time (for me/family)	10
More information/explanations required/need to ensure patient understands information	7
Other	17
No further comments	42

**Q019:****Text****Not back**

We also have a few questions for you that will help us analyse the data.

**Q020: Gender****Single coded****Not back**

Could you please tell me your gender?

**Normal**

<b>Base: All respondents</b>	<b>Public (1018) %</b>	<b>Patient Groups (71) %</b>
Male	49	31
Female	51	69
Other	-	-
Prefer not to answer	-	-

**Q022: Age****Single coded**

<b>Base: All respondents</b>	<b>Public (1018) %</b>	<b>Patient Groups (71) %</b>
16-24	14	3
25-34	16	4
35-44	15	7
45-54	18	27
55-64	15	23
65+	22	37
Refused	-	-

**Q023: SEG**

Single coded

Base: All respondents	Public (1018) %	Patient Groups (71) %
AB	25	48
C1	28	31
C2	19	7
DE	29	8
Do not wish to answer	-	6

**Q025: Location**

Single coded

**Not back**

Which of these best describes where in Scotland you live?

*Please select one answer only***Normal**

Base: All respondents	Public (1018) %	Patient Groups (71) %
North of Scotland (Grampian, Highland, Tayside, Western Isles, Orkney, Shetland)	27	17
West of Scotland (Greater Glasgow & Clyde, Ayrshire & Arran, Lanarkshire, Forth Valley)	46	66
South and East of Scotland (Lothians, Fife, Borders, Dumfries & Galloway)	27	17

## Appendix E

### Key references

- Neal, RD, Tharmanathan P, France B et al. Is increased time to diagnosis and treatment in symptomatic cancer associated with poorer outcomes? Systematic Review. *Br J Cancer* (2015) 112, S92-S107
- McPhail S, Johnson S, Greenberg D et al. Stage at diagnosis and early mortality from cancer in England. *Br J Cancer* (2015) 112, S108-S115
- Neal R, Aligarh V L, Ali N et al. Stage, survival and delays in lung, colorectal, prostate and ovarian cancer :comparison between diagnostic routes. *Br J Gen Pr* (2007)57(536).212-219
- Murchie P, Raja EA, Brewster DH et al. Time from first presentation in primary care to treatment of symptomatic colorectal Cancer: effect on disease stage and survival *Br J Cancer* (2014) 111,461-169
- Murchie P, Raja EA, Lee AJ et al. effect of longer health service provider delays on stage at diagnosis and mortality in symptomatic breast cancer. *The Breast* (2015) 24.248-255
- Lyratzopoulos G, Wardle J, Rubin G. Rethinking diagnostic delay in cancer: how difficult is the diagnosis? *BMJ* 2014;349:g7400
- Murchie P, Chowdhury A, Smith s et al. General practice performance in referral for suspected cancer; influence of number of cases and case mix on publicly reported data *Br J Cancer* (2015)112.1791-1798
- Topping ML, Frydenberg M, Hansen RP et al. Time to diagnosis and mortality in colorectal cancer: a cohort study in primary care. *Br J Cancer* (2011).104, 934-940
- Topping ML, Frydenberg M, Hansen RP et al. (2013)Evidence of increasing mortality with longer diagnostic intervals for five common cancers ;a cohort study in primary care. *Eur j Cancer* 49 ((9) 2187-2198
- Basch E. Patient-reported outcomes – Harnessing patients ‘voices to improve clinical care. *NEJM* (2017) 376; 2.105-108

## **Appendix F**

### **Glossary**

CWT – cancer waiting time

USC – urgent suspicion of cancer

2WW – 2 week wait

DNA – did not attend

MDT – multi disciplinary team

NOSCAN – North of Scotland Cancer Network

QPI – quality performance indicator

ISD – information Services Division

SCAN – South East Scotland Cancer Network

SG – Scottish Government

WOSCAN – West of Scotland Cancer Network

qFIT – quantitative faecal immunochemical test

mpMRI – multiparametric magnetic resonance image

PROM – Patient Reported Outcome Measure



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