TARGET
OVARIAN
CANCER
For every woman. **For life.**

Target Ovarian Cancer
30 Angel Gate
London EC1V 2PT

www.targetovarian.org.uk

info@targetovarian.org.uk
tel 020 7923 5470

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The Target Ovarian Cancer **Pathfinder Study**

First Results June 2009

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> “Ovarian cancer is the fourth most common cause of cancer death in women, with low survival rates that have changed little over the past thirty years. There is so much that can be done to improve this situation and to give women with ovarian cancer across the UK the highest possible quality of life.”

Professor Sir Kenneth Calman[1] PhD MD FRCS FRCP
Patron, Target Ovarian Cancer

> “Ovarian cancer is not a silent killer.
> It’s just not being heard.”

Dr Willie Hamilton, Academic GP, Universiy of Bristol and
Target Ovarian Cancer Pathfinder Study Advisory Panel Member

Target Ovarian Cancer would like to thank everyone who has so far agreed to take part in this study.

Names and have been changed and models used in order to protect identities but the quotes used are from real people.

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Foreword

Ovarian cancer is the fourth most common cause of death from cancer in women in the UK. Each year, 6,800 women are diagnosed with ovarian cancer and each year we lose 4,500 women to this disease.

The EUROCARE-4 study on cancer survival covering the period up to 2002, reported that England had the worst five-year survival rate for ovarian cancer at 30.2%, with the combined figures for the UK only marginally better. This compared to the European average of 36.5%[2].

Over the past thirty years, we have, thankfully, seen significant progress in cancer survival generally in the UK and in particular cancers, for example breast cancer where five-year survival rates have increased from 50% to 80%[3]. In the last decade in the UK there have been considerable advances in the delivery of cancer services. Despite this we are yet to see significant change in five-year survival rates for ovarian cancer, although recent data indicate that one-year survival rates are improving[4].

Typically, most women are diagnosed with late stage disease when the cancer has already spread and there is a significant risk of recurrence and resistance to therapy. It is vital that we strive to secure the best possible outcomes for women with ovarian cancer in the UK, not only matching progress in other countries but ultimately emulating the successes including, crucially, the funding[5], achieved in breast cancer.

The Target Ovarian Cancer Pathfinder Study, for the first time, is bringing all those involved in the patient pathway together to map the experiences of those living and working with ovarian cancer across the UK. It aims to identify clear gaps in knowledge, infrastructure, funding and need with regard to the care and treatment of women with ovarian cancer in the UK and to seek opportunities to improve outcomes not only in survival but also in quality of life and women's experiences of care.

Target Ovarian Cancer will work collaboratively with others both nationally and internationally to bring the following actions to bear so that it fulfils its aim of a long and good life for every woman diagnosed with ovarian cancer.

Professor Robert Haward
Chairman
Target Ovarian Cancer Pathfinder Study Advisory Panel

Annwen Jones
Chief Executive
Target Ovarian Cancer

This report summarises the first results of the Target Ovarian Cancer Pathfinder Study which will continue over several years, and sets out the following actions identified by Target Ovarian Cancer for making progress:

- **Call for a national symptoms awareness campaign targeted at both women and GPs**
- **Help GPs diagnose ovarian cancer earlier**
- **Make sure all women with ovarian cancer have access to good quality emotional and practical support**
- **Champion the role of the Clinical Nurse Specialist**
- **Improve access to clinical trials**
- **Monitor and where appropriate support current trials and audits in gynaecological cancer**
- **Mobilise new funding for ovarian cancer research**
- **Undertake international benchmarking**

> “If people knew about ovarian cancer and understood it a bit more, like breast cancer, they would go to the doctors more empowered and make the doctor think about this so they have the chance to rule it out. I'd rather it be ruled out by a simple examination than not discussed or thought of at all.”

Specialist Nurse, Scotland

The Advisory Panel

Chairman

Professor Robert Haward
Emeritus Professor of Cancer Studies, University of Leeds and Associate Director of the National Cancer Research Network

Membership

Joanna Barker Chair of the Board of Trustees, Target Ovarian Cancer
Dr James Brenton Cambridge Research Institute, University of Cambridge
Professor Hilary Calvert Clinical Director, Northern Institute of Cancer Research, University of Newcastle
Dr Willie Hamilton
Academic GP, University of Bristol
Annwen Jones
Chief Executive, Target Ovarian Cancer
Professor Jonathan Ledermann Chairman, National Cancer Research Institute Ovarian Group, University College London
Professor David Luesley
President, British Gynaecological Cancer Society, University of Birmingham
Professor Glenn McClugagge
President, British Association of Gynaecological Pathologists, University of Belfast
Mr Andy Nordin Clinical Advisor for Gynaecology to the NHS Cancer Improvement Team and Cancer Action Team, East Kent Hospitals University Trust
Mrs Lisa Peck
Interim President, National Forum of Gynaecological Oncology Nurses, Gloucestershire Oncology Centre, Three Counties Cancer Network
Lindy Waldron Patient representative
Howard Webber Relative representative
Sandra Woodward Patient representive (till 05/09)

> “Anything that helps I am happy to do it... if one woman has a chance of a prompt diagnosis that is good enough for me. I am able, because I am one of the survivors, and I want to tell people it's not all bad news.”

Lindy Waldron, diagnosed with late stage ovarian cancer in 2004, Target Ovarian Cancer Pathfinder Study Advisory Panel Member

The Target Ovarian Cancer Pathfinder Study Outline

This study represents a unique initiative within ovarian cancer – an **ongoing** commitment to mapping the experiences of those living or working with ovarian cancer. This is in order to identify the challenges and opportunities to improve the life chances and quality of life for the 6,800 women diagnosed with ovarian cancer in the UK each year.

In order to inform the thinking behind the Target Ovarian Cancer Pathfinder Study, a range of in-depth research was carried out with women, Clinical Nurse Specialists, Clinicians (Surgeons and Oncologists) and Researchers around the UK. Findings were presented to the Advisory Panel at their first meeting in February 2009.

Led by the independent chair, Professor Robert Haward, Emeritus Professor of Cancer Studies at Leeds University, and Associate Director of the National Cancer Research Network, the panel then shaped the outline of the study, and worked closely with Target Ovarian Cancer to develop the individual components. The research company Synovate undertook all phases of the research work unless otherwise specified.

The results reported here, represent the findings from the qualitative work (Oct/Nov 2008) and survey data (April/May 2009). The Advisory Panel has reviewed the results and identified key actions, opportunities and challenges ahead. This has helped us define the Future Directions section of this report. We will continue to canvass the views of women with ovarian cancer and the Clinical Nurse Specialists over the coming months as we develop the next phase of work in all areas.

Elements of Pathfinder Study:	Work undertaken and frst results based on:
Women with ovarian cancer	Initial in-depth interviews were undertaken with 19 women. Findings informed the development of the survey tool which was piloted with 6 women. 132 interviews conducted (online and via post) with a free found sample of UK women diagnosed with ovarian cancer.[67]
Women in the general public	1000 interviews conducted by telephone amongst a nationally representative sample of adult women living in the UK. This component used the first site-specific validated cancer awareness tool [8] – the Ovarian Cancer Awareness Measurement Survey Instrument developed under the National Awareness and Early Diagnosis Initiative. The Ovarian Cancer Awareness Measurement Survey Instrument was developed by Ovarian Cancer Action, The Eve Appeal, Ovacome and Target Ovarian Cancer. It is based on a generic CAM developed by Cancer Research UK, University College London, Kings College London and Oxford University in 2007-8.
General Practitioners	400 interviews conducted online amongst a nationally representative sample of UK GPs.
Clinical Nurse Specialists	Initial in-depth interviews were undertaken with 8 CNSs and one group discussion (7 CNSs). Subsequently 57 interviews were conducted online with a free found sample of Gynaecological Oncology Clinical Nurse Specialists[9].
Clinicians	In-depth interviews with 5 surgeons and oncologists from selected centres around the UK. Given that a number of audits are currently taking place in this area, no further work was commissioned.
Researchers	In-depth interviews with 10 researchers from 8 major research centres, and representing the range of research interest, including those who work as Clinician Researchers.
International Benchmarking	The panel has defined the terms for an international benchmarking study which is being commissioned by Target Ovarian Cancer and will report in Spring 2010.

The journey begins
The route to diagnosis

The path to diagnosis is often not straightforward from a woman's perspective. Many factors can lead to delays in diagnosis with emotional and physical consequences for the women concerned.

Most women know little, if anything, about ovarian cancer prior to their diagnosis

The majority of women with ovarian cancer[6,10] had heard of ovarian cancer but did not know anything about the disease (56%), with only a third of women saying they knew a bit about it prior to their diagnosis. Just over one in ten (13%) of the women had a close relative (mother daughter, sister, aunt, cousin, grandmother) with ovarian cancer.

Amongst women in the general population[8,11], knowledge of the key frequent and persistent symptoms of ovarian cancer is very low, with just one in four spontaneously identifying pain in the abdomen as a potential symptom of ovarian cancer, one in ten identifying pain in the pelvis, or bloating (9%), and almost no one mentioning increased abdominal size (3%), difficulty eating (1%) or feeling full (1%). These symptoms, when present on most days, are now accepted as indicating the possibility of ovarian cancer as a diagnosis[12].

Similarly, knowledge of the two most important risk factors (age and family history) was very low. When asked what factors might be important in increasing the risk of the disease, just 15% mentioned a family history of ovarian cancer, and only 3% mentioned age. When people were asked which groups, out of certain age brackets, were most likely to develop ovarian cancer, 65% said it was unrelated to age.

Most patients delay seeing their GP

Only 2% of women with ovarian cancer who were surveyed said they did not have symptoms prior to their diagnosis. For the 98% who had symptoms, 88% visited their GP, but often after some time (43% within one month; 25% between one and three months; 21% more than three months; 11% not at all). This is in sharp contrast to women in the general population where just 2% believe they would delay more than one month, if they thought they had a symptom that could be ovarian cancer.

Symptoms most commonly experienced by women with ovarian cancer surveyed included persistent bloating (55%), increased abdominal size on most days (53%), passing more urine than usual (39%), extreme fatigue (40%), persistent pain in abdomen (36%), changes in bowel habit (35%), feeling full persistently (33%) and difficulty eating on most days (31%).

Roughly two thirds of women described themselves as very or fairly concerned about their symptoms, with one third either not very or not at all concerned. Those who described themselves as very concerned were more likely to have waited over six months for a diagnosis.

> "I'd been having symptoms, but I just thought it was middle age, going through the change, because I was going to the toilet a lot and getting full very quickly"

Mary (in remission), West Midlands

Women face difficult routes to diagnosis

Nearly a third of women (28%) were fortunate in only visiting their GP once before being referred to an appropriate specialist or urgent tests. A quarter received their diagnosis within one month of their first visit.

For the remaining women the path was not so smooth, with repeated visits to the GP: over a third visited between three and five times, one in ten visited between six and ten times and one in twenty went more than ten times. A quarter were referred to non-gynaecological specialists. For over one in six, it was between three and six months between first visiting their GP and getting their diagnosis, and for almost a third, the period was longer than six months.

> *"I was quite convinced there was something wrong but I was actually told I was in grave danger of becoming extremely neurotic. I was even asked if I would like to go on anti depressants."*
> *Joan (in remission), South West.*

Misdiagnosis and frustration are not uncommon

For the vast majority of women until the point of diagnosis, the GP they saw most frequently did not suggest cancer as a diagnosis. For those who were diagnosed with other conditions irritable bowel syndrome (IBS) featured most commonly (28%), followed by urinary infections (18%), diverticulitis (9%) and menopausal problems (10%). Those with suspected IBS were more likely to get a diagnosis after six months than before.

Nearly two thirds felt that their GP did not take their concerns very seriously and a quarter rated the care they got from their GP as poor or very poor. When being given the diagnosis, those who had waited more than six months to get to that point were more likely to say they felt angry.

98% of women with ovarian cancer think it is a priority for Target Ovarian Cancer to improve levels of awareness amongst women in the general population. Almost all the Clinical Nurse Specialists felt the same

Choosing the right road
Challenges & opportunities in Primary Care

Faced with potentially hundreds of women each year with symptoms such as bloating/abdominal distension or difficulty eating, GPs face an enormous challenge in recognising when ovarian cancer should be considered and women referred on urgently. On average they will see one case diagnosed every five years

Few GPs are aware of new messaging about symptoms

Key messages on ovarian cancer for health professionals were published by the Department of Health in February 2009[13]. They bring up to date the thinking on symptoms and risk factors, and in particular highlight the importance of certain frequent and persistent symptoms. However, awareness of these new messages, and of the importance of frequency and persistency of key symptoms is clearly low at the time of the interviews (May 2009).

When prompted just 24% of GPs were aware of the Department of Health's Key Messages

- Just 51% correctly identified increased abdominal size as the most important feature in relation to ovarian cancer. Pain in the pelvis is mentioned by a quarter, but symptoms such as difficulty eating or feeling full are only mentioned by less than 2% as key
- 69% of GPs were not aware that women who have ovarian cancer are more likely to experience very frequent, sudden onset and persistent symptoms than women with Irritable Bowel Syndrome (IBS) or other benign conditions
- 61% of GPs were not aware of the importance of family history of ovarian cancer on the father's side of the family and 23% of male GPs were not aware of the importance of a family history of breast cancer (4% amongst females). 62% of GPs were not aware that women of Ashkenazi Jewish descent are more likely to develop ovarian cancer

> *"GPs quite clearly still believe what all the medical text books used to say that there were no symptoms until late stage. There is a real danger of a self fulfilling prophecy. What we absolutely have to get across is that ovarian cancer is not a silent killer. It is just not being heard."*

Dr Willie Hamilton, GP and Target Ovarian Cancer Pathfinder Study Advisory Panel Member

Almost all GPs (96%) believe ovarian cancer is 'a silent killer', with almost 8 in 10 saying symptoms present only in late stages

GPs, however, are positive about tools to help them decide whether or not to refer a woman for suspected ovarian cancer

Almost all recognise that women experience delays in their diagnosis and only 5% say they had no need for more support in deciding whether or not to refer. Almost two thirds (62%) will welcome the new NICE guidance (National Institute for Health and Clinical Excellence - due in 2011) on the recognition and initial management of ovarian cancer in terms of helping them decide who to refer. Access to family history tools[14] (53%) and symptom diaries[15] (42%) would also be welcome.

100% of GPs want women, if they are concerned about having ovarian cancer, to discuss it with them

Where GPs suspect ovarian cancer it appears they are on the whole examining women, conducting initial tests and referring them

> *"I know it's a difficult thing to diagnose, but it should have crossed their minds at some point that this could be ovarian cancer."*
> *Constance (who has a terminal diagnosis), West Midlands.*

In the last year over eight in ten GPs surveyed had made a referral for suspected ovarian cancer, with an average of two referrals per GP in the last year. In connection with the last woman they had referred on for suspected ovarian cancer:

- 93% performed an abdominal examination
- 68% had performed an internal examination (this is much more likely to have been performed by a female GP)
- 65% had ordered or taken blood for a CA125 test
- 46% had ordered a Transvaginal Ultrasound scan (TVU)

By and large GPs have good access to non-urgent diagnostic tools such as CA125 and Transvaginal Ultrasound (TVU)

CA125 blood test results are mainly back within 2 weeks (84%) with longer waits for non urgent abdominal or TVU scans (one third wait more than a month). The study with women who have ovarian cancer shows a different picture. Only 70% report having had an abdominal examination, 26% saying they had an internal examination and 29% reporting blood tests and/or scans for ovarian cancer. This along with the supporting evidence cited earlier suggests that there are clearly a proportion of cases where ovarian cancer is not being considered soon enough.

But access to urgent Transvaginal Ultrasound scans is not automatic

Over half of all GPs do not have access to a facility to obtain an urgent TVU, yet almost eight in ten GPs would feel confident using such a facility. This leads to a double gatekeeper system in a proportion of cases which inevitably adds time to the point of diagnosis.

On the road to
Diagnosis & treatment

> “The nurse was lovely, really nice, you feel very comfortable… you felt like you were a person and not just a statistic… She spoke to me and gave me her card, and said I could ring her anytime I wanted to.”

Sarah (in remission), South West

Experiences of being diagnosed with ovarian cancer can vary enormously. Often it comes as a complete shock. Fifty per cent of the women surveyed had no idea they may have the disease. Of the 50% who were aware they may have ovarian cancer, 25% were told by the doctor referring them, 24% by the health professional doing the test and 22% read information which suggested they might have the disease.

How and where women are told they have ovarian cancer is important

Women should have privacy and the chance to have a close family member or nurse with them and be given the details of someone they can contact after diagnosis.

From the study, a substantial minority felt that they were not given enough privacy at this time (four in ten), and were not given, or cannot remember being given, the choice to have a family member present. Women who were diagnosed with stage 3 or 4 ovarian cancer were more likely to have their diagnosis given to them on a hospital ward, than women with earlier stage disease. From our initial work[16] we know this can be distressing particularly when others on the ward then immediately discuss it with them.

At the time when women are receiving the bombshell about their diagnosis they are often left without contact details of those who can help. Nearly three quarters were not given or cannot remember being given clear written information about their diagnosis and just under a half were not given the contact details of their Clinical Nurse Specialist. Indeed over a third were not given any contact details at this point.

Despite this, the period in which women undergo surgery and/or chemotherapy is one in which they feel very satisfied with the care they receive

Confidence in both doctors and nurses during surgery and chemotherapy was very high, with just a tiny number expressing concern that their care was poor or very poor.

> *“I’ve been in hospital 18 times in 6 years…it’s really superb and I can count on the fingers of one hand where I’ve encountered staff who have been less than wonderful.”*
> *Rita (being treated for recurrence), North of England*

Access to clinical trials is patchy

The majority of women were not offered access to a clinical trial (61%). Work undertaken with clinicians and researchers point to the high levels of bureaucracy associated with opening trials in lots of hospitals around the country, and the extra time needed to discuss trials with patients as possible reasons for this figure. It appears that there are quite large areas within the UK where there are no trial centres recruiting patients with ovarian cancer, limiting the opportunities available to women to receive their care within the context of a clinical trial, and thus potentially benefitting from a new treatment or more generally from the modern protocols for treatment at participating trial centres.

For those women who either ask to participate in a trial or were asked to join, most felt that they were given enough information to make a decision. For those who decided not to participate, the range of reasons were widely spread – from not enough benefit for them, uncertainty about receiving a new drug, to the strain placed on patient/family members in terms of handling increased visits. No one in this group said that they did not understand the information that had been given to them.

Above all, women say that survival (66%) is one of the most important factors in choosing a chemotherapy drug[17]

It was closely followed by prolonging life (57%) and a recommendation by their doctor (57%). Factors such as quality of life (28%) or side effects (16%) featured less frequently.

All women who had chemotherapy experienced side effects. Tiredness, hair thinning or hair loss, feeling or being sick and tingling or numbness in the hands or feet were the most common. In general the majority of women had been informed about what to expect.

Guiding the way
Clinical Nurse Specialists (CNS)

Gynaecological Cancer Clinical Nurse Specialists (CNS) play a vitally important role in caring for women with ovarian cancer. As their 'key worker' they act as a patient advocate, helping to ensure coordinated care pathways, and are usually the main point of contact for patients. From the patient perspective they are a vital potential source of information and emotional and practical support.

Almost all women have access to a CNS (84%)[10], but there appears to be considerable variation in terms of the workloads nurses undertake and the resources available to them

Two thirds of CNSs surveyed were 'sole operators'[18]. This does not automatically mean high workloads, but it does however impact the ability to provide cover for absences. For over 60% of sole operators there is no cover available at all. In other places, some telephone cover is provided. Over four in ten nurses surveyed do not receive or do not have access to formal clinical supervision where they can discuss difficult emotional issues. Those nurses who receive such support rate it highly.

> *"I have supervision with a clinical psychologist, it's absolutely key. It helps me cope better, it's constructive, it gives me ideas and a chance to reflect."*
> *Specialist Nurse, South West*

Reports varied as to the number of new gynaecological cancer patients seen each year by each CNS – with a broad estimate of 140 amongst those who responded. This may reflect the nature of the group who chose to participate in this survey, but differs considerably from the average figure as highlighted in the 2008 English Specialist Nursing workforce census (average new gynaecological cancer patients per year in England = 92). Through the course of the study and in discussions it is very clear that, in some instances, individual workloads are considerably higher placing a strain on those in post.

With on average 30%-40% of their patients having ovarian cancer, there is a heavy workload involved with each individual case. Typically there are multiple visits to hospitals for treatment both on initial presentation and for those who go on to relapse. Symptom control in ovarian cancer can also require repeated visits.

Half of all nurses surveyed believed that if their centre/unit employed more Gynaecological Cancer CNSs, patients with ovarian cancer would receive better care. Target Ovarian Cancer will undertake further work in this area to map as precisely as possible the current levels of provision and where inequalities exist.

Protecting key elements of the CNS role is vital to improving services

In-depth work amongst nurses highlighted the challenges of assessing and demonstrating the value of the CNS role, because much of the care they deliver is around emotional support. This is a challenge because NHS Trusts assess service performance against harder indicators around patient throughput, and it is difficult for nurses to make a direct link between their activities and the achievements of these targets. In addition our survey found that the majority of nurses were often asked to take on non-specialist nursing duties (56%). In particular these appear to be administrative in nature, and almost all nurses said that they often carried out duties that could be dealt with by an administrator. Most (88%) nurses surveyed said they would like Target Ovarian Cancer to campaign to protect the key worker role in order to secure or increase contact time with patients.

> "Our role is broadening in that there is more and more you are expected to take on. I know we should be taking on only complex cases but ovarian cancer patients are complex cases. If you are practicing on your own you have to be very careful about how much you take on because it would be very easy to be overwhelmed."

Specialist Nurse, South East

> *"It's not in my job description that it's up to me to ensure everyone gets their appointments on time and everybody is up to speed.. so it's chasing and photocopying, checking appointments are made so people aren't missed.. Those type of things are definitely not part of my job."*
> *Specialist Nurse, Northern Ireland*

Multi Disciplinary Teams are valued by CNS

In particular nurses value the chance to be the patient's advocate, to participate in decision-making and to provide continuity of care for the patient, with a planned coordinated approach. Nurses also highly value the informal support they get from their CNS colleagues, even when they are sole operators.

Time and resources to keep up to date with developments are in short supply

Only just over a quarter of nurses surveyed felt they had enough time to keep up to date with the latest developments in treatment for ovarian cancer, and three in ten were not able to claim back most or all of their travel or course fees in relation to their continued professional development. Most nurses are very positive about the roles Target Ovarian Cancer can play in terms of helping them develop new opportunities and resources for patients, and helping them to share good practice.

Clinicians' viewpoints

Clinicians (oncologists and surgeons) shared their views by means of structured in-depth interviews. In the wider community there are a number of audits and surveys taking place, and the Advisory Panel felt there should not be any further work done until results from these were available.[19]

Improving referrals

As with all participating groups, clinicians identify the initial diagnosis and referral pathway as one of the key weaknesses in the current ovarian cancer patient journey. In terms of GP awareness and diagnosis, they see the move towards more initial testing in community settings as a key opportunity to enable GPs to refer more effectively using ultrasound and CA125 blood tests.

They also see value in improving referral pathways within secondary (hospital) care, as a way of speeding up the diagnostic process, and preventing women being sent back out to their GP after an incorrect referral. Some clinicians have successfully improved referrals within their own Trusts by building personal links with consultants and surgeons in related specialisms.

Health professionals identify a number of recent and potentially beneficial developments around ovarian cancer treatment

Clinicians and nurses commented on the increasingly aggressive approach treatment is taking in terms of chemotherapy for women and note that there are potential developments which will impact on care, for example intraperitoneal chemotherapy.

In particular, the move towards individualised treatments as opposed to a 'one size fits all' approach is beginning to gather pace. As more is understood, tailored treatments are being developed for some of the complex, different subtypes of the disease. This is already evidenced in the progress being made in the development of PARP inhibitors for the treatment of women with ovarian cancer who carry one of the defective BRCA genes[20].

Surgeons say they also see an opportunity for more radical initial surgery and increased use of surgery for women who have recurrences of their cancer, supported by an evidence base.

However there are concerns about constraining factors for these future developments. In terms of individualised treatments, the focus is on the availability of pathology and diagnostic services, and the future funding of increasingly targeted treatments within what is already seen by the pharmaceutical industry as a 'small market cancer'. For those keen to take up the gauntlet of more radical surgery, clinicians are concerned about the capacity of the NHS to deliver given the requirements for multi-disciplinary surgical teams, additional training and associated support for perioperative care.

Multi Disciplinary Teams are highly valued

Clinicians are certain this has a positive impact on patients in addition to improved confidence, trust and respect amongst the team.

There are, however, management pressures to reduce the size or length of MDT meetings because of the amount of resources required. Potentially this means there is not enough time to discuss all cases as deeply as the teams would like.

> *"The team works really well. We get the scans and other diagnostics organised and discuss on a Tuesday. When we see patients on a Wednesday we already have a treatment plan, and so it cuts two to three weeks off the patient pathway."*
> *Ovarian Cancer Clinician, South East England.*

Clinicians are also increasingly feeling pressure on time and resources

Lack of resources encompasses a wide range of issues, including a shortage of clinicians or lack of clinician time, too few Clinical Nurse Specialists, and a lack of administrative support. They also feel affected by the Trusts' focus on targets and 'throughputs' of patients. This impacts on time spent with patients, particularly around the time of diagnosis, and their capacity to recruit patients to clinical trials.

They stress the importance of making ovarian cancer an attractive specialism for new consultants

Key to this would be supplying more training and development opportunities, which would also ensure they and their colleagues are able to provide the best possible treatments. They feel the NHS should have closer links with the Royal Colleges to help deliver this.

> "I think one problem is that it's myself and one colleague that identify suitable patients (for trials) and if we're too busy they tend to slip through, so we need more resource to get us back to strength... We have trouble attracting people (to our region)."

Ovarian Cancer Surgeon, Scotland

Finding ‘my new normal’

Just as women react differently to being diagnosed with ovarian cancer, response to the completion of active treatment is diverse. On the one hand some women want to get on with their lives and try to put the experience behind them as best they can. At the other end of the spectrum some women tell us they have a strong need for continued support, the absence of which can create a sense of feeling bereft and abandoned, although they also have low expectations about what the NHS should be able to deliver.

Emotional support needs are often not met

Some three quarters of women surveyed felt they have needed some form of emotional support since their diagnosis. Of this group a third actively sought out support, a third were offered emotional support and a further third neither sought help nor were offered help. Those who had waited longest for their diagnosis (over two years) appeared most likely to need it.

Health professionals and support groups have an important role to play

44% of women found help via a CNS, 30% via a support group, 23% via their GP and 11% through formal counselling services. Just 6% sought help via a telephone helpline. Of these sources of support, Clinical Nurse Specialists (26%), Support Groups (9%) and GPs (9%) were identified as having given the most emotional support.

Relationships with their primary care team can be affected by the woman’s experience of diagnosis.

“I have to say that since I was diagnosed, although it had to take me to be practically dying and dead, but since then they (GPs) have been fantastic, very supportive and I feel like saying ‘Well why the hell weren’t you like this before?”
Paula (in remission), Northern Ireland

This period immediately after coming off treatment is also recognised by the Clinical Nurse Specialists as a period of instability.

“When patients finish their treatment that can be a big void for patients and they feel lost. I would like to set up an interim review clinic to say to patients ‘we’re still here for you…”
Specialist Nurse, Scotland

In particular, women are concerned about the long term side effects of chemotherapy, and also the fear of recurrence as highlighted in the in-depth interviews.

“I do triage (assess them) over the phone because it’s a very difficult stressful time when they’ve lost contact with the hospital and they’re at home trying to decide is this cancer, is it a cold or is it a tummy bug.”
Specialist Nurse, South East.

Practical support needs are also very evident, though the burden falls on family and friends

Women tell us their most pressing need is help with daily tasks, but a significant proportion of women do not have those needs met (73% said they needed such help, 53% received help). Other help such as benefits (39% needed) and financial advice (20% needed) and help with transport to and from hospital (50% needed) are also key to helping women through this phase.

For the vast majority (82%) help comes from family and friends, though health professionals such as Macmillan nurses and Clinical Nurse Specialists have a role to play.

The majority of both nurses and women with ovarian cancer think Target Ovarian Cancer could help to improve levels of emotional and practical support available to women with ovarian cancer

Methods by which this might happen include improving access to formal support services, increased opportunities to participate in group events, and better promotion of services at a local and national level.

The National Cancer Survivorship Initiative is helping recognise the non-medical needs of patients with cancer

This initiative, which emerged from the Cancer Reform Strategy (2007) is redefining what patient care should incorporate. Macmillan Cancer Support, who are the lead organisation, call in their ‘Two Million Reasons’ Report for ‘health and social care organisations, and cancer charities to put in place services to meet the needs of those people living with or beyond cancer’.[21] Through such work streams there are direct opportunities for Target Ovarian Cancer to inform debate and address some of the key emotional needs of women with ovarian cancer.

“It does wash over you every so often but I realise there isn’t anything anybody can do, I can’t imagine what anybody would do for me in terms of emotional support, but it would be nice if there was something.”

Linda (being treated for recurrence), West Midlands

The research landscape

The ovarian cancer research community in the UK is relatively small. In order to get a breadth of views for the purpose of this study, researchers with a range of interests (including basic biology, clinical trials, familial ovarian cancer) from the 8 major research centres were represented in the sample.

As with the clinicians they identified similar trends in diagnosis and treatment development. Overall they feel that there is a real chance to improve survival and length of life following an ovarian cancer diagnosis.

Key strengths

The key strength of the current UK ovarian cancer research infrastructure identified by several researchers is the cohesive nature of the community. They say there are good existing links between researchers and openness to working together more closely in the future. This is seen as a critical factor given the likely move towards individualised treatment and therefore the need for more targeted clinical trials across a number of centres.

Researchers tell us that forthcoming opportunities include more extensive use of data to understand individual cancers in detail to enable more individualised treatments, and the tracking of tumour mutations and alterations by collecting tissue over a period of time. In addition there are likely to be further developments around biomarkers hopefully leading to earlier diagnosis and improved treatments, and the use of NHS Spine patient data[22] for analysis and research could offer access to a consistent and substantial dataset.

But major challenges

However they also identify a large number of weaknesses in the way that ovarian cancer research works in the UK.

> “The UK has chosen to implement European guidance on clinical trials to the absolute levels so the bureaucracy around clinical trials has exploded over the last three to five years. This makes it much harder and more expensive to deliver clinical trials. We will often discuss a trial with a commercial organisation who will ask us for costings, then politely decline and go to Eastern Europe.”

Ovarian Cancer Researcher, London

Challenges

- Tissue gathering[23] during surgery and treatment

  Tissue sharing between centres is also seen as a problem, making working on more individualised treatments difficult as no one cancer centre has a large enough database to allow for detailed study and analysis of specific ovarian cancer subtypes.

  “I would like my surgeons to have an idea about research… they like operating and are bloody good at it, but getting tissue is a real struggle… I don’t think they can see why giving tissue to me will help them.”
  Ovarian Cancer Clinician-Researcher, South East

- The difficulty of getting clinical trials up and running

  Two factors in particular were mentioned by interviewees. A very strong theme was the bureaucracy associated with trials permissions, not just nationally, but locally too. One researcher described his frustration of always being ‘one trial behind’ by the time permissions had been given.

  They also tell us that the lack of time spent engaging with patients about clinical trials is preventing greater uptake.

- Access to pathology services. Future developments in treatments will certainly rely on increased use of diagnostic and pathology services to understand individual tumours in detail. However some clinicians are already experiencing problems accessing these services as rapidly as they would like because of a lack of capacity and because they are not always based on the same site as the surgery and oncology teams.

  “Close links with pathology is important. It is key we make communication happen between surgeons, medical oncologists, biologists… although there is a clinical multi-disciplinary team there is seldom a true research multidisciplinary team that will involve laboratory researchers”
  Ovarian Cancer Researcher, East Midlands

- There are still current gaps in terms of funding for basic biology, and in areas relating to palliative care, such as the management of bowel obstruction. Funding is largely ‘response mode’ rather than driven by a strategic need.

- Researchers would welcome more funded clinical research fellowships to increase linkages between researchers and clinicians and to help smooth the pathway from PhD to clinical researcher status.

- There are specific fears about funding from the NHS and pharmaceutical industry as ovarian cancer is already regarded as a ‘small market’ cancer, and will become increasingly so as individualised treatments develop. This is in the context of an already underfunded sector which has seen few breakthroughs in recent years, hence the limited range of effective treatment opportunities available for women.

For those who know that their cancer isn't curable

As this study has demonstrated, ovarian cancer 'patient journeys' can take many paths. All too often as we sadly know it ends with a loss of life.

Some women are proactive in terms of remaining treatment options, often challenging clinicians and the system to access drugs. Setting goals and becoming involved in raising awareness of ovarian cancer to ensure other women do not suffer the same experience is not uncommon. For such women it is about quality rather than quantity of life. Others seem to become resigned to their fate.

> "Rather than doing chemo all the time let me do things, and when it's really bad I'll have more chemo... I don't worry about it now. I just take one day at a time because that's the only way to because if they give you a number you are always thinking of that number as opposed to taking it positively. You think, I've got to do this, I've only got this much time. My sisters and my niece keep asking me how long I've got..."

Elana (with familial ovarian cancer, in the terminal stages), London

Support is essential

Women say that contact with their GP and community or Macmillan nurses is vital, as they offer support and practical guidance as well as managing symptoms. GPs, even if they had been slow to diagnose the condition, can be helpful as long as they are in tune with what the women want. Some women, for example, may want to travel and visit family overseas – however this may present problems because of the difficulty of getting travel insurance, or stabilising conditions to be well enough to go.

They also told us of mixed experiences at this time – one woman found that she seemed to be treated as a lower priority to attend to, and had problems getting nurses and clinicians to return her calls. Others felt better supported at this time than during their active treatment. For one lady this was linked to care she received through a local hospice, attending once a week for physiotherapy, support and alternative therapies.

Access and good links to palliative care can be mixed

Clinical Nurse Specialists in the in-depth interviews expressed concern about the lack of community services for palliative care, and personally find it difficult to discontinue the relationship they have established with patients.

> *"It's very difficult for them to let go (of the relationship) and for us to feel that they're not getting the support they need."*
> *Specialist Nurse, group discussion, West Midlands.*

Integration with palliative care teams is very mixed, which affects the experiences of both nurses and women. Although members of the Palliative Care Teams are meant to be present at Multi Disciplinary Team (MDT) meetings, they rarely are. Over half of the CNSs said such staff never attended their meetings regularly.

But when the system works well, everyone benefits

> *"I work closely with the community team – they ring me, I can ring them and we hand over information. The service is so stretched here that I know if they're being cared for well in the community I'm actually very pleased as I know they're getting support and someone is going in."*
> *Specialist Nurse, South East England.*

There are positive stories about women whose cancer is not curable; they are just not often heard

Target Ovarian Cancer Pathfinder Study Advisory Panel Member **Sandra Woodward**, who sadly passed away in May this year, reached her goal of being able to travel to South Africa for the wedding of her niece, returning just three weeks prior to her death. Sandra was a tireless campaigner on behalf of ovarian cancer and for improvement in her local cancer services. She contributed to the work of the panel and was involved in the qualitative research into women's experiences. We hope that as a result of this work we will be able to bring about the improvements to survival and quality of life she so wanted to see.

Future directions

Annwen Jones, Chief Executive Target Ovarian Cancer and
Joanna Barker, Chair of the Board of Trustees, Target Ovarian Cancer

With the Target Ovarian Cancer Pathfinder Study, we set out to identify clear gaps in knowledge, infrastructure, funding and need with regard to the care and treatment of women with ovarian cancer, and seek opportunities to improve quality of life and survival.

This report reflects the first results of the Target Ovarian Cancer Pathfinder Study. The study will continue to collect data in some areas and will develop new areas of activity going forward. It is vital that progress is made.

The Advisory Panel, having reviewed the results of the various research streams, made a number of recommendations to the Board of Target Ovarian Cancer about opportunities to make progress.

As a result Target Ovarian Cancer has identified the following priority actions. We will work collaboratively with others, where possible, both nationally and internationally, to take action so that we work towards our aim of a long and good life for every woman diagnosed with ovarian cancer.

Call for a national awareness campaign targeted at both women and GPs

Within the last year there has been progress in developing Department of Health Messaging around the symptoms of ovarian cancer, and the first Ovarian Cancer Awareness Measurement Tool has been created in line with the National Awareness and Early Diagnosis Initiative[8]. Not withstanding the recent efforts of charities to raise levels of awareness of ovarian cancer symptoms, there is a clear need to do much more. Concerted effort is needed at a national level to raise awareness of the symptoms of ovarian cancer amongst both women and GPs.

Help GPs diagnose ovarian cancer earlier

It is important to develop new and promote existing tools to aid GPs decisions in making referrals for suspected ovarian cancer, and to ensure there is consistent access to urgent diagnostic tools. GPs should consider ovarian cancer sooner rather than later and in their minds at least adopt a ‘rule it out’ approach.

Champion the role of the Clinical Nurse Specialist

Target Ovarian Cancer will work with Clinical Nurse Specialists to:

- Quantify the value of their role in the care of women with ovarian cancer
- Develop resources and initiatives to promote the sharing of good practice
- Enhance resources available to them for supporting women with ovarian cancer

Make sure all women with ovarian cancer have access to good quality emotional and practical support

Develop national programmes to ensure that women with ovarian cancer receive the emotional and practical support they, as individuals, need.

Improve access to clinical trials

Target Ovarian Cancer is developing the first interactive clinical trials information centre specifically for ovarian cancer, and will work to end the postcode lottery in terms of access to clinical trials.

Monitor and where appropriate support current trials and audits in Gynaecological Cancer

Particularly with regard to the collation of evidence regarding radical surgery.

Mobilise new funding for ovarian cancer research:

- To extend the current range of treatments available to women with ovarian cancer especially with recurrent disease
- Develop new joint resources and infrastructure to enable the UK ovarian cancer research community to take full advantage of the scientific and clinical opportunities which are emerging, such as the move towards targeted therapies
- Foster collaborations between centres across the UK

Undertake international benchmarking

Undertake the first ever ‘high resolution’ study to establish the key drivers for comparative ovarian cancer survival rates in Europe and beyond (see over).

Connecting with Europe

The Target Ovarian Cancer International Benchmarking Study

The EUROCARE-4 study[2] on cancer survival in Europe, using data from population based cancer registries, found that age-standardised relative survival for patients with ovarian cancer diagnosed in 1995–1999 varied markedly between countries and that England had the worst reported five-year survival rate in Europe at 30.2 %. The combined figures for the UK are only marginally better. This compares to the European average of 36.5%.

Were survival rates in England to match the European average, some 400 women would be saved each year. Clearly this raises questions which Target Ovarian Cancer seeks to address:

- Are the reported differences in survival between England and other European countries real and still apparent for women diagnosed more recently than 1995-1999?
- What factors explain poorer survival in England (eg later stage of disease at diagnosis, poorer access to optimal treatment, etc)?
- What drives earlier stage at diagnosis in countries that have a higher proportion of women diagnosed at an earlier stage?

We believe that it is essential to answer these questions in order to identify opportunities to improve survival for women with ovarian cancer in England and, more broadly, the United Kingdom.

There are several possible factors that may explain observed differences in survival falling into the broad categories of:

- Late presentation and diagnosis
- Women at high risk
- Initial treatment
- Treatment for recurrent ovarian cancer

On the recommendation of the Target Ovarian Cancer Pathfinder Study Advisory Panel, we have commissioned an expert team to establish whether an in-depth international High Resolution Study could provide good quality evidence to explain the lower observed survival in England compared with the best performers in Europe.

The Research Team

This feasibility study will examine the quality, availability and comparability of data as recorded in case notes in selected cancer registries across Europe and will develop a protocol for the High Resolution Study. It will also examine whether a High Resolution Study could be extended to North America and Australia.

The feasibility study will be carried out by the Trent Cancer Registry, which is the lead registry for gynaecological cancer in the National Cancer Intelligence Network. David Meechan, the Director of the Trent Cancer Registry, will be the study director.

It will be advised by an expert panel including Professor Michel Coleman, Professor of Epidemiology and Vital Statistics at the London School of Tropical Hygiene and Medicine; Professor Jonathan Ledermann, Chairman of the National Institute of Cancer Research Ovarian Cancer Group; Annwen Jones, Chief Executive Target Ovarian Cancer; Mr Andy Nordin, Chair of the NCIN Gynaecological Cancer Clinical Reference Group; Professor Henry Kitchener, Professor of Gynaecological Oncology, University of Manchester; and Milena Sant and Gemma Gatta of the Fondazione Instituto Nazionale per lo Studio e la Cura di Tumori, Milan.

The results of the feasibility study will be reported in Spring 2010.

Ovarian cancer factfile

6,800 women are diagnosed with ovarian cancer in the UK each year.

Three quarters of women are diagnosed once the cancer has already spread.

It is impossible to predict who will or won't develop ovarian cancer, but the most important risk factors for ovarian cancer are a strong family history (two or more cases on one side of the family) and age. Most cases of ovarian cancer are diagnosed in women over the age of 50 who have gone through the menopause.

Cervical screening tests - sometimes known as smear tests - will not help to detect ovarian cancer.

Some of the symptoms of ovarian cancer are similar to those seen in more common conditions, like irritable bowel syndrome (IBS) so GPs may find it hard to diagnose.

Research has shown that ovarian cancer symptoms are:

Frequent – they happen on most days
Persistent - they don't go away

The key symptoms to be aware of are:

Persistent pelvic or abdominal pain

Increased abdominal size/persistent bloating – not bloating that comes and goes

Difficulty eating or feeling full quickly

Occasionally there can be other symptoms such as:

Urinary symptoms (needing to pass water more urgently or more often than usual)

Changes in bowel habit

Extreme fatigue (feeling very tired)

Back pain

These may be experienced on their own or at the same time as the key symptoms.

Ovarian cancer key dates

October 2008 – Department of Health published key messages for women on the symptoms of ovarian cancer[12]
February 2009 – Department of Health published key messages for health professionals[13]
June 2009 – Announcement of the key findings of the Target Ovarian Cancer Pathfinder Study
April 2011 – The National Institute of Health and Clinical Excellence (NICE) will publish new clinical guidance on 'The recognition and initial management of ovarian cancer'
2014/15 – Results to be published from the United Kingdom Collaborative Trial of Ovarian Cancer Screening, the largest screening study in the world (www.ukctocs.org.uk)

About Target Ovarian Cancer

Target Ovarian Cancer is a UK charity working in England, Wales, Scotland and Northern Ireland.

Established in 2008, our goal is to highlight and tackle the very low survival rates of women with ovarian cancer in the UK – 30% over five years and unchanged for 30 years. The charity has a national remit for research, advocacy and education and our mission is to achieve a long and good life for every woman affected by the disease. We want to be there every step of the way with women diagnosed with ovarian cancer, taking on their concerns and pushing for improvements in healthcare.

We aim to do this by:

- Raising awareness of symptoms and risk factors amongst women and GPs to combat late diagnosis
- Working to improve treatment of the disease
- Supporting women with ovarian cancer
- Encouraging more investment in research
- Collaborating to ensure that gaps in healthcare provision are addressed

The Target Ovarian Cancer Pathfinder Study is our first major piece of research. The largest UK-wide mapping exercise of the disease ever to have been commissioned, it will underpin our efforts to break the vicious circle of low survival, low awareness and chronic underfunding by signposting specific ways in which we can help make a difference to women with ovarian cancer. Working with women with ovarian cancer, top cancer specialists, other organisations and Government, we aim to help drive up survival. It is vital that we do so: change is long overdue and women with ovarian cancer deserve nothing less.

Whether you are a woman with ovarian cancer or a family member or friend, whether you are in a position to help secure the funds urgently needed to invest in improvements, whether you are a healthcare professional or researcher or whether you are involved in some other way in securing improvements in quality of life and survival for women with ovarian cancer, we believe that the best way forward is to work together.

Please contact us on **020 7923 5470** or visit our website **www.targetovarian.org.uk**
We will be delighted to hear from you.

Target Ovarian Cancer is dedicated to achieving a long and good life for women with ovarian cancer throughout the UK.

TARGET OVARIAN CANCER
For every woman. **For life.**

Footnotes

1 Professor Sir Kenneth Calman is former Chief Medical Officer for England and Wales, and is current Chair of the National Cancer Research Institute

2 EUROCARE-4. Survival of cancer patients diagnosed in 1995-1999. Results and commentary. Sant M.; Allemani C.; Santaquilani M.; Knijn A.; Marchesi F.; Capocaccia R.; the EUROCARE Working Group. European Journal of Cancer 2009,45:931-991

3 http://www.cancerresearch.org/cancerstats/types/breast/survival

4 Population-based cancer survival trends in England and Wales up to 2007: an assessment of the NHS cancer plan for England. Rachet B, at al. The Lancet Oncology. March 20, 2009, published online

5 In 2007/08, the combined income of the top three site-specific breast cancer charities was £43million compared to £3.3 million for the top three site-specific ovarian cancer charities

6 Women were free found (i.e. self selected) via national PR, professional referrals and snowballing (through their contacts). As such they are a self selected group, and may present particular biases as a result

7 Profiles of participating groups are available on request and will be published in the full report during Summer 2009

8 The Ovarian Cancer Awareness Measurement Survey Instrument was developed by Ovarian Cancer Action, The Eve Appeal, Ovacome and Target Ovarian Cancer. It is based on a generic CAM developed by Cancer Research UK, University College London, Kings College London and Oxford University in 2007-2008

9 Nurses were free found via the National Forum of Gynaecological Oncology Nurses, national PR, professional referral, snowballing and via the Target Ovarian Cancer website. According to the Clinical Nurse Specialist Census (2008) there are some 149 Gynaecological Cancer CNS posts in England

10 Target Ovarian Cancer Pathfinder Study, Women with ovarian cancer June 2009

11 Target Ovarian Cancer Pathfinder Study, Women in the general population June 2009

12 As defined in the Department of Health Key messages for women on ovarian cancer October 2008 (http://www.nhs.uk/Livewell/cancer/Pages/Ovariancancer.aspx).

13 http://www.dh.gov.uk/en/Healthcare/Cancer/DH_095624

14 Eg a tool aimed at GPs along the lines of the OPERA risk assessment tool (http://www.cancerbackup.org.uk/Aboutcancer/Genetics/GeneticBreastOvarianCancerRiskAssessmentTool)

15 Eg http://www.ovarian.org.uk/pdf/diaryGP.pdf

16 In depth interviews with 19 women who had ovarian cancer from around the UK carried out November 08

17 For those women who were offered a choice of chemotherapy

18 This was defined as working in a centre or unit with one (or less) full time equivalent role

19 UK GOSOCS Surgical Audit, CHORUS Trial

20 Familial ovarian cancer is most commonly caused by mutations in the BRCA1 or BRCA2 genes which also raises the risk of breast cancer. Some 10-15% of cases of ovarian cancer each year fall into this group and can be characterised by multiple cases of ovarian and or breast cancer

21 Ciaran Devane, Chief Executive, Two Million Reasons Report, May 2009, Macmillan Cancer Support

22 The 'Spine' will allow secure access from anywhere within the NHS to a patient's summary care record

23 This would allow researchers access to tissue for testing potential new compounds in the laboratories, or for helping define the characteristics and behaviour of different types of ovarian cancer which can inform drug development.

> “I wish Target Ovarian Cancer well in its important work. Ovarian cancer is a challenging disease to diagnose and treat, and it is essential that we continue to work together at every stage of the disease. Groups such as Target Ovarian Cancer can help drive forward progress in improving the accuracy of referrals, access to diagnostic tests and caring for women living with the disease, and I look forward to continuing to work with them in the future.”

Dr Sarah Jarvis GP, and RCGP Spokesperson on Women's Health