

OvaCare Strategy 2022-2025



- **OvaCare's overall goal and mission** is to elevate awareness, accelerate diagnosis and educate women and their families affected by ovarian cancer within Ireland. To source and share knowledge of developments in global research and best practice with the OvaCare community. To provide support and advocacy through OvaCare's dedicated support networks. **Our Vision is that all women concerned about or diagnosed with ovarian cancer have immediate access to the knowledge and support that is available, which empowers them to make critical personal and family decisions in a supportive environment.**
- Ovarian Cancer treatment in Ireland has one of the highest mortalities across 27 countries. Late diagnosis appears to be the key reason. For this reason, OvaCare is supporting the Global Ovarian Cancer Charter, developed following a survey of 1500 women worldwide, including Irish women.
- The first step in developing this strategy was to ask our members what they needed. We surveyed all our current community members in May 2022 to ask them what support and information they are seeking and thus based OvaCare's goals on that feedback.



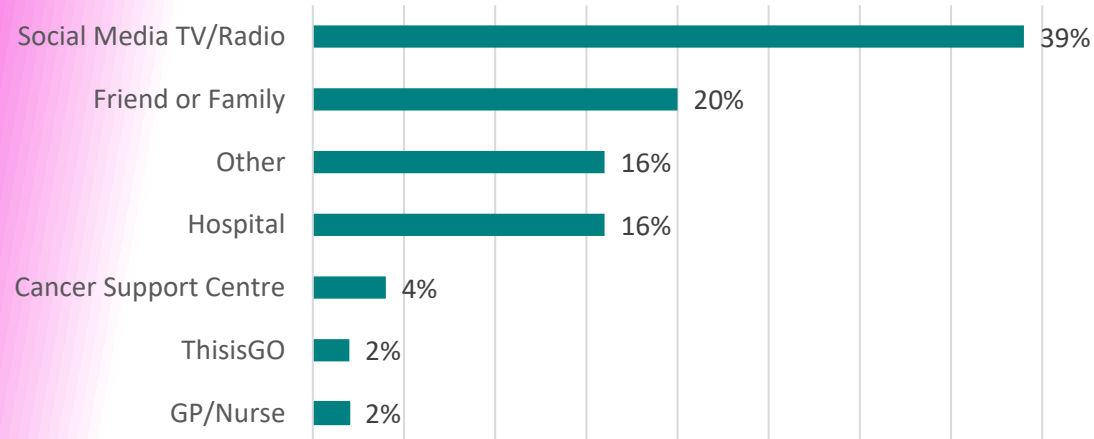
Survey 2022

OvaCare Survey 2022 – Background and Methodology

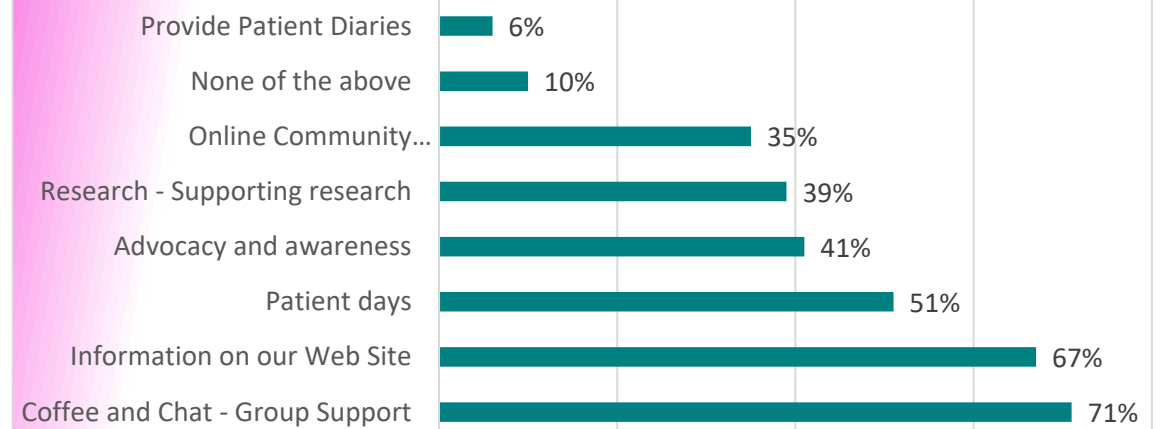
- **Purpose of Survey** - to seek feedback from patients and their loved ones on the services provided by OvaCare in order to review the strategy plans for OvaCare over the next 2-5 years.
- **Who** – respondents included members of OvaCare, patients, their families and friends and some healthcare professionals. 65% of respondents are members of OvaCare. 61% of respondents were diagnosed with ovarian cancer. 27% indicated they were either a family member or friend. 14% were healthcare professionals
- **When** – 6th April – 14th May, 2022.
- **What** – 19 Questions in total were asked covering the services provided by OvaCare seeking feedback on how we can improve support over the next few years.
- **How** – electronically using a tool called Survey Anyplace – a link was issued to members via mail, website, twitter, Instagram and forwarded to other cancer support groups. Survey was anonymous.

Some questions respondents were asked:

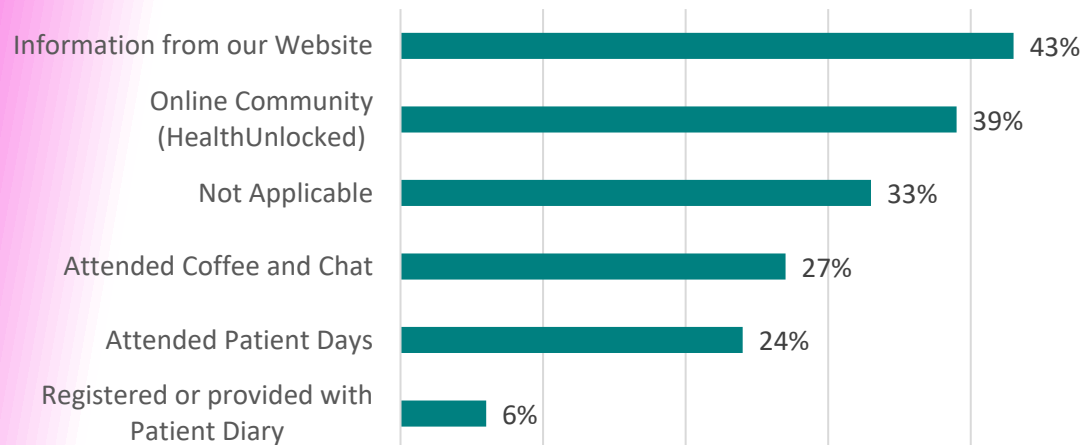
How did you first hear about OvaCare?



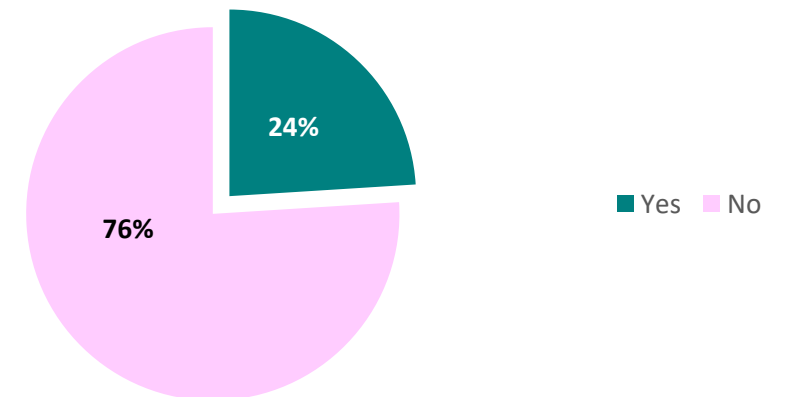
Are you aware of the services we provide?



Have you used OvaCare for support?



Have you seen our new upgraded Website?



Respondents were asked to rank our services in order of importance to them

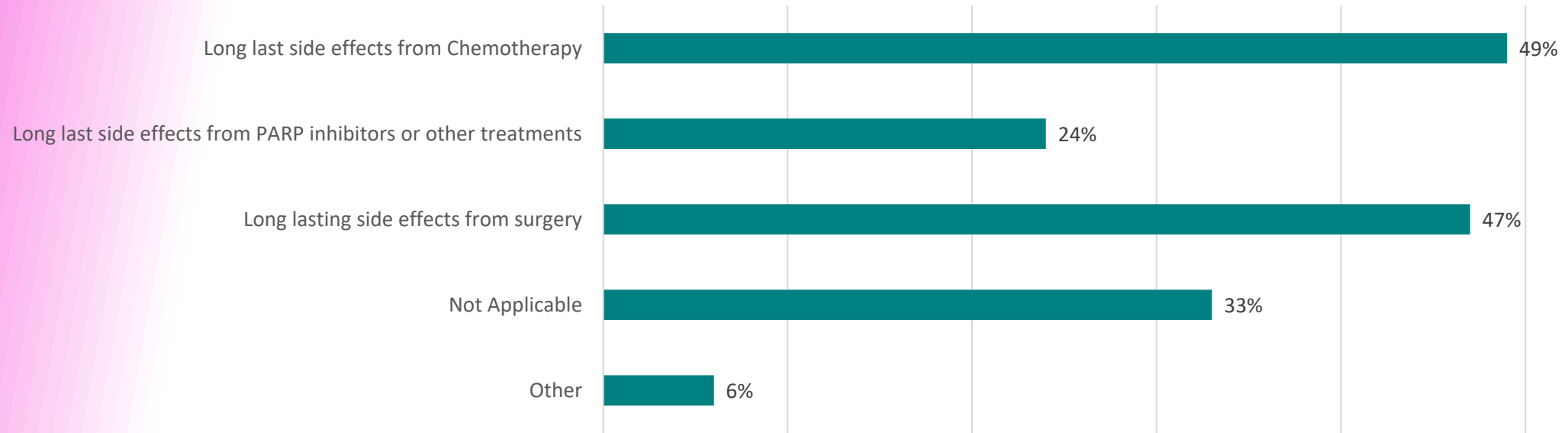
1. **Research** was voted the first priority for respondents.
2. The next most important service to respondents is the information provided on the **Website**.
3. **Support** - Patient Days, Online Community, Coffee and Chat.

Respondents are very clear in what they want from a support group.

1. **Meet with others** with the disease.
2. Having an **environment** with a **positive mindset** with focus on **friendship**, and availability of **information** on treatment options. A chance to share.
3. Getting **structured information**.
4. A **safe place** to talk.

Experienced lasting side effects from surgery or treatment – additional support sought:

Lasting side effects- which area to support



- Dealing with **body image** after surgery, sexual & intimacy problems.
- Information in relation to possibility of not being able to **have children** after treatment.
- **Psychological effects** of full hysterectomy. IVF or surrogacy options information.
- Help with the **emotional aftermath** of diagnosis, surgery and chemo.
- Provide a **follow up care** plan for patients

Responding to what changes if any, were needed in the services we provide at OvaCare:

When asked about our services and whether they want to continue them as is, increase frequency or discontinue them, the respondents were happy to continue as is with some **increase in frequency**, in particular patient days, availability of information, online community and research. See some additional comments below:

- **Patient Days** – little more time for patients to meet with each other to chat during the day.
- **Coffee and Chat** – suggestions in relation to having speakers, more accessibility in the Midlands, and a return to in person sessions.
- **Information available on our Website** - some suggestions on content and highlighting positive stories.
- **Research - supporting research from fundraising activities and sharing updates on trials & treatments** - Respondents highlighted the importance of receiving updates on trials and treatments on a frequent basis.
- **Online Community (HealthUnlocked)** - Respondents highlighted the importance of cancer care and getting help in relation to treatment side effects etc.

Suggestions on other services patients would like OvaCare to provide:

- Online exercise and relaxation classes.
- Buddy system where a new patient can get support from someone who has been through treatment already.
- Counselling service.
- Dedicated sections in relation to psychosexual and menopause issues.
- Sharing the lived experience of an Ovarian Cancer patient to the healthcare community to raise the profile of Ovarian Cancer on the minds of our future Doctors and Nurses.
- Awareness in Consultant Rooms/ Gynae Clinics and ensure nurse specialists in the oncology area inform patients of the service available at OvaCare.
- End of life service & counselling.
- Advice on aftercare.
- A few fun events to spread a little joy and positivity.

Additional comments from respondents:

- Ensure that the **Liaison Person** in the Cancer Department has been in touch and **given information** to the patient and help them to get in touch with **OvaCare**.
- **Special avenue** for cancer patients having to attend **A & E or hospital and GP Services** to avoid delays and the fear of getting sick during treatment as a direct contact.
- Treatment Protocols to eliminate **treatment cancelations** due to bed capacity.
- Highlight successful outcomes to spread **hope and positivity**.
- Highlight **post treatment issues** e.g. medical induced menopause especially for younger women.
- **Increase national awareness** in all hospitals of OvaCare and the support it provides.

Findings and recommendations:

- Increase OvaCare Membership to support more patients and loved ones affected.
- Awareness and accessibility – more work needs to be done in terms of services i.e. PR & Marketing Strategy.
- Website – low levels currently utilising so there is a need to promote the Website further.
- Survivorship – spread hope and positivity. Peer to Peer.
- 16% heard about OvaCare via the hospital and only 2% heard from their GP/Nurse. Awareness campaign needed to encourage more information sharing within the healthcare services.
- Continue supports like Patient days and Coffee and Chat with a view to more in person sessions and increased frequency.
- Consider a support line or WhatsApp group so that patients and families have more immediate access to supports.
- Research is clearly a priority, communicating trials and treatments and possibly investing funds needs to be included in strategy plan.

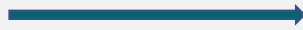
Acknowledgement:



Administrative costs of this survey were kindly sponsored by GSK. GSK had no input into the content of the survey and will not access data generated other than any reported information made publicly available by OvaCare.

We would like to thank them sincerely for their generosity

OvaCare's Core Goals 2022-2025



Alignment with the Global Ovarian Cancer Charter

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The key areas from the Charter we thought best aligned with OvaCare's goals are as follows:-

- 1. **Rapid Diagnosis** – Women must have access to diagnosis without delay
- 2. **Best possible care** - Women must have access to surgery, treatments and clinical trials that optimize their chances of survival and quality of life, no matter where they live.
- 3. **Family History** - Women and doctors must have access to appropriate and timely genetic testing and counselling.
- 4. **Information and support** - Women must have access to good-quality information and support in their own language that helps them to live well with the disease.

Sharing Knowledge

Supporting our members

Increasing Awareness of OvaCare / Ovarian Cancer

