

### Ovarian Cancer Action Plan Progress Report

## 10<sup>th</sup> March 2022

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Author(s)	North Cancer Alliance Ovarian Cancer Action Plan Group (Appendix A)	
	Chair: Dr. Malcolm Metcalfe, Deputy Medical Director, NHS Grampian	

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#### 1. Executive Summary

Outcomes from cancer treatment are a matter of public interest and essential measures of clinical quality. In order to ensure the highest standards across Scotland, three regional bodies were set up, in part to deliver the National Cancer Quality programme. Public Health Scotland (PHS) also supports the programme and publishes its findings in the public domain. The latter identified that outcomes for ovarian cancer treatment did not appear to be as good in the North as either the West or East Regions, through assessment utilising data collected in the clinical audit by boards on patients diagnosed with Ovarian Cancer between October 2013 and September 2017.

The Medical Directors within the North Region (Grampian, Highland, Tayside, Orkney, Shetland and the Western Isles) therefore commissioned a review from the North Cancer Alliance chaired by an independent clinician – Dr. Malcolm Metcalfe. This work is being supported by the respective Chief Executives, with regular updates to the North of Scotland Medical Directors group chaired by Michael Dickson (Chief Executive for NHS Orkney & Shetland).

For patients diagnosed between October 2013 and September 2017, overall survival was 29% in the North compared to 42% and 43% in the other regions. Median survival being 1.9 years for the North and 2.8 years for the other Regions. In the North there were more FIGO stage 4 patients, an older age group and fewer patients undergoing surgery. These being the three major determinates of survival.

A Conditional Survival Analysis was undertaken for those women surviving six months. Survival after this period showed no statistical difference between the networks suggesting that all survival benefit is driven by treatment decisions which will be influenced by FIGO stage at presentation.

Between 2016 and 2020 survival had improved so that no statistical difference was observed between the Regions (p=0.14). There was still a suggestion that the curves were separating but a longer observation period will be required to be certain.

Surgery rates for patients presenting with advanced disease in the North of Scotland have improved since the release of the survival outcomes in late 2018 although remain less than for other regions as demonstrated in the latest <u>North of Scotland QPI Annual Report</u> (2019/20 patients).

The North of Scotland has adopted the surgery decision-making guidelines from the South-East Region and incorporated this into decision-making at the regional MDT.

The North continues to have more women aged more than 65 years and more patients presenting with advanced disease than either East or West. The reasons for late stage presentation are unknown, however a review of staging in one board within the NCA has highlighted that 71% of patients had FIGO stages 3 or 4 disease at presentation. The reasons for these late presentations remain unknown but are currently being investigated. It is intended to repeat this exercise for all patients in the North of Scotland included within the audit.

Deep analysis of the most recent (2019-21) QPI data has highlighted that over this period approximately 68% of patients presented in Tayside with advanced disease (FIGO 3 & 4) with many presenting through emergency pathways. The reasons for this are also unknown but subject to current investigation.

The limitations of the data set used to undertake the survival analysis also need to be recognised, in that there is no measure of patient fitness for surgery by performance status at presentation, or any record of comorbidities that mean surgery is not the best option for some patients. PHS survival outcomes are also not measured on an intention to treat basis and this is a limitation of this data set that needs to be highlighted.

Work to develop a weekly North of Scotland Ovarian Cancer MDT, with shared decisionmaking, has considerably developed since 2018 and now all patients are discussed collaboratively by all ovarian cancer clinicians involved in their care. All patients that are potentially operable and fit for surgery are offered debulking surgery. However there are limited data on the patients presenting who are unfit for surgery, or where disease is inoperable.

Theatre capacity for current ovarian cancer surgery volumes has traditionally been felt sufficient for the NCA but the consensus is that the data for QPI 10 suggests that additional lists and resources are required as part of a multi-factorial approach to allow the volume of women having surgery to increase especially in Tayside. All patients who are operable and fit for surgery following discussion at the regional MDT are offered this but may decline travel to Grampian. This factor is being investigated to understand patient choice factors and whether this affects surgery rates in the North of Scotland.

A prehabilitation pathway, to optimise patients for surgery, is required to ensure a smooth pathway of care for these women. One factor that is not known is the effects of rurality and travel to a tertiary centre on patient acceptance of surgery.

In addition to the weekly Regional MDT other improvements to the service have either been achieved or are work in progress. For example the Regional MDT is now just that and not three separate MDTs. The use of a MS Teams platform has obviated communication difficulties in the meeting, funding has been obtained to appoint a Regional Pathway Coordinator and plans are in place to appoint a fourth Gynae-Oncologist Surgeon within the team at Aberdeen Royal Infirmary.

There remain three key actions to progress:

- Development of national ovarian radiological staging guideline between the 5 Scottish cancer centres to ensure agreed staging practice is consistently applied within MDTs.
- Explore why the North of Scotland has more patients with advanced disease, including route of presentation, taking action to encourage earlier presentation and diagnosis.
- Embed a regional approach to prehabilitation for North ovarian surgery patients.

These actions will be progressed within the North region and in collaboration with South East and West Regions as a matter of priority. We also await the outcomes of the updated PHS Survival Analysis for patients diagnosed since 2018 to ascertain the differences these actions highlighted in this report, have made to survival for women in the North of Scotland.

#### North Cancer Alliance: Ovarian Action Plan Progress Report (10th March 2022)

#### 2. Introduction

Since August 2018, significant work has been underway across the North Cancer Alliance (NCA; a collaboration of 6 health boards comprising NHS Grampian, NHS Highland, NHS Orkney, NHS Shetland, NHS Tayside and NHS Western Isles) in response to a Public Health Scotland (PHS) analysis of survival outcomes for women diagnosed with ovarian cancer between 1<sup>st</sup> October 2013 and 31<sup>st</sup> September 2016 (publication expected 8<sup>th</sup> March 2022).

The analysis concluded that there was a significant difference in survival outcomes for patients diagnosed in the different cancer networks in Scotland, with observed proportionally less access to upfront primary and interval delayed surgery for patients in the North compared to the rest of Scotland. It was also observed that there were proportionally more Stage 4 patients diagnosed in the NCA than in either the South-East Scotland Cancer Network (SCAN) and West of Scotland Cancer Network (WoSCAN).

A national review group comprising clinicians and management was convened in September 2018 to collaboratively assess the analysis and through the NCA Gynaecological Cancer Pathway Board, a sub-group formed in the North to deliver an action plan within the North of Scotland health boards and primarily through the three cancer centres hosted by NHS Grampian, NHS Highland and NHS Tayside. Surgery for advanced disease is delivered for the region by the NHS Grampian team, at Aberdeen Royal Infirmary.

Collaborative assessment and action planning on outcomes for women in the North of Scotland commenced in this sub-group in late 2018, with a business case for additional resources and a number of actions agreed by the clinical and management group. Several immediate actions including the adoption of SCAN's ovarian cancer surgery decision-making guidelines (approved August 2019) and work to increase access to surgery for patients diagnosed within the North of Scotland.

Intelligence through the Quality Performance Indicators (QPI) has continued to be monitored, assessed and action-planned throughout this time. A further action plan was agreed by the North of Scotland Medical Director's group in March 2021 with immediate actions for progress and appointment of a senior medical chair, Dr. Malcolm Metcalfe, to oversee the action plan and support regional collaborative investigation and action planning on Ovarian Cancer pathways.

Since March 2021, there has been significant progress against the updated action plan including the development of a regional MDT for discussion of Ovarian patients, assessment of routes of presentation within the North of Scotland and consensus on the radiological staging of patients with suspected ovarian cancer.

It has also been noted that the PHS Survival Analysis for patients diagnosed between October 2013 and September 2016 does not include any analysis of outcome by intention to treat, or factors including deprivation, patient co-morbidity or performance status at presentation. We are therefore unable to assess whether patient fitness for surgery was a factor in less women in the North of Scotland receiving access to upfront or interval delayed primary surgery.

The latest QPI data for patients diagnosed between October 2020 and September 2021 has demonstrated that an increased percentage of patients with FIGO stage 2, 3 & 4 disease have received access to upfront primary and interval delayed surgery in the North. There remain differences in some health boards where patients do not appear to present with

symptoms in Primary Care requiring an Urgent Suspected Cancer referral to secondary care, and work is underway to take action to encourage earlier presentation and improve earlier detection and referral.

Recent data has demonstrated an increasing proportion of women in the North of Scotland are beginning offered access to surgery for advanced Ovarian Cancer (FIGO stage 2 or higher). The latest data has shown that patients diagnosed in NHS Grampian and NHS Highland meet the 65% QPI target for the first time ever, although the full impact of the COVID-19 pandemic has not been fully understood. In depth analysis of patients at NHS Tayside has indicated that all patients who were fit for surgery at presentation received this. There are actions required to encourage earlier presentation and ensuring appropriate referral for investigations for patients presenting with symptoms.

The North of Scotland Ovarian Cancer action plan group await future updates on survival data and outcomes for patients to assess whether changes in pathways within the North of Scotland has impacted on survival outcomes for our patients and rectified previously observed differences between outcomes for patients in different parts of Scotland.

#### Summary of Key Risks as at 31<sup>st</sup> March 2021

- 1. Surgery rates within the North of Scotland is lower than recommended and below other regions in Scotland.
  - Surgery rates for women with FIGO Stage 2+ disease within the North of Scotland is below the recommended target level (QPI 10 (i) 2018/19 data NCA 46% against target of >60%)
  - Surgical rates for women with FIGO Stage 2+ disease across the region has increased over the last three years
  - There is variation across the three Scottish networks in numbers of patients with advanced ovarian cancer undergoing surgery (2018/19 NCA 46%, WOSCAN 58% and SCAN 79%)
  - There is variation in surgery rates across the three mainland Boards in the NCA network

(2018/19 Grampian 46%, Highland 52% and Tayside 32%).

- Surgery for this group of women is thought to be the most effective way of influencing future survival
- In view of this survival advantage the QPI 10 (i) target was raised to target to 65% as of September 2020.

Possible factors influencing access to surgery in NCA and the variation across individual Boards.

- a. Variation in individual NCA Board pathways that lead to the diagnosis of ovarian cancer and then consideration in an MDT for complex surgery. This may result in a number of women who might benefit from surgery not being consider within the regional MDT.
- Regional MDT decision making process does not follow best practice leading to some suitable women not being offered a surgical option that would lead to better outcomes
- c. Subsequent decisions to proceed with surgery are not followed through or are delayed beyond current recommended timescales
- d. Overall resource availability for ovarian cancer surgery is influencing surgical intervention rates.

- 2. Profile of ovarian cancer staging in NCA region appears significantly different from the rest of Scotland.
  - There are significantly more stage IV women in the NCA Boards compared to other regions (Oct 2013 – Sept 2016 cohort FIGO Stage 4,4a+4b: NCA 34%, SCAN 21% and WOSCAN 22%)
  - Stage of disease affects both survival chances and therapeutic management decisions

Possible factors influencing staging profile in NCA.

- a. The profile of ovarian cancer staging at diagnosis in the NCA region reflects intrinsic population level factors
- b. The profile relates to the diagnostic pathways available to women in the NCA region either through the USC referral route or via other incidental detection routes. This could be differences in time to test, differential access or variation in the diagnostic test used.
- c. The profile relates to the NCA approach to how women are staged by the specialist team
- 3. Overall survival of women with ovarian cancer in the NCA region could be lower than elsewhere in Scotland or the UK.
  - Ovarian cancer survival analysis from Oct 2013 Sept 2016 cohort was significantly lower in the NCA region compared with other regions in Scotland (4 year survival NCA 29%, SCAN 42% and WOSCAN 43%)
  - Ovarian cancer survival analysis from Oct 2016 Sept 2018 was not significantly different from other regions in Scotland
    (3 year survival NCA 44%, SCAN 51%, WOSCAN 49% p=0.14)
  - It is not clear if the analysis from the 2016-2018 cohort represents an improving position or that the smaller size and shorter follow up time of the cohort is under powered to reveal a real continuing difference.
  - Late stage disease was associated with worse outcome (Higher in NCA as detailed above)
  - Surgical intervention was associated with better outcomes (Lower in NCA as detailed above)

Possible factors influencing adverse survival of women in NCA.

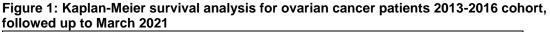
- a. Relative high rate of advanced stage disease as detailed above
- b. Relative lower rate of surgery as detailed above
- c. Other factors

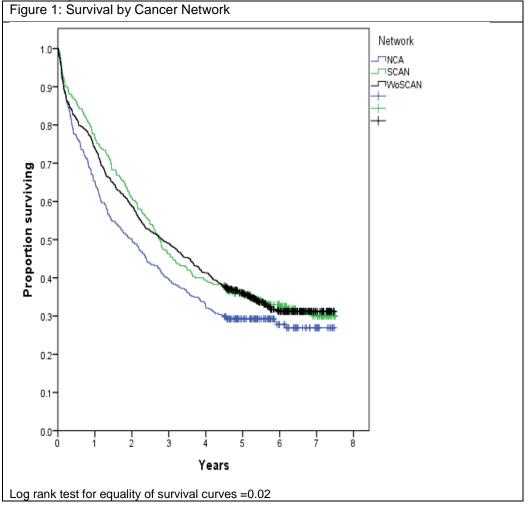
#### 3. Background

The initial Ovarian Cancer survival analysis data undertaken by PHS was presented to a national ovarian cancer review group in September 2018. This analysis was updated in August 2020, with follow up to December 2017, following correction of the CHI numbers from the initial analysis. This showed that at the end of 2017, there had been 679 deaths (49%) in the cohort of 1,377 women. There was also a significant difference in survival at four years between the cancer networks, with 29% alive in NCA compared with 42% and 43% alive in SCAN and WoSCAN respectively (p=0.002; see Figure 1 below).

The PHS report was updated in November 2021 and provides updated results for this cohort, with follow up now extended to March 2021. As of this censoring point, there were 940 deaths (68%) among the 1,377 women.

In the updated survival analysis report, there remains a significant difference in survival between the cancer networks (p=0.02; Figure 1). For example, there was still a substantial absolute gap in survival at one year between women treated in NCA compared with women treated in the other two networks (65% in NCA; 77% in SCAN and 74% in WoSCAN). This pattern remained at five years after diagnosis (29% in NCA; 36% in both SCAN and WoSCAN). On deeper examination, the survival curves have already started to separate by six months, with NCA having lower survival than SCAN by this point (77% compared with 86%).





Given this early separation of the survival curves, a conditional survival analysis was performed on the 1,123 women who had survived beyond six months (i.e. the 254 women (18%) who died within the first six months were excluded). This conditional survival analysis showed no difference between the cancer networks over the whole period of follow-up (p=0.19), with 1-year survival (conditional on having lived at least six months) of 84.9% (95% CI: 80.6%, 89.2%) in NCA; 89.0% (95% CI: 85.5%, 92.5%) in SCAN and 90.6% (95% CI: 88.2%, 93.0%) in WoSCAN.

This analysis provides further support for previous findings suggesting that the difference are driven by the FIGO stage and decision around the type of surgical intervention. Even after review of all of the women deemed to be 'Stage Not Applicable' or 'Stage Not Recorded', there remained differences between networks in the proportions of cases within each of the FIGO stage groups, with NCA having significantly more Stage IV patients (33%) than the other two networks (16% in SCAN and 24% in WoSCAN; p<0.001; Table 1).

	NCA	SCAN	WoSCAN	Total	D value1
	No. (%)	No. (%)	No. (%)	No. (%)	P value <sup>1</sup>
Age group					0.13
15-54	60 (17.0)	74 (21.1)	123 (18.2)	257 (18.7)	
55-64	67 (19.0)	81 (23.1)	173 (25.6)	321 (23.3)	
65-74	110 (31.3)	101 (28.9)	201 (29.8)	412 (29.9)	
75+	115 (32.7)	94 (26.9)	178 (26.4)	387 (28.1)	
FIGO stage					<0.001
I	59 (16.8)	71 (20.3)	142 (21.0)	272 (19.8)	
II	27 (7.7)	24 (6.9)	43 (6.4)	94 (6.8)	
III	148 (42.0)	183 (52.3)	296 (43.9)	627 (45.5)	
IV	117 (33.2)	55 (15.7)	163 (24.1)	335 (24.3)	
Not applicable	1 (0.3)	13 (3.7)	20 (3.0)	34 (2.5)	
Not recorded	0	4 (1.1)	11 (1.6)	15 (1.1)	
Surgery groups					<0.001
Primary	118 (33.5)	193 (55.1)	306 (45.3)	617 (44.8)	
Delayed	45 (12.8)	68 (19.5)	139 (20.6)	252 (18.3)	
None <sup>2</sup>	189 (53.7)	89 (25.4)	230 (34.1)	508 (36.9)	
Macroscopic Residual disease					<0.001
No residual disease	102 (29.0)	148 (42.3)	257 (38.1)	507 (36.8)	
>0 to <1cm residual disease	10 (2.8)	52 (14.9)	82 (12.1)	144 (10.5)	
1cm or greater residual disease	12 (3.4)	32 (9.1)	58 (8.6)	102 (7.4)	
Residual disease not recorded	39 (11.1)	29 (8.3)	48 (7.1)	116 (8.4)	
No surgery	189 (53.7)	89 (25.4)	230 (34.1)	508 (36.9)	
Total	352 (25.6)	350 (25.4)	675 (49.0)	1,377 (100)	

Table 1: Numbers and percentages of characteristics in the different	t networks
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1 - chi-squared tests of association

2 - includes 23 patients who had no surgery due to having died before this was an option

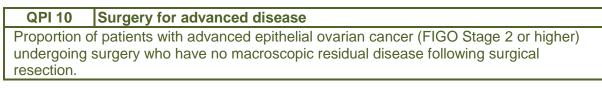
Surgical practice also differed significantly between networks, with 54% of patients in NCA not receiving surgery compared to 25% in SCAN and 34% in WoSCAN. From the data available, it is not possible to determine whether women in NCA have inherently poorer disease at presentation, and therefore were unable to receive any surgical intervention, or the choice of the decision not to operate was due to other factors. SCAN operated immediately on 55% of their patients, with the corresponding figure of 45% in WoSCAN but only 34% in NCA.

Examination of yearly cohorts revealed a change in the proportions of patients presenting with FIGO Stage 4 disease, and a reduction in the numbers of women not receiving any surgery in NCA (66% had no surgery in the Oct 13–Sep 14 cohort compared with 46% in the Oct 15-Sep 16 cohort).

Since initial findings from the original analysis became known in August 2018, work has been underway through a North of Scotland Ovarian Cancer group to progress actions to improve access to surgery for women with FIGO stage 2+ disease.

Monitoring of this through QPI 10 (i) did not identify significant improvement required and a further action plan was developed through the North Cancer Alliance in March 2021, with targeted actions to improve access to surgery for these women.

#### Figure 2: Extract from NCA Ovarian Cancer QPI Annual Report (2019-20)





Specification (i) Patients who undergo surgery (primary of delayed).

In the interim, updated results for QPI 10 (i) for patients diagnosed October 2019 to September 2020 have shown that surgery rates have improved for patients diagnosed in NHS Grampian and NHS Highland. Surgery rates for patients in NHS Tayside remain lower although this may be explained by the higher proportion of patients presenting as emergencies or incidental findings than would be expected on a population basis.

Results of an audit are provided in the table below on route of presentation:

Figure 3: Extract from audit on referral source of ovarian cancer patients diagnosed 2019-2020.

Referral Source	Grampian	Highland	Tayside	NCA
Primary Care Clinician	47%	89%	27%	46%
(GP, Nurse, Practitioner)				
Incidental Finding	24%	0%	40%	26%
GP referral directly to	9%	0%	30%	18%
hospital (A&E / other)				
Review Clinic	15%	0%	3%	6%
Other	5%	11%	0%	4%

Other factors subject to investigation include the impact on COVID-19 pandemic on the results of this QPI, with 19% less patients diagnosed with Ovarian Cancer than the previous five-year average, while access to surgery from March 2020-June 2020 was limited across the NHS due to ITU/HDU capacity deployed for the first wave of COVID patients.

The North of Scotland Ovarian Action Plan group await the QPI results for patients diagnosed October 2020 to September 2021 to assess any further impacts with an expected recovery in North of Scotland incidence across all tumour groups including ovarian cancer.

#### 4. Situation

A number of actions have been progressed since August 2018, initially through the NCA Gynaecology Pathway Board and more recently through a sub-group involving senior medical and management colleagues across the three mainland North health boards.

The North of Scotland was involved through our Ovarian Cancer Clinical Lead and NCA representative into the national SLWG to assess and action plan against the PHS Ovarian Cancer Survival Analysis.

Initial conclusions by the group noted that there was less access to surgery for women in the NCA compared to the other two regions, and that it was recognised that the NCA boards had more women presenting with advanced disease.

In taking this forward, the NCA began development of a business case and action plan to support an improvement in services.

Actions taken in 2018-2020 include:

- Engagement with colleagues through NCA Gynaecology Pathway Board and forming of a clinical sub-group for ovarian cancer
- Attended the SCAN Gynaecology MDT to assess decision-making and process to incorporate into North of Scotland MDT requirements
- Adopted the SCAN ovarian cancer surgery decision-making guidelines
- Agreement to develop a single North of Scotland ovarian cancer MDT
- Documented additional resources required to deliver increased volume of surgery activity through current centralised services at Aberdeen Royal Infirmary; allocation of additional resources remains outstanding
- Third Gynaecology Oncologist appointed March 2020 in established ARI team; funding secured for additional fourth Gynae Oncologist but so far unable to recruit to this post at NHS Grampian.
- Establishment of the regional MDT for discussion of North of Scotland Ovarian Cancer patients

These significant early actions did not provide the required level of improvement into surgery rates for women with FIGO stage 2, 3 & 4 disease. This was escalated through the NCA governance structures, the North of Scotland Medical Directors commissioned a refreshed Action Plan and this was formally approved in March 2021.

Actions since March 2021 include:

- National meeting held in April 2021 to assess any difference in radiological staging between the 5 cancer centres. Recommendations for changes to differentiation between stage 3 and stage 4 implemented in practice
- Dr. Malcolm Metcalfe appointed to lead North of Scotland Ovarian Cancer Action Plan group as of April 2021
- Dr. Trevor McGoldrick, Consultant Oncologist, NHS Grampian, appointed to chair regional Ovarian Cancer MDT and appropriate representation from across the multidisciplinary teams at the three cancer centres is tracked and managed to ensure meetings are quorate
- Change to technical platform utilising Microsoft Teams for improved virtual meetings including advanced audio between locations and sharing of radiological images
- Establish a weekly surgery planning meeting to manage capacity and support team planning for complex cases
- Funding for a Regional Pathway Coordinator agreed to support rapid patient investigations and input to MDT for early decision-making; recruitment remains outstanding
- Documentation of decision-making relating to surgery and reasons why surgery is contraindicated, recorded in the patient record
- Single MDT referral form implemented with coordinated arrangements for listing of patients, with local data collection
- Agreement of cohorts of patients to be discussed at MDT and vetting of patients undertaken as part of board processes
- Developed process for circulation of MDT outcomes to relevant colleagues at boards
- Agreement of NCA Ovarian Cancer clinical management guideline in December 2019 and refreshed in December 2020 with additional SACT regimen information
- Review of 31 and 62-day ovarian cancer Urgent Suspected Cancer pathways reviewed at local board levels.

Significant work has also been undertaken looking at various pieces of intelligence on Ovarian Cancer patients diagnosed 2017-2021. This includes population standardised incidence, staging, route of presentation, urgency of referral, staging by first treatment and more.

The results of this data highlighted that patients diagnosed in NHS Tayside are more likely to present as emergencies, either directly through A&E or in primary care where an admission to hospital follows.

Service improvements have been initiated and this includes work with GPs on referral pathways for women with suspected ovarian cancer, work with radiologists on integration of USS in the referral pathway for women with suspected ovarian cancer, use of structured descriptors in scans of ovarian cysts etc.

There are also a significant amount of incidental findings of ovarian cancer across the North of Scotland, which is likely inherent for this tumour group where patients do not necessarily present with symptoms indicative of an ovarian cancer referral. Patients can also present through other cancer / standard acute pathways.

Where patients have a treatment plan agreed through the regional MDT, there are no significant differences in the pathways of patients progressing for upfront or interval delayed surgery following an audit undertaken into the timescales undertaken for the 2019/20 patient cohort.

While there has been significant progress against the NoS Ovarian Cancer Action Plan (March 2021), there remain a number of actions which have not yet progressed including:

ACTION	WHY NOT PROGRESSED?
Implementation of a North of Scotland	Technical challenges with services delivered
ovarian cancer patient database and	across three boards, but the appointment of
undertake routine Key Performance	Regional Pathway Coordinator will support
Indicator (KPI) reporting	data collection and expected developments
	required in technical systems. Thereafter will
	look for real-time reporting of KPIs to support
	service monitoring and planning.
Actions to encourage earlier presentation	Referral pathways from Primary to
within NHS Tayside.	Secondary Care are being revised and
	appropriate vetting protocols put in place.
	Engagement with public health to encourage
	earlier presentation of symptomatic patients
	is being looked at.
Undertake an audit of current time spent in	Awaiting appointment of Regional Pathway
Ovarian Cancer MDT discussing each	Coordinator for data collection.
patient vs. time required for discussion of	
all Gynae patients in regional forum	
Development of radiological staging	To be incorporated into the Ovarian Cancer
guideline	Surgery Guidelines currently being reviewed.
	Development of additional radiological
	guidelines follows national meeting held in
	April 2021 to discuss staging practice.
Funding for additional Radiology and	At present, the throughput of patients is
Pathology required as a result of	managed with current resources.
expanded ARI surgery service	5
Embed a regional approach to	Project is currently mapping and scoping
prehabilitation for North of Scotland	community assets; work on North of
surgery patients	Scotland pathway for prehabilitation to begin
	in 2022 for this patient cohort. Board
	developments already underway as part of
	Cancer Waiting Times pathways.
All changes to MDT to be captured in MDT	Draft documents awaits developments
Constitution document	relating to a MDT Outcomes form and other
	outstanding improvements.
Increase proportion of ovarian cancer	Local team are looking to enable pathway
patients presenting through Primary Care	improvements to improve access to
pathways, including expanding referrals	diagnostics within primary care. Adoption of
for urgent ultrasound.	Urgent Suspected Cancer Referral
	Guidelines agreed for referral vetting.
Implement MDT that also encompasses	Job plans of individual members of staff do
cervix and endometrial to ensure no	not currently allow for this but an aspiration
patient is disadvantaged by the regional	to enable regional MDT for Cervix and
ovarian MDT	Endometrial to be progressed imminently.

#### 5. Analysis

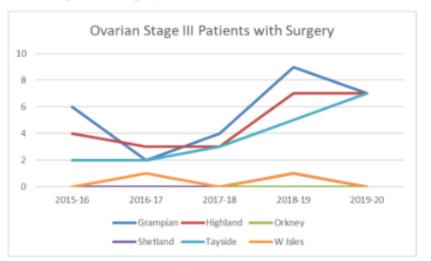
In assessing the current challenges prompted by the PHS Survival Analysis of ovarian cancer patients diagnosed 2013-2016, the key risk areas outlined are:

- 1. Surgery rates within the North of Scotland were lower than recommended and below other regions in Scotland.
- 2. Profile of ovarian cancer staging in NCA region appears significantly different from the rest of Scotland with more patients presenting with stage 4 cancer.
- 3. Overall survival of women with ovarian cancer in the NCA region could be lower than elsewhere in Scotland or the UK.

**Key Risk 1**; surgery rates have improved in the North of Scotland as demonstrated by the latest results for QPI 10 (i). However there is still variation within the North of Scotland and work is underway at NHS Tayside to understand the reasons why a higher proportion of patients do not present earlier through Primary Care.

However through implementation of a single regional Ovarian Cancer MDT, agreement of surgery decision-making guidelines and use of collaborative video conference platform, there is a shared team ethos through the North of Scotland ovarian cancer MDT. It has been demonstrated that an increased number of stage 3 patients have had greater access to surgery in recent years, supporting a more aggressive surgical approach through the region.

# Figure 4: Numbers of Ovarian Patients 2015-2020 with FIGO Stage 3 disease receiving primary or interval delayed surgery



1. Stage III with Surgery

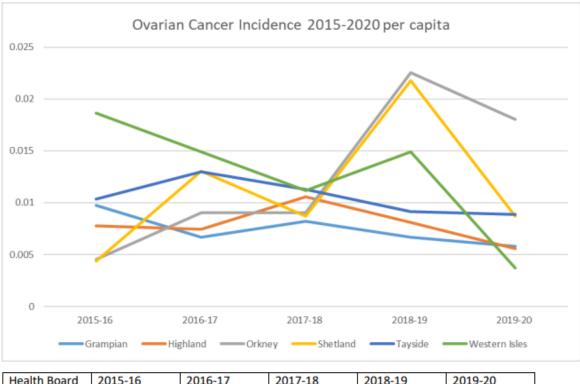
Health Board	2015-16	2016-17	2017-18	2018-19	2019-20
Grampian	6	2	4	9	7
Highland	4	3	3	7	7
Orkney	0	0	0	0	0
Shetland	0	0	0	1	0
Tayside	2	2	3	5	7
W Isles	0	1	0	1	0

**Key Risk 2**; any perceived differences in staging have been difficult to assess however some differential staging practices were identified and have been rectified following the national Ovarian Cancer meeting held in April 2021.

The reasons as to why there is a greater proportion of stage 4 presentation in the North of Scotland, and in particular for patients diagnosed within NHS Tayside, is unclear.

Incidence within the North of Scotland has been assessed and case ascertainment in NHS Tayside is observed to be higher than expected, per head of population. The reasons for this remain unclear.

#### Figure 5: North of Scotland Ovarian Cancer Incidence 2015-2020 per capita



North of Scotland Ovarian Incidence 2015-2020 (Data extracted from eCase on 24/11/2021)

Health Board	2015-16	2016-17	2017-18	2018-19	2019-20
Grampian	0.009751091	0.006671799	0.008211445	0.006671799	0.00581644
Highland	0.0077688	0.007458048	0.010565569	0.008079553	0.005593536
Orkney	0.004506534	0.009013069	0.009013069	0.022532672	0.018026138
Shetland	0.004349717	0.013049152	0.008699435	0.021748586	0.008699435
Tayside	0.010334551	0.012978273	0.011295905	0.009132859	0.008892521
Western Isles	0.018635855	0.014908684	0.011181513	0.014908684	0.003727171

However, more patients present as emergencies within NHS Tayside and there is a significant amount of incidental findings across the North of Scotland. While patients with FIGO 4 disease are considered for surgery (as all patients are as per the NCA Ovarian Cancer clinical management guideline) often surgery is contraindicated.

Staging practices within the North of Scotland continue to evolve with the development of a regional Ovarian MDT and better virtual sharing of radiological imaging; providing peer support and review of staging opinion and also ensuring collective MDT decisions on recommended treatment, including whether upfront or interval delayed surgery is recommended for each individual patient discussed at the MDT meeting.

**Key risk 3**; further analysis of future cohorts of patients is required to assess whether the actions undertaken will improve survival for ovarian cancer patients in the North of Scotland. Current updates of patients diagnosed since 2017 are encouraging and have shown no significant difference in survival between the networks, although caution must be added as follow-up for some patients has not yet extended beyond 18 months.

The rolling programme of survival analysis undertaken by Public Health Scotland (PHS) will support the North of Scotland in monitoring survival outcomes for patient in the North of Scotland.

In the interim, a development of a North of Scotland patient database specific to ovarian cancer patients will support real-time monitoring of patient survival.

#### 6. <u>Conclusions</u>

Extensive work has been undertaken since August 2018 upon the escalation of these key risks relating to differential outcomes for patients in the North of Scotland compared with other parts of Scotland.

Significant improvements have been made in pathways, MDTs, investigations and ethos, with the North of Scotland taking an inclusive approach in assessing every patient for potential surgical intervention.

Surgery rates for patients presenting with advanced disease in the North of Scotland have improved since the release of the survival outcomes in late 2018. The North of Scotland has adopted the surgery decision-making guidelines from the South-East Region and incorporated this into decision-making at the regional MDT.

A year by year analysis of management was undertaken. Surgery rates have increased but not to the level of the other regions, demonstrated in the latest <u>North of Scotland QPI Annual</u> <u>Report (2019/20 patients)</u>.

The North continues to have more women aged more than 65 years and more patients presenting with advanced disease. The reason for late stage presentation are unknown, however a review of staging in one board has highlighted that around 71% of patients had FIGO stages 3 or 4 disease at presentation. A case review has been undertaken on these patients to ascertain the individual factors for these patients and it is intended to repeat this exercise for all patients in the North of Scotland included within the audit.

The limitations of this data set used to undertake the survival analysis also need to be recognised, in that there is no measure of patient fitness for surgery by performance status at presentation, or any record of comorbidities that mean surgery is not an option for some patients. PHS survival outcomes are not measured by intention to treat and this is a limitation of this data set that needs to be highlighted in analysing the data.

Work to develop a North of Scotland Ovarian Cancer MDT with shared decision-making has accelerated since 2018 and all patients are now discussed collaboratively in the North of Scotland by all ovarian cancer clinicians. All patients that are operable and fit for surgery are offered this however there is limited data on the patients presenting who are unfit for surgery, or where disease is inoperable.

Theatre capacity for current ovarian cancer surgery volumes has traditionally been felt sufficient for the NCA but the consensus is that the data for QPI 10 suggests that additional lists and resources are required as part of a multi-factorial approach to allow the volume of women having surgery to increase especially in Tayside. All patients who are operable and fit for surgery following discussion at the regional MDT are offered this but may decline travel to Grampian. This factor is being investigated. A prehabilitation pathway, to optimise patients for surgery, is required to ensure a smooth pathway of care for these women. One factor that is not known is the effects of rurality and travel to a tertiary centre on patient acceptance of surgery.

The most recent QPI data has highlighted that patients within NHS Tayside are presenting with more advanced disease and as emergency / incidental findings. An audit into this has been undertaken on the most recent cohort of patients resulting in a significant amount of patients upstaged to FIGO stage 4 disease, from stage initially recorded at MDT discussion. This suggests the limitations of this data in not being able to demonstrate the role of patient fitness, comorbidity and patient choice in these survival outcomes.

Other improvements to the service have either been achieved or are work in progress. For example the Regional MDT is just that and not three separate MDTs, this being ably chaired by Dr. Trevor McGoldrick. The use of a MS Teams platform has obviated communication difficulties, funding has been obtained to appoint a Regional Pathway Coordinator and plans are in place to appoint a fourth Gynae-Oncologist Surgeon within the team at Aberdeen Royal Infirmary.

There remain three key actions to progress:

- Development of national ovarian radiological staging guideline between the 5 Scottish cancer centres to ensure agreed staging practice is consistently applied within MDTs.
- Explore why the North of Scotland has more patients with advanced disease, including route of presentation, taking action to encourage earlier presentation and diagnosis.
- Embed a regional approach to prehabilitation for North ovarian surgery patients.

These actions will be progressed within the North region and in collaboration with South-east and West Regions as a matter of priority. We also await the outcomes of the updated PHS Survival Analysis for patients diagnosed since 2018 to ascertain the differences these actions highlighted in this report, have made to survival for women in the North of Scotland.

#### 7. <u>References</u>

- NCA Ovarian Cancer Surgery Decision-Making Guidelines (Published August 2019; <u>https://www.nhsscotlandnorth.scot/uploads/tinymce/NCA/CMGs/NCA-SUR-OVA%20Surgery%20Guidelines%20for%20Ovarian%20(Approved%20August%202 019).pdf</u> Accessed 16/01/22)
- 2. NCA Ovarian Cancer Clinical Management Guideline (Published December 2020; https://www.nhsscotlandnorth.scot/uploads/tinymce/NCA/CMGs/NCA-CMG-OVA Ovarian Cancer Final(December%202020).pdf Accessed 16/01/22)
- 3. NCA Ovarian Cancer QPI Annual report 2019/20 patients (Published March 2022; https://www.nhsscotlandnorth.scot/uploads/tinymce/NCA-QPI-OVA21%20Ovarian%20Cancer%20QPIs%20(2019-20%20patients)%20Final.pdf Accessed 10/03/22)
- 4. The International Federation of Gynaecology and Obstetrics (FIGO) staging for ovarian cancer (<u>https://www.figo.org</u>)

### Appendix A

Membership of North of Scotland Ovarian Action Plan Group

NAME	ROLE
Dr. Malcolm Metcalfe	Chair, Associate Medical Director, NHS Grampian
Mr. Nick Abbott	Cancer Strategy Lead, NHS Highland
Dr. Ibrahim Alsharaydeh	Consultant Gynaecologist, NHS Highland
Dr. Hugh Bishop	Cancer Strategy Lead, NHS Grampian
Dr. Mary Cairns	Consultant Gynaeoncologist, NHS Grampian
Louise Cobb	Gynaecology CNS, NHS Grampian
Dr. Michelle Ferguson	Consultant Oncologist, NHS Tayside
Dr. Ann-Maree Kennedy	NCA Gynaecology Clinical Lead
Dr. Mahalakshmi Gurumurthy	Consultant Gynaeoncologist, NHS Grampian
Alison Hardy	Head of Cancer Performance, NHS Grampian
Dr. Elaine Henry	Associate Medical Director, NHS Tayside
Catherine Lamberton	Gynaecology CNS, NHS Grampian
Derick Macrae	Cancer Service Manager, NHS Highland
Dr. Trevor McGoldrick	Consultant Oncologist, NHS Grampian
Bryan McKellar	Interim NCA Manager
Dr. Neil McPhail	Consultant Oncologist, NHS Highland
Dr. Fiona Payne	Consultant Pathologist, NHS Grampian
Sasia Pryor	Cancer Performance Service Manager, NHS Grampian
Dr. Kalpana Ragupathy	Consultant Gynaecologist, NHS Tayside
Dr. Emma Ramage	Consultant Radiologist, NHS Grampian
Lynn Smith	Service Manager, NHS Grampian
Alice Li	Senior Health Intelligence Analyst, NCA