Patient perspective on Inhibin A and Inhibin B testing for those diagnosed with granulosa cell tumours of the ovary

Victoria Clare[1], Linda Langdale[1, 2], Suzanne Love[2], Megan Pearson[2], Courtney McMullan[3], Stephen Dobbs[3], Annie West[1], Anna Hudson[1]

[1]Ovacome, 52 Featherstone St, London EC1Y 8RT; [2]GCT Sisters; [3]Belfast City Hospital

Aims

To understand patient perspective on testing for diagnosis and monitoring of granulosa cell tumour of the ovary (GCT).

Methodology

UKGCTSS and Ovacome collaborated on a questionnaire for those living in the UK, diagnosed with GCT and over the age of 18. Questions were disseminated via Survey Monkey link in December 2023; through online forums, emails to eligible individuals and across social media platforms. 111 eligible individuals responded, all anonymously.

Background

- UK GCT Survivor Sisters (UKGCTSS) is a non-constituted patient group founded in 2018, with a current membership of 200. Its aim is to provide a platform for information sharing and support for those living with the disease in the UK and Ireland. The group is affiliated to a worldwide group (GCT Survivor Sisters) which has 2000+ members.
- Ovacome is the UK's ovarian cancer support charity. We have been providing personalised support and information to anyone affected by ovarian cancer since 1996.
- Granulosa cell tumours (GCT) are sex cord stromal tumours, accounting for 2–5% of all ovarian tumours. Approximately 95% of all granulosa cell tumours occur in adults with a peak incidence at 50–55 years. Adult GCTs are the most common malignant ovarian tumours that secrete hormones which may result in hormone-related symptoms. They are usually considered low-grade and with possibility of late relapse.

Participant information

Of the 111 participants 97.3% (108 people) were diagnosed with Adult GCT, 2.7% (3 people) were diagnosed with Juvenile GCT. Participants gave the year of their diagnosis between 1994 and 2023. Participants responded from every region and country in the UK. There were 3 respondents from the Republic of Ireland.

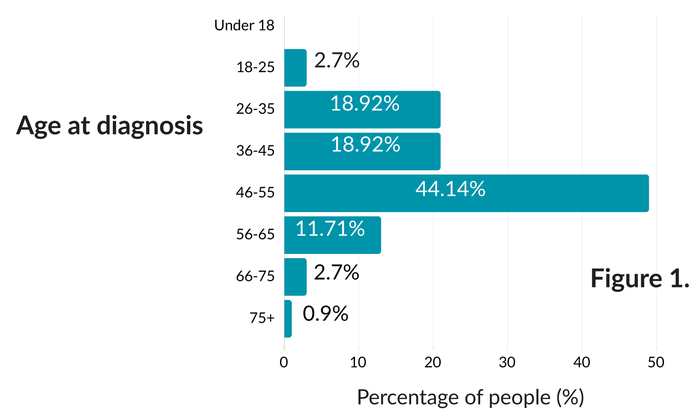


Figure 1.

Diagnosis and initial treatment

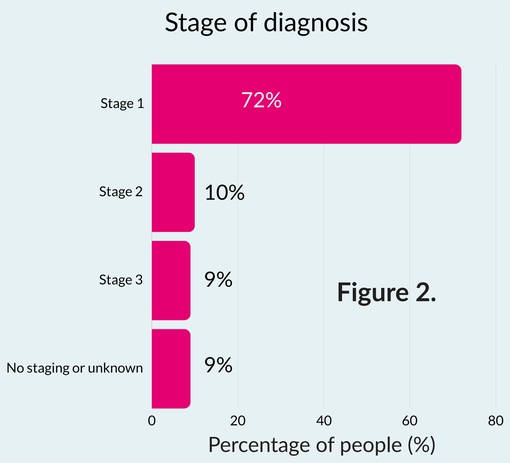


Figure 2.

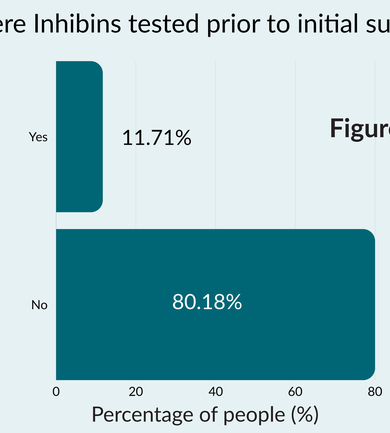


Figure 3.

Hormonal symptoms could increase suspicion of GCTs, indicating inhibin and AMH testing as well as CA125 during diagnostic investigations. European Society for Medical Oncology (ESMO) guidelines for diagnosis and pathology state: "Inhibin B is secreted by granulosa cell tumours and could be a useful marker for the disease. Serum anti-Mullerian hormone (AMH) may be a marker of ovarian reserve and granulosa cell."[1]

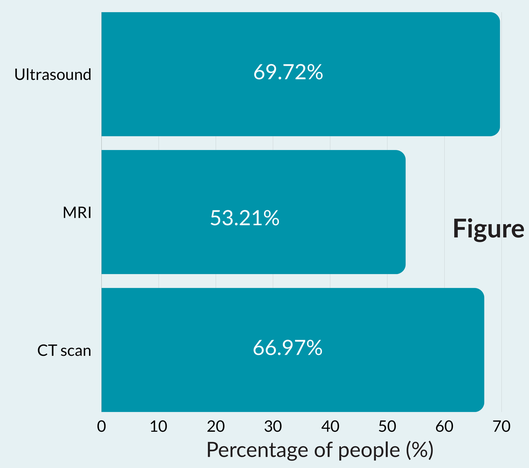


Figure 4.

*Other tests included (listed in order of most used to least used):
CA125, Endometrial Biopsy, PET scan, X ray

Monitoring and recurrence

21% After initial surgery, 21% of patients waited longer than 7 months for their first Inhibin test or have never been tested.

Where Inhibin A and/or B testing is used for monitoring, 62.5% receive results within 2 months, with 37.5% waiting over 2 months for their results. 7% wait more than 6 months which meant test results could still be outstanding by the time of next clinic appointment when subsequent tests would be ordered.

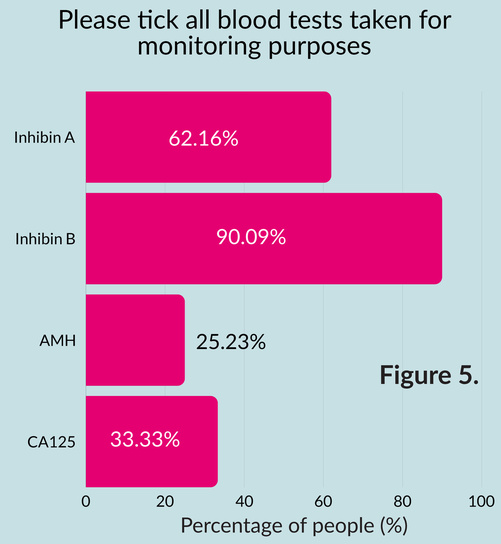
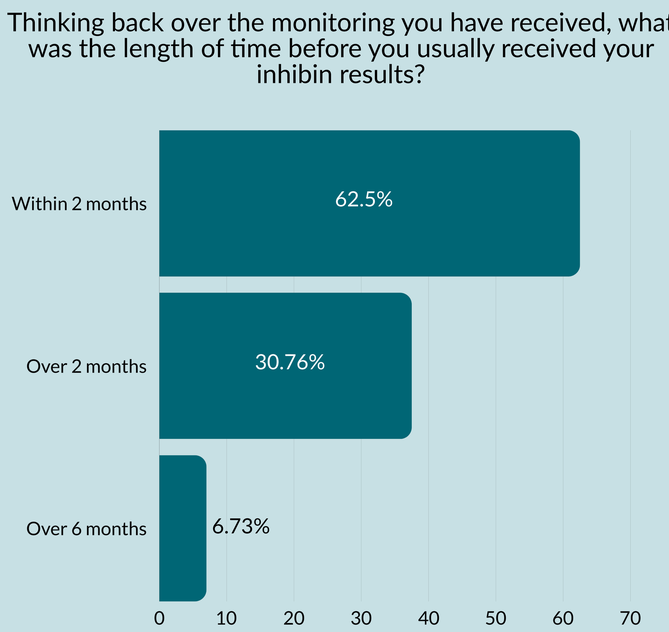


Figure 5.

*Others included: Estradiol (E2) and Testosterone



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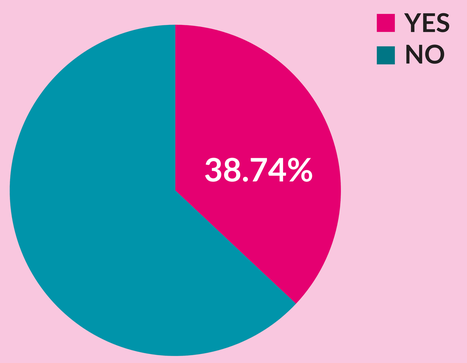

Figure 7.

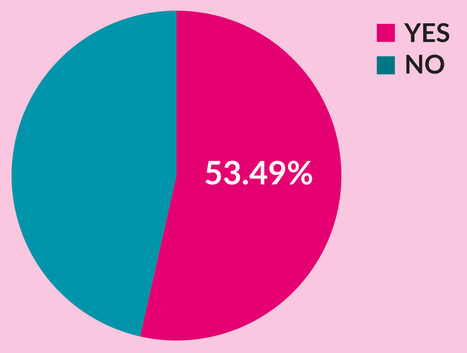

Figure 8.

Of the 22 people reporting a recurrence was not indicated by Inhibin testing, recurrence was identified due to: MRI/CT scans, Symptoms (including ruptured tumour), Ultrasound and surgery.

Impact of testing

77% 77% of respondents report increased anxiety whilst awaiting results exacerbated by delays. Over 40% report experiencing low mood or depression as a result of delays.

97% 97% report that Inhibin testing is helpful and want it continued.

Travel time - 6% of respondents travelled for over 3 hours for blood tests.

Some patients reported self funding AMH tests due to NHS non-availability. Others reported not having the AMH test (and no possibility of self funding).

CONCLUSIONS

- There is wide variation in GCT patient experience across the UK.
- When tests are undertaken, there can be long delays in receiving results, causing increased anxiety.
- The delays in results are due to very few labs in the UK processing samples.
- Some patients are self-advocating or self-funding tests.
- There needs to be more research into GCT.

References: [1]I. Ray-Coquard, P. Morice, D. Lorusso, J. Prat, A. Oaknin, P. Pautier & N. Colombo, on behalf of the ESMO Guidelines Committee (2018) Non-Epithelial Ovarian Cancer: ESMO Clinical Practice Guidelines Ann Oncol (2018) 29 (Suppl 4): iv1–iv18

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