



WORLD
OVARIAN
CANCER
COALITION

THE
EVERY
WOMAN
STUDY™

EVERY WOMAN STUDY CLINICIAN REPORT

April 2018

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Our sincere thanks go to the members of our Every Woman Study Expert Advisory Panel for their oversight and input.

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EXECUTIVE SUMMARY

The mission of the World Ovarian Cancer Coalition is to ensure the best possible chance of survival, and the best possible quality of life for every woman with ovarian cancer, wherever she lives.

The World Ovarian Cancer Coalition's Every Woman Study aims to bring together an authoritative evidence base that speaks to the views of women with ovarian cancer across the globe and those involved in their care. This will enable the coalition to formally highlight gaps, challenges, opportunities and good practice to set out what needs to be done to make the mission a reality.

This report presents information gathered during qualitative interviews with a range of clinicians in different locations around the world early in 2018, and from an online survey conducted between May 8th and June 23rd 2018. There were 28 respondents. The aim of both aspects was to:

- Gather rich material that could be quoted in reports particularly from countries where the World Ovarian Cancer Coalition does not yet have a strong presence.
- Gain insight on potential factors which may give rise to different patient and clinician experiences around the world, and how those might vary.
- Identify a sample range of opinions on the challenges and opportunities to improve survival and quality of life for women diagnosed with ovarian cancer.

The interviews were arranged through partner and affiliate members, or contacts made to date. Clinicians were given information in advance about what to expect from the interview, and how the information gathered would be used, and their consent sought at the start of the interview. A template of interview questions was used, with additional questions asked as follow-up where necessary. The online survey was developed following analysis of the clinician interviews and was tested with 5 clinicians from different countries. In total 37 clinicians from 15 countries have contributed their views to this report. They included one gynecologist, eight gynecologic oncologists and nine medical or clinical oncologists trained in gynecologic cancers, and 19 clinicians who perform both surgery and give systemic therapies.

KEY FINDINGS

A number of themes dominated the results. They were late diagnosis, the challenges in ensuring women receive specialist treatment, and the opportunities going forward with increased genetic testing to improve primary prevention and access to targeted treatments:

DELAYED DIAGNOSIS

- Without fail clinicians who were interviewed were very pre-occupied with the challenges of delayed diagnosis, and their ability to treat women. They said that a significant proportion of women were too ill to begin or tolerate treatment. Some cited short-term mortality data.
- They recognised that screening and more effective diagnostic tests were still some way off, and that there was an imperative to
 - Improve the knowledge of women so that they do not delay seeking help.
 - Improve the knowledge of general doctors and gynecologists when women present with these challenging and non-specific symptoms so they investigate or refer without delay.
- They felt strongly that a lack of awareness of symptoms on the part of women and doctors contribute to delays in diagnosis. The effect of these interventions would be to improve a woman's ability to undergo and tolerate treatment, which could potentially lead to improvements in five-year survival.

TREATMENT IN SPECIALIST CENTRES

- Treatment in specialist centres is far from universal and this was reinforced in the online survey. Some (Canada, Germany and UK) have made significant national or provincial effort in implementing centralised care, via guidelines, but so far with varied success. The UK had the highest proportion of women undergoing surgery in specialist centres (above 90%), and Canada has made good progress despite some challenges implementing the regime. Germany still has a considerable way to go to improve the proportion of women receiving as optimal surgical management (participants estimated between 10 and 80% but most responses said below 50%).
- Major challenges include workload and required infrastructure. In other countries clinicians are driving the effort regionally or just locally. Some face issues of insufficient specialist trained workforce, for others that is not a problem. Almost all talked about the need for general doctors/surgeons/gynecologists to understand the benefits of specialist care and the need to improve the proportion of women referred to specialist centres.
- Countries vary in terms of national or regional health government, and this can lead to variations of access to drugs/surgery/clinical trials region by region.
- Significant delays do occur – in terms of accessing operating room time, imaging, pathology, genetic counselling and testing. Together with the challenge of increasing workloads this led some clinicians to say treatment is given in terms of what they can provide, rather than what is best for the woman.

GENETIC TESTING

- Clinicians were clear that genetic testing was one of the most encouraging advances in recent years, offering better treatments and primary prevention for families who carry a faulty BRCA1 or BRCA2 gene. It was described as a 'game-changer' for the disease.
- Whilst there has been a radical shift towards testing women diagnosed with high grade serous ovarian cancer, they acknowledged that it was not yet as widespread or accessible in a timely fashion, as it could be.

OTHER ISSUES

- Concern was raised that the voices heard, and the data gathered in relation to ovarian cancer are predominantly Caucasian. Note was made that certain ethnic groupings (e.g. Asian, Black) develop the disease about a decade earlier, but there was no or little understanding of this, and most studies/trials are dominated by data on Caucasian women. This contrasts with the fact that most women in the world with ovarian cancer are from other ethnic groups.
- There is an increasing recognition of the importance of quality of life issues, but that data, and access to supportive services and information is very limited.
- In the interviews, clinicians said that the World Ovarian Cancer Coalition could contribute to the articulation of key issues at a regional and national level, and this could help individuals and groups at regional and national levels make progress. There was also the suggestion that clinicians would benefit from leadership and advocacy training to this effect.
- It was recognised that there are opportunities for progress in terms of improving survival and quality of life, and many of these opportunities come from tackling the identified challenges.

SUGGESTED PRIORITIES FOR THE WORLD OVARIAN CANCER COALITION

The clinicians questioned suggested priorities for action by the World Ovarian Cancer Coalition that were then discussed by the Expert Advisory Panel:

- Raise awareness of the symptoms of ovarian cancer so that:
 - Women do not delay seeking help
 - Doctors do not delay investigations.
- Promote the value of specialist treatment to women, family doctors and gynecologists. This could be done by:
 - Producing recommendations and sources of information online, to support local clinicians develop appropriate services and advocate effectively.
 - Consider opinion pieces in journals or other vehicles of communication targeting family doctors and gynecologists, possibly in partnership.
 - Encourage partner organisations to support a campaign in their own country
 - Help women become aware of the importance of specialist treatment

- Share examples of educational tools for family doctors on the symptom profile of ovarian cancer and the importance of complete family history.
- Call for nations or regional areas to collect data on short term mortality.
- Support global calls for better cancer registration.
- Promote the importance of diversity of data collection to better reflect local populations and those in areas of low resource.
- Consider developing information on clinical trials and quality of life issues (as a minimum) that can be translated and used locally, utilising materials existing within partner groups.
- Consider developing an advocacy toolkit that groups or individuals can use as necessary to help advocate for the issues above, based around what might be considered 'the best possible patient pathway'.

IN MORE DETAIL

Partner organisations assisted in locating clinicians to be interviewed. A protocol sheet was prepared and given to clinicians in advance. Conversations were recorded, transcribed and summarised. The interviewees then checked this copy for accuracy and were allowed to make amends. Their permission was sought to use their words in this and the summary report. Participants in the online survey were allowed to choose whether they remained anonymous or not, and whether or not they were happy for any comments they made to be used in reports. Following feedback during testing the survey was reduced to around 30 minutes to complete all questions, and clinicians were given the option to choose up to 8 sections they wanted to answer. Not all clinicians responded to all questions.

Clinicians from the following countries responded:

Austria	India
Australia	Italy
Brazil	Japan
Canada	Portugal
Finland	Romania
Germany	Spain
Hungary	United Kingdom
	United States of America

LATE DIAGNOSIS

Without exception, all the clinicians who were interviewed spoke of the challenge of trying to treat women diagnosed with advanced ovarian cancer.

“Late stage diagnosis is a catastrophe – we don’t have much success in treating this ugly disease if it is discovered in the advanced stage....all the other challenges have secondary importance in relation to this”.

Dr Zoltán Novák, Hungary.

LACK OF SCREENING TOOLS

With a lack of effective screening tools, or early diagnostic tests, interviewees highlighted the importance of investment in research in these areas, and in the need to ensure women who are experiencing symptoms are investigated rapidly, allowing them to be diagnosed promptly and operated on by specialist surgeons.

“The focus of research should be mandatory to find biomarkers to help screen or find early diagnostic tools” **Dr Sandro Pignata, Italy.**

“I run a study called Rocket which tries to identify better tests for ovarian cancer ...(biomarkers/ultrasound/circulating tumour DNA). I’m very cognisant of the fact that many of the people you will talk to are treating women with ovarian cancer – they don’t see the diagnosis issue upfront. Usually these surveys come out very much in favour of esoteric treatments that provide an extra six weeks of progression free survival and everyone gets very excited.

At the end of the day you are not curing themall you are doing is buying them an extra bit of time. These surveys are heavily dominated by oncology, as are the funding bodies. This is what I need you to remember.”

Mrs Sudha Sundar, UK.

One clinician in the online survey (Canadian) had a different viewpoint: “The major impact in mortality with ovarian cancer is as a result of serous cancers. Based on the pathophysiology of these cancers it is unlikely that screening will ever work as a strategy. Of course, if there are molecular pre-cursors that can be identified it would be different but that would revolutionize all cancer screening and assessment not just ovarian. What is most important in serous ovarian cancer is appropriate risk stratification and aligning with risk reducing surgery”.

NEED TO IMPROVE THE SPEED OF DIAGNOSIS

“The dream is a screening programme that works, but I think we are many many many years from that. So, what can we do in the first instance? It’s going to be about rapid access to diagnosis, which involves patient, public and GP [general practitioner/family doctor] education..... I know that women often present with symptoms when the cancer is advanced, but there can be a big difference between [even in stage 3c disease]. You can be fit and well, but four weeks later you can be absolutely ‘gubbed’ – that’s a Glaswegian expression for really, really sick. One thing I’ve observed, having now worked in several cancer centres around the UK, is that for women going to the GP, the time that it then takes to be diagnosed can be painfully long.” **Professor Iain McNeish, UK.**

The impact of such late diagnosis is clear:

“About 20% of women don’t receive any treatment at all because we are not diagnosing them in time. They don’t need a stage shift, they don’t even need to have lower tumour volume though this is always presented (talked about) – but if we can diagnose them with a better performance status then we will improve mortality.” **Mrs Sudha Sundar, UK.**

The figure of 20% not receiving any treatment (or palliative only) was also reflected in other countries, such as Brazil in the online survey. One respondent in Canada said the figure was under 30%. Several respondents (including 5/7 from Germany, 2/3 from Spain, and 1 each from Canada, Italy, Portugal and the USA) said all women received treatment.

“In most of the cases (presenting as an emergency) the patients are not fit enough to receive any part of the management pathway – to see the good effect of treatment we need to be able to make the patient bear the two modalities of treatment, but in many instances the general health is not permitting, so we are defeated in the first place – upsetting for patients and us.” **Dr Manas Chakrabarti, India.**

KNOWLEDGE OF OTHER HEALTH PROFESSIONALS

Most interviewees stressed the importance of making general physicians/family doctors and gynecologists more aware of potential symptoms. Some countries have established GP education programmes (United Kingdom, Italy, and Canada), which have already shown impact:

“Ovarian Cancer Canada, our national society for patients has done an excellent job at educating the family doctor and medical students in what to look for. They do small groups for medical students and online learning webcasts for family doctors, so I’d say that has improved during my journey in gynecologic oncology.” **Dr Laurie Elit, Canada.**

Clinicians in other countries were keen to have such tools:

“We should help train our GPs and colleagues to be attentive to this, to ask for a gynecologic opinion. The ability of have access to online training tools for GPs would be extraordinary, as there is in the UK”.
Dr Zoltán Novák, Hungary.

Despite having guidance from the National Institute for Health and Care Excellence (NICE) for GPs in England, a UK clinician said there were still certain GPs who were unaware of its existence. They also commented that GPs are not forced to refer to secondary care. They highlighted that the issue of lack of awareness was not just amongst GPs but among physicians more widely, meaning patients often stay on medical wards for weeks until a diagnosis is finally made. This was also picked up on by another gynecological oncologist from the UK who said, “Most women with advanced ovarian cancer do not present through the traditional GP to rapid access clinic. Instead they present to secondary care where their symptoms are not identified as being compatible with ovarian cancer. We have audit data to suggest that another factor is delays in getting treatment started”.

In some countries, even where a visit to a family doctor is free, women may choose to go to a gynecologist privately:

“In Valencia most women would see a gynecologist for their symptoms, it is less common that women go initially to the general practitioner. The patient has the possibility to go to public health for free, but generally they have to await a long period of time to be seen by a specialist. If they want to have a visit in advance, they can visit the private office of a gynecologist.”
Dr Lucas Minig, Spain.

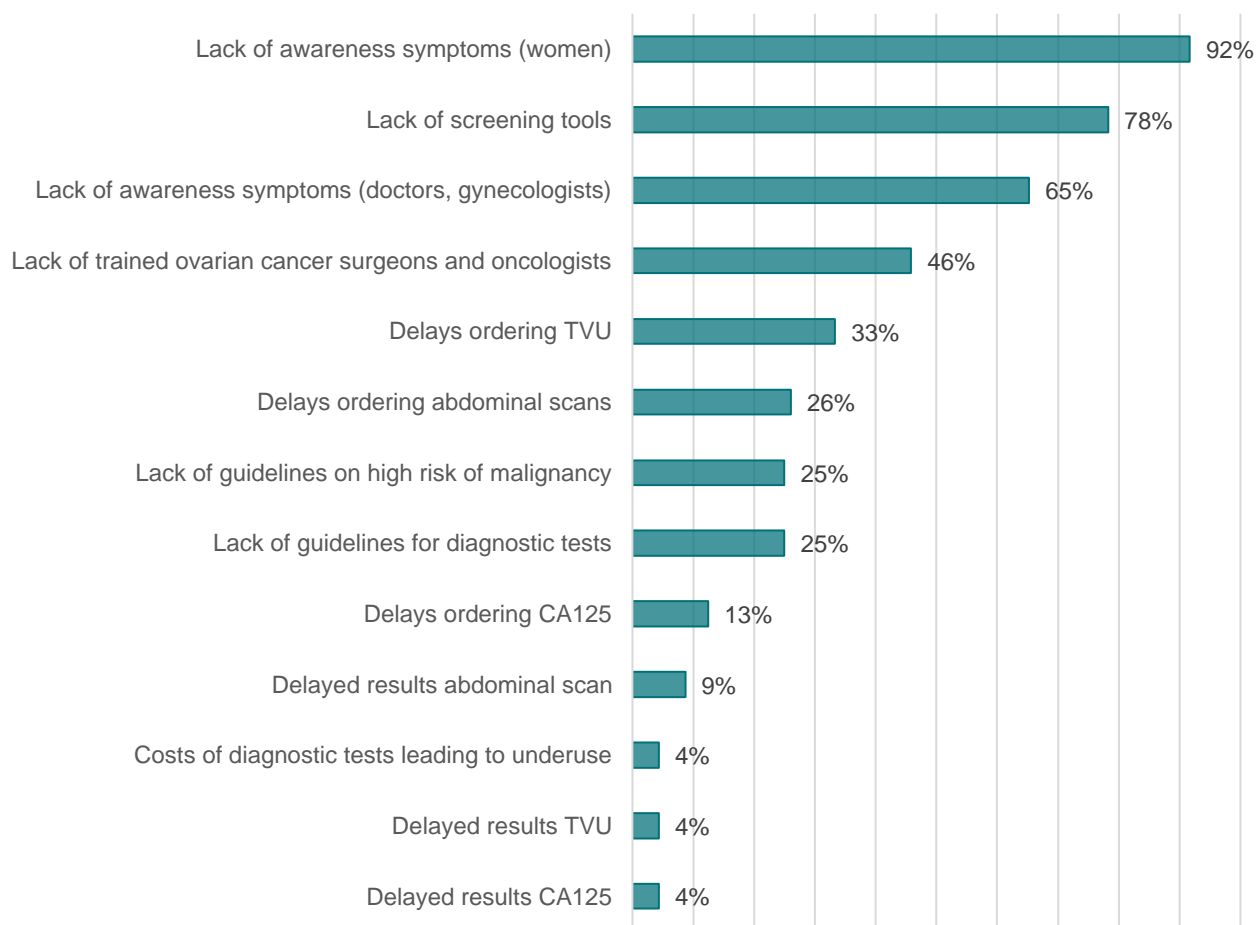
In terms of responses to the online survey, 25/28 (89%) clinicians believed that the time to diagnosis could be improved for women with ovarian cancer that they see. Interestingly the three who responded negatively to this all came from Germany, which, according to the results from the women’s survey (1531 responses in total), had the highest proportion of women visiting a doctor about symptoms within a month of their start (77.3% vs average 46.3%).

When asked what contributed to delays in diagnosis, clinicians were given a range of options, and asked to determine whether these factors were very significant, significant, contribute to a small extent or not applicable:

<p>Very significant</p>	<ul style="list-style-type: none"> • 65% (15/23) highlighted the lack of effective screening tools. • 54% (13/24) selected the option 'women not realising the symptoms may be due to ovarian cancer'. • 26% (6/23) highlighted 'family doctors or gynecologists not realising that symptoms may be due to ovarian cancer'.
<p>Significant</p>	<ul style="list-style-type: none"> • 39% (9/23) highlighted 'family doctors or gynecologists not realising that symptoms may be due to ovarian cancer'. • 38% (9/24) selected the option 'women not realising the symptoms may be due to ovarian cancer'. • 33% said a lack of trained ovarian cancer surgeons and oncologists (8/23).
<p>Contributes to a small extent</p>	<ul style="list-style-type: none"> • 78% (18/23) said there were delays getting results of TVU scans. • 74% (17/23) said there were delays getting the results of CA125 tests. • 65% (15/23) said there were delays getting the results of abdominal ultrasound scans.

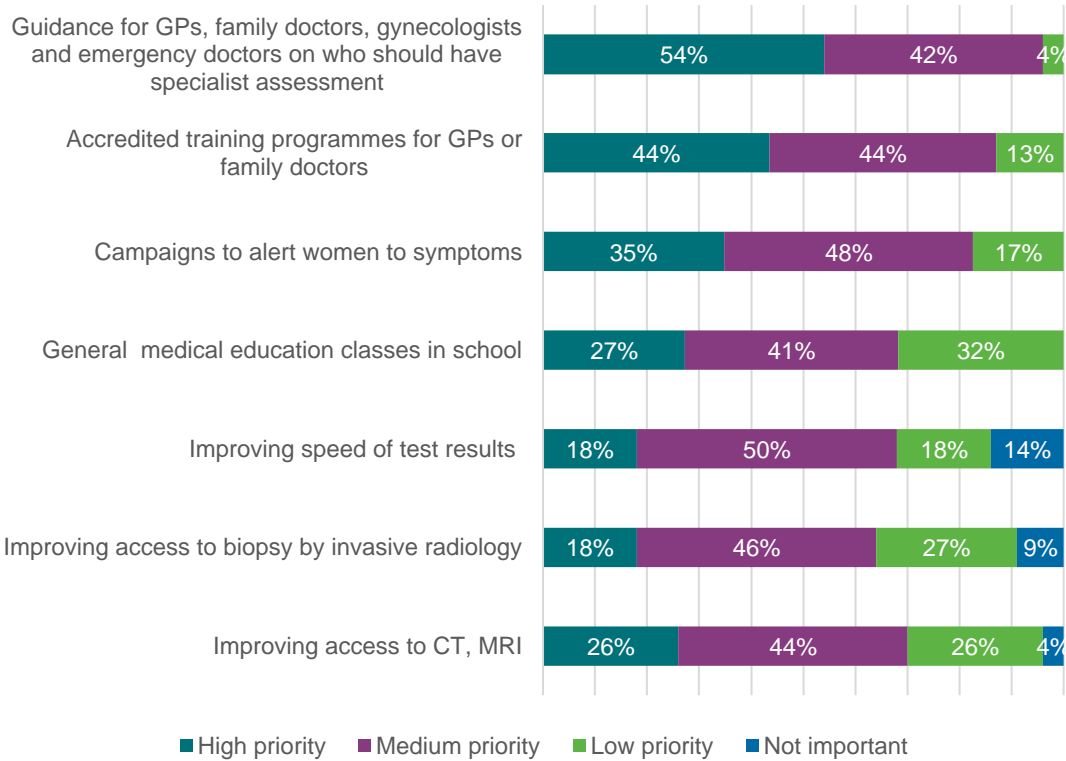
In terms of putting significant and very significant factors together an overall ranking was achieved in the following table:

PROPORTION HIGHLIGHTING THIS AS VERY SIGNIFICANT OR SIGNIFICANT
IN TERMS OF DELAYS DIAGNOSING WOMEN N=24



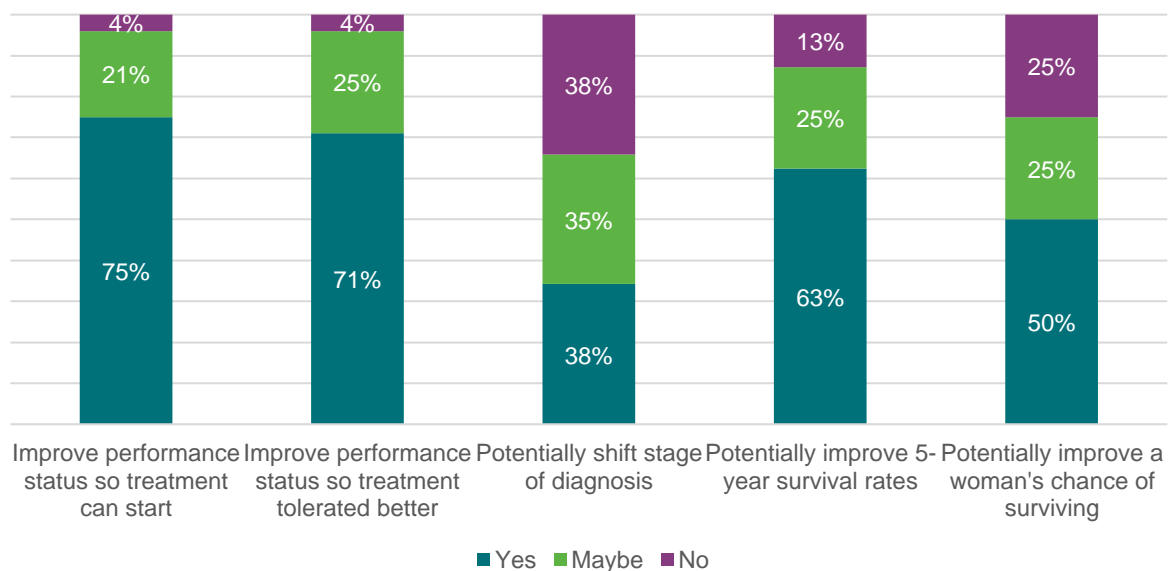
The clinicians in the online survey who said they felt the time to diagnosis could be improved were then asked whether any of the following actions could help reduce delays in the diagnosis of ovarian cancer. They were asked to select whether they were high, medium, low priority or not important. 24 responded.

PRIORITIES TO HELP REDUCE DELAYS IN DIAGNOSIS N=24



Clinicians were then asked about their beliefs in terms of the impact reducing the time to diagnosis could have. They were given five options, and asked to select yes, no or maybe.

HOW REDUCING DELAYS IN DIAGNOSIS MIGHT IMPACT N=24



DIAGNOSTIC TESTS

For most respondents to the survey, the cost of diagnostic tests such as CA125 and ultrasound scans was not an issue, but rather timely access to the tests or the results. In Brazil, a gynecologic oncologist said it would routinely take three months to obtain a CT assessment, and two months for an MRI. In Japan however, the clinician who responded said it took three days to get CT assessment, and one week for an MRI. In the USA these tests similarly took no more than a few days. A UK clinician highlighted the low number of CT and MRI scanners per 100,000 population, and that there was a national shortage of interventional radiology in the UK. In Spain, issues in accessing and getting results for scans (both TVU and abdominal) were an issue that caused delays.

TREATMENT IN SPECIALIST CENTRES

In addition to discussion about the challenge of treating women diagnosed with late stage disease, all the clinicians in the interviews focussed strongly on the role of treatment and in particular surgery, at specialist centres dealing with high volumes of cases carried out by specially trained experts. Without exception they recognised the importance of treatment in this way, to improve outcomes for women with ovarian cancer.

VARIATION

There was considerable variation in terms of whether this was an ambition, work in progress, or current practice. Countries vary as to whether it is nationally recognised with a co-ordinated response, or whether it is the response of local groups of clinicians.

“There are currently in Hungary around 150 hospitals treating or operating on women with ovarian cancer, where the total population is under 10 million...[ESGO guidelines would suggest centralising to five or so centres].. This is my personal goal to fight for this in the future... I am hopeful I can persuade the powers that be. I need to believe in this!”

Dr Zoltán Novák, Hungary.

“As in the great majority of countries, the treatment is non-centralised.... We are now working closely with other colleagues in our State ..(Valencia)... to centralise treatment at least in our area because it has been demonstrated to be the most powerful tool to obtain beneficial results for women.”

Dr Lucas Minig, Spain.

“In Italy, about half of women are treated surgically in centres of less expertise. There are guidelines, but not all centres see the same number of women, so inevitably there are quality differences, just because they don't see the same number of patients.” **Dr Sandro Pignata, Italy.**

A gynecologic oncologist from the UK who participated online pointed out that 'surgery is the only prognostic factor we can influence. Patients should be centralised to specialist centres – supra-specialisation'. This clinician also estimated that the proportion of women in the UK who had their surgery undertaken by a trained specialist was very high - 90% or above. This was supported by other respondents from the UK.

Geography within a country can play an important role in terms of the success of setting up such centres, and women's ability to reach them:

"The issue is that it is a problem for women to travel, it is not like the rest of Europe, the roads are not very good." **Dr Dragos Median, Romania.**

One Canadian gynecologic oncologist said there were just two specialist centres in their province. This made assessment by MDT a challenge for those who live far from a gynecologic oncology centre. They called for tertiary centres to be better spread across a geographic area, and for a better spread of gynecologic oncologists. In Australia there are efforts to run a 'hub and spoke' system, where specialist clinicians travel out to triage women, though very little major gynecologic oncology surgery is carried out in rural regional towns. They are also increasingly trying to use telemedicine. However where specialist centres exist, this does not mean women end up there:

"Despite this system, there are a number of ovarian cancer patients who are never given the chance to have an MDT assessment, or told they could have the option to have it discussed. They are diagnosed outside of a gyn-onc unit – you are totally dependent on the person treating them to refer them in. There is no guarantee that will happen." **Professor Peter Grant, Australia.**

"We need to let gynecologists know the latest evidence, so they understand that the very best approach to treat women with ovarian cancer is by specialist surgeons operating as part of a multidisciplinary team. The main problems [of getting women to the treatment centres] include the fact that some women prefer the obstetricians who delivered their children, many of them are desperate to start treatment, and think there is no time to find a specialist, that some do not know that gynecologic oncologists exist, others have economic difficulties for moving to another city for treatment, or the 'ego' of some physicians without special training in cytoreductive surgical techniques." **Dr Lucas Minig, Spain.**

"There is huge variability in knowledge. We have a lot to do in terms of educating our gynecology colleagues as to what they should or shouldn't take on. I've been tempted to write a book for gynecologists – in the UK we have Improving Outcomes Guidance, but it would be really helpful to have a manuscript, guidelines or book which says for the wider world 'this is what you need to look out for - these are high risk patients that should be managed

at a cancer centre from the outset'. I still have the brief for that and I'd be happy to ping that across". Mrs Sudha Sundar, UK.

Not only can sub-optimal treatment threaten a woman's chance of surviving, but it can also have a devastating impact financially for them:

"Sometimes after the time is spent, even when treatment is not fulfilled, they give up and go back to their villages exhausting their life time savings. So improving the referral pathway is a really important thing to get to the right person, for the right treatment." Dr Manas Chakrabarti, India.

In Brazil, it was estimated there were just 10 specialist centres for a total population of 207 million. In Spain it was estimated by two clinicians that there were 150 centres (46 million population) whilst a third said 50.

The table below represents relevant responses from the online survey. It shows that variation is wide not only between countries but within countries, and that there are uncertainties among clinicians as to their national picture. It also highlights the variation in: delays to start treating; proportion of women who have surgery first; average length of operations; numbers of operations carried out each year by the particular surgeons; the optimal debulking rates; and the estimates of the proportions of operations on women with ovarian cancer carried out by gynecologic oncologists. Only rarely was this information recorded for regional or national data collection. There is also clearly variation between hospitals within countries.

Country	Delays to start treatment (weeks)	Estimated specialist centres in country (country popn)	Proportion who have surgery first	Number of ops per annum by respondent and average time	Optimal debulk rate in their hospital	Prop of ops in country by gyn-oncologists
Australia	1	10 (24m)	70%			
Brazil	8-12	10 (207m)	5%	60 (6h)	30-40%	20%
Canada	2	15 (36m)	50%	20 (3.5h)	70-80%	80%
	2		50%	50 (3h)	40-50%	80%
	2-4 (surgery)		45%	25 (4-5h)	70-80%	80%
	3	15	50%	25 (6h)	70-80%	80%
Germany	3	100 (83m)	95%	25 (6h)	70-80%	40%
	1	100 (10 super)	80%		90+%	50%
	3	100	95%	6h	70-80%	10%
	2	100	50%	30 (5h)	70-80%	60%

	2	80	80%	40	60-70%	80%
	3	100	95%	90 (6h)	70-80%	20%
Spain	2	150 (47m)	70%	30 (5h)	70-80%	50%
	4	150	30%			
	2	50	50%			
Japan	2	100 (127m)	40%			
USA	3	60 (323m)	60%	10 (4h)	60-70%	70%
	2	lots	75%	30 (3h)	60-70%	
United Kingdom	3	26 (65m)	40%	25 (6h)	70-80%	90%
	2		50%		60-70%	
	3	75	50%	33 (3+h)	70-80%	95%

A German clinician said ‘it is specified in our national guidelines that only trained gynecologic oncologists should perform surgery on women with ovarian cancer’. In reality there were low and varying estimates for the actual proportion achieving this (from 10 to 80%). However, all the German gynecologic oncologists said that that all women who they saw received treatment as part of their care, whereas most other respondents said 10 to 20% of patients did not receive care, primarily because they were not well enough.

Whilst some clinicians wanted national guidelines, others believe it doesn’t necessarily have to be government led.

“We expect this because we are in a publicly funded healthcare system in the UK. Many of these gynecologists or general surgeons – it is an access to knowledge issue. If you think of thrombolysis for myocardial infarction – and how to manage that – that wasn’t government led, it was people saying and passing on knowledge. People get on the bandwagon quickly. It happens because people know about it – patients, doctors. Now, if you are saying you are not thrombolysing, people say, ‘what sort of silliness is that?’ There are different ways of percolating information.” Mrs Sudha Sundar, UK.

“[We must] reinforce the network – general gynecologists, general physicians, and let them know the relevance of treatment by specialists. The other week I heard that the complexity of an ovarian cancer operation is the same as an organ transplant, involving many different specialisms – complex treatment, high incidence of complications, so both are comparable. You would not do organ transplants in every hospital in a region. So we need to spread the word.” Dr Lucas Minig, Spain.

CHALLENGES OF CENTRALISED SERVICES

Some countries have made significant progress towards centralisation of treatment, but there can still be major problems, or room for progress.

“There has been a great improvement in women coming in to tertiary centres. We introduced guidelines in 2013 to say if RMI was higher than a certain amount (200) then you needed to be seen in a specialist centre, but actually we see them at lower levels too..... **Dr Laurie Elit, Canada.**

However, she is also seeing there can be negative effects of attempts to centralise cancer care (across many types) in particular leading to major problems in accessing operating rooms and diagnostic facilities.

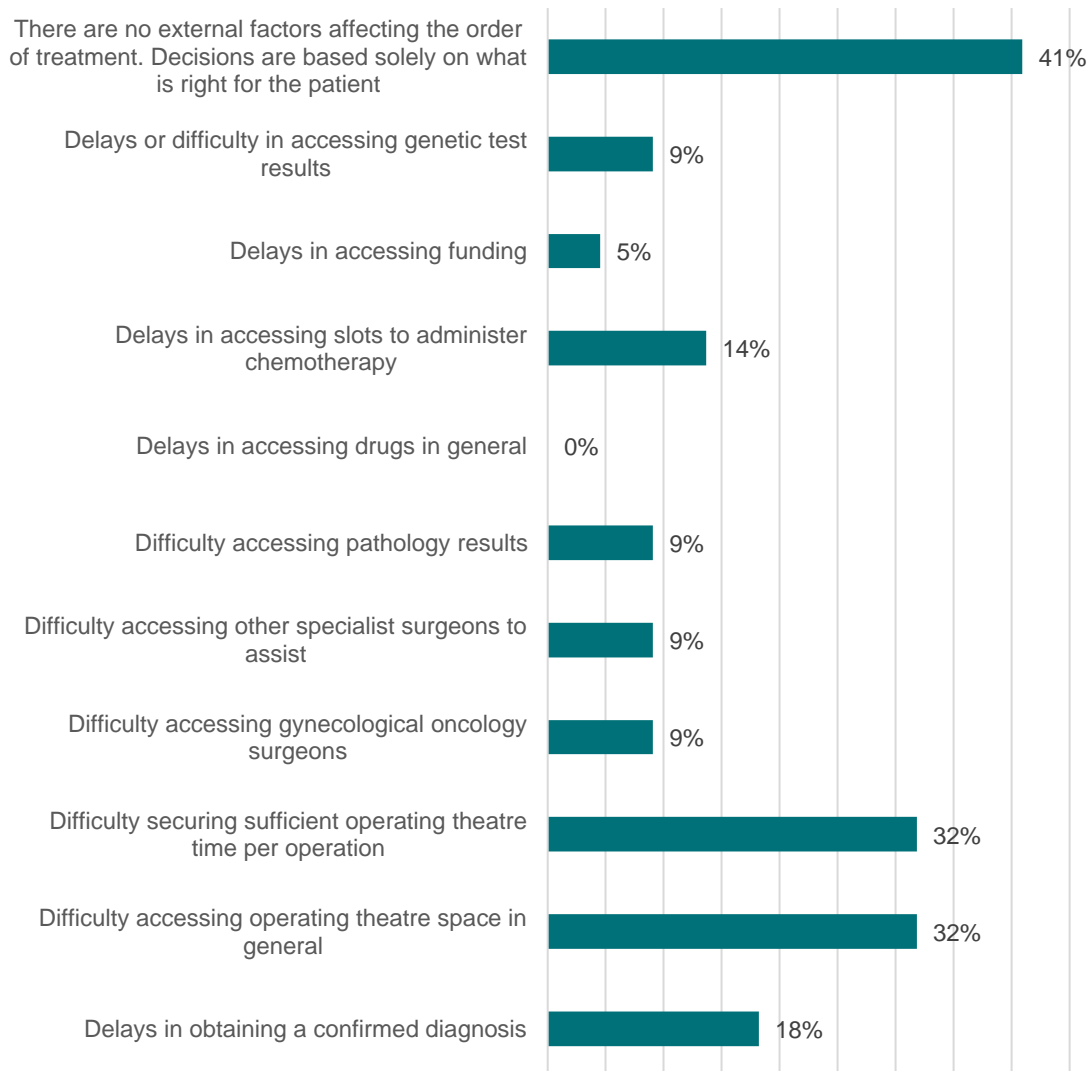
“Our wait for surgery is six to eight weeks at present. This fluctuates during the year but is at least four weeks. If emergency surgery is needed it has to be performed in the evenings or at weekends. It’s really bad, really bad. It is definitely getting worse, and has deteriorated in the last year. I don’t know how my centre relates to others in the region, but it is an issue across the cancer types due to an increase in evolving technologies, for example laparoscopic surgery, and the fact that more patients are going in to tertiary centres”. **Dr Laurie Elit, Canada.**

Australia is another country facing challenges:

“There are real and increasing pressures on the system. We are seeing more women in the tertiary centres now than the infrastructure can manage. It puts enormous pressure on the system. It starts with just trying to find the time to see these women, which we manage, but there is a very real issue with availability of theatre time, ...and infrastructure to care and support them..... We are very much at crisis point being able to manage our patient load. In the last three to four years it has become really a critical issue where part of the decision about patient management may well be made about what is available in a timely fashion rather than what is best for women.”
Professor Peter Grant, Australia.

The online survey respondents were asked about factors that delay the start of treatment. Delays in obtaining a confirmed diagnosis (8/24), difficulty accessing theatre space in general (6/24) and difficulty securing sufficient operating theatre time per operation (5/24) were the most commonly cited main reasons, and also scored most highly for the option ‘contributes to delays’. Indeed, responders showed that a significant proportion admitted that often decisions about patient management were affected by a number of issues other than what was considered best for the woman in question, and the same three issues were most commonly cited, with access to surgical time (in general and per operation) each affecting 7/22 respondents. Only 9 of the 22 (41%) respondents said there were no external factors affecting the choice of treatment, and that decisions were based solely on what was right for the patient.

WHAT FACTORS DETERMINE THE ORDER OF TREATMENT? N=22



Even when a network of specialist centres exists and works well, there can still be variations in outcomes between specialist centres. This UK clinician spoke about the need to recognise that the right people need to be in the right place for the right operation, and with services organised accordingly:

“In the UK we have got that people should be treated in specialist centres...I’m not saying that all gynecologic oncology surgeons need to be able to do ultra-radical surgery, but you need the right people for the right operation. So in some centres, one highly skilled and experienced surgeon may be able to do the [complete] operation, but elsewhere it might be important to bring in the expertise of a gut or urology or bowel surgeon. The NHS [National Health Service] is not very good at enabling team working across different specialities but ovarian cancer is no particular respecter of anatomical boundaries.

People will often think you need new drugs, but that comes [later], but it’s the stuff that happens up to then.... You have to have enough surgeons, enough

operating theatres so that women can be operated on the next week. Not four weeks later. You need to be able to operate on them (clicks fingers) like that. Because in advanced ovarian cancer three weeks WILL make a difference between being pretty well or pretty unwell.”

Professor Iain McNeish, UK.

WORKFORCE – SPECIALIST SURGEONS

In terms of workforce – with particular reference here to gynecologic oncology specialist surgeons, the situation is varied:

In Valencia, in **Spain**, **Dr Lucas Minig** has been working to develop specialised services and train new fellows in gynecological cancer:

“We cannot offer good treatment for patients if we do not have enough well-prepared surgeons. We need to train more fellows in Spain. We have obtained ESGO accreditation to train more. We have one fellowship at present, and will get a second soon. It takes three years to train. The ESGO programme is two years, but because we don’t have a high volume of patients they have allowed us to train over three years.... The best strategy is to start with a good surgery. Then we can do everything else we want. But if we don’t start with that, then anything we do in future is not useful, and expensive. “

Dr Dragos Median in Romania says there are very few specialised clinics for women with gynecological cancer, and there is no special fellowship training programme dedicated to gynecologic oncology. Most operations are carried out by gynecologists.

In **India**, **Dr Manas Chakrabarti** outlined a major lack in trained workforce:

“In terms of young workforce there are issues and frustration. I hope things will improve because gynecologic oncology was not a recognised separate speciality in India until recently. There were only three recognised training posts for gyn-oncology teaching in the whole of India which I think is shocking. We need a lot more focus on audit/teaching/research and a lot more people in gyn-oncology. There are now some more training posts, barely into double figures, which is scanty for a country with a 1.3 billion population. India has had hardworking gynecologic oncologists though – like me, many got trained abroad and returned with a passion. But we need an awful lot more.”

A gynecologic oncologist from Brazil said there is a shortage of both gynecologic oncology surgeons and oncologists to treat women with gynecological cancers. They estimated that just 20% of women with ovarian cancer have their surgery performed by a gynecological oncology surgeon. Between 30 and 40% of women are optimally debulked. Surgery is often performed by gynecologists or general surgeons (‘inadequately’). Often gynecological oncology staff are made to work in the emergency department, and only a few are left in the unit to do the routine work. This

seems to be the major issue. The impact is enormous. Treatment usually starts 8-12 weeks after diagnosis, primarily because there are so many patients, so few staff and many administrative problems. They also estimated that 95% of women start with chemotherapy as their first treatment.

With regard to **Hungary**, **Dr Zoltán Novák** said,

“We have more than enough gynecologic oncologists who think they are able to do it properly, but they are not in each corner of the country. Workforce will not be the problem, there are lots of people who want to do this and have an interest in learning new things, and to be a better surgeon...”

MULTI-DISCIPLINARY TEAMS (MDT)

MDT management is universally seen as a good thing, and even where there are no trained surgical specialists, such as in Romania, many patients get reviewed by an MDT. Time pressures though impact on the ability to hold such meetings and to include the involvement of other professionals.

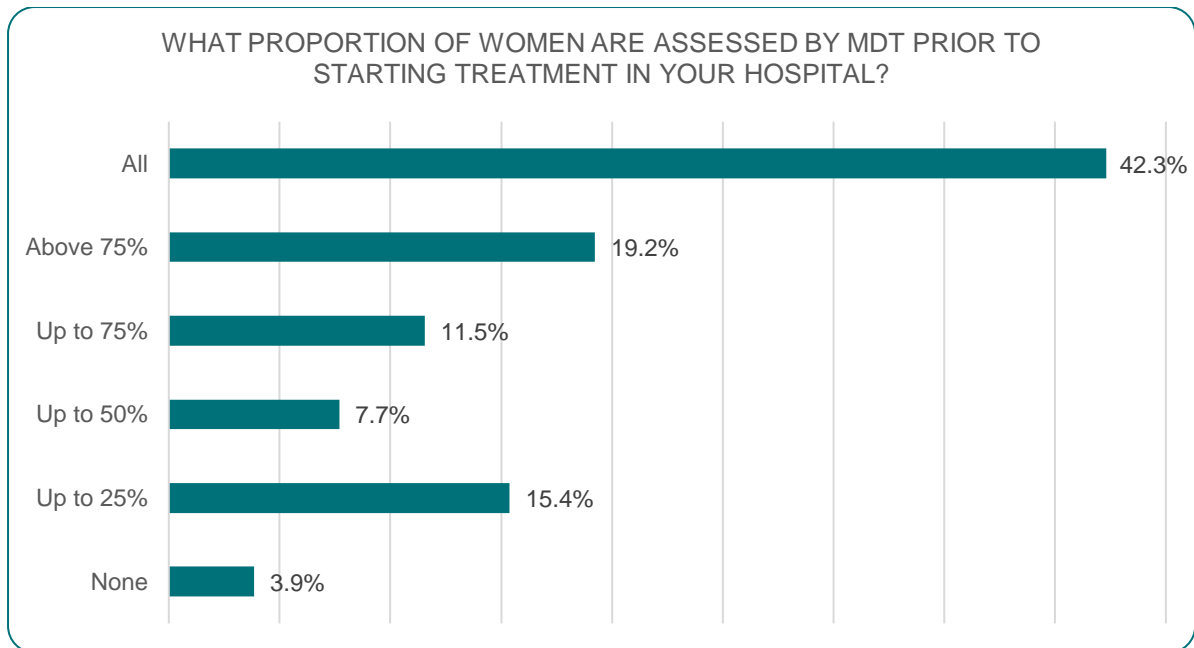
“There is only one palliative care doctor at the cancer centre, so they do not attend MDT meetings, in fact I rarely actually see them... At the MDT meeting – it’s so bad we have one meeting with radiology in the morning, and then with pathology, medical oncology and gynecologic oncology in the afternoon. It’s because we cannot get everyone together at the same time because of workload.” **Dr Laurie Elit, Canada**

A Japanese clinical oncologist highlighted that the MDT only met occasionally. They estimated that just 25% were reviewed by an MDT prior to treatment beginning. In Brazil the figure was also 25%. A gynecologic oncologist in Spain highlighted that all patients at their hospital are assessed prior to treatment.

All three UK respondents said all women were routinely assessed by MDT. One commented that there was an excellent set up for MDT in the UK. Another however noted that the caseload of seeing all patients was very challenging, because it was difficult to maintain proper concentration during extremely lengthy meetings. The third UK clinician highlighted that MDTs can delay the pathway, and that ‘we should be promoting good clinical care with ratification at the MDT rather than an overall reliance on the MDT to make all the decisions’. They gave the example that invasive radiology biopsy is often only done after MDT review and should be considered earlier.

All the German responses reported high (and mainly complete) MDT levels of assessment, and at all key points in time (leading to diagnosis, before treatment, on recurrence).

Of all the online survey answers the proportions were as follows:



In terms of other professionals who attend MDT meetings almost a third never have a palliative care specialist present, only a third have one attending regularly, and almost a half never have psychological or psychiatric specialist involvement, and only one in four have regular involvement.

WORKFORCE - OTHERS

The supply of trained specialist surgeons has already been discussed, but several points were raised by clinicians about the lack of other specialists, for example oncologists, pathologists, cancer nurses, stoma specialists, psychologists, and palliative care.

“We have a supportive care unit, without psychiatric involvement or psychological counselling, but it is very strapped for resource. Palliative care is not well organised. We do have access to nutrition and physio, but exercise after first line treatment, getting your pre-survivorship status back are poorly done in our environment. The patient has to go looking for it. I’m trying to use things like physiatry (rehab medicine) to try and augment what little we have.” **Dr Laurie Elit, Canada.**

In addition, in her hospital in Canada, there are issues accessing pathology services – with long waiting times for diagnostic biopsies.

“Sometimes we cannot take part (in clinical trials) as we have long waiting times for diagnostic biopsies (invasive radiology), it takes a month to order a biopsy, and then between two and four weeks to get the result. If I take a patient to OR [operating theatre] it takes a month to get the pathology back. If you want a CAT scan, it can take a month in our centre – an MRI – all of these things take a while”. **Dr Laurie Elit, Canada.**

A clinical oncologist from the UK highlighted the lack of junior doctors as a permanent problem, and one which was only likely to be exacerbated by Britain's departure from the European Union (which they also said would cause nursing numbers to 'really suffer').

In **Romania, Dr Dragos Median** says there used to be problems with pathology reports, but this has improved in the last year, but issues remain with imaging:

“Pathologists didn't use to report the grade of the cancer, but since Olaparib has become available as a maintenance therapy, it is now commonplace to report on grade to identify high grade serous patients. The pathology reports are much better. There are problems with access to imaging.... TVU is the main test (and access is ok) but there are delays in getting CT or MRI depending on where you live. In Bucharest it is two to three weeks, but in other cities it could be one to two months or even more.”

Professor Peter Grant in Australia is clear on the benefits of wider team involvement:

“In the Mercy Hospital we are very fortunate to have a very interested psycho-oncologist as part of our unit, who we make extensive use of to manage depression. And we are now starting post-chemotherapy rehabilitation programmes. It's not easy to access in many centres. It has a huge benefit on quality of life.”

The Japanese clinical oncologist who responded online said that many of the 'other services' – such as palliative care, psychiatry, psychological support, nutritionists, physiatry, counsellors were not recognised as an essential part of care by the National Health Insurance System, and that most hospitals will not pay for these services.

Germany however stood out in the online survey with all 6 respondents to the online survey saying they had access to most if not all of the additional specialists, though one clinician did comment 'Good is never good enough...'. There was also concern that the 'economisation of medicine is hampering optimal workforce planning in many centres'.

Looking at all the online results, 55% of respondents said they had sufficient workforce in their hospital to treat women with ovarian cancer as they wished. 45% said they did not. By far the most common request was for more nurses (7/9).

There are major differences in the role of nurses. In some countries (Canada, USA, UK) nurses play a more active role in support, treatment and follow up. In other countries there are rarely specialised cancer nurses (trained and dealing only with gynecological cancer patients):

“We are not well organised to give a good role to the nurses in terms of supporting the patients. I think this is something that should be improved.”
Dr Sandro Pignata, Italy.

Dr Zoltán Novák in Hungary said that the situation was even harder when treatment took place in regional hospitals:

“Their level of care is definitely not the same as in a specialised centre. This is valid for surgery, chemotherapy, nurses, stoma therapists, psychologists and of course it has multiple consequences on their level of care.”

Clinicians in the online survey were positive about the role the nurses currently perform, and how that might develop in future, but recognised that there was a lack of recognition for the role, a lack of training and a lack of funding that might hinder this.

ACCESS TO TREATMENTS

Clinicians in Italy, and Hungary were very positive about their ability to access new drugs. In Romania, they are positive about the forthcoming approval of Bevacizumab as a treatment for women. But in other countries, for example in Canada, the situation is not so positive:

“In Canada the biggest challenge for me is access to various agents for chemotherapy or biologic therapy for treatment. Canada is pretty restricted, and you have to have a high level of evidence to get it approved, and then to get it funded, there is a whole other level of process at the provincial level to get it covered for patients. For example, we have only just got access to Bevacizumab for women who are sub-optimally debulked for upfront treatment, or as 2nd line treatment for platinum sensitive women. Canada is only just looking at parp inhibitors, and currently they are only available on compassionate release or clinical trials.”

Dr Laurie Elit, Canada. [Since this interview, access has been agreed.]

In Spain, access to drugs is determined region by region.

“In the last two or three years we have been discussing Bevacizumab for treating patients with advanced ovarian cancer. In other regions they have different indications, regimes and drug doses because the two biggest studies used different schemes. Different regions approved one or the other. Patients cannot transfer treatment to another region, except by paying themselves. Some patients change affiliation and rent an apartment in a new region to access treatment”. **Dr Lucas Minig, Spain**

In general, respondents to the survey said access to drugs was not an issue in their country (90%). However just under half of the respondents (9/20) said there were occasional delays starting treatment with drugs. The main reason was difficulty accessing slots in chemotherapy suites (4/8) followed by waiting for pathology results (3/8).

One UK clinician highlighted that they wanted access to some of the newer drugs for example Bevacizumab for relapse, and Olaparib and Niraparib as maintenance treatments upon first relapse. This clinician also highlighted that it can be hard to get treatments slots in the chemotherapy unit, and that this can occasionally cause delays to treatment. Another UK clinician (surgeon) commented though that one

factor that should be addressed was to improve the attitude towards ovarian cancer amongst some oncologists, who they said regarded ovarian cancer as a disease to palliate from primary presentation.

One Canadian clinician called for access to Rucaparib, Nuraparib and Paziparib for all patients.

CLINICAL TRIALS

As with access to drugs, thoughts on clinical trials provide mixed responses. In some countries systems are advanced, and there is a strong focus on trying to include women in trials. Very positive comments came from the clinicians in Spain and Italy. In other countries people are finding it hard to be able to participate in time (due to delays in tests or regulation), or difficult to get through the added bureaucracy. An example of this has already been cited from Canada, where delays in pathology reporting impact on ability to participate. **Dr Laurie Elit** also from Canada commented on the increase in regulatory burden as trials become more complex, but is hopeful for the future:

“The hope is we can make them less complicated and less regulated. There have been improvements in Canada – Instead of everyone having a Research Ethics Board, they are becoming more centralised in the province. I’d like to see that too for the costings of trials (financial evaluation) – that would be great, because currently every hospital has to sign on and do their own financial evaluation as to whether they can do the trial or not. Clinical trials as a concept is great, but it’s the details where we struggle.”

Professor Peter Grant in Australia is similarly concerned about the need for greater infrastructure to participate in trials.

The reporting requirements are stricter and increasing significantly which makes it harder to run – data collection is much more onerous and difficult. It requires personnel and funding.”

There is a recognition and plea on the importance of clever trial design, particularly in determining who will benefit from what, making cost effectiveness better:

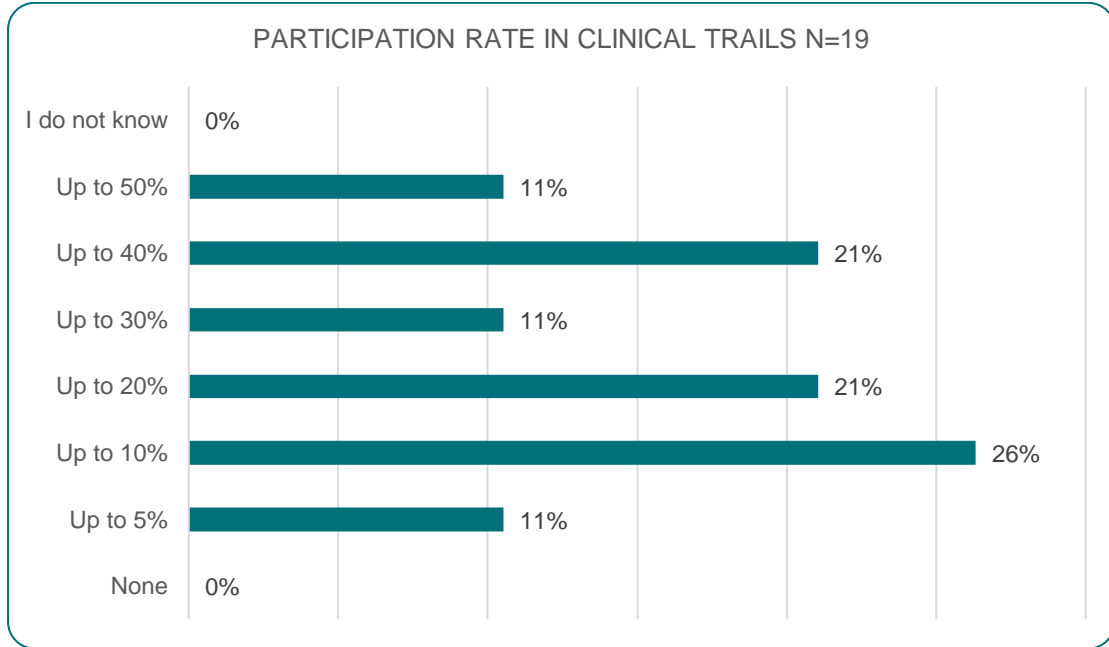
“You need proactive, clever design of trials upfront, even if you are recruiting everyone. You need to stratify in advance, not retrospectively, and look at subgroups, perhaps four or five, so that you’ll be able to say this drug works brilliantly in sub group A or whatever. Then the cost per QALY (Quality Adjusted Life Year) becomes much better..... It’s not for want of trying, it’s just very difficult.” **Professor Iain McNeish, UK.**

Dr Dragos Median from Romania, hoped that European Law could help women in Romania access new drugs in trials.

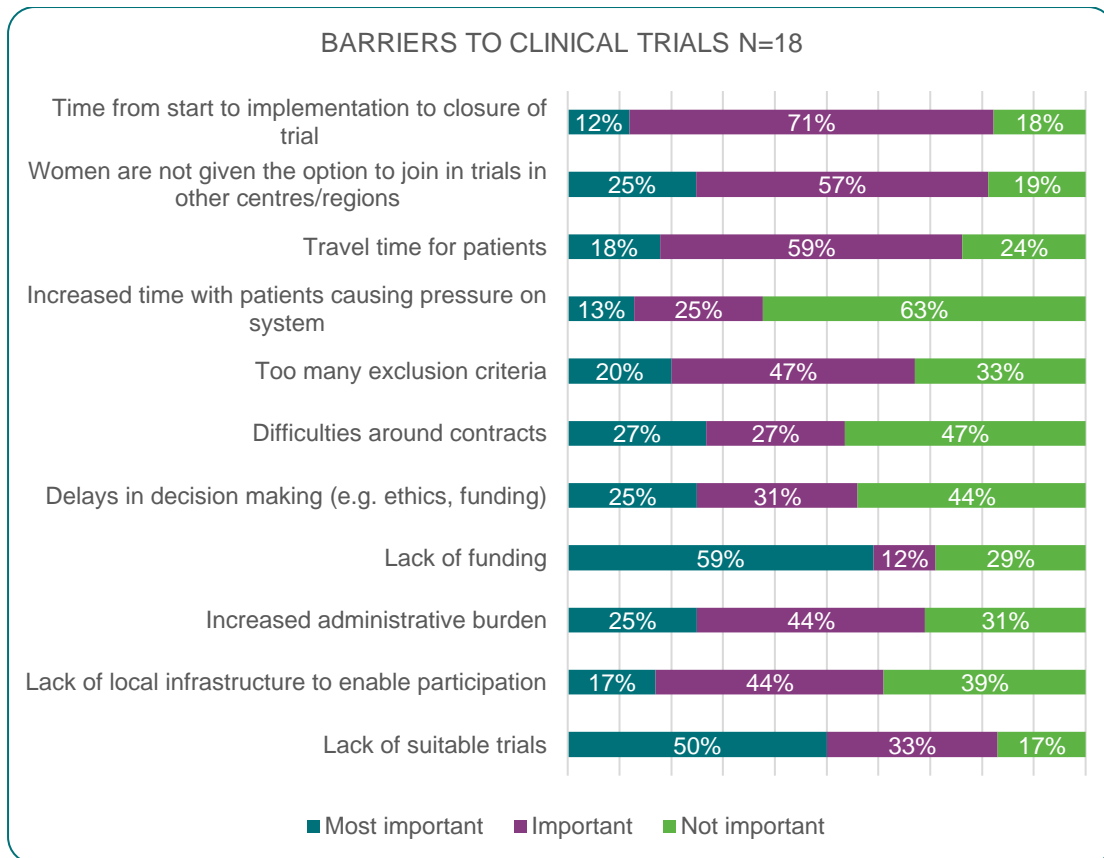
“There is a European law, which allows women to travel to another country to take part in trials if they are not available in her country, but it does not happen. I don’t know how to make this happen, but it’s important for women

to have the chance to get the drugs. In Romania it's not fair for a woman not to have access to a drug, just because she is not from Hungary or France.”

Respondents to the online survey were asked what proportion of women being treated in their hospital participate in clinical trials. The range of answers was as follows:



Respondents to the survey were then asked about barriers to clinical trials.



GENETIC TESTING

One of the most encouraging advances in recent years, according to the clinicians, has been about the potential for better treatment, and primary prevention in relation to those women who have a faulty BRCA 1 or 2 gene.

There has been a radical shift towards testing women diagnosed with ovarian cancer but it is still not yet as widespread or accessible in a timely fashion as it could be.

“Understanding that 10-15% of women with high grade serous ovarian cancer will have a germline BRCA1 or 2 mutation has been a game changer. We are now offering testing to everyone with high grade serous ovarian cancer, then not only can we identify those who could benefit from Parp Inhibitors, but we can also identify daughters, sisters, nieces who may be at risk. We [his Scottish group] are just publishing our experience of open access genetic testing, and half the people we found with a germline mutation had no family history – they would have failed the test for accessing the test based on family history. Parp inhibitors will certainly help. Whether we cure, we don’t know, but we can certainly help them live longer.”

Professor Iain McNeish, UK.

In Romania, access to genetic testing is provided by a pharmaceutical company, and in other countries such as Italy, regional control of health budgets is impacting ability to obtain the test, despite national guidelines.

“There are national guidelines (2015) which allow women with ovarian cancer to be tested independent of their family history for BRCA mutations...Health government is not central. There are 20 health regions, and each region adopts its own health rules and can decide what they will pay for. Some are paying for it, some are not because of financial issues.”

Dr Sandro Pignata, Italy.

A Canadian clinician said that genetic testing took six to 12 months, primarily because batch testing holds up the process. Another Canadian clinician highlighted that genetic testing took place at another hospital – over an hour away.

Another important aspect of genetic testing is access to counselling. For this clinician in Canada, delays are a real issue:

“We put referrals in when we have the pathology, but it takes nine months to get counselled. We will be in trouble if we have upfront parp inhibitors approved for treatment.... As the waiting times are so long. The whole process will have to be condensed. We only have blood testing (not tumour testing, which would be quicker – but they are not validated in the Ontario setting – there are very few labs approved for testing). We are ok for second line treatment, as they will have had their genetic counselling by the time they need this treatment.” **Dr Laurie Elit, Canada.**

Access to counsellors was also an issue for a medical oncologist in Australia, where the wait is three to four months in their area. However, they pointed out that if they do ‘mainstreaming’ for approved indications then the results are usually there within four to six weeks.

In the UK there were reports that it takes two to three months for the process to be carried out. A medical oncologist highlighted that the slow element for them was waiting for the blood results.

A gynecologic oncologist in the USA said it would take a total of 14 days to go through the process from suggesting tests, getting counselling, and obtaining the results.

In Japan, it was highlighted that women pay for genetic testing themselves (the women’s survey highlighted the rate of genetic testing was very low amongst Japanese women with ovarian cancer). The process from suggesting genetic testing, to counselling and results takes about three months for the clinical oncologist who responded, but they said this means that it can affect the order of treatment or delay the start of treatment. The clinical oncologist was very keen that in future, genetic testing be covered by the National Health Insurance Scheme in Japan.

In Brazil there are no guidelines as to who should be offered genetic testing.

DATA EQUITY

The issue of genetic testing, as raised by two clinicians, highlights the issue of data equity and the role the World Ovarian Cancer Coalition could have in highlighting this issue:

“There is the opportunity for good quality research. Sometimes we are so embroiled in providing day to day care that we almost become consumers of science – we forget to contribute to it. The patients here have a different

genetic profile to Caucasian women with the disease. We need powerful research in the local population. That is why after a tiring busy day looking after patients, I am here in the lab trying to forge some collaborations, and trying to persuade the government to listen. Look, we are following the research of the Western World. That is fine, but we need to make sure it is valid in our scenario too. Take for example the incidence of BRCA testing in our local population. We do not even know the local incidence. We need to sharpen all these to make the treatment meaningful for the patient.”

Dr Manas Chakrabarti, India.

“What we do know, for breast cancer too, is that these women (Asian, black) tend to get ovarian cancer a whole decade younger, but nobody understands this, what happens to these people, because the literature is extremely dominated by Caucasian people. I’m not sure we have equity of access, or equity of knowledge certainly. I’m sounding resentful here but we spend bucket loads of money providing an extra two weeks of progression free survival but we can’t be bothered to find out some of these basic issues that affect the vast majority of women in the world diagnosed with ovarian cancer, that today do not happen to be in the driving seat. That will change but it will take time.

For the World Ovarian Cancer Coalition, this is a very important thing to talk about – and I would be happy to come and spout about this – I feel particularly strongly. We are managing very diverse groups of women based on information that is completely Caucasian in origin. This is a big issue for us in Birmingham and have started doing a matched study in Birmingham and Punjab.” **Mrs Sudha Sundar, UK.**

The clinical oncologist in Japan said there was not sufficient data regarding local populations; they would like to see more complete cancer registration; and more data on basic biology and different types of ovarian cancer. This view was echoed in the response from Brazil and Spain. Most clinicians in the online survey (75%) said they wished to see more complete data in cancer registries (local or national).

Dr Dragos Median (Romania) says that basic data is lacking in his country:

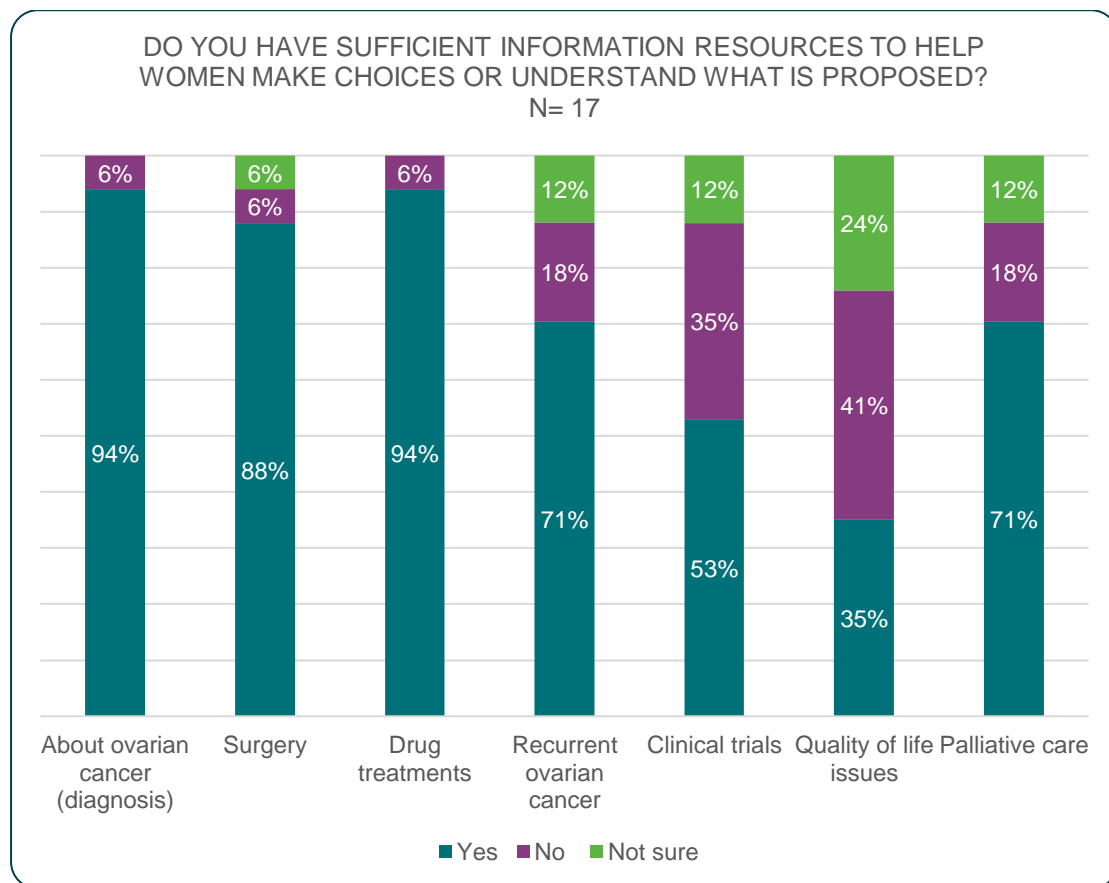
“There is no collection of cancer data, no national cancer registry. In Romania there is just one regional registry that covers less than 15% of the country, and this data is used to extrapolate national figures for Globocan. Our country has tried to introduce national collection, they tried to put it on the doctors, but they didn’t have the time to complete the database, then they tried others but that did not work. I would be curious how others have achieved national registration.”

The Australian clinician was particularly keen to stress that there needs to be not just better data, but better information for women diagnosed with different types of ovarian cancer, and that all too often generic terms are used:

“There is one thing that confronts me – the lack of explanation that this is not one disease – and there is not general recognition. The community information and perception are lacking. Ovarian cancer has a much broader

disease profile than breast or pancreatic cancer. There is a vast difference between low grade borderline disease in a 24 year-old women and high grade serous in a fifty year-old woman. It causes a lot of confusion and concern for women about their long-term outlook. Every woman should be told what sort of ovarian cancer they have, and what it means in the scheme of things.” **Professor Peter Grant, Australia.**

In Japan it was suggested that whilst there is good information about the disease in general and treatments, there were gaps when it came to good information about clinical trials and quality of life issues. This was also highlighted in Canada. The gynecologic oncologist in Brazil said there was insufficient information for women – about all issues. Some respondents felt there was sufficiently good information on most aspects of care. The summary of responses is in the table below:



QUALITY OF LIFE

In the online survey, most clinicians (44%) felt that not enough was done to help women get the best quality of life. 38% said yes, and 18% said they were not sure.

Most would like to be able to offer women a wide range of services, but in particular the strongest support was for patient navigators, psychologists, palliative care specialists and nutritionists.

Most (63 to 82%) of respondents were supportive of

- Information to help women make choices about treatment.

- Information to help clinicians better understand quality of life issues.
- Data to help clinicians better understand quality of life issues for women.
- And most commonly support to help women with anxiety or depression.

Issues relating to quality of life, according to **UK clinician Mrs Sudha Sundar**, are extremely important to understand, and document.

“We are running a study commissioned by NICE (National Institute of Health and Care Excellence) to look at patient reported outcomes after extensive surgery. If you buy people four months of extra time, but for that they feel shit – we honestly have to ask ourselves, or at least be honest with the people we are treating that ‘we can do this – it might give you four months but this is the price you will pay for that’ – in terms of stoma, or pain. This is what we are finding out. We have to be honest with the women.”

Professor Peter Grant in Australia, is heavily involved in researching quality of life, and believes progress is beginning to be made. He was keen to highlight:

“Quality of life issues have been under-measured, under-reported and under-managed for years. At least we are now beginning to develop systems.... It’s far from being a mature system but it is happening.... I think we certainly underestimate the effect of depression which is under-diagnosed and under-treated (not necessarily drug treatments but talking therapies too). We are becoming increasingly aware of the importance of physical therapy during the recovery phase, and how it should be an essential part of our discussion with every woman.... The evidence is overwhelming that this is a useful strategy.”

An Australian medical oncologist highlighted in the online survey that in their hospital not enough is done to address quality of life issues, and that clinicians often get caught up with the treatment, and some quality of life factors get forgotten or neglected. They wanted to see more information for women on quality of life issues.

German clinicians were largely very supportive of quality of life being a focus for activity to improve the experience for women, and to collect data on patient reported outcome measures.

PATIENT SUPPORT AND ADVOCACY

Dr Manas Chakrabarti returned to his home city of Kolkata in **India**, following his training in the UK. In addition to trying to set up a gynecological cancer service, he is trying to build up not only research, but patient support.

“We still lack the patient support charities like you have in the UK. I believe the patient self-support group is absolutely important in terms of modern cancer care, particularly [women with gynecological cancer] where it is not just cancer care, but very important emotionally to the patient – far beyond conventional medical science. It affects the fertility, sexuality of the women, unsettles their religious belief, modifies their survivorship priorities.”

Of the 16 clinicians who responded to the online survey, just two said their hospital did not run support groups for people with cancer. 11 said they either had groups for anyone with cancer, women with cancer, or women with gynecological cancer. Just

three said there were groups for women with ovarian cancer. It should be noted here that in the results of the Women’s Survey, women overwhelmingly said they would prefer to be in groups for women with ovarian cancer, rather than other cancers.

Dr Manas Chakrabarti also believes the World Ovarian Cancer Coalition has an important part to play in raising the voice of women and their families.

“There is a desperate need for vision change. We need effective collaboration amongst national and international institutes in all aspect of gynecological cancer care, including the setting up of patient self-help groups.....Patients and family will raise their voices and ask for more, and collaborate with government, which is far stronger than our voice as health care professionals. We need some global help to tackle the social stigma (of cancer). I have a young patient with a germ cell tumour (early). She has a 98% chance of being cured. I asked her to do some exercise – to do some walking. She comes to me after three months’ time and says ‘I cannot go out of the house because wherever I go, be it the grocery shop, the bazaar (market), everyone says why are you coming out of the house? You have cancer’. India has a long way to go on this. Many believe cancer is contagious – that if they sit beside them they will get cancer by default.”

Dr Laurie Elit in Canada also believes there is great benefit in good advocacy, and that it would be useful for clinicians to improve their skills:

“Societies like Ovarian Cancer Canada have made a huge impact – there is strength in their lobbying at a federal government level. We don’t have that lobbying for cervix or endometrial cancer, but it is a real asset for ovary. As clinicians we are taught about the disease and how to deal with it, but not about advocating for resources. We need to get polished up on advocacy and leadership.”

OPPORTUNITIES

All the clinicians interviewed felt there were significant opportunities to improve survival and quality of life. Their emphasis varied, and usually came as a corollary to the challenges they faced. For that reason, they are just summarised in brief here.

One UK clinician (Professor Iain McNeish) is a firm believer in marginal gains.

“You make everything a little bit better than it is, and you make a big difference. I don’t think there is one magical thing that you do -everyone getting Avastin or Olaparib is not suddenly going to cure everyone.”

The factors mentioned included:

- Improving knowledge amongst family doctors about the symptoms of ovarian cancer.
- Developing effective screening and early diagnosis techniques.
- Improving access to specialist surgeons.

- Educating gynecologists and health providers of the importance of specialist surgery.
- Tackling system delays and lack of infrastructure.
- The importance of sharing information, and learning from others.
- Improving data equity and data registries.
- Improving access to drugs.
- Making clinical trials more accessible.
- The role of parp inhibitors and genetic testing in terms of treatment and primary prevention.
- Understanding more about the different types of ovarian cancer, and how different communities vary in terms of data and profile.
- Increased focus on patient reported outcomes and quality of life.
- Provision of better services to support women, particularly support for
- Tackling the stigma of cancer in some communities.
- The need for more non- pharmaceutical research.
- Improving the advocacy and leadership skills of clinicians.
- Understanding your own national picture, and how your hospital might vary from that, and how your country might vary in relation to others.

And finally, several clinicians expressed the feeling that the World Ovarian Cancer Coalition had an important role to play in articulating and highlighting the challenges, and needs for progress. This was mentioned in particular when trying to convince national or regional bodies of the need for improved services.

“You have an international platform and if I am allowed to send across a clarion call, I would say that people here are in desperate need for good quality gynecological oncology services. If there is anything you can do in terms of training, government policy making, training for doctors and nurses, good quality research, our people will value that.” **Dr Manas Chakrabarti, India.**