

Advocating for Centralised Specialist Care for Ovarian Cancer across Europe

Dçn't Overlook

Advocacy Planning Toolkit

This toolkit was co-developed by the European Society of Gynaecological Oncology (ESGO), the European Network of Gynaecological Cancer Advocacy Groups (ENGAGe), and AstraZeneca with funding provided by AstraZeneca, as a part of the Ovarian Cancer Commitment.



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We would like to thank Assis. Dr. Maja Pakiz MD, PhD; Ane Gerda Zahl Eriksson MD, PhD and Prof. Dr. Viola Heinzelmann-Schwarz for their contribution to this toolkit.

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1. Introduction

Thank you for joining the Advocating for Centralised Specialist Care for Ovarian Cancer across Europe training programme organised by the Ovarian Cancer Commitment (OCC). Through this training, you have the opportunity to share and expand your knowledge with your colleagues. By discussing your insights and documenting best practices, you can build on your knowledge and add to your existing expertise in your efforts to advocate for the centralisation of specialist care for ovarian cancer patients.

Introduction to the toolkit

Now that you have shared information, experiences and expertise with your colleagues, we want you to be empowered with the tools you need to transfer your acquired knowledge to members of your organisation and other members of your community in your own countries.

As patient advocates who care for your work with ovarian cancer patients, you understand the challenges of this disease and the need for comprehensive care, including rapid diagnosis, multidisciplinary treatment and support for patients' well-being and quality of life.

This toolkit has been prepared to support you as you champion the importance of access to centralised specialist care for ovarian cancer.

How to use the toolkit

We have created this toolkit as an interactive modular PDF booklet, so that the content can be expanded as the training progresses, ultimately creating a fully developed guide to advocating for centralised specialist care. You can print off different modules as needed and find useful online links to further resources.

The toolkit features information on understanding centralised specialist care for ovarian cancer and how ESGO have worked on raising awareness of its importance and encouraging its implementation. The toolkit also supports your strategic advocacy planning in your own country with a step-by-step quide to introducing centralised specialist care as part of your existing advocacy strategy, providing practical advice on setting goals and objectives, stakeholder mapping, and creating a workplan and budget.



STAKEHOLDER MAP

DIARY PLANNER



Ovarian Cance









1. Introduction

You will also find a *lexicon* of key terms and a comprehensive <u>reading</u> *list* themed around key topics, such as effective advocacy, centralised specialist care and health literacy. Other resources in the toolkit include useful advocacy planning templates for <u>stakeholder mapping</u>, and <u>diary</u> <u>planning</u>, plus a <u>SWOT analysis tool</u> to help you set objectives, create a checklist of key steps and measure your success.

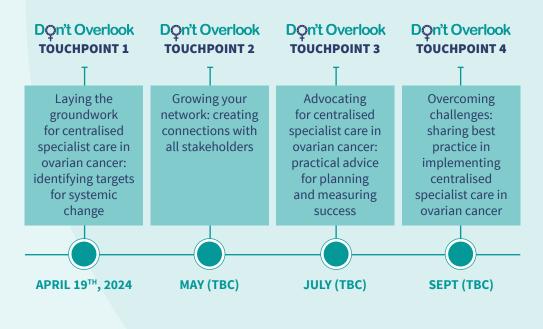
As we consolidate information and discussions from the workshop, we will add case studies from Slovenia, Norway, Germany, UK, and Hungary, including the advocacy landscape, details of actions undertaken, future touchpoints and local contact details for reference, plus a link to the ESGO website for live updates. <u>www.esgo.org</u>

Please also visit our Olivia website for guidance on cancer care. Olivia offers detailed information for every step of the ovarian cancer pathway, and includes four pathway sections: About Ovarian cancer, Primary Treatment, Ongoing Care, and Recurrent Disease at <u>https://ovarian.gynecancer.org/en/pathway-guide/</u>

Timeline of future sessions

We hope to have your continued interest and participation throughout 2024 with further touchpoints and activities including a peer-to-peer training webinar, sharing examples of best practice, and the development of useful tools and resources to support your advocacy efforts.

We have provided a timeline of the upcoming online meetings below. We hope you will join us and expand your knowledge of advocating for centralised specialist care for ovarian cancer.



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2. Centralised Specialist Care

What is centralisation of specialist care?

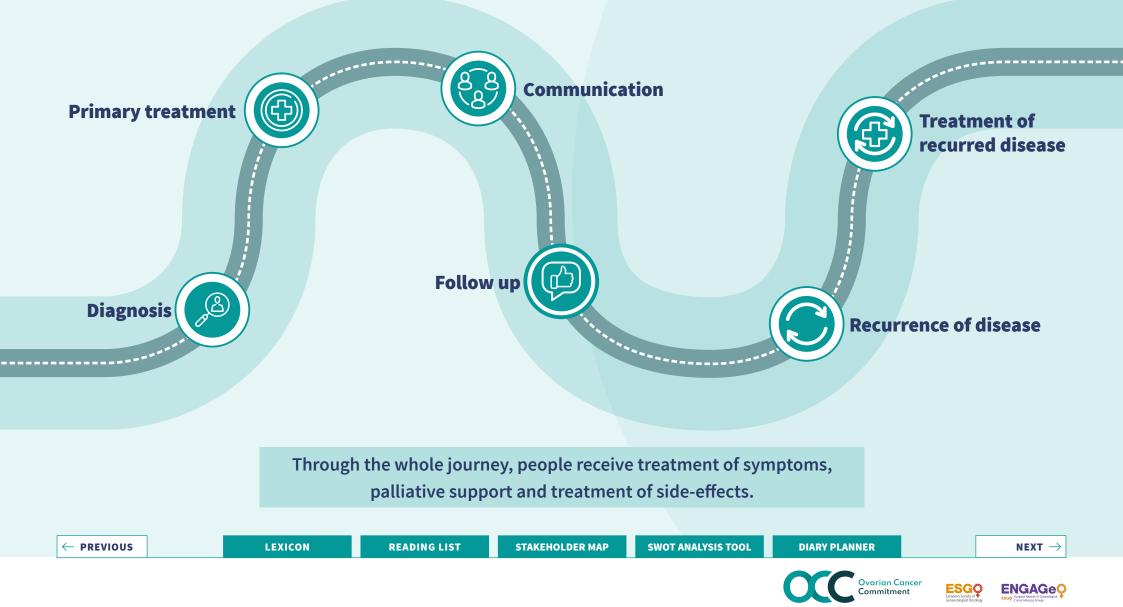






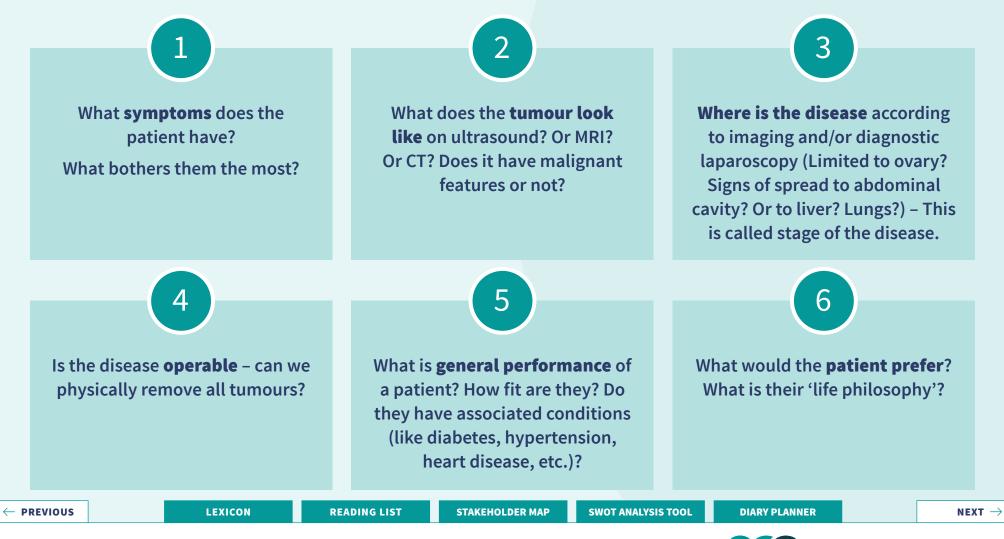
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The life journey of people with cancer





1. Diagnosis: What we need to know before starting treatment









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What kind of care is needed?

2. Treatment: We need to decide what treatment plan would be best, so we need close collaboration of:

Gynaecologist who is dedicated to surgical treatment of gynaecologic malignancies	Expert radiologist in gynaecologic ultrasound who is dedicated to diseases in abdomen	Pathologist who has experience in gynaecologic tumours
Medical oncologist who is also a subspecialist in gynaecological oncology	Anesthesiologists with an intensive care unit in the centre	 At a centre with blood transfusion, laboratory tests, CT scan available 24 hours/7days. The decision should be made at a multidisciplinary tumour board and with collaboration with the patient.





3. Communication with the patient

- The patient experiences a high level of stress at diagnosis.
- They may need support by doctors, close friends and family members
- They may need psychological or social support. Psychological consultation with someone with the skills and experience to communicate effectively can empower patients to make difficult decisions.
- A palliative care specialist means treatment of symptoms, not only end of life care (chronic pain, taking care of preventing losing muscles, relieving profound nausea, etc.).

- The gynaecological oncologist needs a high level of experience and skills in their field as well as psychological skills to communicate with the patient.
- The person who speaks with the patient needs to have experience and skills on how to deliver information so they come to the **best** possible care together as partners.





4. Follow up



The time when the patient treatment (surgery, chemotherapy target maintains therapy) is **finished.**



The patient may feel **distressed** – ovarian cancer patients report significant quality of life issues that persist after the end of treatment.¹



The patient does not have signs of disease.



Usually regular check-ups are performed. However, sometimes these are associated with higher level of stress, remind patient of their disease and are usually very quick (as too many patients need to be seen by one doctor).



The patient may experience long-term side effects - influence on quality of care.





5. Disease recurrence

- We need the same specialists, at the same table, at the same time, to discuss the best possible care.
- The patient should have access to new modalities of treatment, to be included in **clinical trials.**
- The patient should receive the best possible care, including symptoms relief, palliative support, psychological support, social support.

- **Symptoms** should be assessed by specialists dedicated to gynaecologic oncologic patients.
- **Specialists should have lots of experience** with patients with this condition.
- Communication should **empower the patient** so decisions can be made in partnership.

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What does 'centralisation of care' mean?

All providers of care are available within one institution or at least within closely collaborating institutions

Centralisation means in practice:

All patients with ovarian cancer should be **referred** to a limited number of institutions within one country.

Diagnosis and treatment is concentrated within only a few highly equipped hospitals with dedicated specialists. Institutions should have enough new patients for doctors to obtain experience and to have **financial capacity** to have all necessary equipment.

- Each country usually has its own **cancer registry** you can check for your country how many new patients with ovarian cancer are treated each year.
- Patients should be referred as soon as the first suspicion of cancer is made. The patient should go directly to such a centre and not to a
 general hospital.

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Levels of care



General hospitals

- Usually have **general gynaecologic departments** and deal with the most common conditions
- Do not always have blood transfusion, intensive care unit, laboratory tests or imaging (24/7).
- Doctors do not have special knowledge, experience and skills needed to take care of complex oncologic patients.



University level hospitals

- All specialists are subspecialists, with special skills.
- Usually have equipment and facilities, for chemotherapy for instance.

Note: There may be differences between countries.



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What are the benefits for patients if the care is centralised?

- The pathway between different specialists is automatic and smooth. The hospital has enough new patients they can afford equipment,
- All specialists are included in decision making.
- Specialists have enough knowledge, experience and skills to communicate with and empower the patient.
- All included specialists will be able to obtain enough **practical skills** to provide the best possible care.
- The hospital has enough new patients to **employ other staff** (psychologists, physiotherapists, social workers, specialised nurses, etc).

- The hospital has enough new patients they can afford **equipment**, laboratory tests and imaging being available 24/7.
- The hospital has enough new patients that they can establish a **structured education of young doctors.**
- The hospital has enough new patients to be able to include patients in clinical trials.





Why cancer care is not centralised

- Historically, **all doctors treated all diseases.** There were few hospitals and they treated all patients.
- Patients had difficulty commuting to the hospitals.
- Equipment is improving but becoming more expensive (MRI, CT, PET CT, etc.).

Fortunately:

- Knowledge is improving quickly.
- Specialisations and subspecialities are developing.

However - the organisation and financing of healthcare and attitudes of doctors may not follow these changes quickly enough.

ESGO stimulates centralisation of care. The help of patient advocacy groups are crucial.





Centres accredited in Advanced Ovarian Cancer Surgery

Ane Gerda Zahl Eriksson, MD, PhD





86 centres accredited in advanced ovarian cancer surgery in 23 countries Out of these: 63 regular accreditations 23 Centres of Excellence





ESGO Accreditation in Advanced Ovarian Cancer Surgery



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Centres accredited in Endometrial Cancer Surgery



19 centres accredited in endometrial cancer surgery in **11** countries



Out of these: 9 regular accreditations and 10 Centres of Excellence





Centres accredited in Endometrial Cancer Surgery



Launched in October 2022





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ESGO Accreditations in Ovarian and Endometrial cancer surgery

Accreditations and re-accreditations in ovarian and endometrial cancer surgery are held electronically in the REDCap platform.







Commitment

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Quality Indicators: Advanced Ovarian Cancer Surgery

			Society statement	Int J
	INTERNATIONALIOUENALIOF CYNECOLOGICAL CANCER	Quality indicators for a cancer surgery from th Gynaecological Oncolog	e European Society of	Gynecol Gancer: first pu
		Christina Fotopoulou ⁽³⁾ , ¹ Nicole Concin, ² Franço Andreas du Bois, ⁷ Denis Querleu ⁸	is Planchamp, ³ Philippe Morice, ⁴ Ignace Vergote, ^{5,6}	published as 10.11;
Published 2016 Updated 2020	For numbered affiliations see end of article. Correspondence to Professor Christina Fotopoulou, Gynaecologic Oncology, Imperial College London Faculty of Medicine, London SW7 2DD, UK; chlotopoulou@gmail.com CF and NC contributed equally. Accepted 24 January 2020	In 2016, the European Society of Gynaecological Oncology (ESGO) developed a list of quality indica- tors (QIs) for advanced ovarian cancer surgery with the aim of helping and auditing clinical practice. ¹ The QIs were based on evidence-based research, meet- ings of a multidisciplinary International Development Group, an internal validation of the targets and scoring system, and an external review process involving physicians and patients. The ultimate plan was for QIs to be used for self-assessment, quality assurance programs, and for certification of centers. More recently, a number of amendments were	The process of definitions and modifications are summarized as follows. The QIs for advanced ovarian cancer surgery were developed using a four-step evaluation process based on physical meetings of the multidisciplinary committee. The process was founded on the following values: (1) multidisciplinary international expert panel, (2) evidence-based medi- cine and expert consensus, (3) patient engagement, (4) external review process, (5) structured format to present QIs, and (6) strict assessment of conflicts of interests. This development process is outlined in Table 1.	136/IJgc-2020-001248 on 20 February 2020 Oncology.

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The ESGO Candidacy Countries Project

Prof. Dr. Viola Heinzelmann-Schwarz

How can we help the centralisation process in countries within the candidacy countries programme?





What defines quality of care?



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ESGO Centre Candidacy Programme

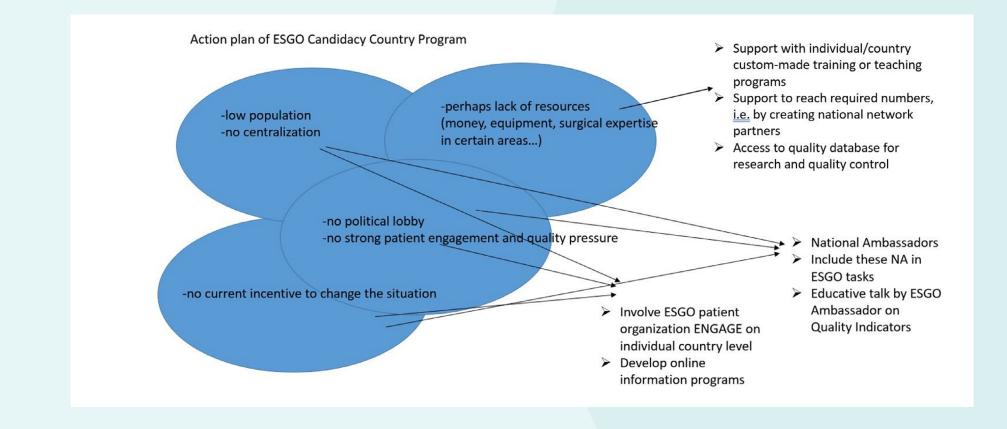
For countries without accredited centres

In 2022, ESGO initiated the Centre Candidacy Programme to assist these centres that may not initially meet the accreditation requirements, but have the potential to improve and provide comparable quality of care.



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Candidacy programme common problems



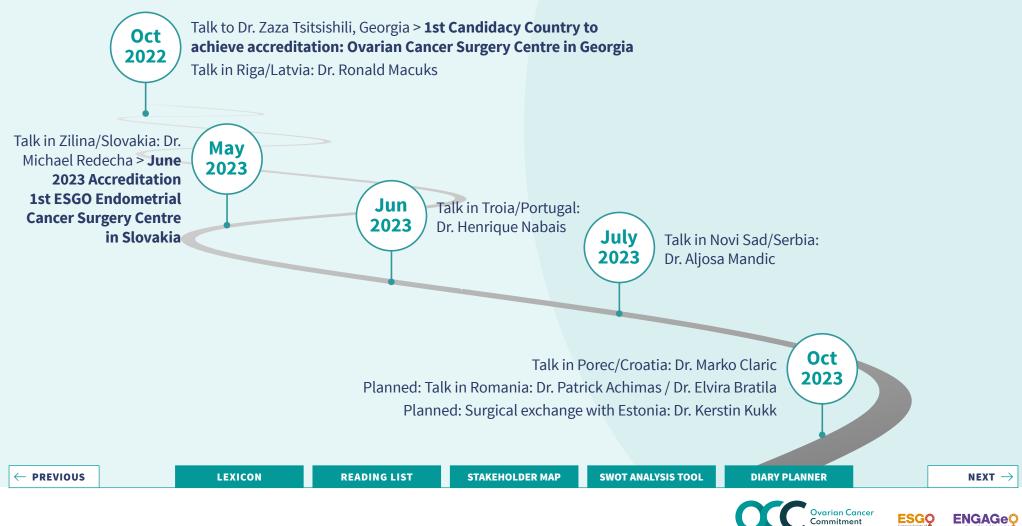


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Action 1: Identify, enable and collaborate with national partners

Visit to Candidacy Countries / Meet National Ambassadors





Action 2: Grant access and support to individual needs







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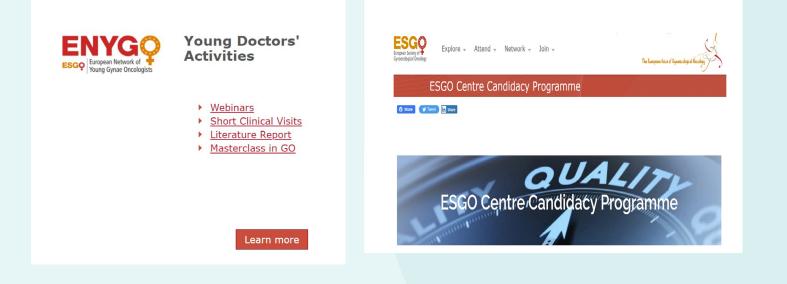
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Action 3: Involve ESGO support structures

- ENGAGE
- ESGO Centre Candidacy Programme
- European Network of Young Gynae Oncologists



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Action 4: Demonstrate quality during centralisation – the Swiss Pilot Project

Within the ESGO Candidacy Countries Programme, there will be a **second identical database for Candidacy Countries "Swiss Pilot Project"**

Swiss Pilot Project - non-accredited centres during centralisation

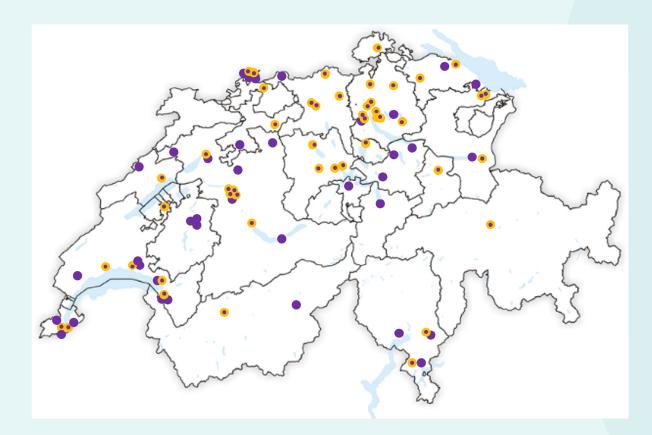
- Demonstrate existing quality
- Facilitate the step of becoming an accredited ESGO centre
- Ideal for research within the whole or parts of the network
- Quality can be proven before and after accreditation
- Data can be used by each participating country for their own research

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Short excursion to my own country

Complex gynaecological tumours – Swiss landscape



- Hospitals treating ovarian cancer in 2019
- Hospitals treating ovarian cancers + vulvar, vaginal and cervical cancer in 2019

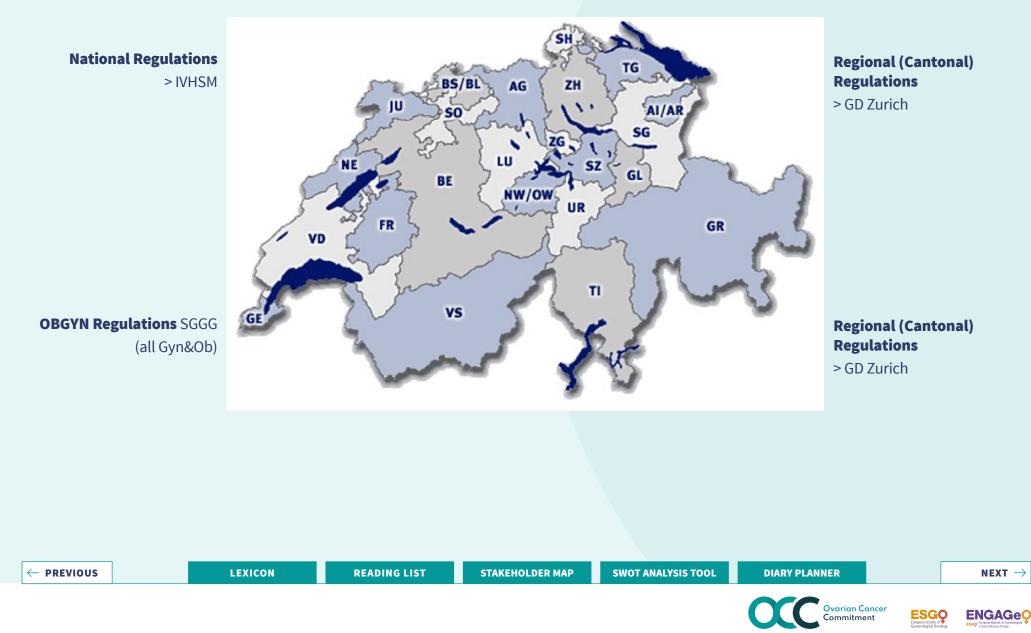
Data source: hospital medical statistics

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Government-driven centralisation process in Switzerland

Ovarian cancer 600 ovarian cancers newly diagnosed per year		Vulvar, vaginal and cervical cancer 130 vulvar cancers, 30 vaginal cancers and 250 cervical cancers newly diagnosed per year	Trophoblastic tumours (GTD) Incidence: 0.5-1.5 per 1000 live-births		
2019 806 cases in 85 Swiss hospitals		2019 79 cases in 48 Swiss hospitals	2019 3 cases in 6 hospitals		
 Not all cancer patients are recorded in the national cancer registry! The experience in some hospitals is low! 					

• Lack of quality leads to longer hospital stays and higher healthcare costs!

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IVHSM - March 2008 Art. 39 Abs. 2bis KVG

Intercantonal agreement on the regulation of highly specialised medicine

Process of ivHSM in Switzerland

- Led/implemented on national level by Country Health Law Organisation
- Head of HSM process Prof. Martin Fey, em. Prof. Med. Onc. Bern
- Advisory Board of Subspecialists in Gynaecological Oncology, led by Prof. Michel Müller, Berne
- Other members of Begleitgruppe: Prof. Seraina Schmid, Grabs; Prof. Mathias Fehr, Frauenfeld, Prof. Daniel
 Fink, Zürich; Dr. David Ehm; Prof. Daniela Huber, Sion; Prof. Viola Heinzelmann-Schwarz, Basel

- Diseases and definitions of minimal requirements decided (Aug. 2021)
- Requests for assignments open till Nov. 20 2021
- Review of applications
- Definition of continuous quality assessments > via ESGO Swiss Pilot Project (Database)
- Probably middle of 2024 start of HSM/specialised centres





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3. Strategic advocacy planning

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A step-by-step guide to introducing the topic of centralised specialist care in ovarian cancer as part of your advocacy strategy

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3. Strategic advocacy planning

Introduction

Ovarian cancer is the leading cause of gynaecological cancer death and the fifth most common cause of death in women.¹ By 2050, estimates indicate a 22.5% increase in occurrence and 32.2% increase in mortality across Europe.² The survival rate at five years is 48.6%.¹ Unfortunately, most cases are not diagnosed until the advanced stages of disease.¹ Early and rapid diagnosis can provide women the best chance for a positive outcome.1

Surgery is a powerful tool for improving chances of survival, but it must be performed by an experienced gynaecological oncologist.³ Data shows that women with gynaecological cancers treated in specialised centres or hospitals with specialist resources survive longer than those managed elsewhere.⁴ Centralising ovarian cancer care into specialist hospitals or treatment centres can improve access to gynaecological oncologists and multidisciplinary specialist cancer care teams, which may in turn help to increase the chance for survival and improve a patient's guality of life.⁴ Access to specialist care, however, varies widely across the globe.⁵

To reach these goals, advocates need to develop an effective and strategic advocacy plan for centralised specialist care for ovarian cancer specific to the local, country context. A good plan responds to identified needs, builds on opportunities, overcomes barriers and measures impact.

The aim of this practical step-by-step guide is to support and guide your advocacy strategy to support the establishment or optimisation of centralised specialist care for ovarian cancer in your country. The guide presents seven main steps to advocating for centralised specialist care with examples, plus guidelines and tips for setting goals, building your network and sharing your message.

This strategic advocacy planning guide has been designed to develop your knowledge and understanding of how to define and analyse the impact your organisation can have towards your desired goals, and to help you measure the outcomes achieved.

It is important to remember that you cannot do it alone. Reaching the goal of centralised specialist care of ovarian cancer is a team effort and this work can bring the stakeholders in your country closer together.

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3. Strategic advocacy planning

STEP 1:

Creating an advocacy situation analysis in your country

What is a situation analysis?⁶

A situation analysis is the first step in the process of creating systemic change. To reach your goal of implementing centralised specialist care for ovarian cancer, a situation analysis provides a framework to collect and study health, demographic and socio-economic data, to identify and understand the current status of ovarian cancer care in your country. It will also help you examine the social, economic, political and healthcare landscape you will need to navigate in your journey to achieve centralised specialist care.

How do I conduct a situation analysis?

To complete an effective analysis of your situation, you need to identify and gather information in four key areas^{6,7}:

- 1. The problem or challenge how serious is it and what is causing it?
 - Develop a problem statement, for example: 'Women with ovarian cancer need access to centralised specialist care in their country'
 - Conduct a desk review to find information about the problem and relevant legal and policy documents from sources such as your local clinical guidelines or data or, if you are struggling to find local information, look externally to WHO, peerreviewed journals and media reports
- 2. The people affected by the problem (potential audiences)
 - Collect data from key informants through in-depth interviews, focus groups, community conversations and stakeholder workshops
 - Conduct surveys (health, social service, religious or other facilities)
- 3. The broad context in which the problem exists
 - Take stock of what is happening in terms of centralised specialist care in your local area, country, or region
 - Note the policy and legal environment and its key stakeholders
- 4. Factors inhibiting or facilitating behaviour change
 - Determine who can help or hinder your advocacy efforts
 - Determine your access to resources and support systems
 - Evaluate beliefs and attitudes of key policymakers

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7. NCD Alliance Advocacy Institute (2023). Practical Guide to Strategic Advocacy Planning. Available from: https://www.ncdalliance.org/resources/practical-guide-to-strategic-advocacy-planning Accessed: 9 February 2024



STEP 2:

Setting priorities, goals and objectives

Your long-term goal is your vision for change, to implement centralised specialist care for ovarian cancer in your country. To reach that goal, you need short-term objectives to address the obstacles and find solutions to the issues along the way as you work towards achieving success.⁷

Using your advocacy situation analysis:

- Analyse and identify the problems, the situation and the availability of resources in your country.
- Decide which issue is your priority. For example, you may need to start by gathering more data or finding and talking with more stakeholders, e.g. HCP specialists in ovarian cancer.
- Write down the change you want to achieve, who will make the change and when you would like it to happen. A long-term goal of any comprehensive cancer control programme is to reduce cancer incidence and mortality and improve quality of life.8
- Determine specific short-term objectives:
 - o Create action-oriented targets that will help you progress toward your long-term goal.
 - o Objectives should be SMART (Specific, Measurable, Achievable, Realistic and Time-bound).8

Well-planned priorities, goals and objectives for your advocacy strategy will provide a clear roadmap on your journey to achieving your vision of centralised specialist care for ovarian cancer in your country.

 NCD Alliance Advocacy Institute (2023). Practical Guide to Strategic A Accessed: 9 February 2024 Cancer Control: Knowledge into Action: WHO Guide for Effective Prog 		 Ovarian Cano Commitment	er Escopensioner Society of Gynaecologial Oncology	



STEP 3:

Building a stakeholder map

As you develop your strategies and investigate the health and political landscape for ovarian cancer care in your country, you will need to understand the stakeholders you will be working with to achieve your goal. Stakeholders are individuals or groups who are impacted by the outcome of a project, such as patients, caregivers, support groups, health care professionals, researchers, parliamentarians and policymakers.

The political system and the individuals involved in public health decision making will play a key role in the outcome of your advocacy strategy. The first step is to identify the key policy decision makers and government bodies involved in centralised specialist care for ovarian cancer and how they may influence and affect your short- and long-term goals.

The key to understanding the power, influence, motivation and engagement of these stakeholders is to build a stakeholder map. This process will guide you in your evaluation of who is willing to support your advocacy efforts, how they may help and what processes you may need to achieve results.⁷

What is stakeholder mapping?

Stakeholder mapping is the process of creating a visual representation of everyone who has a stake in your strategy, plans and your ultimate goal in one place. In this map, you can document the roles and responsibilities of all the stakeholders and your relationship with them.

The benefit of creating a stakeholder map is that you can clearly see who can influence your advocacy plan and how they may influence each other. Through this process, you can improve stakeholder engagement and develop your relationships with key individuals in the overall strategy.⁹

How do I build a stakeholder map?⁷

- Identify decision makers with the power to influence your objectives and goals.
- Investigate policy-making processes and create profiles of stakeholders, their position, interests, relationships, views, opinions, and actions that are relevant to your vision.
- Categorise individuals into champions, allies and opponents.
- Determine your advocacy tactics and develop effective advocacy messages.
- <u>Create a map</u> that can be updated throughout your advocacy strategy, as stakeholders' positions change over time.





STEP 4:

Developing key messages

Effective communication with stakeholders, including policymakers, requires the development and planning of key messages to express your goals and vision clearly. Key messages tell people with influence why you are advocating for centralised specialist care for ovarian cancer and why you need their support.¹⁰

Key messages consist of primary and secondary messages. Your primary message should be simple, direct and appeal to all audiences. For example, 'Every year, thousands of women die from ovarian cancer because they have not been rapidly diagnosed and treated via centralised specialist care. Now is the time to change!' Secondary messages support the primary message and explain how it can be achieved. They should address the needs, perceptions and preferences of the target audiences.

Key messages need to demonstrate both the problem and a solution. Ensure sure your messages are:¹⁰

- credible, clear, compelling and concise, consistent and convincing
- simple and persuasive
- include a call to action
- repetitive and reinforced

How do I create key messages?¹⁰

- Research your audience so you understand them
 - o What will motivate them to act?
 - o What benefits will your advocacy work bring to them?
 - o What attitudes or beliefs will prevent them from acting?
- Tailor your messages to your audience's level of understanding and awareness about centralised specialist care and ovarian cancer
- Consider cultural and political sensitivities and connect to your audience's values and political views
- Dispel common myths or misunderstandings about ovarian cancer care, for instance, that it is too expensive
- Messages should be based on your objectives for your advocacy strategy, focused on your target audience and consider available resources
- Keep your messages short and succinct
- Develop your messages to gain the greatest support from different audiences
- Communicate with the media to spread your message
- Find appropriate individuals to share your messages



 Cancer Control: Knowledge into Action: WHO Guide for Effective Programmes: Module 6: Policy and Advocacy. Geneva: World Health Organization; 2008. Advocacy Step 5: Developing Key Messages Available from: https://www.ncbi.nlm.nih.gov/books/NBK195426/ Accessed: 9 February 2024



STEP 5:

Growing your advocacy network

Spreading the message about your advocacy for centralised specialist care involves telling people about the situation and asking them to become part of solution. When people connect on shared ideas and goals, you can mobilise them into action and create a strong commitment to realising your vision. To broaden your scope and ensure you have the individuals you need as you progress toward your goal, you need to grow your support network.

Once you have identified the key stakeholders you will need to become allies in your advocacy plan, contact them and share your key messages. These stakeholders may come from organisations within the health sector or from other areas, such as environment, urban planning, or gender studies, and bring their own resources, networks, experiences, expertise, and institutional values to your mission. To support your outreach efforts, you can use the resources and templates provided in this toolkit.

Your potential advocacy network may include:⁷

- patients and people living with ovarian cancer and their families
- community groups
- professional societies
- media sources
- multilateral organisations (United Nation's agencies, World Health Organisation)
- medical community and professional societies and associations
- public health experts (academics, government, research institutions, etc.)
- parliamentarians
- government policymakers (Health, Transport, Finance, Agriculture, etc.)

Use stakeholder mapping to gather information on stakeholders' profiles, activities, strengths, needs, challenges, and opportunities for progressing the centralisation of specialist care for ovarian cancer in your country.





STEP 6:

Creating a workplan and budget

What is an advocacy workplan?

A workplan is a tool to support your advocacy efforts and provide a roadmap as you strive for and reach your advocacy objectives.

A successful advocacy workplan includes:⁷

- Key messages to keep you focused and on track toward your goal
- Goals, objectives, allies, opponents, and key stakeholders • (as identified in your *stakeholder mapping* step).
 - o For each stakeholder, list the different activities, roles, responsibilities and resources
- Prioritisation of issues and activities •
- Resources needed to put your plan into action •
- Budget for building and allocating resources and include a breakdown • of costs

STEP 7:

Measuring success

Success depends on evaluating your advocating efforts and monitoring and measuring your results. Throughout your advocacy journey, keep track of your strategy activities and assess your progress while celebrating the steps you have taken toward your goal.

You can monitor and measure your progress against your objectives to see what you have accomplished and what actions still need to be taken, as well as what activities succeeded, and which ones failed to achieve the desired outcome. Evaluate both the process (how you worked) and the impact (what changed).¹¹

How do I monitor my progress?¹¹

- Keep records of meetings, correspondence or conversations with stakeholders
- Note when your key messages are used by elected officials or the media
- Carry out surveys and interviews to determine the impact of your actions
- Monitor the media and keep track of coverage of your topic in the media.

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How do I measure my success?¹¹

Ask yourself questions to evaluate the impact of your work, such as:

- Have you achieved your objectives?
- What were the outcomes of meetings with key decision makers?
- What actions were taken by these decision makers? •
- Is the situation better than before? By how much? •
- If there is no change, how might you change your advocacy methods? •
- Are the people involved with the advocacy effort happy with the results and the way the work was implemented?

Tips to monitor success¹¹⁻¹³

- Make sure your advocacy objectives are <u>SMART</u>
- Collect evidence to assess your progress
- Refine and adapt your strategy as you proceed, based on your achievements, challenges and the results of your activities
- Stay focused on your goal and objectives
- Adapt your short and long-term objectives as policies and systems change over time
- Work with new partners or decision makers if you are not making progress
- Celebrate your progress and advocacy successes with your allies, which will help them stay engaged and motivated
- Thank your supporters, especially those with decision-making power, to encourage them to see the benefits of helping your advocacy efforts

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CASE STUDY:

Advocacy in Action: Leveraging the Power of Patient Voices to Impact Ovarian Cancer Outcomes in Canada¹⁴

In March 2019, the federal government of Canada approved funding of CDN\$10 million for ovarian cancer research with a clear five-year plan - to improve the outcomes of women diagnosed with ovarian cancer.

To carry out this plan, Ovarian Cancer Canada created three objectives:

- 1. Develop new research models to validate new treatments by funding the researchers
- 2. Identify and prioritise new treatments by funding new therapeutic approaches
- 3. Advance clinical trials by categorising patients into treatments based on the features of their disease

To ensure patient voices were heard, the organisation added a fourth objective which was to more actively involve patients in the planning process for health research, using their experience and expertise to develop new therapies.

How did they reach their goal?

- Consulting with clinical and research communities
- Working with researchers across the country
- Developing a solid advocacy plan with consistent and clear key messages
- Stating its goal to save women's lives
- Planning strategic advocacy objective to increase research funding
- Developing a united community with one voice, including patients, clinicians and researchers around a common goal with measurable outcomes
- Understanding the government's priorities and how to envelope them into their strategy
- Creating an evolving, focused plan to engage policymakers, build partnerships and leverage key opportunities
- Growing their support network by training fifty volunteer advocates and creating advocacy teams with a staff member, a researcher and a person living with ovarian cancer to create a powerful union of expert research knowledge and lay experience with clear roles and responsibilities for each member

Note: This section to be expanded with further case studies from the live workshop



Don't Overlook

Conclusion

Advocating for centralised specialist care for ovarian cancer is one of the key mechanisms for saving women's lives and improving their quality of life.

This step-by-step guide provides a tool to support advocates to use their knowledge and experience to make an impact and create real change in the way ovarian cancer is diagnosed and treated.

We hope that advocacy organisations continue to broaden their understanding and share their insights on the importance of centralised specialist care for ovarian cancer to improve the lives of women and their families across Europe.

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4. Supporting resources - Lexicon

Advocacy: Any action that speaks in favour of, recommends, or argues for a cause, supports or defends, or pleads on behalf of patients. Patient advocates are the voice of the community they represent, engaging with health care policymakers to help deliver critical research funding and access to integrated, people-centred health care and support

Centralised specialist care for ovarian cancer: Health care providers with specific knowledge, skills and experience related to ovarian cancer who are located at the same institution and work as a team

Centre of excellence: An ESGO certification awarded to health care centres which provide the best available surgical approaches in ovarian cancer. Centres of Excellence highlight the quality assurance program and offer leading roles in education, improving quality and to set the basis for a European network of Centres of Excellence.

Certified gynaecologic oncologist: A physician who specialises in diagnosing and treating cancers that are located on a female's reproductive organs. Gynaecologic oncologists have completed obstetrics and gynaecology residency and then pursued subspecialty training through a gynaecologic oncology fellowship.

Clinical psychologist: A person who specialises in the study of the mind and behaviour or in the treatment of mental, emotional, and behavioural disorders **De-centralised care:** Control and operation of a system of care from a single place to several smaller ones

ENGAGe: The European Network of Gynaecological Cancer Advocacy Groups **ESGO:** The European Society of Gynaecological Oncology

ESGO accredited centres: visit Accredited centres - ESGO - European Society of Gynaecological Oncology | ESGO – European Society of Gynaecological Oncology

Evidence-based advocacy: Advocating in a targeted, well-educated and professional manner, based on the best available, current, valid and relevant evidence, and measuring the impact and outcomes of the advocacy work **Landscape analysis:** An outline of the presence, activities, resources and needs of a particular community

Medical oncologist: A doctor who has special training in diagnosing and treating cancer in adults using chemotherapy, hormonal therapy, biological therapy, and targeted therapy

Multidisciplinary team (MDT): The cooperation between different specialist professionals such as gynaecologic oncologists, general surgeons, anaesthesiologists, pathologists, radiologists, medical oncologists, radiation oncologists, palliative care specialists, psychologists, physiotherapists, specialised nurses, social workers, and others with the goal of improving treatment efficiency and patient care as a team

Oncologist: A doctor who treats cancer and provides medical care for a person diagnosed with cancer, or a cancer specialist

Ovarian cancer: Uncontrolled growth and division of abnormal cells in the ovary, which form a growth (tumour)

Palliative care specialist: The holistic care of patients with advanced progressive illness including pain management and provision of psychological, social and spiritual support to achieve the best quality of life for patients and their families

Pathologist: A physician who interprets and diagnoses the changes caused by disease in tissues and body fluids

Patient engagement: The desire and capability to actively choose to participate in care in a way uniquely appropriate to the individual, in cooperation with a health care provider or institution, for the purposes of maximising outcomes or improving experiences of care



4. Supporting resources - Lexicon

Pathway of cancer: The patient's journey from the initial suspicion of cancer through clinical investigations, patient diagnosis and treatment

Patient Reported Outcome (PROs): Any report of the status of a patient's health condition that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else

Physiotherapist: A medical professional who specialises in treating injuries and conditions that impact movement

Policymaker: A member of a government department, legislature, or other organisation who is responsible for making new rules or laws

Quality of life: An individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns

Quality indicators (QI): Standardised, evidence-based measures of health care quality that can be used with readily available hospital inpatient administrative data to measure and track clinical performance and outcomes.

Quality cancer care: Cancer diagnosis and treatment programmes aim to cure or considerably prolong the life of patients and to ensure the best possible quality of life for cancer survivors. The most effective treatment programmes are those that are linked to early detection and accurate diagnosis and staging, adhere to evidence-based standards of care, and are provided in an equitable and sustainable way.

Radiation oncologist: A doctor who specialises in treating cancer with radiation therapy

Radiologist: A doctor who has special training in creating and interpreting pictures of areas inside the body using medical imaging

Social worker: A person who engages people and structures to address life challenges and enhance well-being

Specialist care: A medical professional with experience and training in specific

types of ovarian cancer who provides medical advice and support to patients and collaborates with treatment teams to provide the best possible health care experience for patients with ovarian cancer

Specialist nurse: An advanced practice registered nurse who has earned a master's or doctoral degree in nursing who uses their expertise to assess, diagnose, and treat patients

Stakeholders: Patients, caregivers, support groups, professionals, researchers, regulators, payors, insurers, media, parliamentarians and policymakers **Stakeholder mapping:** A stakeholder map is a visual representation of individuals or groups with a vested interest in an idea. Stakeholder mapping helps you identify key stakeholders, understand their influence, and develop a strategy for stakeholder management

Subspeciality training with certification and accreditation processes:

An ESGO recognition process for the expertise and skills of experienced gynaecological oncologists. The ESGO hospital accreditations in advanced ovarian and endometrial surgery assess the adherence to the guidelines, evaluate the quality of surgery, and play an essential political role in the centralisation of care

SWOT analysis: SWOT stands for Strengths, Weaknesses, Opportunities and Threats. A SWOT analysis is an analytic tool used by many industries to assess a current organisation or business, to refine a strategic action plan to meet their desired objectives

Systemic change: Systemic change occurs when change reaches all or most parts of a system, thus affecting the general behaviour of the entire system. **Wellbeing:** A person's quality of life and their ability to contribute to the world with a sense of meaning and purpose





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4. Supporting resources

Stakeholder map

	NAME	ROLE	SUPPORT TYPE (CHAMPION, ALLY, OPPONENT)	INFLUENCE LEVEL (HIGH, MEDIUM, LOW)	CONTACT	ACTIONS	
PATIENTS							
CAREGIVERS							
SUPPORT GROUPS							
HEALTH CARE PROFESSIONALS							
POLICYMAKERS							

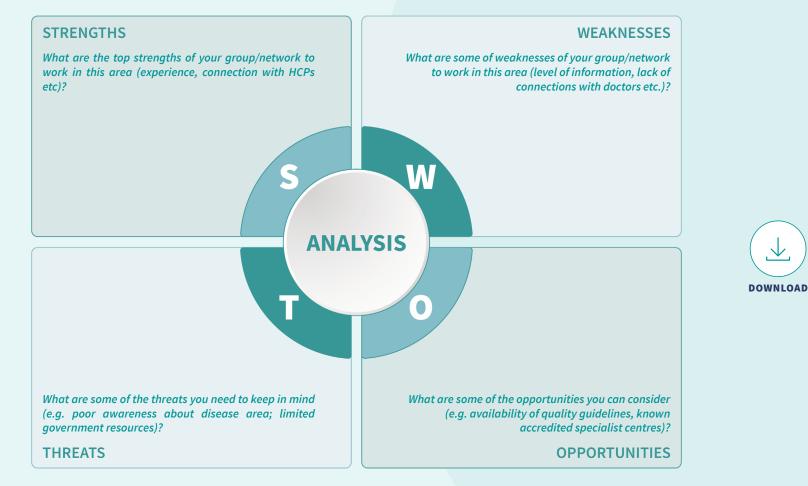


Don't Overlook

4. Supporting resources

SWOT Analysis Tool

A SWOT analysis tool can help you assess a current situation and refine your strategic action plan to meet your objectives. Think about the long-term systemic changes you need to make to provide the best possible care scenario.



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4. Supporting resources

Diary Planner

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26	26	26	26	26	26	26	26	26	26	26	26	26
27	27	27	27	27	27	27	27	27	27	27	27	27
28	28	28	28	28	28	28	28	28	28	28	28	28
29	29	29	29	29	29	29	29	29	29	29		29
30	30	30	30	30	30	30	30	30	30	30		30
31		31		31	31		31		31	31		31



Commitment

ENGAGE Esco Esco Esco Caner Advicary Groups

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