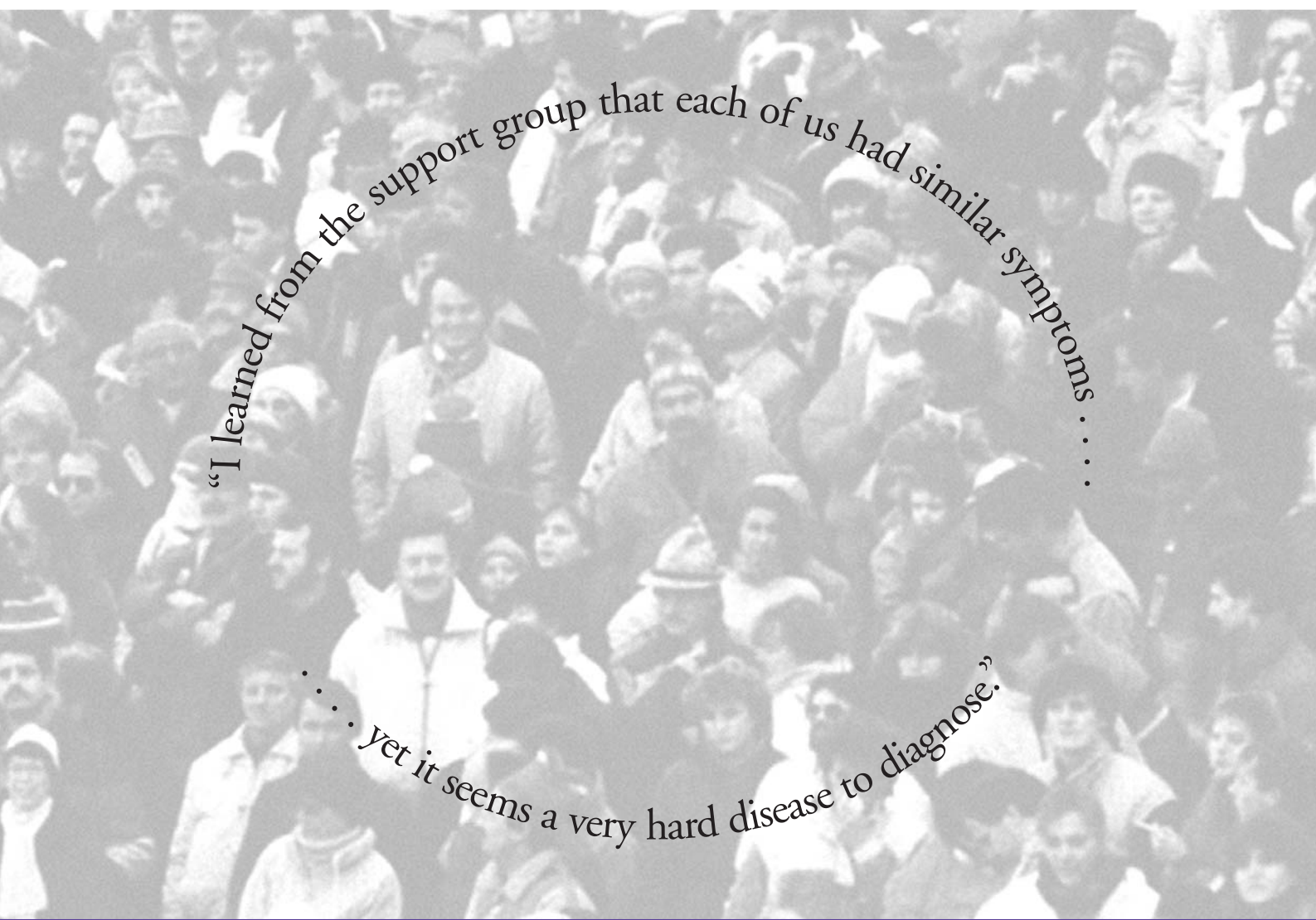




Cancer Services Audit 1996 & 2001
Ovary and Cervix



“I learned from the support group that each of us had similar symptoms . . .

. . . yet it seems a very hard disease to diagnose.”



Queen's University
Belfast



Cancer Services Audit 1996 & 2001
OVARY AND CERVIX

Edited by: **Pauline Monaghan, Anna Gavin and Lisa Ranaghan**

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FOREWORD

I have been aware of the great efforts made to improve cancer services in Northern Ireland by my predecessor, Dr Campbell. Developments have spanned prevention, early detection and screening, diagnosis, management and palliative care.

Since 1996 we have seen the establishment of Cancer Units at Altnagelvin, Antrim, Belfast City, Craigavon, and Ulster hospitals and a regional Cancer Centre in Belfast. The Cancer Units are now the main focus for the delivery of services for people with the more common cancers. In addition, some services for other less common cancers are provided from Cancer Units, in conjunction with the Cancer Centre, on a shared care basis. The N. Ireland Cancer Registry has played an important role and made a vital contribution in monitoring this progress.

This report on ovarian and cervical cancer is very welcome. It is the seventh in a series that examines in detail the pathways of care for patients with cancer here. The reports provide a fascinating insight into how care has changed over the period. They will also facilitate the ongoing work of improving services and patient care.

This work marks a significant step in the evaluation of cancer care and confirms the great value of the Registry as a public health tool. I look forward to future reports which provide updates of the changing process of cancer care.



Dr Michael McBride
Chief Medical Officer

ACKNOWLEDGEMENTS

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The work of this project would not have been possible without the additional funding received from the various sources outlined below:

- Department of Health, Social Services & Public Safety (DHSSPS)
- Eastern Health and Social Services Board
- Northern Health and Social Services Board
- Regional Multiprofessional Audit Group
- Research and Development Office
- Southern Health and Social Services Board
- Western Health and Social Services Board

The quality of data in this project is a result of the work of the present and past Registry Tumour Verification Officers especially Bernadette Anderson, Carmel Canning, Kate Donnelly and Rosemary Ward and Data Manager Richard Middleton who meticulously extracted detailed information from clinical records for analysis and presentation in this report. The cleaning and analysis of data for this report was undertaken by Pauline Monaghan. A special word of gratitude to the Medical Records staff from all the hospitals in Northern Ireland who, in the course of the audit for all sites pulled an estimated 10,000 charts.

We are grateful to the clinicians especially Dr. Price who commented on the detail of data to be collected, its interpretation and final presentation.

The work of the N. Ireland Cancer Registry including the production of this report, is the result of the work of the team listed below:

Bernadette Anderson	Dr Finian Bannon	Carmel Canning	Dr Denise Catney
Dr David Donnelly	Kate Donnelly	Donna Floyd	Colin Fox
Wendy Hamill	Anita Jones	Jackie Kelly	Gavin Kennedy
Heather Kinneer	Julie McConnell	Susan McGookin	Dr Richard Middleton
Pauline Monaghan	Eamon O'Callaghan	Giulio Napolitano	Dr Lisa Ranaghan
Dr Jeffrey Robertson	Breige Torrains	Rosemary Ward	

I wish also to record my thanks to the Management Group and Council of the Registry who guide the work.

This presentation, I feel, has been enhanced by the stories from patients who have walked the patient journey. A journey we have attempted to analyse and quantify with a view to identifying current practice so clinicians may be facilitated in improving care.

Anna Gavin .

A Gavin
Director, NICR
2006

PATIENT STORIES

“For about one month I had a sharp intermittent pain in my upper abdomen almost in my chest. It moved and was similar to a pain I had experienced previously with gallstones. It was worse when I was lying down. I knew something was wrong and I couldn’t get comfortable no matter how I lay. Because the pain was sometimes there and sometimes not, I didn’t make an appointment to see the GP as the Health Centre was very busy and it could take up to 2 weeks to get an appointment. However, one day the pain was very bad and I drove to the Health Centre doubled over in agony. The GP sent me for a chest x-ray. They found fluid on my lung and I was referred quickly to see chest physicians in Belfast City Hospital. For the first time, about then, I got very short of breath after I had climbed about four flights of stairs.

The afternoon after I was seen at the chest clinic, I was admitted to the City Hospital for investigations. I was there for 3 weeks and after some time had several litres of fluid taken off my chest. This showed cancer cells however, I was not told this immediately and felt I was kept in the dark and given mixed messages. I had waited ages for a gynae opinion and they came 5 minutes before I was supposed to go home for the weekend.

Five weeks after I had gone to my GP, I was admitted to the gynae ward for surgery where my diseased ovaries were removed. I was sore after the surgery and was still in a lot of pain 8 days later when I was discharged home. After some time I had 6 episodes of chemotherapy which lasted for 1 day and were spaced every 3 weeks. During this time I lost my hair but I got a nice wig. I felt tired but was not sick. I felt the chemotherapy clinic was very well organised. All the people with the same condition seemed to be there on the same day. This was good for support. At first I was the new girl and the people who were there for their second or third dose of chemotherapy took me under their wing and explained what to expect. I never felt the need to go to support groups.

When I had finished the chemotherapy I had radiation treatment to my abdomen 5 days a week for 6 weeks. I travelled to Belvoir Park Hospital by patient ambulance and found that satisfactory. In preparation for the radiation they put permanent tattoos on my tummy so they didn’t have to set the machine every day. These were just pin pricks but they were sore at the time. It is now almost 5 years since my diagnosis and I am reviewed every 6 months.

Having cancer was something I didn’t suspect, but now with hindsight, I realise some of the symptoms were pointing to that diagnosis. Following the treatment I don’t have the same energy I had in the past, perhaps that’s because I am a few years older. I am also still prone to diarrhoea, a side effect from the radiation. I felt that once I was diagnosed with cancer that the investigations were organised smoothly. However, before the diagnosis, I felt I was passed from pillar to post with no consistency in advice or information.”

~



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“I was in my early 60s and had not been feeling well for several years. In the last year I had been losing weight, about 1 stone, and had gone to my GP several times. My GP had organised several tests including an ultrasound scan, colonoscopy and a barium meal which all had come back clear. I also had a pain on my right side and had difficulty walking because of the pain. When I was lying down I could only get relief if I lay on my left side.

I was then referred to a general medicine consultant who after another ultrasound scan referred me to the gynaecologists. Things happened quite quickly then and I was in hospital 10 days later. I had an operation to remove an ovarian tumour which had been attached to my bowel and some of my bowel was also removed. After 10 days in hospital I was told the tumour was cancerous and that I would be offered further treatment. I was invited to go on a trial and agreed however, the tablets did not agree with me so I couldn't finish it. I did however have normal chemotherapy. Unfortunately I also took a reaction to the second course of chemotherapy and was unable to complete the full course. The chemotherapy left me really tired. I was in bed a full week after it and by the third week I was feeling good but then it was time to start the chemotherapy cycle again.

I now get scans every three months and I was seen by the genetics service. At the minute I don't feel too bad, I am tired however and never got my energy back. I also get the pains in my stomach if I exert myself. I had my diagnosis and surgery 3 years ago and I am still looked after regularly by the oncologists. I also attend a patient support group and find that very good. One thing I noticed at the support group was that each of us with ovarian cancer had similar symptoms and yet it seems a very hard disease to diagnose.”

~

SECTION I - INTRODUCTION

This Report is the seventh in a series which examines in detail the pathway of care for cancer patients in Northern Ireland. Gynaecological cancer represents a major female cancer and the years 1996 and 2001 represent two points in time either side of the publication of the Campbell Report **“Cancer Services - Investing for the Future”¹**.

The Campbell Report resulted from the work of many clinicians, service planners and patients who worked together with the aim of improving cancer services in Northern Ireland. The Campbell Report made 14 recommendations (see Appendix A).

Subsequent to the publication of the Campbell Report, a Cancer Working Group in Northern Ireland produced a sub-group report on Gynaecological Cancer² which made specific recommendations on the future of gynaecological cancer services in Northern Ireland (see below):

Recommendations of N. Ireland Cancer Working Group on Gynaecological Cancer, 1996.

- Vulval cancer should be treated by a single multiprofessional expert team based in a Cancer Centre.
- All women with a persistently abnormal cervical smear should be referred to a colposcopy service that complies with current quality standards.
- All patients with invasive cervical cancer should be evaluated by a single multiprofessional expert team located in a Cancer Centre.
- Cancer of the uterine body should be managed by specialist teams working in Cancer Units.
- All general surgeons, physicians and gynaecologists should be familiar with current guidelines for the management of ovarian cancer.
- Patients with ovarian cancer should be managed in Cancer Units, by the same teams as manage cancer of the uterine body.
- Women under the age of 35 and any women suspected of having a germ cell tumour, should be referred to a single central team working in the Cancer Centre.
- A gynaecological Cancer Unit should have a workload sufficient to maintain the expertise of the team.
- There is the need for a pathologist, with a special interest in gynaecological pathology, in the Cancer Centre.
- Within Northern Ireland, gynaecologists should develop regional management guidelines for all gynaecological cancers.
- A regional gynaecological cancer audit group should be established.

During 2006, consultation with a gynaecological cancer expert confirms that colposcopy units are in the process of undergoing accreditation visits. Cervix and vulval cancers are managed at centre level via multidisciplinary teams (MDTs). Endometrial and ovarian cancers are mostly managed at the Cancer Centre or at a Unit after discussion at the centre MDT. A specialist pathologist is in place and younger women are referred to the Cancer Centre.

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In 1999, the NHS produced a document outlining guidance on commissioning cancer services: **“Improving Outcomes in Gynaecological Cancer - The manual”**³. Key recommendations in relation to gynaecological cancer were outlined as follows:

- Dedicated diagnostic and assessment services should be established in Cancer Units, to which all women with possible or suspected gynaecological cancers should be referred. This includes women with symptoms and those who present through the cervical screening programme.
- There should be specialist multiprofessional gynaecological oncology teams based in Cancer Centres. These teams should be responsible for the management of all women with ovarian cancer and the majority of women with other gynaecological cancers.
- The specialist gynaecological oncology and palliative care teams in each Cancer Centre and associated Cancer Units should agree clear local policies for the management of women with advanced or progressive disease. These policies should be designed to ensure the co-ordination of high quality care between Cancer Centres, Cancer Units, palliative care, primary care and community services.
- There should be rapid and efficient communication systems for liaison and cross-referral between all levels of service. Audit should take place across the entire service delivery network, including the Cancer Centre and all related Units.

This guidance also provided a summary of recommendations in specific topic areas – **Guidance for General Practitioners and Primary Care Teams – Improving Outcomes in Gynaecological Cancer** (see Appendix B)⁴.

The Department of Health Social Services and Public Safety in Northern Ireland in 2002 produced a report **“Guidance for the Management of Gynaecological Cancer”**⁵ a summary of which is included in Appendix C for completeness.

There was further published work on gynaecological cancer services between 1996 and 2001:

- NHS centre for reviews and dissemination. Management of gynaecological cancers, effective health care⁶.
- Report of the cervical screening working group. Department of Health and Social Services of N. Ireland⁷.

PROJECT AIM

This Report aims to measure changes to care for patients with ovarian or cervical cancer from a baseline in 1996 and to determine whether they are in keeping with the recommendations of the Campbell Report¹.

BACKGROUND

Gynaecological cancers are an important cause of morbidity and mortality. The ovary, endometrium (uterus) and cervix are the fifth, seventh and twelfth most common cancers in females in N. Ireland. Cancers of the vulva are relatively rare⁸.

OVARIAN CANCER

Ovarian cancer is the most common of the gynaecological cancers with 168 cases and 99 deaths on average in N. Ireland each year, accounting for 4% of all cancers registered. Between 1993 and 2001, there were no statistically significant trends in European age-standardised rates for incidence or mortality in N. Ireland. Overall relative survival is poor (45% at 5 years, 1996-1999) but is improving. Survival is highly dependent on stage at diagnosis with 72% survival for Stage I compared to 5% for Stage IV⁸. The reason for this poor overall survival is because the ovaries are situated deep within the pelvis and therefore early stage disease may cause no symptoms. Cancer of the ovary starts in one or both ovaries and may spread to the abdominal cavity. The most important factors affecting outcome are the stage of the tumour, its grade and whether it can be completely removed by surgery. The earlier stages may often be cured by surgery alone, with more advanced stages requiring chemotherapy to control the disease and offer a chance of cure. Known risk factors include older age, higher social class, ovulation history and number of pregnancies^{9,10}.

CERVICAL CANCER

Cervical cancer is the twelfth most common cancer in females in N. Ireland and the twentieth most common cause of cancer mortality. Each year on average (1993-2001), 83 new cases were diagnosed and 32 deaths were reported. Between 1993 and 2001, there were no statistically significant trends in European age-standardised rates for incidence or mortality in N. Ireland. Survival from cervical cancer is good and dependent on stage of disease, the five-year relative survival rate (diagnosed 1993-1999) for Stage I (early) cervical cancer is 82%, compared to 2% for Stage IV (late) disease⁸. Known risk factors include smoking, social class and Human Papilloma Virus (HPV)^{11,12}.

NOTE

Endometrial and vulval cancers have been included below for completeness but are not included in the audit.

ENDOMETRIAL CANCER

Cancer of the uterus is the seventh most common cancer in females in N. Ireland and with, on average, 113 cases diagnosed each year, it accounts for 3% of all registered cancers in females. There is a 6% annual increase in the incidence rate of uterine cancer in N. Ireland¹³. Endometrial/uterine cancer is the twenty-first most common cause of cancer mortality in females in N. Ireland with 14 deaths reported annually⁸. Survival from cancer of the uterus is good, with the most recent five year estimate being 75%. Endometrial cancer rarely develops before the menopause and since it causes abnormal vaginal bleeding, it is usually diagnosed at an early stage¹⁴. Known risk factors include high oestrogen levels, increasing age, years of menstruation, nulliparity, obesity, diabetes, oestrogen only pills, tamoxifen and family history (first degree relative)¹⁵.

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VULVAL CANCER

Vulval Cancer is relatively rare and is usually a disease of elderly women¹⁶. There are, on average, 25 patients diagnosed with vulval cancer in N. Ireland each year and there are 8 recorded deaths. (Data from NICR: 1993-2001, unpublished). Risk factors include previous Human Papilloma Virus (HPV) infection, previous cervical/vaginal cancer, smoking, age and Human Immunodeficiency Virus (HIV)¹⁶.

Average annual incidence and deaths for gynaecological cancers in N. Ireland

Figure 1.1 Average annual incidence of gynaecological cancers in N. Ireland (1993-2001)

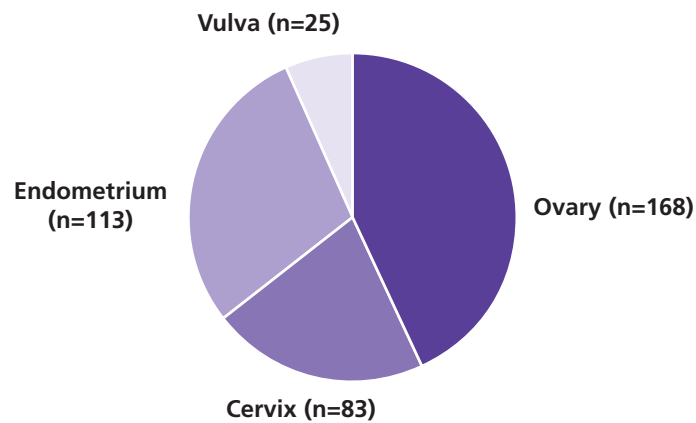
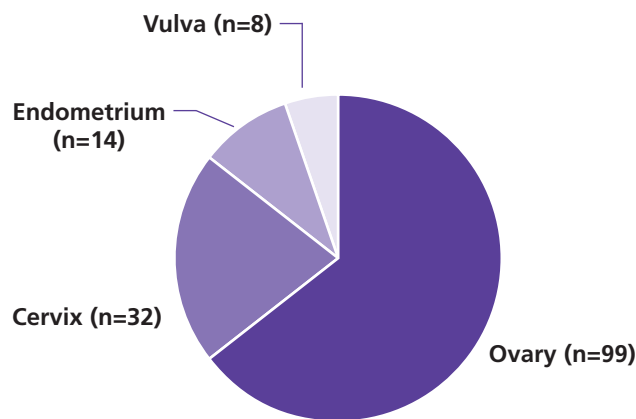


Figure 1.2 Average annual deaths from gynaecological cancers in N. Ireland (1993-2001)



METHODS

DATA COLLECTION

Registry Tumour Verification Officers (TVO's) collected data by reviewing clinical notes of patients with a new primary ovarian (ICD10-C56) or cervical cancer (ICD10-C53) already registered with the N. Ireland Cancer Registry. Data were then entered into an electronic proforma, copy available at www.qub.ac.uk/nicr

EXCLUSIONS

Patients were excluded if their records lacked sufficient information or if information was available from a death certificate (DCO).

ANALYSIS

After cleaning and validation, data analysis was carried out using SPSS. A column has been presented in some tables summarising borderline ovarian tumours, however the main comparisons between 1996 and 2001 exclude the borderline ovarian tumours. Comparisons were tested using the chi-square test of association/t-test. Survival analysis was performed using Kaplan-Meier and Cox's regression analysis. Information on deaths were available until 31/12/2003 for all patients.

SECTION II – OVARIAN CANCER

RESULTS

Study patients

Patients	1996	2001
Total number of patients	150	155
Exclusions – Death certificate only	2	5
Exclusions – Lack of information	10	4
Exclusions – Post mortem only	2	0
Total number including borderline tumours	136	146
Borderline tumours	15	24
Total number excluding borderline tumours	121 (100%)	122 (100%)
Average age at diagnosis	62	60
Median age at diagnosis	63	64

- In 1996 and 2001, 150 and 155 patients respectively were registered with ovarian cancer, these included 39 borderline tumours. After exclusions, 121 patients remained in 1996 and 122 in 2001.
- The median age at diagnosis was similar in both years.

Socio-economic status of patients

Deprivation quintile	Number of Patients* (%)	
	1996 (n=136)	2001 (n=146)
Quintile 1 (Most Deprived)	31 (23%)	33 (23%)
Quintile 2	30 (22%)	29 (20%)
Quintile 3	22 (16%)	21 (14%)
Quintile 4	30 (22%)	32 (22%)
Quintile 5 (Least Deprived)	23 (17%)	31 (21%)

* Includes borderline tumours

- If a disease is not related to deprivation in the general population, it is expected that 20% of all cases of disease would fall in each quintile. As expected, our data demonstrates no link between ovarian cancer and deprivation which is in keeping with previous published reports.⁸

Source of referral to specialist care and mode of presentation

Source	Number of Patients* (%)	
	1996 (n=136)	2001 (n=146)
General Practitioner (GP)	89 (65%)	108 (74%)
Other **	17 (13%)	24 (17%)
Accident & Emergency	3 (2%)	12 (8%)
Not recorded	27 (20%)	2 (1%)
Mode of Presentation		
Outpatient referral	56 (41%)	71 (49%)
Emergency admission	48 (35%)	61 (42%)
Other	7 (5%)	13 (9%)
Not recorded	25 (18%)	1 (<1%)

* Includes borderline tumours **Includes self-referrals and referrals from other hospital departments

- Recording of information improved in 2001.
- The majority of ovarian cancer cases in both years came from GP referrals.
- Over one third of patients were recorded as presenting as emergencies.

Family history of ovarian and other cancer

Family History	Number of Patients* (%)	
	1996 (n=136)	2001 (n=146)
Positive family history of ovarian cancer	2 (2%)	7 (5%)
Negative family history of ovarian cancer	36 (26%)	71 (49%)
No recorded family history of ovarian cancer	98 (72%)	68 (47%)
Positive family history of other cancer	11 (8%)	33 (23%)
Negative family history of other cancer	35 (26%)	51 (35%)
No recorded family history of other cancer	90 (66%)	62 (43%)

*Includes borderline tumours

- By 2001, recording of a family history of ovarian or other cancer had improved.
- In 2001, 5% of patients had a positive family history of ovarian cancer and just under one quarter of patients had a positive family history of other cancer.
- In 2001, 5% of patients had a positive family history of breast cancer (all first degree relatives). This data was not collected in 1996.
- In 2001, 3 of the 7 family members with ovarian cancer were first degree relatives (not shown). This data was not collected in 1996.
- In 2001, 32 out of the 33 family members with other cancers were first degree relatives (not shown). This data was not collected in 1996.

Co-morbidities

Co-morbidities found to be significant predictors of 1-year mortality for patients with ovarian cancer using the Charlson index¹⁷ are presented below.

Co-morbidity	Percentage of Patients with co-morbidity* (% not recorded)	
	1996 (n=136)	2001 (n=146)
Hypertension	17% (15%)	30% (1%)
Cardiovascular disease	19% (15%)	16% (1%)
Arthritis	10% (15%)	13% (2%)
COPD**	6% (15%)	8% (1%)
Diabetes	4% (15%)	2% (1%)
Dementia	2% (15%)	<1% (1%)
Cerebrovascular disease	3% (15%)	4% (1%)
Insulin dependent diabetes (IDD)	<1% (15%)	<1% (2%)
Osteoporosis	2% (15%)	6% (1%)
Alzheimers	<1% (15%)	1% (1%)
Breast cancer	2% (15%)	3% (2%)

*Includes borderline tumours **COPD=Chronic Obstructive Pulmonary Disease

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- There was better recording of co-morbidity information in 2001.
- A personal history of breast cancer was recorded in 2-3% of patients in both years.

Symptoms/signs at presentation (NOTE: Patients may present with more than one symptom)

Symptom/sign	Percentage of patients with symptom at any time (% not recorded)		
	Borderline (n=39)		
	1996 & 2001	1996 (n=121)	2001 (n=122)
Pain	46% (5%)	44% (15%)	34% (2%)
Abdominal distension	56% (8%)	29% (15%)	67% (1%)
Abdominal discomfort	49% (5%)	26% (15%)	65% (2%)
Weight-loss	10% (5%)	17% (15%)	28% (4%)
Dyspepsia	8% (5%)	13% (15%)	3% (2%)
Weight-gain	5% (5%)	3% (15%)	2% (3%)
Urinary frequency	18% (5%)	7% (15%)	14% (2%)
Post menopausal bleeding	13% (5%)	7% (14%)	12% (2%)
Per vaginal discharge	3% (5%)	2% (15%)	4% (2%)
Anorexia	3% (5%)	4% (15%)	22% (2%)
Flatulence	- (5%)	2% (15%)	3% (2%)
Incidental	5% (5%)	3% (16%)	3% (2%)
Asymptomatic	- (5%)	3% (15%)	3% (1%)

- By 2001, recording of presenting symptoms/signs had improved.
- About 3% of patients in both years were asymptomatic or presented as incidental findings.
- Typically, abdominal pain/discomfort and abdominal distension were the most common presenting symptoms (60% of patients had any of these 3 symptoms in 1996, compared to 77% in 2001).
- One quarter of all patients in 2001 presented with weight loss compared to 17% in 1996. The proportion presenting with weight gain remained steady at 3%.

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Symptoms/signs and duration

Symptom/sign		Number of Patients* (% of patients)				Total patients
		Less than 6 months	6 – 12 months	Over 1 year	Not recorded	
Pain	1996	46 (75%)	7 (11%)	2 (3%)	6 (10%)	61
	2001	47 (92%)	1 (2%)	-	3 (6%)	51
Abdominal distension	1996	35 (83%)	3 (7%)	1 (2%)	3 (7%)	42
	2001	70 (72%)	6 (6%)	1 (1%)	20 (21%)	97
Abdominal discomfort	1996	30 (83%)	2 (6%)	2 (6%)	2 (6%)	36
	2001	72 (77%)	6 (6%)	-	16 (17%)	94
Weight loss	1996	15 (68%)	5 (23%)	1 (5%)	1 (5%)	22
	2001	22 (59%)	3 (8%)	2 (5%)	10 (27%)	37
Dyspepsia	1996	16 (94%)	-	-	1 (6%)	17
	2001	2 (40%)	-	-	3 (60%)	5
Weight gain	1996	4 (100%)	-	-	-	4
	2001	1 (25%)	1 (25%)	1 (25%)	1 (25%)	4
Urinary frequency	1996	8 (73%)	1 (9%)	-	2 (18%)	11
	2001	14 (67%)	2 (10%)	-	5 (24%)	21
Post menopausal bleeding	1996	5 (45%)	2 (18%)	2 (18%)	2 (18%)	11
	2001	13 (76%)	2 (12%)	-	2 (12%)	17
Per vaginal discharge	1996	1 (50%)	1 (50%)	-	-	2
	2001	4 (67%)	1 (17%)	-	1 (17%)	6
Anorexia	1996	3 (60%)	-	-	2 (40%)	5
	2001	22 (79%)	1 (4%)	-	5 (18%)	28
Flatulence	1996	2 (100%)	-	-	-	2
	2001	2 (50%)	-	-	2 (50%)	4

*Includes borderline tumours

- The majority of patients presented within 6 months of having symptoms.
- By 2001, patients were significantly more likely to have had a shorter duration of the commonly presenting symptom - pain ($p < 0.05$).
- Patients who had post menopausal bleeding were more likely to present earlier in 2001 than in 1996.

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PRESENTATION

Hospital of presentation

Hospital	Number of Patients #(%)	
	1996 (n=136)	2001 (n=146)
Belfast City (BCH)*	15 (11%)	20 (14%)
Antrim (ANT)**	16 (12%)	12 (8%)
Ulster (UH)**	9 (7%)	20 (14%)
Craigavon (CAH)**	9 (7%)	13 (9%)
Altnagelvin (AH)**	4 (3%)	13 (9%)
Royal Victoria (RVH)	10 (7%)	13 (9%)
Mater (MIH)	10 (7%)	7 (5%)
Erne (ERN)	8 (6%)	5 (3%)
Coleraine (COL) / Causeway (CAU)	5 (4%)	7 (5%)
Downe (DH)	5 (4%)	3 (2%)
Tyrone County (TCH)	4 (3%)	5 (3%)
Ards (AR)	3 (2%)	0
Daisy Hill (DHH)	3 (2%)	8 (6%)
Roe Valley (RV)	3 (2%)	0
Ulster Independent (UIC)***	3 (2%)	3 (2%)
Lagan Valley (LVH)	2 (2%)	6 (4%)
Route (ROU)	2 (2%)	0
South Tyrone (STH)	2 (2%)	1 (<1%)
Whiteabbey (WHA)	2 (2%)	7 (5%)
Dalraida (DAL)	1 (<1%)	0
Moyle (MLE)	1 (<1%)	0
Mid-Ulster (MUH)	1 (<1%)	2 (1%)
North West (NWC)***	1 (<1%)	0
Waveney (WAV)	1 (<1%)	0
Other (Private Not Specified)	1 (<1%)	1 (<1%)
Not recorded	15 (11%)	0

- In 1996, 136 patients presented to 24 hospitals, whilst in 2001, 146 patients presented to 17 hospitals.
- In 2001, 54% of patients presented to a Cancer Centre/Cancer Unit, 40% presented to these same hospitals in 1996.

*Cancer Centre ** Cancer Unit *** Private hospitals #Includes borderline patients

Patients presenting within their own Board

Board of residence	Number of Patients* (% resident in that Board)	
	1996 (n=136)	2001 (n=146)
NHSSB	27 (79%)	26 (67%)
EHSSB	49 (88%)	60 (98%)
SHSSB	13 (48%)	22 (96%)
WHSSB	16 (84%)	22 (96%)
Not recorded	16 (12%)	-

*Includes borderline patients

- The majority of patients presented to hospitals within their own Board of residence. This was more marked in 2001.
- In 2001, patients residing in the Northern Board who presented outside their own Board area mostly presented in the Eastern Board.
- In 1996, 15% of Southern Board residents presented to hospitals in the Eastern Board and 11% to the Western Board and 22% did not have a hospital of presentation extracted from the notes.

Investigations (NOTE: Patients may have had more than one type of investigation)

Investigation	Number of Patients (%)*			
	1996		2001	
Age (years)	70 and under (n=95)	Over 70 (n=41)	70 and under (n=100)	Over 70 (n=46)
AFP/HCG**	3 (3%)	-	9 (9%)	8 (17%)
Ultrasound abdomen	68 (72%)	25 (61%)	60 (60%)	34 (74%)
Chest X-ray	41 (43%)	12 (29%)	37 (37%)	26 (57%)
CA125**	48 (51%)	11 (27%)	89 (89%)	43 (94%)
CT scan	27 (28%)	8 (20%)	67 (67%)	34 (74%)
Cytology of ascites	36 (38%)	15 (37%)	71 (71%)	31 (67%)
Vaginal ultrasound	4 (4%)	-	8 (8%)	-

*Includes borderline patients **AFP/HCG Alpha-fetoprotein/human chorionic gonadotrophin is a diagnostic test effective for germ-cell tumours of the ovary

- In 1996, patients aged 70 and under were significantly more likely to receive investigations than patients in the older age group (cytology of ascites, not significant). This however had changed by 2001, where the older age group were more likely than the younger group to receive investigations. This however did not reach statistical significance.

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Ovary

Method of Diagnosis

In agreement with national and international guidelines, NICR uses a hierarchy when deciding the certainty of a cancer diagnosis. Microscopic verification (MV) (histology/cytology) is generally most reliable. However, if this is not possible, results of imaging procedures such as CT scan, which for some patients are the only way of confirming a diagnosis, are accepted. In the absence of any microscopic or visual confirmation of the ovarian cancer, the N. Ireland Cancer Registry (NICR) accepts the opinion of a clinician (CO).

Method of diagnosis	Number of Patients (%)				
	Borderline Patients	All Patients (excl borderlines)		Surgery Patients	
	1996 & 2001 (n=39)	1996 (n=121)	2001 (n=122)	1996 (n=112)	2001 (n=118)
Histopathology	39 (100%)	97 (80%)	95 (78%)	108 (96%)	116 (98%)
Cytology	-	13 (11%)	16 (13%)	4 (4%)	2 (2%)
CT scan	-	3 (3%)	6 (5%)	-	-
Ultrasound	-	4 (3%)	3 (3%)	-	-
Clinical opinion	-	4 (3%)	2 (2%)	-	-

- Over 90% of all patients and 100% of surgery patients in both years had a histologically/cytologically confirmed diagnosis of ovarian cancer.
- All patients diagnosed by clinical opinion had died within 2 weeks of diagnosis.

HISTOPATHOLOGY

Approximately 90% of all ovarian cancers are of epithelial cell origin. These epithelial tumours have benign counterparts of similar histological appearance and can also exist as "borderline" cancers which are classified as tumours of low malignant potential. These give rise to a variety of adenocarcinomas including serous, mucinous, endometrioid and clear cell-types. Malignancies can also arise from the ovarian stroma or the germ cells within the ovaries. These comprise 10% of ovarian tumours. The stromal tumours, granulosa tumour, sertoli-leydig tumour and sersil variants are often hormone producing. Germ cell tumours tend to be highly aggressive and occur primarily in younger women.

Tumour Type

Histological type	Number of Patients (%)	
	1996 (n=136)	2001 (n=146)
Epithelial	98 (72%)	95 (65%)
Germ cell	-	2 (1%)
Sex cord	5 (4%)	4 (3%)
Secondary	-	4 (3%)
Other	-	1 (<1%)
Unspecified	18 (13%)	16 (11%)
Borderline	15 (11%)	24 (16%)

- As expected, around 80% of cancers in 1996 and 2001 were epithelial tumours of the ovary.
- There were 5% more borderline tumours in 2001 than 1996.

Histological grade

Histological grade	Number of Patients (%)	
	1996 (n=136)	2001 (n=146)
Poorly differentiated	30 (22%)	35 (24%)
Moderately differentiated	11 (8%)	24 (16%)
Well differentiated	19 (14%)	6 (4%)
Undifferentiated	1 (<1%)	4 (3%)
Borderline	8 (6%)	24 (16%)
Grade cannot be assessed/ not recorded	67 (49%)	53 (36%)

- By 2001, two thirds of tumours were graded histologically compared to half in 1996.
- Of tumours that could be graded the majority were poorly differentiated.

STAGING

See also Appendix E.

Ovarian cancer is surgically/pathologically staged, in order to establish a definitive diagnosis of ovarian cancer and to exclude other primary malignancies which can present with similar clinical findings. The FIGO staging system is widely used¹⁸. Surgery plays a crucial role in the management of ovarian cancer. A detailed staging laparotomy with intact resection of the ovarian mass, multiple cytological washings, omentectomy, evaluation and biopsy of all frequently involved visceral and peritoneal sites, including diaphragm and regional lymph node sampling, is advised. Removal of the reproductive organs (uterus, fallopian tubes and remaining ovary) is usual, but in younger women with early stage disease who wish to maintain fertility, this may be omitted. Imaging studies (chest X-ray, bone scans, CT and PET scanning) performed in conjunction with surgery may identify distant metastases. Approximately 40% of women present with locally advanced Stage III disease. For these patients the amount of residual tumour present after their definitive surgery is a major prognostic factor, hence the primary function of surgery is tumour debulking. With optimal tumour debulking, these patients have an increased likelihood of achieving a complete response to adjuvant chemotherapy.

FIGO Stage

Stage	Number of Patients (%)				
	Borderline Patients	Patients (excl borderlines)		Surgery Patients	
		1996 & 2001 (n=39)	1996 (n=121)	2001 (n=122)	1996 (n=112)
I	39 (100%)	29 (24%)	35 (29%)	42 (38%)	43 (36%)
II	-	11 (9%)	11 (9%)	10 (9%)	11 (9%)
III	-	48 (40%)	39 (32%)	43 (38%)	37 (31%)
IV	-	14 (12%)	12 (10%)	11 (10%)	5 (4%)
Stage not recorded/known	-	19 (16%)	25 (21%)	6 (5%)	22 (19%)

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- Recording of stage was poor, more so in 2001 where one fifth of patients did not have a stage recorded.
- As expected, approximately 50% of patients (for whom a stage is known) present with Stage III/IV disease.
- About one third of patients were recorded as presenting with early Stage I disease.

MULTIDISCIPLINARY TEAM MEETINGS

Research has shown that patients who are managed in a multidisciplinary setting have improved outcomes¹⁹. The effective management of ovarian cancer patients requires input from a range of experts. Multidisciplinary team meetings (MDMs) involve a group of healthcare professionals meeting to discuss the diagnosis and treatment of patients. As there are a range of potential treatments that could be carried out, multidisciplinary discussions are of great importance. With respect to MDMs it should be noted that discussions among healthcare professionals, regarding the diagnosis and treatment of patients, may have taken place but may not have been recorded in the patient notes. Data for 1996 MDMs was considered unreliable and have not been reported, the results for 2001 have been presented in order to facilitate comparisons in the future.

Multidisciplinary team meetings recorded in the notes

MDM	Number of Patients* (%)
	2001 (n=146)
Yes	58 (40%)
No/Not recorded	88 (60%)

- In 2001, 40% of patients had a record of their case being discussed at a MDM (45% of surgery patients).

* Includes borderlines

Multidisciplinary team meetings recorded in the notes by Health Board of residence

Area of residence	Number of Patients (% Patients having an MDM recorded in their notes)*
	2001
NHSSB	14 (36%)
EHSSB	28 (46%)
SHSSB	8 (35%)
WHSSB	8 (32%)
N. Ireland	58 (40%)

* Includes borderlines

- In 2001, patients in the EHSSB were more likely to have a record of MDM discussion in their notes than patients from other Board areas. This likely reflects the establishment of the regional gynaecological Cancer Centre at BCH where 74% of patients were recorded as having been discussed at a MDM.

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SURGICAL PROCEDURES

Curative Surgery includes any patient who has had:

bilateral oophorectomy (BO), bilateral salpingo-oophorectomy (BSO), right salpingo-oophorectomy (RSO), left Salpingo-oophorectomy (LSO), oophorectomy

Other Surgery includes:

Palliative surgery e.g. patient had colectomy, ileostomy and RSO, laparotomy, omentectomy, cystectomy, hysterectomy

Biopsy includes: biopsy of lesion, tumour biopsy

Hospital of operation

Hospital	All Patients ❖ (%)		Curative Surgery ❖ (% of all surgery)	
	1996 (n=136)	2001 (n=146)	1996 (n=98)	2001 (n=105)
Belfast City (BCH)*	23 (17%)	45 (37%)	20 (87%)	39 (87%)
Antrim (ANT)**	15 (11%)	19 (16%)	13 (87%)	16 (84%)
Ulster (UH)**	9 (7%)	7 (6%)	9 (90%)	7 (100%)
Craigavon (CAH)**	11 (8%)	13 (11%)	10 (83%)	12 (92%)
Altnagelvin (AH)**	3 (2%)	11 (9%)	3 (75%)	10 (91%)
Royal Victoria (RVH)	9 (7%)	5 (4%)	8 (89%)	4 (80%)
Mater (MIH)	5 (4%)	5 (4%)	5 (100%)	5 (100%)
Erne (ERN)	4 (3%)	1 (<1%)	4 (100%)	1 (100%)
Coleraine (COL)/ Causeway (CAU)	7 (5%)	2 (2%)	4 (57%)	2 (100%)
Downe (DH)	3 (2%)	1 (<1%)	3 (100%)	-
Tyrone County (TCH)	3 (2%)	-	2 (67%)	-
Ards (AR)	2 (2%)	-	2 (100%)	-
Daisy Hill (DHH)	2 (2%)	3 (3%)	2 (100%)	3 (100%)
Roe Valley (RV)	3 (2%)	-	3 (100%)	-
Ulster Independent (UIC)***	2 (2%)	3 (3%)	2 (100%)	3 (100%)
Lagan Valley (LVH)	2 (2%)	3 (3%)	2 (100%)	3 (100%)
Route (ROU)	2 (2%)	-	2 (100%)	-
South Tyrone (STH)	1 (<1%)	-	1 (100%)	-
Whiteabbey (WHA)	2 (2%)	-	2 (100%)	-
Mid-Ulster (MUH)	1 (<1%)	-	1 (100%)	-
Not recorded****	26 (17%)	3 (3%)	-	-
Not applicable*****	1 (<1%)	25 (17%)	-	-

❖ Includes borderline patients *Cancer Centre **Cancer Unit ***Private hospital ****No record in notes whether patient did or did not have surgery *****Patient did not have surgery and percentages do not reflect these patients

Cancer Services Audit 1996 & 2001

Ovary

- 112 patients were operated on in 20 hospitals in 1996 and 118 patients were operated on in 13 hospitals in 2001.
- By 2001, 79% of patients had their surgery performed in specified Cancer Units/Cancer Centre (not including those affiliated) compared to 47% in those hospitals in 1996, in keeping with the recommendations of the Campbell Report¹.
- By 2001, the number of patients having their surgery performed in BCH (Cancer Centre) doubled.

Surgery performed

- For most patients with ovarian carcinoma (excluding borderline patients), surgery is not curative due to dissemination of throw cells throughout the abdominal cavity. The use of post operative chemotherapy prolongs survival and is now standard therapy for all patients with advanced disease and for some with earlier stage disease.

Surgery	Number of Patients (%)			
	All Patients		Patients 70 years and older	
	1996 (n=136)	2001 (n=146)	1996 (n=45)	2001 (n=49)
Curative intent	98 (72%)	105 (72%)	21 (47%)	23 (47%)
Other	11 (8%)	13 (9%)	3 (7%)	4 (8%)
Biopsy only	1 (<1%)	-	1 (2%)	-
No surgery/Not recorded	26 (19%)	28 (19%)	18 (40%)	22 (45%)

- In both years more than 70% of all patients underwent surgery with curative intent.
- Curative intent surgery was more likely in younger patients than older, 85% in under 70's compared to 47% in 70 years and over.
- There was no difference in the percentage of patients having curative intent surgery between 1996 and 2001 for all patients and for patients aged 70 years and over.
- Of those patients who did not have surgery in 2001, 40% were recorded as unfit and 40% were over 80 years old.

Oncology

Oncology details	Borderline Patients	Number of Patients (%) (excl borderlines)		
		1996 & 2001 (n=39)	1996 (n=121)	2001 (n=122)
Management discussed with oncologist		11 (28%)	71 (59%)	99 (81%)
Referred to Belvoir/City Hospital		5 (13%)	71 (59%)	90 (74%)
Recorded as not referred to oncology centre/no record at all		32 (82%)	50 (41%)	26 (21%)

- By 2001, the actual number of referrals to oncology increased by 27%.
- By 2001, 81% of patients (excluding borderlines) had a record of their case being discussed with an oncologist.

Cancer Services Audit 1996 & 2001 Ovary

Oncology treatment intent

Recorded Intent	Borderline Patients		Number of Patients (%) (excl borderlines)	
	1996 & 2001 (n=5)	1996 (n=71)	2001 (n=90)	
Curative/Adjuvant	5 (100%)	29 (41%)	44 (49%)	
Palliative	-	32 (45%)	22 (24%)	
Neo-adjuvant	-	-	2 (2%)	
Not recorded	-	10 (14%)	22 (24%)	

- Approximately 50% of patients had treatment intent recorded in their notes in both years.
- Of those not referred to the oncology centre (inc borderlines), the average (median) age was 60 years (65 years), 40% were borderline patients, one third had no surgery and almost two thirds of the non-borderline patients had died within 1 year.

Oncology treatment received

Treatment	Borderline Patients			Number of Patients (%) (excl borderlines)		
	1996 & 2001 (n=39)	1996 (n=121)	2001 (n=122)	1996 & 2001 (n=39)	1996 (n=121)	2001 (n=122)
	Chemotherapy			Radiotherapy		
Yes	2 (5%)	67 (55%)	74 (61%)	1 (3%)	5 (4%)	5 (4%)
No/NA/not recorded	37 (95%)	54 (45%)	48 (39%)	38 (97%)	116 (96%)	117 (95%)

- As expected more than half of patients in both years had chemotherapy with less than 5% of patients having radiotherapy.

Treatment modalities as recorded in clinical notes

Treatment	Number of Patients (%)	
	1996 (n=136)	2001 (n=146)
Surgery alone	46 (34%)	48 (33%)
Chemotherapy alone	7 (5%)	5 (3%)
Combination (chemo & surgery)	57 (42%)	65 (45%)
Combination (radio & surgery)	2 (2%)	-
Combination (chemo, radio & surgery)	4 (3%)	5 (3%)
None of the above treatments/not recorded	20 (15%)	23 (16%)

- Just under half of patients had surgery with chemotherapy in both years. One third of patients had surgery only in both years.
- Over three quarters of patients in both years had surgery performed.

chemo - chemotherapy, radio – radiotherapy

Cancer Services Audit 1996 & 2001

Ovary

Treatment modalities by stage of disease

Stage		Surgery	Chemotherapy	Radiotherapy	No active Treatment / Not recorded
Borderline Patients	1996 (n=15)	14 (93%)	1 (7%)	1 (7%)	1 (7%)
	2001 (n=24)	24 (100%)	1 (4%)	-	-
I	1996 (n=29)	29 (100%)	13 (45%)	1 (3%)	-
	2001 (n=35)	35 (100%)	22 (63%)	3 (9%)	-
II	1996 (n=11)	9 (82%)	9 (82%)	1 (9%)	1 (9%)
	2001 (n=11)	11 (100%)	9 (82%)	-	-
III	1996 (n=48)	42 (88%)	35 (73%)	3 (6%)	6 (13%)
	2001 (n=39)	37 (95%)	31 (79%)	2 (5%)	2 (5%)
IV	1996 (n=14)	10 (71%)	5 (36%)	-	1 (7%)
	2001 (n=12)	5 (42%)	8 (67%)	-	4 (33%)
NK	1996 (n=19)	5 (26%)	5 (26%)	-	11 (58%)
	2001 (n=25)	6 (24%)	4 (16%)	-	17 (68%)

- Chemotherapy was most commonly given to Stage II and Stage III patients.
- The majority of borderline, Stage I and Stage II patients had surgery.

Frequency of ovarian cancer surgery* carried out by surgeon

Surgery workload	Number of Surgeons (% of procedures)	
	1996	2001
10 procedures or more	1 (9%)	5 (58%)
5-9 procedures	3 (14%)	1 (4%)
2-4 procedures	16 (36%)	8 (19%)
1 procedure	43 (41%)	23 (19%)
Total surgeons	63	37
Total procedures	109	118

* Surgery includes curative and other (palliative) surgery and does not include biopsies.

- By 2001, 58% of ovarian cancer operations were performed by 5≥surgeons with high case volumes (10 procedures or more), reflecting increased surgical specialisation.
- By 2001, the number of surgeons performing gynaecology surgery had fallen by 41% from 63 to 37 surgeons.
- The number of surgeons performing fewer than 10 procedures decreased by 48% from 1996 to 2001.
- The largest number of operations performed by a single surgeon was 10 in 1996 and 18 in 2001.

Cancer Services Audit 1996 & 2001 Ovary

Single operator procedures (Note: The highest level procedure has been taken for each patient)

Procedures	Number of surgeons/procedures (% of single procedures)	
	1996 (n=43)	2001 (n=23)
Bilateral salpingo-oophorectomy	30 (70%)	15 (65%)
Left salpingo-oophorectomy	4 (9%)	2 (9%)
Right salpingo-oophorectomy	3 (7%)	-
Laparotomy	2 (5%)	3 (13%)
Biopsy	1 (2%)	-
Oophorectomy	1 (2%)	3 (13%)
Loop colostomy	1 (2%)	-
Hartman procedure	1 (2%)	-
Total surgeons	43	23

- The majority of procedures carried out by single operators were curative procedures.
- The number of surgeons performing single operations almost halved by 2001, reflecting increasing specialisation in gynaecology surgery.

Single operator hospitals

Hospital	Number of procedures (% of single procedures)	
	1996 (n=43)	2001 (n=23)
Belfast City (BCH)*	6 (14%)	3 (13%)
Royal Victoria (RVH)	6 (14%)	2 (9%)
Craigavon (CAH)**	4 (11%)	1 (4%)
Antrim (ANT)**	3 (7%)	1 (4%)
Coleraine (COL)/Causeway (CAU)	3 (7%)	2 (9%)
Tyrone County (TCH)	3 (7%)	-
Ulster (UH)	2 (7%)	2 (9%)
Altnagelvin (AH)**	1 (4%)	3 (13%)
Ards (AR)	2 (5%)	-
Downe (DH)	2 (5%)	1 (4%)
Daisy Hill (DHH)	2 (5%)	3 (13%)
Mid-Ulster (MUH)	2 (5%)	-
Roe Valley (RV)	2 (5%)	-
Lagan Valley (LVH)	1 (2%)	3 (13%)
Mater (MIH)	1 (2%)	-
South Tyrone (STH)	1 (2%)	-
Ulster Independent (UIC)***	1 (2%)	1 (4%)
Whiteabbey (WHA)	1 (2%)	-
Erne (ERN)	-	1 (4%)
Total surgeons	43	23

- In all hospitals performing gynae surgery in 2001, there were single operators (except the Mater Hospital).

*Cancer Centre **Cancer Unit ***Private hospital

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Ovary

TIMELINES/WAITING TIMES

Summary timeline for all patients

Time	Referral # - First seen at hospital		Referral # - CT scan***	Referral # - US abdomen***	First seen - Surgery	
	1996* (n=136)	2001* (n=146)	2001* (n=98)	2001* (n=94)	1996* (n=112)	2001* (n=118)
Same day	60 (44%)	89 (61%)	5 (5%)	20 (21%)	4 (4%)	3 (3%)
1 – 14 days	21 (15%)	32 (22%)	54 (55%)	48 (51%)	43 (38%)	34 (29%)
15 – 33 days	13 (10%)	11 (8%)	13 (13%)	9 (10%)	21 (19%)	44 (37%)
More than 33 days	10 (7%)	13 (9%)	26 (27%)	11 (12%)	32 (29%)	37 (31%)
Minus values**	3 (2%)	-	-	4 (4%)	-	-
Not recorded	29 (21%)	1 (<1%)	-	2 (2%)	12 (11%)	-
Average (Median) days	7 (0)	8 (0)	29 (10)	12 (3)	123 (15)	32 (23)

#Referral to hospital *Includes borderline patients **Minus values – Patient seen for other reason then referred
 ***Dates for CT scan and ultrasound not captured in 1996

- Between 1996 and 2001 the percentage of patients seen within 2 weeks of referral increased from 59% to 83%.
- Three quarters of patients receiving an ultrasound of the abdomen do so within 2 weeks of referral.
- There was improved extraction of dates in 2001 compared with 1996.

Summary timeline excluding emergencies

Time	Referral # - First seen at hospital		Referral # - CT scan***	Referral # - US abdomen***	First seen - Surgery	
	1996* (n=88)	2001* (n=85)	2001* (n=54)	2001* (n=50)	1996* (n=70)	2001* (n=73)
Same day	20 (23%)	34 (40%)	2 (4%)	12 (24%)	1 (1%)	1 (1%)
1 – 14 days	17 (19%)	26 (31%)	21 (39%)	19 (38%)	23 (33%)	17 (23%)
15 – 33 days	13 (15%)	11 (13%)	9 (17%)	4 (8%)	15 (21%)	27 (37%)
More than 33 days	9 (10%)	13 (15%)	22 (41%)	9 (18%)	20 (29%)	28 (38%)
Minus values**	1 (1%)	-	-	4 (8%)	-	-
Not recorded	28 (32%)	1 (1%)	-	2 (4%)	11 (16%)	-
Average (Median) days	16 (4)	14 (3)	44 (15)	17 (3)	133 (19)	39 (29)

#Referral to hospital *Includes borderline patients **Minus values – Patient seen for other reason then referred
 ***Dates for CT scan and ultrasound not captured in 1996

- Recording improved by 2001.
- After exclusion of emergencies, by 2001 over 70% of patients were seen within 2 weeks of referral.
- After exclusion of emergency cases, by 2001, 60% of patients had their surgery within 33 days of referral.
- After exclusion of emergency cases, by 2001, 6 patients had their surgery more than 6 months from date of referral.

Information recorded in notes

Information	Number of Patients* (%)	
	1996 (n=136)	2001 (n=146)
Diagnosis discussed with patient (recorded in notes)	63 (46%)	120 (82%)
Diagnosis not discussed with patient (recorded in notes)	4 (3%)	10 (7%)
Patient seen for counselling (recorded in notes)	8 (6%)	32 (22%)
Not seen for counselling/not recorded	128 (94%)	116 (79%)

* Includes borderline patients

- By 2001, over 80% of patients had a record of discussion of diagnosis in clinical notes, compared with 46% in 1996.
- Referrals for counselling had increased substantially by 2001, yet only one fifth had such a referral recorded.
- An active decision not to discuss the diagnosis with the patient was recorded in 7% of patients in 2001.

Entered for clinical trials

Clinical trails	Number of Patients* (%)	
	1996 (n=136)	2001 (n=146)
Offered and accepted	18 (13%)	15 (10%)
Offered and declined	5 (4%)	8 (6%)
Not offered/not recorded	113 (83%)	123 (84%)

*Includes borderline patients

- The offer of clinical trials was similar in both years with 10% of patients enrolled in clinical trials.

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FOLLOW-UP CARE DETAILS

This relates to information recorded in the discharge letter from hospital to GP.

After care recorded

After care	Borderline Patients (%)	Number of Patients (%) (excl borderlines)	
		1996 & 2001 (n=39)	1996 (n= 121)
Hospice	-	8 (7%)	4 (3%)
Macmillan nurse	1 (3%)	4 (3%)	13 (11%)
Marie Curie nurse	-	-	5 (4%)
Discussed with palliative medicine consultant	1 (3%)	1 (<1%)	25 (20%)
Other*	3 (8%)	-	6 (5%)
No onward referral	6 (15%)	-	14 (11%)
Not recorded	28 (72%)	108 (89%)	55 (45%)

*Other=Action cancer, district nurse, Gerard Lynch centre, health visitor, oncology review, gynae O/P review

- By 2001, recording of referrals to palliative medicine (Hospice/Macmillan/Marie Curie) had increased with 18% of patients having such a referral, this likely reflects increased availability of such services.

Information in GP letter

Information	Borderline Patients (%)	Number of Patients (%) (excl borderlines)	
		1996 & 2001 (n=39)	1996 (n= 121)
Diagnosis discussed with patient	14 (36%)	43 (36%)	62 (51%)
Prognostic information	15 (39%)	44 (36%)	21 (17%)
Management plan	35 (90%)	96 (79%)	116 (95%)

- In the GP letter, recording of diagnosis discussion with the patient and management improved in 2001.
- Recording of prognostic information was poorer in 2001 than 1996.

PATIENT OUTCOMES

Survival analysis was performed on patients diagnosed in 1996 and 2001, with sub-group analysis for surgery patients and stage of disease.

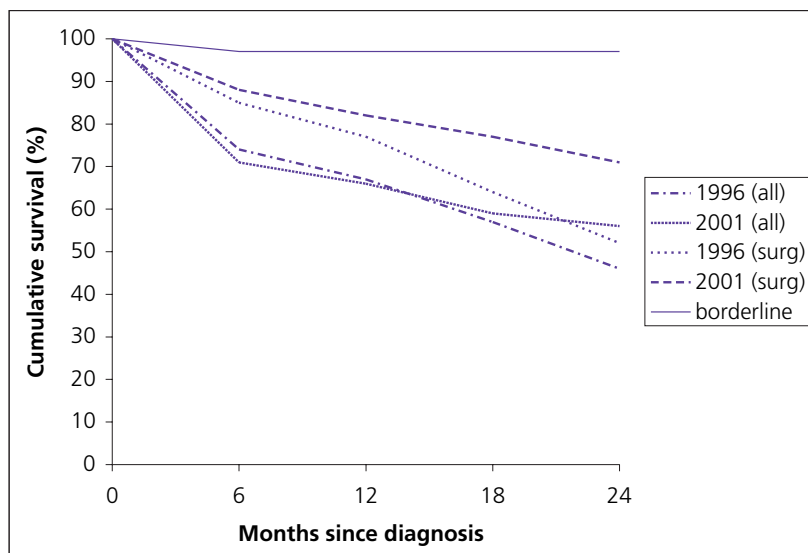
Death information was available until 31/12/2003 for all patients and this has been used as the censor date.

Percentage of patients alive at various times after diagnosis

Time	Surgery Patients (excl borderlines)		Borderline Patients	All Patients (excl borderlines)	
	1996	2001	1996 & 2001	1996	2001
30 days	94%	100%	97%	82%	93%
60 days	91%	94%	97%	79%	80%
6 months	85%	88%	97%	74%	71%
1 year	77%	82%	97%	67%	66%
2 years	52%	71%	97%	46%	56%
Total patients	95	94	39	121	122

- Although survival was better for “all patients (excl borderlines)” in 2001 than in 1996, this was not statistically significant (p=0.17).
- However, by 2001, the percentage of surgery patients alive at 2 years increased to 71% from 52% in 1996, [exp(b)=0.88 (CI:0.81,0.96), p=0.004], after adjustment for age at diagnosis, stage of disease and receipt of chemotherapy, there was still improved survival between the years [exp(b)=0.91 (CI:0.82,1.00), p=0.05].

Ovarian Cancer observed survival for borderline patients and by year for all patients (excl borderlines) and surgery (excl borderlines) patients



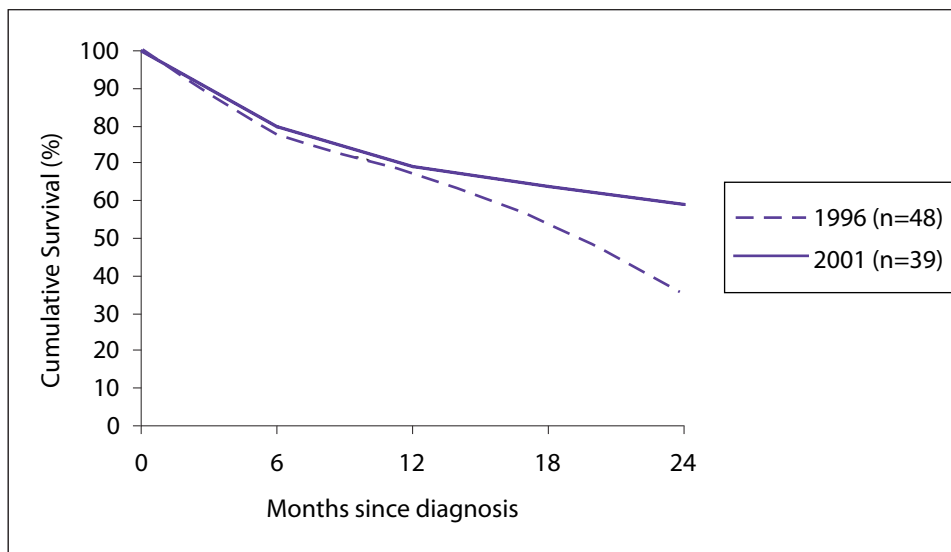
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Percentage of patients alive at various times after diagnosis by Stage (all patients excl borderlines)

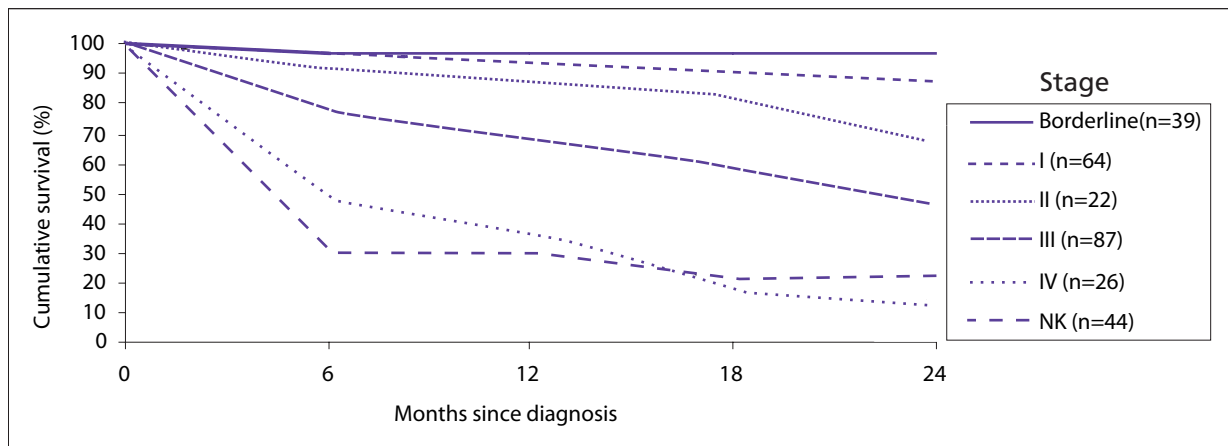
Time	Stage									
	I		II		III		IV		Unstaged	
	1996 (n=29)	2001 (n=35)	1996 (n=11)	2001 (n=11)	1996 (n=48)	2001 (n=39)	1996 (n=14)	2001 (n=12)	1996 (n=19)	2001 (n=25)
30 days	97%	100%	91%	100%	83%	100%	79%	92%	53%	68%
60 days	97%	97%	91%	91%	83%	87%	64%	83%	42%	40%
6 months	93%	97%	91%	91%	77%	80%	50%	50%	42%	24%
1 year	90%	97%	91%	82%	67%	69%	43%	33%	37%	24%
2 years	83%	89%	64%	73%	35%	59%	14%	16%	32%	16%

Ovarian cancer observed survival by year –Stage III



- There was a difference in the overall survival of Stage III patients between 1996 and 2001 $\exp(b)=0.88$ (CI: 0.79, 0.99), ($p=0.03$). This may reflect improved tumour debulking.
- There was no difference in the overall survival for any other stage of disease.

Overall survival all patients (both years combined) by stage



SECTION III – CERVICAL CANCER

RESULTS

Study patients

Patients	1996	2001
Total number of patients	96	70
Exclusions – lack of information	10	1
Total number reported on	86 (100%)	69 (100%)
Average age at diagnosis	48	47
Median age at diagnosis	47	42
Minimum, maximum age at diagnosis	(22,92)	(18,87)

- The NICR identified 96 patients in 1996 and 70 in 2001 registered with invasive cervical cancer. After exclusions, 86 remained in 1996 and 69 in 2001.
- Although the numbers of cervical cancer cases are decreasing, there is no significant trend⁸.

Socio-economic status of patients

Deprivation quintile	Number of Patients* (%)	
	1996 (n=86)	2001 (n=69)
Quintile 1 (Most Deprived)	30 (35%)	22 (32%)
Quintile 2	13 (15%)	17 (25%)
Quintile 3	15 (17%)	9 (13%)
Quintile 4	12 (14%)	10 (15%)
Quintile 5 (Least Deprived)	16 (19%)	11 (16%)

- If a disease is not related to deprivation in the general population, it is expected that 20% of all cases of disease would fall in each quintile. Our data shows that there is no difference in the levels of cervical cancer with deprivation between 1996 and 2001 ($\chi^2 = 2.54$, $p=0.638$), although the highest percentage of cases fall in the most deprived quintiles for both years, the failure to show significance may be due to small numbers. Previous N. Ireland Cancer Registry reports show significant increasing trends in incidence rates for cancer of the cervix with increasing deprivation in keeping with national and international findings⁸.

Method of Presentation

Presentation	Number of Patients (%)	
	1996 (n=86)	2001 (n=69)
Colposcopy clinic	43 (50%)	30 (44%)
Gynaecological clinic	33 (38%)	34 (49%)
Urology	2 (2%)	-
Emergency	1 (1%)	1 (1%)
Other*	3 (4%)	4 (6%)
Not recorded	4 (5%)	-

- Around 90% of patients present to a colposcopy or gynaecological clinic.

* Other comprises patients who presented to antenatal clinic, general surgery or admitted to general ward for other problems.

Cancer Services Audit 1996 & 2001 Cervix

Symptoms/signs at presentation (Note: Patients may have had more than 1 symptom/sign)

Symptom/Signs	Percentage of Patients with symptom/sign at any time (%)	
	1996 (n=86)	2001 (n=69)
Abnormal vaginal bleeding	27 (31%)	40 (58%)
Abnormal smear	29 (34%)	28 (41%)
Vaginal discharge	7 (8%)	1 (1%)
Pain	1 (1%)	6 (9%)
Tiredness	-	2 (3%)
Weight loss	1 (1%)	1 (1%)
Heavy periods	2 (2%)	1 (1%)
Swelling/bloated	3 (4%)	-
Pain on passing urine	-	1 (1%)
Menstrual irregularities	1 (1%)	-
Swelling in neck	1 (1%)	-
Other*	2 (2%)	4 (6%)
Not recorded	17 (20%)	-

* Other includes urinary frequency, sweating, anuria

- Symptom recording was better in 2001.
- Over a third of patients presented as a result of an abnormal smear test result.
- Abnormal vaginal bleeding was the most common presenting symptom in 2001.

Investigation: CT Scan

Investigation	Number of Patients (%)			
	All Patients		Surgery Patients*	
	1996 (n=86)	2001 (n=69)	1996 (n=53)	2001 (n=48)
CT scan	28 (33%)	22 (32%)	10 (19%)	10 (22%)

*Surgery includes patients who had therapeutic or radical surgery

- About one third of all patients in both years had a CT scan while 1 in 5 surgery patients had a CT scan in both years.

CT Scan by Stage category (see Appendix E for Stage information)

CT Scan	Stage of disease (%)	
	up to Stage IIB (n=89)	Stage IIB or higher (n=61)
Yes	16 (18%)	34 (56%)
No	3 (4%)	-
Not Recorded	70 (79%)	27 (44%)

- Across both years, 32% of patients who had a CT scan, were staged lower than Stage IIB.
- Around one fifth of patients staged lower than IIB had a CT scan, compared to over half of patients staged IIB or above.
- Those with more advanced disease were more likely to have a CT scan.

CT Scan by age of patient: percentage of patients 70 years and under compared with over 70 years

Investigation	Number of Patients (%)			
	70 years and under		Over 70 years	
	1996 (n=75)	2001 (n=58)	1996 (n=11)	2001 (n=11)
CT scan	24 (32%)	17 (29%)	4 (36%)	5 (46%)

- The over 70 age group were more likely to have a CT scan than younger patients in both years (based on small numbers).
- In 2001, 10% more patients in the older age group were receiving CT scans compared to patients in 1996.
- The over 70 age group were significantly more likely to present with late stage disease than those aged under 70 ($p < 0.001$).

METHOD OF DIAGNOSIS

In agreement with national and international guidelines, NICR uses a hierarchy when deciding the certainty of a cancer diagnosis. Microscopic verification (MV) (histology/cytology) is generally most reliable. However, if this is not possible, results of imaging procedures such as CT scan or chest X-ray, which for some patients is the only way of confirming a diagnosis, is accepted. In the absence of any microscopic or visual confirmation of the cervical cancer, the NICR accepts the opinion of a clinician (CO).

Method of diagnosis	Number of Patients (%)	
	1996 (n=86)	2001 (n=69)
Histopathology	85 (99%)	69 (100%)
Clinical opinion	1 (1%)	-

- In both years almost all patients have a histological/cytological confirmation of their diagnosis.
- The patient diagnosed by clinical opinion refused surgery and was staged clinically with extensive disease.

PATHOLOGY

Tumour Type

Cell type	Number of Patients (%)	
	1996 (n=86)	2001 (n=69)
Squamous cell carcinoma, NOS*	54 (63%)	34 (49%)
Squamous cell carcinoma, microinvasive	11 (13%)	17 (25%)
Adenocarcinoma, NOS*	12 (14%)	12 (17%)
Carcinoma, NOS*	4 (5%)	4 (6%)
Adenosquamous carcinoma	3 (4%)	2 (3%)
Mucin producing adenocarcinoma	1 (1%)	-
Neoplasm malignant	1 (1%)	-

* NOS=Not otherwise specified

- As expected squamous cell carcinoma was the most common histological type with three quarters of patients in both years having this cell type.

STAGING

See Appendix F

Staging of cervical cancer

As many patients with cervical cancer are treated by radiotherapy and never undergo surgical pathological staging, the dual TNM system is not favoured. The more widely accepted clinical staging for cervical cancer is the FIGO (International Federation of Gynaecology and Obstetrics) classification¹⁸, which provides uniformity and is therefore preferred.

Clinical staging¹⁸

The clinical stage should be determined before the start of definitive treatment and should not be changed because of subsequent findings. Clinical stage is determined on the basis of careful pelvic clinical examination, colposcopy, endocervical curettage, hysteroscopy, cystoscopy, proctoscopy, intravenous pyelogram (IVP) and chest X-ray. Although the results of other imaging such as CT scanning, MRI, PET scanning, laparoscopic or CT-guided biopsy all provide important information on the extent of pelvic disease useful for treatment planning, they should not (at present) be used to determine clinical stage.

Pathological staging

In cases treated by surgical resection eg. hysterectomy, pathological examination of the resected specimen adds significant information to this process. The TNM nomenclature can be applied to assess the extent of the primary tumour (T), the status of regional nodes (N) and distant metastases (M). The definitions of the T categories correspond to the FIGO stage group.

FIGO Stage

Stage	Number of Patients (%)			
	All Patients		Surgery Patients*	
	1996 (n=86)	2001 (n=69)	1996 (n=53)	2001 (n=46)
I	43 (50%)	40 (58%)	41 (77%)	38 (83%)
II	20 (23%)	16 (23%)	9 (17%)	6 (13%)
III	12 (14%)	9 (13%)	1 (2%)	2 (4%)
IV	5 (6%)	4 (6%)	-	-
Stage not recorded/known	6 (7%)	-	2 (4%)	-

*Surgery patients include those who had therapeutic or radical surgery (excludes diagnostic surgery patients)

- About three quarters of patients were recorded as having Stage I/II disease.
- In both years, 6% of patients presented as Stage IV.
- The majority of surgery patients were Stage I or II.

SMEAR TESTS

The National Health Service Cervical Screening Programme (NHSCSP) has played a major role in reducing mortality from cervical cancer in England and Wales²⁰. Figures produced from the Office of National Statistics for 2001 shows the uptake of screening is lowest in N. Ireland (70.1%) compared to any other region of the United Kingdom (83.5%)²¹. In its priority for action statement, the Department of Health N. Ireland set a target for the cervical screening programme that by 2004, 75% of the eligible female population of N. Ireland would be screened at least once in the previous 5 years²². More recent figures from 2004 show N. Ireland's uptake of screening at 71% compared to 81% for the rest of the UK²³.

Cervical cancer screening and death rates, 2001 and 2004, UK^{21,22}

Country	Percentage screened		Age-standardised death rates*	
	2001	2004	2000	2004
England	83%	81%	5.3	4.5
Northern Ireland	70%	71%	4.8	5.1
Scotland	87%	86%	5.8	5.6
Wales	81%	77%	5.5	4.6

* Deaths registered in 2000 and 2004 per 100,000 women respectively, standardised to mid 1991 and 2003 UK population respectively

Cancer Services Audit 1996 & 2001

Cervix

Smear history of cervical cancer patients in Northern Ireland, 1996 and 2001

Smear History	Number of Patients (%)	
	1996 (n=86)	2001 (n=69)
No record of a smear	27 (31%)	2 (3%)
1 smear	40 (47%)	33 (48%)
2 smears	14 (16%)	14 (20%)
3 smears	5 (6%)	7 (10%)
Not recorded in notes	-	13 (19%)

- By 2001, only 3% of patients had a record of never having had a smear test compared to 31% in 1996, although the smear status is unknown in 19% of patients in 2001. This reflects increased uptake of the screening programme.

Screening History	Number of Patients (%)	
	1996 (n=86)	2001 (n=69)
Diagnostic smear	40 (47%)	40 (58%)
Screening smear	10 (12%)	7 (10%)
Historical smear	3 (3%)	5 (7%)
Not known	33 (38%)	17 (25%)

- Around half of patients in both years have had a smear test performed 6 months prior to their diagnosis.

Diagnostic smear=smear performed 6 months prior to diagnosis.

Screening smear=smear performed more than 6 months prior to diagnosis but less than 5 years prior to diagnosis.

Historical smear=smear performed more than 5 years prior to diagnosis.

STAGE BY SMEAR TEST HISTORY

Year	Smear History	Stage (%)				
		I	II	III	IV	NK*
1996	No smears	6 (14%)	7 (35%)	6 (50%)	4 (80%)	4 (67%)
	Any	37 (86%)	13 (65%)	6 (50%)	1 (20%)	2 (33%)
	Total	43	20	12	5	6
2001	No smears	-	5 (31%)	6 (67%)	4 (100%)	-
	Any	40 (100%)	11 (69%)	3 (33%)	-	-
	Total	40	16	9	4	-

*NK= Not known

- Patients diagnosed with earlier Stage I/Stage II disease were more likely to have had a history of screening smears than those diagnosed with later Stage III or Stage IV disease.
- For both years combined, there was a significant association between Stage and screening history, 90% of patients with Stage less than IIB had a history of having a smear test compared to 52% of Stage IIB or above patients ($p<0.05$).

SURGICAL PROCEDURES

Surgery has been defined as follows:

Diagnostic surgery = biopsy or Iletz or cone biopsy or simple hysterectomy (except Stage 1A1)

Therapeutic surgery = the surgery performed has completed the treatment with curative intent

Stage 1A1 patients = cone biopsy (LLETZ or cold knife) and simple hysterectomy

Stage 1B patients = hysterectomy and radiotherapy

Radical surgery = radical hysterectomy and node dissection or radical excision of cervix and node dissection

Surgery	Number of Patients (%)			
	All Patients		Patients over 70 years old	
	1996 (n=86)	2001 (n=69)	1996 (n=11)	2001 (n=11)
Diagnostic	33 (38%)	23 (33%)	8 (73%)	11 (100%)
Therapeutic	21 (24%)	22 (32%)	-	-
Radical	27 (31%)	19 (28%)	2 (27%)	-
Radical with adjuvant chemo	5 (6%)	5 (7%)	-	-

- Surgery patterns were similar in both years.

Treatment modalities for cervical cancer patients as recorded in notes

Stage		Treatment		
		Surgery*	Chemoradiation	Radiotherapy
I	1996 (n=43)	41 (95%)	-	7 (16%)
	2001 (n=40)	38 (95%)	7 (18%)	-
II	1996 (n=20)	9 (45%)	3 (15%)	11 (55%)
	2001 (n=16)	6 (38%)	13 (81%)	2 (13%)
III	1996 (n=12)	1 (8%)	3 (25%)	9 (75%)
	2001 (n=9)	2 (22%)	5 (55%)	4 (44%)
IV	1996 (n=5)	-	3 (60%)	1 (20%)
	2001 (n=4)	-	1 (25%)	2 (50%)
Not known	1996 (n=6)	2 (33%)	1 (17%)	3 (50%)

*Surgery includes patients who had therapeutic or radical surgery

- The majority of Stage I patients, one third of Stage II patients, one fifth of Stage III patients and no Stage IV patient had therapeutic or radical surgery in 2001.
- Use of chemoradiation increased in 2001 from 1996 for all stages of disease up to Stage IV.

Cancer Services Audit 1996 & 2001 Cervix

Treatment modalities for cervical cancer patients as recorded in notes

Stage	Treatment			
		Surgery*	Chemoradiation	Radiotherapy
Less than stage IIB	1996 (n=46)	42 (91%)	-	9 (20%)
	2001 (n=43)	40 (93%)	8 (19%)	1 (2%)
Stage IIB or higher	1996 (n=35)	10 (29%)	10 (29%)	19 (54%)
	2001 (n=26)	6 (23%)	18 (69%)	7 (27%)
Not known	1996 (n=5)	1 (20%)	-	3 (60%)

*Surgery includes patients who had therapeutic or radical surgery

- The majority of patients with Stage less than IIB received therapeutic or radical surgery. The majority of patients with stage higher than IIB received diagnostic surgery.
- By 2001, 96% of patients with Stage IIB or above were recorded as receiving chemoradiation or radiotherapy.

TIMELINES/WAITING TIMES

Summary timeline for all patients

Time	Presentation-Diagnosis**		Diagnosis-First Treatment	
	1996 (n=86)	2001 (n=69)	1996 (n=57)	2001 (n=58)
Same day	14 (16%)	20 (29%)	5 (9%)	7 (12%)
1 – 14 days	34 (40%)	15 (22%)	6 (11%)	5 (9%)
15 – 33 days	14 (16%)	14 (20%)	13 (23%)	9 (16%)
More than 33 days	12 (14%)	19 (28%)	31 (54%)	36 (62%)
Minus values*	12 (14%)	-	2 (4%)	1 (2%)
Not recorded	-	1 (1%)	-	-
Average (Median) days	21 (6)	47 (13)	65 (37)	61 (47)

*Minus Values **patient had a diagnosis made by smear test before she presented at clinic

- Just under one third of patients in 2001 were diagnosed on the same day as presentation.
- About one half of patients in both years were diagnosed within 2 weeks of presentation.

PATIENT OUTCOMES

Survival analysis was performed on patients diagnosed in 1996 and 2001, with sub-group analysis for surgery patients and stage of disease.

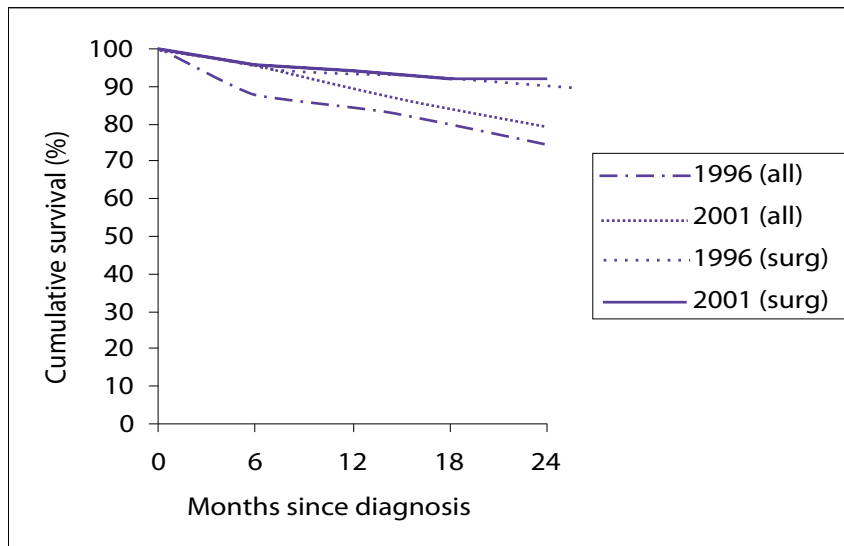
Death information was available until 31/12/2003 for all patients and this has been used as the censor date.

Percentage of patients alive at various times after diagnosis

Time	Surgery* only Patients		All Patients	
	1996 (n=53)	2001 (n=46)	1996 (n=86)	2001 (n=69)
30 days	100%	100%	99%	99%
60 days	98%	100%	97%	99%
6 months	94%	98%	87%	96%
1 year	94%	96%	84%	90%
2 years	93%	94%	74%	80%

*Surgery = therapeutic or radical surgery (excludes diagnostic)

Cervical cancer observed survival by year (all patients and surgery patients)



- Survival from cervical cancer is good with 80% alive 2-years after diagnosis. There was, however, no difference in the overall survival of patients in 1996 compared with 2001 ($\chi^2=1.403, p=0.236$).
- For those patients who had surgery, there was no difference in the overall survival of patients in 1996 compared with 2001 ($\chi^2=0.03, p=0.863$).
- Survival for surgery patients was better than all patients, a marker of improved patient selection (and Stage of disease).

Cancer Services Audit 1996 & 2001

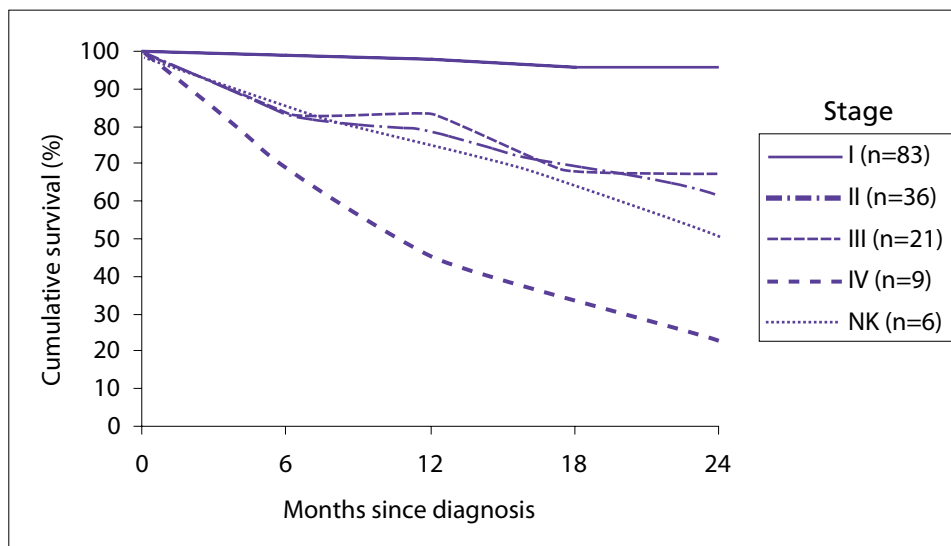
Cervix

Percentage of patients alive at various times after diagnosis by Stage

Time	Stage									
	I		II		III		IV		NR	
	1996 (n=43)	2001 (n=40)	1996 (n=20)	2001 (n=16)	1996 (n=12)	2001 (n=9)	1996 (n=5)	2001 (n=4)	1996 (n=6)	2001 (n=0)
30 days	100%	100%	100%	100%	100%	100%	100%	100%	75%	83%
60 days	100%	100%	90%	100%	100%	100%	100%	100%	75%	83%
6 months	100%	98%	75%	94%	75%	100%	60%	75%	83%	-
1 year	100%	95%	70%	88%	75%	78%	20%	75%	83%	-
2 years	98%	95%	55%	69%	50%	56%	20%	25%	67%	-

- There was a marked difference in survival by stage of disease with 95% of Stage I patients alive at 2-years compared with 25% of Stage IV patients.
- There was no difference in overall survival between 1996 and 2001 for any stage of patients. However, 10% of patients in 1996 had no information recorded and were excluded from the analysis. These patients may have had poorer survival than those included in the analysis.

Cervical cancer observed survival by stage



SECTION IV

OVARIAN CANCER SUMMARY

PRESENTATION

- Two thirds of diagnosed ovarian cancer cases were referred from their GP in 1996 (65%) compared to three quarters in 2001 (74%).
- Over one third of patients presented as an emergency in both years.
- As expected, the majority of patients presented to hospitals within their own Health Board of residence.
- Pain was the most common presenting symptom in 1996 (44%), abdominal distension was the most common presenting symptom in 2001 (67%).
- Hypertension and cardiovascular disease were the most commonly reported co-morbid conditions in both years.
- In 1996, 136 patients presented to 24 hospitals, whilst in 2001, 146 patients presented to 17 hospitals.

INVESTIGATIONS

- In 2001, patients were more likely to have serum tumour markers measured (9% vs 3%), a CT scan (67% vs 28%) and cytology of ascites (71% vs 38%).
- There was no difference in levels of investigation for the sub-group of patients who had surgery.
- Patients in the 'over 70' age group were more likely to have all relevant investigations performed in 2001 compared to 1996.

HISTOLOGY

- In both years, 91% of all patients (excluding borderline patients) had a histologically/cytologically confirmed diagnosis of ovarian cancer.
- All surgery patients in both years had a histologically/cytologically confirmed diagnosis of ovarian cancer.
- As expected, the majority of ovarian cancers in both years were epithelial tumours.
- There was improved histological grading of tumours in 2001.
- Of tumours that could be histologically graded, the majority were poorly differentiated.

STAGING

- Staging information was available for 86% of all patients in 1996, compared to 83% in 2001.
- Staging information was available for 95% of surgery patients in 1996, compared to 81% in 2001.
- As expected, half of all patients (for whom a stage is recorded) presented with advanced Stage III/IV disease.
- Over one third of surgery patients present with Stage I disease.

RECORDING OF MULTIDISCIPLINARY TEAM MEETINGS

- In 2001, 40% of patients had a record of their case being discussed at a MDM (information not available 1996).
- Patients in the Eastern Board were the most likely to have a record of MDM discussion in their notes than patients from other Board areas.

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Ovary Summary

SURGERY AND ONCOLOGY

- Patients were operated on in 20 hospitals in 1996, compared to 13 hospitals in 2001.
- By 2001, the number of patients having their surgery in the regional centre (BCH) doubled.
- By 2001, the number of surgeons performing gynae-oncology surgery had fallen by 41%.
- The largest number of operations performed by a single surgeon was 10 in 1996 and 18 in 2001.
- The number of surgeons performing fewer than 10 procedures decreased by 48% from 1996 to 2001.
- The number of surgeons performing single operations almost halved by 2001.
- The number of hospitals with surgeons performing one operation decreased from 18 in 1996 to 12 in 2001.
- In both years the majority of patients underwent surgery with curative intent.
- Of those patients who did not have surgery in 2001, 40% were recorded as unfit.
- By 2001, over three quarters (81%) of patients had their management discussed with an oncologist compared to over half of patients in 1996 (59%).
- Of those patients not referred to oncology, 40% were borderline patients, one third had no surgery and almost two thirds of the non-borderline patients had died within 1 year.
- Half of patients in both years had chemotherapy.
- Less than 5% of patients in both years had a record of receiving radiotherapy.

TIMELINES/WAITING TIMES

- Between 1996 and 2001 the percentage of people seen within 2 weeks of referral increased from 59% to 83%.
- Around one third of patients had their surgery within 2 weeks from first being seen at hospital in both years.
- After exclusion of emergency cases, by 2001, 60% of patients had their surgery within 33 days of referral.

COMMUNICATION/FOLLOW-UP CARE

- By 2001, over 80% of patients had discussion of diagnosis recorded in the notes, an improvement from 1996 (46%).
- Referrals for counselling had increased substantially by 2001, yet only one fifth had such a referral.
- Similar proportions of patients were offered clinical trials in both years (16%-17%).
- By 2001, recording of referrals to palliative medicine consultants (Hospice/Macmillan/Marie Curie) had increased with 18% of patients having such a referral.
- Recording of diagnosis discussion with the patient improved in the GP letter by 2001.

OUTCOMES

- Although survival was better in 2001 than in 1996, this was not statistically significant.
- There was a difference in the overall survival of Stage III patients between 1996 and 2001 (CI:0.82,1.00) $p=0.05$ after adjustment for age, stage and receipt of chemotherapy.
- There was no difference in overall survival for any other stage.

SECTION V

CERVICAL CANCER SUMMARY

PRESENTATION

- The majority of patients presented to a colposcopy or gynaecological clinic in both years.
- Over one third of patients in both years presented as the result of an abnormal smear test result.
- Abnormal vaginal bleeding was the most common presenting symptom in 2001 (58%).

INVESTIGATIONS

- By 2001, only 3% of patients had no record of ever having had a cervical smear compared to 31% in 1996.
- There was decreasing likelihood of patients ever having had a smear test with increasing stage of disease.
- Smear history was unknown for one fifth of patients in 2001.
- About one third of patients in both years had a CT scan.
- More surgery patients in 2001 (22%) had a CT scan compared to 1996 (19%).
- Patients aged over 70 were more likely to have a CT scan in 2001 (46%) than patients of a similar age in 1996 (36%).

HISTOPATHOLOGY

- As expected squamous cell carcinoma was the most common histological type (1996:76%, 2001:74%).

STAGING

- Approximately three quarters of all patients and over 90% of surgery patients in both years had Stage I/II disease.
- In 2001, all Stage I patients had a smear history compared with 86% of Stage I patients in 1996.

SURGERY AND ONCOLOGY

- Over 90% of patients with stage less than IIB had surgery in both years.
- Two thirds of all patients had surgery (therapeutic/radical) in both years, the remaining one third had diagnostic surgery.
- Chemoradiation was given to 19% of stage less than IIB patients in 2001 whereas it was not recorded as being administered in 1996.
- Chemoradiation was given to 40% more patients with stage greater than or equal to IIB in 2001 compared to 1996.
- Fewer patients had radiotherapy in 2001.



Cancer Services Audit 1996 & 2001 Cervix Summary

TIMELINES

- About half of all patients in both years were diagnosed within 2 weeks of presentation.
- The average and median delay from presentation to diagnosis increased from 1996 to 2001 by 26 days and 7 days respectively.
- The majority of patients have to wait more than 1 month from diagnosis before receiving treatment, the proportion increased slightly in 2001.

OUTCOMES

- There was no difference in overall survival of total or surgery patients in 1996 compared to 2001.
- There was no difference in overall survival between 1996 and 2001 for any stage of patient.

CONCLUSIONS (OVARY AND CERVIX)

By 2001, the following improvements were apparent:

- Evidence of centralisation in ovarian cancer.
- Patients were more likely to have investigations (serum tumour markers, CT Scan).
- Increased surgical specialisation for ovarian patients.
- Increased chemoradiation for cervical cancer patients.
- Shorter delay from referral to first seen for ovarian patients.
- Slightly increased delay from diagnosis to first treatment for cervical cancer patients.
- Improved survival for Stage III ovarian cancer patients.

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APPENDIX A

Campbell Report : Recommendations regarding Cancer Services in N. Ireland, 1996¹.

1. The management of patients with cancer should be undertaken by appropriately trained, organ and disease specific medical specialists.
2. All patients with cancer should be managed by multidisciplinary, multiprofessional specialist cancer teams.
3. A Cancer Forum should be established involving all key interests in the delivery of cancer services.
4. Cancer Units should, in conjunction with local GPs and other providers, develop an effective communication strategy.
5. Northern Ireland should have one Cancer Centre, which in addition to its regional role, should act as a Cancer Unit to its local catchment population of around half a million.
6. There should be four other Cancer Units, one in each Board area, each serving a population of around a quarter of a million.
7. Radiotherapy services, together with chemotherapy services, should be moved as soon as possible to the Belfast City Hospital and become an integral part of the regional Cancer Centre.
8. Each Cancer Unit should develop a chemotherapy service. This service should be staffed by designated specialist nurses and pharmacists, and should be overseen by the non-surgical oncologist attached to the Unit, with back-up from a haematologist.
9. There should be a minimum target of 13 consultants in non-surgical oncology for Northern Ireland by 2005.
10. Any new appointments of trained cancer specialists should be to Cancer Units or to the Cancer Centre.
11. Guidelines should be drawn up and agreed for the appropriate investigation and management of patients presenting to non-cancer unit hospitals who turn out to have cancer.
12. The Cancer Centre and Cancer Units should each develop a specialist multiprofessional palliative care team.
13. There should be a comprehensive review of palliative care services in Northern Ireland.
14. The Northern Ireland Cancer Registry should be adequately resourced.

The above recommendations outlined the change that was necessary to improve cancer care.

APPENDIX B

Improving outcomes in gynaecological cancer, UK Department of Health, England & Wales 1999⁴. Guidance for general practitioners and primary care teams

Summary Recommendations in specific topic areas

1 Specialist Services and Multiprofessional Teams

- Any woman with suspected gynaecological cancer should be referred to a designated Cancer Unit for assessment by a team of staff with a specialist interest in gynaecological cancer.
- Cancer Unit services should include rapid assessment and diagnosis of gynaecological cancer, and surgery for superficially invasive cervical cancer and early endometrial cancer.
- Women with other, or more advanced, gynaecological cancers should be referred to a Cancer Centre after initial assessment by the Cancer Unit team. This will include all women with ovarian cancer.
- Specialist multiprofessional gynaecological oncology teams working at Cancer Centres will take responsibility for the treatment of women with ovarian cancer, more advanced cervical or endometrial cancers, vulval cancer and rarer gynaecological cancers.
- The gynaecological oncology team will be responsible for maintaining close contact with the Cancer Unit and GPs and primary health care teams, and with other professionals actively involved in supporting patients, e.g. social workers, psychologists and counsellors.
- Depending on local circumstances, chemotherapy and palliative care may be delivered by Cancer Units, working in conjunction with Cancer Centres.
- Patients and their GPs should be given written information about the members of the teams involved in their management.

2 The Patient's Perspective

- Delay between initial suspicion of cancer, referral and treatment should be kept to a minimum.
- Women should be encouraged to bring a partner, close friend or relative with them to the clinic appointments, particularly when they could be told of a cancer diagnosis.
- Health service staff need to be sensitive to potential problems with communication, both with women who have gynaecological cancer, and with their partners.
- Women should be given as much information about the cancer, proposed treatment, and potential adverse effects as they want; knowledge may reduce anxiety even when the news is bad. Most women want full, clear and accurate information which should be provided in a humane way, with sensitivity and respect.
- Detailed and realistic information about both long and short term effects of treatment, including adverse effects, is particularly important when different treatment modalities may be equally effective for controlling the disease, as with early cervical cancer, or when there may be uncertainty about benefits, as with adjuvant radiotherapy in some situations.
- Women should be encouraged to make their personal priorities clear to clinicians, who should always respect patients' views.
- Women who have treatment that is likely to affect sexual activity (in particular, radiotherapy or surgery to the cervix, vagina or vulva) should be offered counselling with their partners to reduce adverse effects on their relationships.

3 Ovarian Cancer

- Screening is not recommended, but women who have two or more close relatives with ovarian cancer and are anxious about their own risk, should be referred to cancer genetics clinics.
- Any woman who has symptoms which could be due to ovarian cancer (pelvic mass and/or persistent pain, abdominal distension, unexplained bowel symptoms, weight loss) should be referred to the lead gynaecologist at a designated Cancer Unit. GPs should be alert to the possibility that women with persistent unexplained abdominal symptoms might have ovarian cancer, particularly if they are over 50 years old.
- Assessment at the Cancer Unit should include full abdominal and vaginal examination, transvaginal ultrasound and CA125 assessment. Women who are judged likely to have ovarian cancer should be referred to the specialist gynaecological cancer team at the Cancer Centre, which should be responsible for their management.
- Surgery is the cornerstone of treatment but complete removal of the tumour is often impossible. Surgery should be carried out by gynaecological oncologists, who achieve better results than non-specialists.
- Most women with ovarian cancer are likely to benefit from chemotherapy, normally paclitaxel plus platinum. Second-line chemotherapy can lead to good responses, particularly in women who have had over 6 months' remission after a previous course of chemotherapy.

4 Endometrial Cancer

- Women with post-menopausal bleeding, however light, should be referred for investigation in out-patient rapid assessment clinics, where they should have transvaginal ultrasound to assess the thickness of the endometrium.
- If the endometrium is over 5mm thick, biopsy should be carried out, normally as an out-patient procedure. Diagnostic dilatation and curettage (D&C) should be used only when out-patient biopsy is inappropriate or unsuccessful.
- Transvaginal ultrasound should be used to assess the extent to which the tumour penetrates the myometrium. This information should be used in combination with biopsy results to identify women with low-risk disease who may be treated by hysterectomy at the Cancer Unit. Women with higher-risk tumours (about 60%) should be referred to the Cancer Centre.
- Surgery is appropriate for the majority of women with higher-risk disease, but radiotherapy may be used when the tumour is more advanced or surgery is contra-indicated.
- Progestogens should not be used for the treatment of endometrial cancer and there is no evidence of benefit from adjuvant chemotherapy.
- Recurrent endometrial cancer usually causes vaginal bleeding. Radiotherapy can be effective for treatment of women who have not had radiotherapy for primary disease.

5 Cervical Cancer

- Women with post-coital or persistent inter-menstrual bleeding, persistent vaginal discharge, or whose cervix looks or feels abnormal, should be referred without delay for assessment at a colposcopy clinic.
- In this situation, a cervical smear should not be taken because it may not detect cancer.
- Diagnosis of invasive cancer requires biopsy, which should be carried out at a Cancer Unit. Loop or cone biopsy may be sufficient for treatment when specialist pathology review finds no evidence of tumour at the margins.

- If biopsy results suggest deeper invasion, a higher stage tumour, or poor prognostic factors, the patient should be referred to the specialist gynaecological oncologist at a Cancer Centre.
- Early invasive cervical cancer is usually treated by radical hysterectomy. Adjuvant radiotherapy should be avoided if possible, but may be appropriate when adverse prognostic factors are discovered during or after surgery.
- Primary radiotherapy, normally using a combination of intracavity brachytherapy and external beam radiotherapy, is appropriate for women with later-stage cervical cancer. Concurrent chemotherapy using cisplatin should be considered.
- Sexual problems are common. Sexually active women should be offered specialist counselling to help them to cope with potential adverse effects.
- There is no reliable evidence that chemotherapy is beneficial for women with primary cervical cancer except when given concurrently with radiotherapy.

6 Vulval Cancer

- Women with symptoms that might be caused by vulval cancer, including persistent vulval itching or ulceration that fails to respond to local treatment, or visible abnormalities, should be referred to the lead gynaecologist at a Cancer Unit.
- If the diagnosis is confirmed by biopsy, the woman should be referred to the specialist gynaecological oncology team at a Cancer Centre for treatment.
- Surgery is the main form of treatment, even for very elderly women. It should be carried out by specialist gynaecological oncologists but other surgical specialities may also be involved.
- Other forms of treatment – chemotherapy or radiotherapy – may be appropriate for women with advanced disease.

7 Post-Treatment Support and Follow-Up

- Follow-up should be tailored to the needs and preferences of individual women.
- Patients and their GPs should be given full information about how they can access services for any problems or symptoms that may develop after treatment for gynaecological cancer.
- Women who have undergone radical treatment should be informed about possible long-term adverse effects such as lymphoedema, and should have a clear access route to specialist help if symptoms develop.
- There is no evidence that routine follow-up for asymptomatic women offers any benefit after curative treatment of endometrial cancer.
- Women who have no symptoms suggesting recurrence 3 years or more after curative treatment for cervical or endometrial cancer are unlikely to develop recurrence.
- Vaginal vault smears should not be used to detect recurrent disease.

8 Palliative Care

- Symptom management and social and psychological support should be provided by multiprofessional palliative care teams, which should work closely with GPs. These teams should liaise with other professionals who can offer counselling, spiritual guidance, dietary advice, and practical help.
- Women who want to remain at home should be given sufficient support to enable them to do so.



Cancer Services Audit 1996 & 2001

Ovary and Cervix

- Pain relief is very important and primary health care teams should ensure that their patients receive adequate treatment for pain. Many women with advanced gynaecological cancer suffer severe pain, but effective interventions are available and should be used.
- Any woman with uncontrolled symptoms should be referred without delay to a specialist in palliative care. Specialist palliative care should be available on a 24-hour basis for all women with advanced gynaecological cancer, both in hospital and in the community. There should be local arrangements to ensure continuity of care.
- Women with advanced disease may suffer chronic intestinal obstruction, pain, nausea, vomiting, constipation and bleeding. These problems are usually managed by medical means, but palliative surgery may be appropriate for some patients.

APPENDIX C

Guidelines for the Management of Gynaecological Cancer N. Ireland⁵, 2002 (Summary of guidelines)

1 Quality

- A regional audit of the management of all patients with gynaecological cancer should be conducted following implementation of these guidelines.
- Members of the gynaecological cancer multidisciplinary teams (MDTs) must ensure their training and continuing professional development (CPD) equips them with the skills to promote and maintain a quality service.

2 Initial Presentation/Referral

- Referral guidance that provides clear and concise information on when and where to refer patients with suspected gynaecological cancer should be produced and disseminated to all GPs.
- Gynaecological cancer should be included as a topic for CPD aimed at primary care professionals and family planning doctors.

3 Diagnosis

- Magnetic resonance (MR) scanners should be acquired for the Cancer Centre and the Cancer Units, to reduce waiting times for this service.
- Appropriate training and CPD should be available for radiologists providing a service to gynaecological oncology.
- Examination results to be shared with patients as quickly as possible.
- Pathologists at the Cancer Centre and Cancer Units should share information. When a second opinion is required this must be facilitated as quickly as possible.
- When gynaecological oncology is not the main interest of the pathologist examining specimens of malignant tissue at a Cancer Unit, a second opinion should be sought from a pathologist with expertise in gynaecological oncology.
- A Quality Control Group should be established to oversee regional audit of gynaecological pathology and to ensure a quality service.

4 Multidisciplinary Assessment

- Regular MDT meetings should take place for gynaecological oncology at the Cancer Units and Cancer Centre.
- The MDTs at the Cancer Centre and Cancer Units should include a specialist in palliative care.
- The Lead Unit Clinician should attend the MDT meetings at the Cancer Centre.

5 Ovarian Cancer

- Following initial presentation and investigation, all women with suspected ovarian cancer must be referred to the Lead Unit Clinician at a Cancer Unit for management. If investigations indicate a fixed tumour or an RMI>200 then patients should be referred to the Cancer Centre for treatment.
- Women assessed as having a mobile Stage 1 ovarian tumour with an RMI<200 may have initial surgical intervention at a Cancer Unit by the Lead Unit Clinician. If the diagnosis confirms malignancy patients must be referred to the Cancer Centre for consideration of adjuvant therapy.
- Women under age 35 years whose investigations suggest a diagnosis of ovarian cancer should be referred to the Cancer Centre for treatment.
- Chemotherapeutic management regimes for ovarian cancers should all be determined by the medical oncologists at the Cancer Centre and administered under their supervision.
- Continuous regional audit of the management of ovarian cancer must be conducted. Details of all patients diagnosed with ovarian malignancy must be included in a regional database.
- Lead Unit Clinicians in gynaecological oncology in Cancer Units and those in the Cancer Centre should work as a team to develop common protocols.

6 Endometrial Cancer

- Early endometrial disease may be treated at a Cancer Unit by the designated Lead Unit Clinician.
- Details of all cases of endometrial cancer, regardless of stage of disease or where initial treatment is conducted, should be included in a regional database. This will facilitate audit and, where appropriate, patient inclusion into clinical trials.
- Patients with advanced disease should be referred to and managed at the Cancer Centre.

7 Cervical Cancer

- All women diagnosed with cervical cancer must be treated at the Cancer Centre.

8 Vulval/Vaginal Cancer

- All women diagnosed with vulval or vaginal cancer must be treated at the Cancer Centre.

9 Specialist Nursing

- The role of the specialist nurse should be further developed by encouraging attendance at accredited courses and resources should be made available to facilitate this. The skills of nurses with specialised training should be fully utilised by the Cancer Centre and Cancer Units.

10 Palliative Care

- Referral guidelines for Specialised Palliative Care Services should be developed at Health and Social Services Board level.

11 Lymphoedema Services

- Regional audit of all lymphoedema services should be carried out and service provision should be planned on the basis of audit findings.

- All staff providing a lymphodema service should be appropriately trained.
- The awareness of the relevance and management potential of lymphodema treatments should be encouraged among health care professionals.
- A dedicated multiprofessional lymphodema clinic should be available to patients at the Cancer Centre and Cancer Unit levels and the professionals involved in these clinics should take part in audit and standard setting.

12 Psychosexual Services

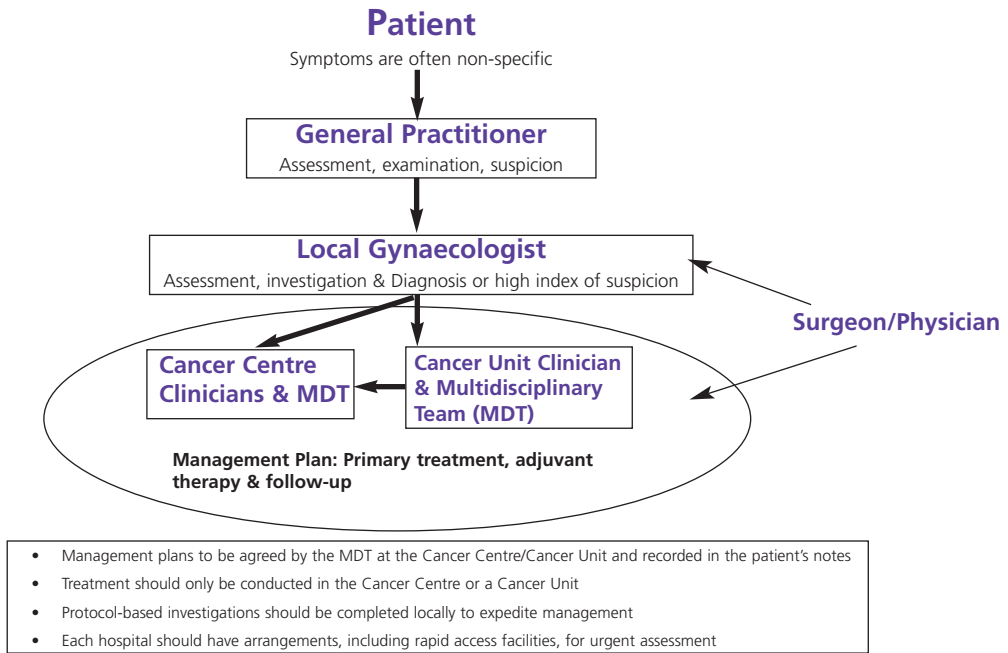
- Attendance at accredited courses in psychosexual counselling should be encouraged for doctors likely to manage patients with gynaecological cancer.
- A specialist regional psychosexual counselling service should be established at the Cancer Centre.

13 Psychological Support

- All patients diagnosed with gynaecological cancer should be made aware of the support services available and given appropriate literature.
- Counsellors from the voluntary sector should be invited to participate in multidisciplinary team activities as appropriate.

APPENDIX D

GYNAECOLOGICAL CANCER GUIDANCE: A PATIENT'S PATHWAY



TYPICAL PRESENTATION, DIAGNOSIS AND TREATMENT

	OVARY	CERVIX	VULVA/VAGINA	UTERUS
Symptoms	Abdominal distension or discomfort	Recurrent postcoital, latermenstrual, or post-menopausal bleeding	Vulval itch or discomfort especially in elderly	Post menopausal or intermenstrual bleeding. Abnormal bleeding for 4 weeks after stopping HRT
Signs	Suspicious pelvic mass Suspicious mass on USS	Suspicious lesion on cervix especially if hard, irregular or ulcerated	Suspicious lesion on vulva, especially if ulcerated.	

REFER TO CONSULTANT GYNAECOLOGIST FOR INVESTIGATION/DIAGNOSIS

Investigation and Diagnosis	USS/CTCs 125 Risk of Malignancy Index (RMI) calculated	Cervical Biopsy MRI	Biopsy CT	Hysteroscopy/Biopsy MRI
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REFER PATIENT TO THE CANCER CENTRE OF CANCER UNIT FOR AGREED MDT MANAGEMENT

MULTIDISCIPLINARY TEAM MANAGEMENT eg Staging of Disease, Nature & Location of Treatment, Adjuvant Therapy, Patient Registration, Follow-up

Primary Treatment	CANCER UNIT Surgery CANCER CENTRE Radical/Surgery +/- Chemotherapy CANCER CENTRE ONLY	Radical Hysterectomy or Chemoradiation CANCER CENTRE ONLY	Radical vulvectomy CANCER UNIT	Hysterectomy - DSO CANCER CENTRE Hysterectomy - DSO +/- Radiotherapy
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CONTINUING CARE AND FOLLOW-UP SHOULD BE AGREED BY THE CANCER CENTRE AND CANCER UNITS MDT.

	SPECIALIST PALLIATIVE CARE	PSYCHOSEXUAL COUNSELLING
Continuing Care	<p>All patients should receive information and literature on community-based support. Most palliative care provided by primary care team. Refer as appropriate at any stage for psychosexual counselling or specialist palliative care.</p> <ul style="list-style-type: none"> • Physical uncontrolled pain, intestinal obstruction, lymphoedema, drug side effects • Psychological complex emotional issues • Rehabilitation 	<ul style="list-style-type: none"> • Social complex family issues • Spiritual: loss of hope, cultural or religious issues • Respite Care • Terminal Care • Severe adjustment reaction to the diagnosis of cancer or the effect of treatment • Physical complications affect normal sexual function • Psychosexual difficulties directly or indirectly related to disease

Appendix E

FIGO staging of ovarian cancer¹⁸

(TNM system included for comparison)

FIGO stage	TNM Equivalent
I tumour limited to ovaries (one or both)	T1 N0 M0
IA tumour limited to one ovary, capsule intact, no tumour on ovarian surface, no malignant cells in ascites or peritoneal washings	T1a N0 M0
IB tumour limited to both ovaries, capsules intact, no tumour on ovarian surface, no malignant cells in ascites or peritoneal washings	T1b N0 M0
IC tumour limited to one or both ovaries with any of the following: capsule ruptured, tumour on ovarian surface, malignant cells in ascites or peritoneal washings.	T1c N0 M0
II tumour limited to one or both ovaries with pelvic extension and /or implants	T2 N0 M0
IIA extension and /or implants on uterus and/or tube(s). No malignant cells in ascites or peritoneal washings.	T2a N0 M0
IIB extension to and /or implants on other pelvic tissues. No malignant cells in ascites or peritoneal washings.	T2b N0 M0
IIC pelvic extension and/or implants with malignant cells in ascites or peritoneal washings.	T2c N0 M0
III tumour involves one or both ovaries with microscopically confirmed peritoneal metastases outside the pelvis.	T3 N0 M0
IIIA microscopically confirmed peritoneal metastases beyond pelvis (no macroscopic tumour)	T3a N0 M0
IIIB macroscopic peritoneal metastases beyond pelvis 2cm or less in greatest diameter.	T3b N0 M0
IIIC peritoneal metastases beyond pelvis more than 2cm in greatest diameter and/or regional lymph node metastases.	T3c N0 M0 any T N1 M0
IV distant metastases	any T any N M1

APPENDIX F

FIGO staging for cervical cancer¹⁸

(TNM system included for comparison)

FIGO stage	TNM equivalent
I cervical carcinoma confined to the uterus	T1 N0 M0
IA invasive carcinoma diagnosed only by microscopy (not visible)	T1a N0 M0
IA1 invasion no greater than 3mm in depth and 7.0mm or less in horizontal spread	T1a1 N0 M0
IA2 invasion more than 3mm and not more than 5mm in depth with a horizontal spread of 7.0mm or less.	T1a2 N0 M0
IB clinically visible lesion confined to the cervix or microscopic lesion greater than IA2/T1a2	T1b N0 M0
IB1 clinically visible lesion 4cm or less in greatest dimension	T1b1 N0 M0
IB2 clinically visible lesion more than 4cm in greatest dimension	T1b2 N0 M0
II cervical carcinoma invades beyond the uterus but not to the pelvic wall or lower third of vagina	T2 N0 M0
IIA tumour without parametrial involvement	T2a N0 M0
IIB tumour with parametrial involvement	T2b N0 M0
III tumour extend to pelvic wall and /or involves lower third of vagina, and /or causes hydronephrosis or defunctioning kidney	T3 N0 M0
IIIA tumour involves lower third of vagina, no extension to pelvic wall	T3a N0 M0
IIIB tumour extends to pelvic wall and/or causes hydronephrosis or defunctioning kidney.	T1 N1 M0 T2 N1 M0 T3a N1 M0 T3b any N M0
IVA tumour invades mucosa of bladder or rectum, and /or extends beyond the true pelvis.	T4 any N M0
IVB distant metastases	any T any N M1

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