Personalised Stratified Follow-Up following Ovarian cancer treatment

University Hospitals of Leicester NHS
NHS Trust

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Contents

1. Introduction and who the guideline applies to:

There are approximately 7,500 new ovarian cancer cases diagnosed each year in the UK[1] with the incidence being highest in women aged 75 to 79 years old. Although there are around 4,100 ovarian cancer deaths in the UK every year, survival has almost doubled in the last 50 years, with the highest mortality rate in women aged 85 to 89 years and nearly half of all deaths (45%) being in women over 75 years. Despite the majority of patients being diagnosed with advanced disease it is estimated that more than 1 in 3 (35.3%) women diagnosed with an ovarian cancer survive their disease for ten years or more. In particular, 81.2% women aged 15-44 survive their disease for ten years or more, compared with only 21.5% of women diagnosed aged 75-99. This is likely to be due to younger women being more likely to be diagnosed with a mucinous, germ cell or sex-cord stromal tumour compared to older women. As a result, the ovarian cancer patient population is very mixed with a wide range of post-treatment survivorship issues and future treatment options.

Borderline ovarian tumours, although morphologically contain no invasive characteristics, clinically do not always behave in a benign manner. Overall, they are associated with a good prognosis, 99.6% disease-free survival for Stage I patients, falling to 89% for Stage III cases[2] however, recurrences can occur many years after diagnosis. The risk of malignant progression is low (approximately 2%) but occurs in a third of patients who have a recurrence. After fertility-preserving surgery, completion surgery could be considered when fertility is no longer desired since the recurrence risk is higher than with bilateral salpingoophorectomy, 11% versus 1.7%[3]. Follow-up with ultrasound scan in patients after fertility-sparing surgery is advisable[4].

Personalised stratified follow-up (PSFU) is the overarching term to describe the process of individualising cancer follow-up depending on a patient's tumour characteristics and personal needs. The aim is that people diagnosed with cancer are able to access help and empower them to self-manage and live well with and beyond cancer with a greater emphasis on quality of life and responsibility to the individual. It is beneficial to the individual and also as a way to address capacity issues within the NHS. The British Gynaecological Cancer Society has produced guidance[5] on the option of alternative follow-up schemes for ovarian cancer including telephone follow-up (TFU) with the option of blood biomarker monitoring or Patient Initiated Follow-Up (PIFU), known at UHL as Supportive Self-Management (SSM) in order to avoid confusion with the benign pathway. It is estimated that the proportion of ovarian cancer patients who would be suitable for such schemes would be small and primarily comprise of patients with early stage low-grade mucinous, endometrioid and granulosa cell tumours. The blood-based biomarkers would depend on the histological subtype, for example CA125 for epithelial ovarian cancers and Inhibin B and AMH for granulosa cell tumours.

As with other PSFU schemes, the patient's individual needs have to be kept central and they should have a voice in which follow-up pathway they are placed on and be able to change pathways if they wish. The need for open access to the clinical nurse specialists (CNS) and access to urgent investigations and clinical review/appointments is essential for a successful PSFU scheme, and patients who have communication challenges or lack the confidence to telephone the CNS need to be assessed to see whether it is safe for them to be placed on this pathway. For patients choosing their preferred pathway, fear of cancer recurrence was no different between SSM and hospital- based follow-up (HFU)[6].

Supporting patients to self-manage their own health and wellbeing can meet unmet needs and reduce demand on services, which can be done in the following ways:

- Stratifying patients to an appropriate pathway based on clinical and individual needs.
- Organising needs assessments and care plan reviews at key points in the pathway – for example, at the end of treatment or when problems arise.
- Providing a treatment summary that is a succinct record of diagnosis, treatments, potential side effects of treatment, contact details and other key information.
- Improving access to clinical and non-clinical support services.

'Stratified' means that the clinical team and the person living with cancer make a decision about the best form of aftercare based on their knowledge of the disease (the type of cancer and what is likely to happen next), the treatment (what the effects or consequences may be both in the short and long term) and the person (whether they have other illnesses or conditions, and how much support they feel they need).

Safety issues have been considered. This guidance has been produced in line with the BGCS PIFU guidance. Regular audits will be performed in order to ensure patient acceptability and accessibility. Future developments for PSFU include the creation of multi-lingual information materials, the addition of a messaging platform for patients to contact the CNS.
These guidelines apply to all staff working within the ovarian cancer patient pathway and their patients. The Gynaeoncology MDT has a decision-making role in the selection of patients for the different pathways and all staff involved will implement the pathway thereafter.

2. Patient selection

The follow-up pathway advised for patients will be based on the BGCS guidance[5]. Suitability will be determined by the MDT, the patient's clinical and CNS team*.

Epithelial ovarian cancer
Stage I A/B: RMS/SSM after completing 2 years of clinical follow-up[5].

Stage IC-IV: TFU with RMS (CA125 monitoring) Year 4 and 5 if no recurrence
Not suitable for SSM

Borderline ovarian tumours
All patients except cases identified by the MDT as not being suitable for RMS/SSM

Granulosa cell ovarian cancer
All stages: RMS (inhibin B and AMH monitoring, USS if ovary remaining) Year 3 onwards

This structured follow-up schedule may be individualised depending on a patient's need/wishes.

3. PSFU pathways

Epithelial ovarian cancer

The BGCS PIFU guidance focused on epithelial ovarian cancer and did not include sex-chord stromal or germ cell tumours. Patients undergoing fertility sparing surgery should have regular HFU and not be offered PIFU given the similar recurrence and survival rates to standard treatment.

Routine follow-up of patients with ovarian cancer does not appear to improve survival[7-11]

Patients with stage I A/B ovarian cancer who have been appropriately staged, with pelvic and para-aortic lymph node dissections and peritoneal biopsies (if indicated) [12] can be offered PIFU after completing 2 years of clinical follow-up [5].

OVO5 study compared initiation of chemotherapy on clinical/symptoms versus a CA125 rise. This showed no difference in survival and a lower quality of life in the CA125 arm[13]. However, this study was conducted before the paradigm shift in ovarian cancer surgery, in particular before the regular use of secondary cytoreductive surgery and therefore given the dramatic impact of this change, along with new systemic therapy options, on patient survival the results cannot be extrapolated for current practice[12, 14].

BGCS advise that patients should attend HFU for the first 3 years after completing treatment, since the majority of recurrences occur in this time frame[15].

Stage IC to IV ovarian cancer patients can be offered the option of TFU with CA125 monitoring for Year 4 and 5 after competing 3 years of clinical HFU if they have not experienced cancer recurrence. However, if this is not possible then clinical HFU should be follow-up for 5 years[5]. This patient population is not suitable for PIFU.

Granulosa cell ovarian cancer

Granulosa cell ovarian tumours (GCTs) are reported to account for 8% of all ovarian cancers and can be divided into: juvenile type (rare); and adult type (AGCT) [16]. The median age at diagnosis is 50-54 years but unlike other ovarian cancer subtypes the time to recurrence is very long, median 6-8 years [17] but they can recur 20-40 years after diagnosis [18]. Surgery is the main treatment for both primary and recurrence and therefore lifelong follow-up and early detection of recurrent disease are advised in order to increase the likelihood of complete cytoreduction [19].

The BGCS and ESMO ovarian cancer guidelines[20] support the option of a blood monitoring scheme for AGCTs with inhibin B and anti-Mullerian hormone every 6 months indefinitely, given the late recurrences that can occur. In addition, pelvic ultrasound is recommended every 6 months for patients who have undergone fertility-sparing surgery.

The evidence for the use of the chosen serum tumour markers is because they have been identified as having a high sensitivity/specificity to detect recurrence[21] and have a lead time over radiological/clinical relapse:

1) Inhibin B – lead time of 11 months to 2.8 years[22]

2) anti-Mullerian hormone (AMH) – lead time of 3.4 years[21]

Inhibin B has been shown to be superior to Inhibin A (sensitivity 88-100% versus 67-77%)[22-24], however 10-15% of AGCT are inhibin B negative [22, 24]. AGCT express AMH [25] (sensitivity 76-100%) [23, 25-29]. AMH and inhibin B have been shown to be raised in AGCT regardless of menopausal status, and only 6% of AGCTs have both normal values of both markers. Advice is that both markers should be measured at diagnosis, to confirm positive marker(s), and then both markers be used during follow-up. The frequency of testing has not been established in clinical trials and consensus opinion is that 6 monthly may be needed initially until further evidence of the utility of such a scheme is confirmed in prospective audits.

Borderline ovarian tumours

Given the low risk of recurrence and malignant transformation, patients who have undergone removal of both ovaries for a borderline tumour are suitable for follow-up on a supported-self management (SSM) pathway, since the addition of blood-based tumour markers will not increase the detection of recurrence. Patients who have not had both ovaries removed should be placed on a remote monitoring pathway since ultrasound scan monitoring of the remaining ovary/ovaries is advised 6-monthly. Patients should be offered completion surgery when fertility is no longer desired.

4. Remote monitoring scheme

- Suitable patients will be identified from MDT or by their managing clinician and a decision made as to whether blood test monitoring is advisable
- The patient will be added to the Remote Monitoring System (RMS) by the RMS team.
- The patient will have a follow-up clinic appointment for the decision to transfer to the RMS pathway to be discussed with the clinician in charge of their care
- The surgical team will confirm the suitability of the patient for RSM with the CNS/RMS team. A dedicated email mailbox has been created to facilitate contact.
- An appointment with the Gynaecology Clinical Nurse Specialist (CNS) will be arranged within 4 weeks following the patient's post RSM discussion clinic appointment. A face-to-face or telephone appointment will be offered to the patient.
- At the CNS appointment, a further Holistic Needs Assessment (eHNA) undertaken, along with a nutritional (MUST) and menopause assessment/signposting
- A printed information leaflet (Appendix A) explaining the SSM will be given/emailed to the patient along with a copy of their eHNA
- The RMS will send a reminder letter (Appendix B) for blood tests (if indicated) and results will be recorded by the RMS team. Results outside of predetermined thresholds will be sent to the CNSs for discussion with the clinician in charge of their care.
- The RMS will send a reminder letter (Appendix C) for an ultrasound scan and results will be reviewed by a member of the gynaecological oncology team before being recorded by the RMS team.
- Failure to comply with blood test or ultrasound scan monitoring will result in the patient being transferred back to HFU
- After 5 years the patient will be notified through a RMS letter (Appendix C) that they will be discharged to primary care. The letter will contain a link/QR code to an information video explaining pathways for re-referral (Video 4).

Telephone Follow-Up (TFU)

For patients with language issues or concerns that they may not contact with CNS team if placed on RMS, the TFU pathway may be suitable.

- Patients suitable for the TFU will be identified from MDT

- The patient will receive a follow-up clinic appointment at approx. 6-8 weeks post-treatment with the surgical team when starting on the TFU pathway will be discussed

- The surgical team will confirm the suitability of the patient for TFU with the CNS team. A dedicated email mailbox has been created to facilitate contact.

- An appointment with the Gynaecology Clinical Nurse Specialist (CNS) will be arranged within 4 weeks following the patient's post operative clinic appointment or final decision to place into SSM. A face-to-face or telephone appointment will be offered to the patient.

- At the CNS appointment, a further Holistic Needs Assessment (eHNA) undertaken, along with a nutritional (MUST) and menopause assessment/signposting

- The patient will receive a telephone call from the CNS at set time points (see flow chart). The patient will be informed of the time/date of the appointment so as to invite a family member to be present on the call if they wish

- The CNS will cover a list of questions (Appendix B) to elicit signs/symptoms of recurrence, before asking about any unmet meets

- A DICT3 letter will be dictated by the CNS following the appointment in order to record the appointment findings, a copy will be sent to the patient's GP

- In cases of language issues, Language Line can be used to facilitate the consultation

Hospital Follow-Up (HFU)

Patients at risk of cancer recurrence or with specific complex needs will remain under regular clinical follow-up. The duration of HFU and the possibility of transferring to TFU or RSM will be discussed with the patient at appropriate times in their pathway. The majority of patients on the HFU pathway will have received systemic anti-cancer treatment and will have a greater likelihood of recurrence and late-treatment effects.

5. Pathway for patient contacts

If a patient contacts the CNS the following pathway will be followed in order to assess and triage the contact and arrange appropriate investigations or clinical review:

1) collection of details by support worker/CNS – using contact proforma (Appendix F)

2) the contact will be triaged by a CNS, contacting the patient if more information is needed

3) contacts reporting symptoms suspicious for recurrence will be discussed with the patient's consultant or the follow-up lead and a management plan determined

4) in cases of suspected recurrence, patients should be seen in a clinic within 2 weeks of contact for clinical examination and appropriate investigations organised

5) cases of recurrence should be discussed in the MDT to determine their further management.

6. Ongoing audit and pathway review

All cases of ovarian cancer recurrence in patients transferred to RMS will undergo review in order to identify and investigate any issues with the RMS pathways.

Patients will be requested to complete quality-of-life measures and symptom measures at times in their pathway to enable the identification of unmet needs and areas for further service development.

The trialling on new development developments in clinical practice will follow-up Good Clinical Practice and research governance guidelines.

7. Education and Training

No new skills are required to implement the guideline however, there does need to be awareness training of the PSFU pathway model and SSM pathway. At the outset a communication plan will be devised which will include both Gynaecology and Oncology Services and GPs. The aims of this will be in order that staff support the revised approach should patients raise unfounded concerns and more importantly, ensure that patients can make a timely return into the hospital processes should signs and symptoms dictate.

It is the responsibility of the CNS to ensure they regularly update their knowledge and skills in line with continuing professional development in line with the NMC Code (October 2018). The CNS has undergone adequate preparation for the development of this practice, supported by the Clinical Lead (Appendix A).

On an on-going basis, new staff joining the MDT will need to be aware of the guidelines in the context of the revised service model.

8. Monitoring and Audit Criteria

Key Performance Indicator	Method of Assessment	Frequency	Lead
Time between patent contact and clinical assessment	CNS contact log	3 monthly	RMS team
Number of ovarian cancer cases, pathway selection by risk classification, patient contacts		Annually	

Time from contact with symptoms to diagnosis of recurrence	Patient's medical notes and CNS records	6 monthly	Gynae /Oncology CNS/Remote monitor co-ordinator

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10. Key Words

Epithelial ovarian cancer, Borderline ovarian tumours, Granulosa cell ovarian cancer, inhibin B, anti-Mullerian, Hospital follow-up, Remote monitoring scheme, Telephone follow-up

The Trust recognises the diversity of the local community it serves. Our aim therefore is to provide a safe environment free from discrimination and treat all individuals fairly with dignity and appropriately according to their needs.

Development and approval record for this document		
Author / Lead Officer:	Esther Moss Job Title: Consultant Gynaecological Oncologist	**Executive lead:** Chief Medical Officer
Reviewed by:	Gynaecological Oncology MDT	

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Date	Issue Number	Reviewed By	Description Of Changes (If Any)
01/04/24 August 2024	1	Esther Moss Gynaecology Governance Committee UHL Women's Quality & Safety Board; 23/08/24	New guideline

Appendix A: Training and assessment required for the Clinical Nurse Specialist for clinic

CNS wishing to see patients as part of the clinic must complete the appropriate training and assessments:

- The registered nurse must have an in-depth understanding of relevant two week wait cancer pathways as per NG12 NICE guidance
- The registered nurse must have completed advanced communication skills training.
- If appropriate, the registered nurse must arrange and co-ordinate any further tests / appointments which are indicated following discussion with the relevant senior clinician at the MDT
- The nurse must be familiar with all relevant National Guidelines and keep up to date with any changes and recommendations

Training and Assessment Proforma for the CNS:

Record of Diagnosis Support Clinical Nurse Specialist Competence

Demonstrate in depth knowledge in assessing / triaging referrals through discussion and reflective learning for a minimum of 10 individual cases (depending on individual level of competence) which includes:

No.	Competence	CNS Sign / Date	Lead CNS Sign / Date
1	Review referral of patients that are referred via the pathway discussed at the MDT		
2	Discuss in detail with patient that they understand their diagnosis and treatment prior to PSFU follow up		
3	Advanced communication skills training completed		
4	Interpreting outcomes, (blood tests as per the referral criteria) and explaining the proposed pathway for onward referral		
5	Escalating where appropriate with a clear rationale		
6	Communicating with a patient in an appropriate and sensitive manner when explaining PSFU over the telephone		
7	Documenting clearly the patients plan on Somerset under CNS activities		
8	Adhering to the NMC Code (2018) and recognising their level of competence and any limitations and working appropriately.		

Number of reflective clinical discussion held ……………………………………………….

This is to confirm, that ………………………………………………………………….……… is competent to triage referrals as the Clinical Nurse Specialist as defined within the boundaries of these guidelines.

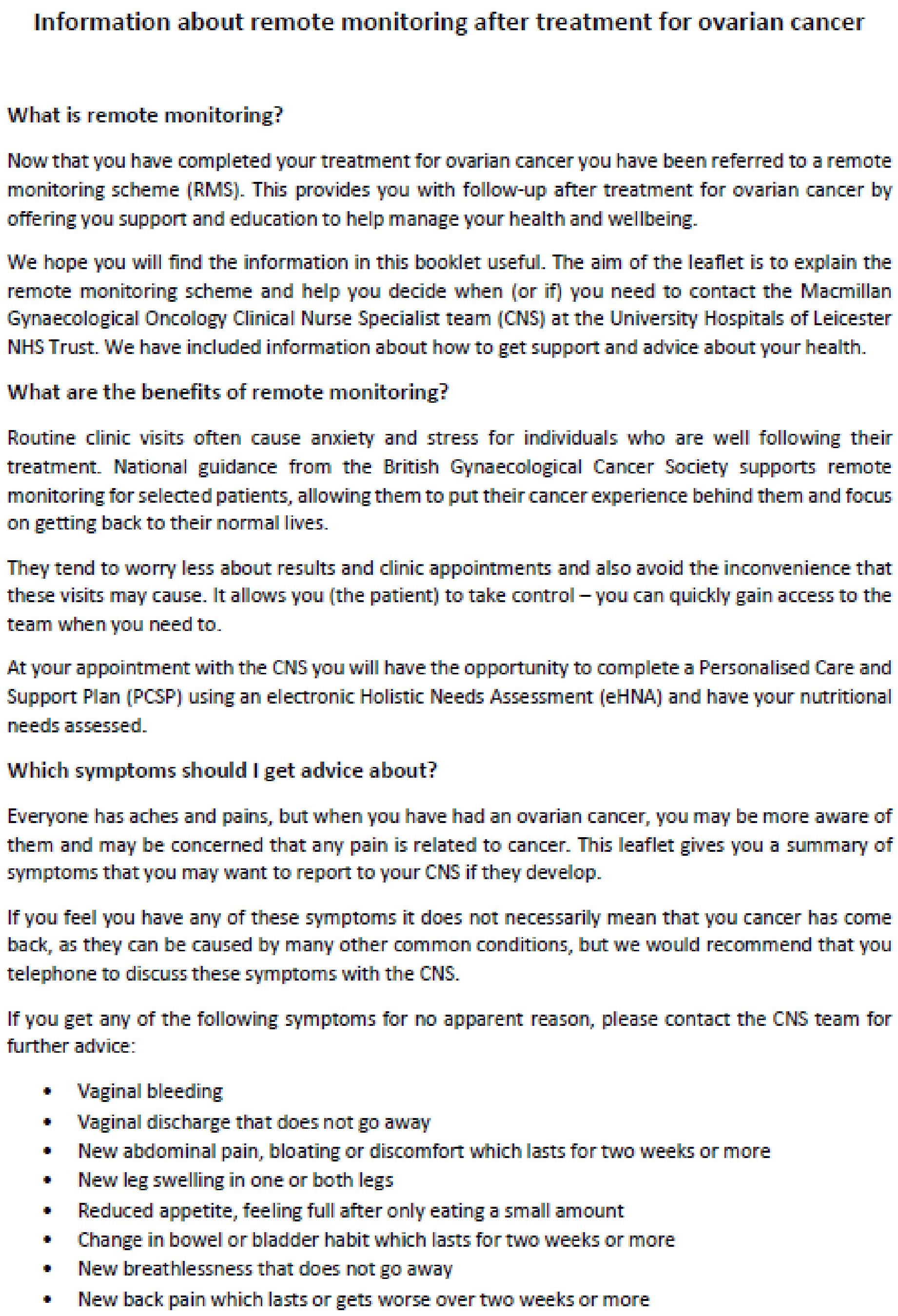
Signature ……………………………………………………… (Clinical Lead)

Print ……………………………………………………………….

Date ……………………………………………………

Appendix B: Remote Monitoring Patient Information Sheet

Ovarian Cancer



Information about remote monitoring after treatment for ovarian cancer

What is remote monitoring?

Now that you have completed your treatment for ovarian cancer you have been referred to a remote monitoring scheme (RMS). This provides you with follow-up after treatment for ovarian cancer by offering you support and education to help manage your health and wellbeing.

We hope you will find the information in this booklet useful. The aim of the leaflet is to explain the remote monitoring scheme and help you decide when (or if) you need to contact the Macmillan Gynaecological Oncology Clinical Nurse Specialist team (CNS) at the University Hospitals of Leicester NHS Trust. We have included information about how to get support and advice about your health.

What are the benefits of remote monitoring?

Routine clinic visits often cause anxiety and stress for individuals who are well following their treatment. National guidance from the British Gynaecological Cancer Society supports remote monitoring for selected patients, allowing them to put their cancer experience behind them and focus on getting back to their normal lives.

They tend to worry less about results and clinic appointments and also avoid the inconvenience that these visits may cause. It allows you (the patient) to take control – you can quickly gain access to the team when you need to.

At your appointment with the CNS you will have the opportunity to complete a Personalised Care and Support Plan (PCSP) using an electronic Holistic Needs Assessment (eHNA) and have your nutritional needs assessed.

Which symptoms should I get advice about?

Everyone has aches and pains, but when you have had an ovarian cancer, you may be more aware of them and may be concerned that any pain is related to cancer. This leaflet gives you a summary of symptoms that you may want to report to your CNS if they develop.

If you feel you have any of these symptoms it does not necessarily mean that you cancer has come back, as they can be caused by many other common conditions, but we would recommend that you telephone to discuss these symptoms with the CNS.

If you get any of the following symptoms for no apparent reason, please contact the CNS team for further advice:

- Vaginal bleeding
- Vaginal discharge that does not go away
- New abdominal pain, bloating or discomfort which lasts for two weeks or more
- New leg swelling in one or both legs
- Reduced appetite, feeling full after only eating a small amount
- Change in bowel or bladder habit which lasts for two weeks or more
- New breathlessness that does not go away
- New back pain which lasts or gets worse over two weeks or more

Monitoring tests

Depending on the type of ovarian cancer that you were treated for, you may be asked to have blood tests as part of your follow-up pathway. If this is the case you will be sent a form to have blood tests performed through your GP surgery. The blood test will be reviewed by the RMS team who will contact you with the results. If you do not have the blood test taken, you will receive a reminder letter from the RMS team.

If one of your ovaries was not removed at surgery, you may be asked to have an ultrasound scan as part of your follow-up pathway. An appointment for a scan will be organised through the RMS team and they will write to you with the results.

Should a blood test be raised or the scan identify an abnormality, you will be contacted by the CNS, usually a telephone call, to explain the next step. This will usually be a scan, often a CT or MRI scan, or it may be a clinic appointment.

Feelings and emotions

Everyone will have different feelings when they no longer need to see their medical team regularly. Some people feel relieved that they can start to get their lives back to normal, others may be concerned about what can happen in the future and anxious about losing contact with the hospital where they received their treatment. Most people worry about the cancer coming back. This is very normal and usually these anxieties lessen with time. Realising that there is a problem and getting help is the most important thing to do. While it is normal to feel low from time to time, sometimes you may find the way you are feeling is interfering with your enjoyment of life.

If you are finding it difficult, please do not hesitate to contact the CNS team.

Our commitment to you

If the CNS teams feels that you should be seen in one of our clinics because of any symptoms you are experiencing, we will make sure that you are offered an appointment within 14 days of telephoning us. If the team feel that you do not need to come to clinic, they will advise you to contact your GP as your symptoms may not be due to your previously treated ovarian cancer or reassure you that no further action is needed.

After your treatment has finished

Once treatment is over, people often want to know what they can do to stay healthy. You may have questions about your diet, exercise and general wellbeing which we will be happy to talk about. We also offer advice on:

- Menopausal symptoms
- Your body image and sexuality
- Self-help courses after completion of treatment
- Financial support
- Counselling and support

The CNS team would rather help you with something that turns out to be nothing, than for you to be at home worrying. They are here to help you, so please telephone if you have questions or concerns.

Please note, this service is not for acutely unwell patients, so if you suddenly feel unwell, please seek urgent medical attention through your GP, the Emergency Department or the 111/999 services.

Information about remote monitoring after treatment for granulosa cell ovarian cancer

What is remote monitoring?

Now that you have completed treatment for a granulosa cell ovarian cancer you have been referred to a remote monitoring scheme (RMS). This provides you with long-term follow-up after treatment by offering you blood test monitoring, support and education to help manage your health and wellbeing.

We hope you will find the information in this booklet useful. The aim of the leaflet is to explain the remote monitoring scheme and help you decide when (or if) you need to contact the Macmillan Gynaecological Oncology Clinical Nurse Specialist team (CNS) at the University Hospitals of Leicester NHS Trust. We have included information about how to get support and advice about your health.

What are the benefits of remote monitoring?

Routine clinic visits often cause anxiety and stress for individuals who are well following their treatment. Patients who have undergone treatment for a granulosa cell tumour are advised to stay on life-long follow-up due to the chance of cancer recurrence many years after treatment. National guidance from the British Gynaecological Cancer Society supports remote monitoring for patients treated for a granulosa cell ovarian cancer, supporting them to put their cancer experience behind them and focus on getting back to their normal lives. They tend to worry less about results and clinic appointments and also avoid the inconvenience that these visits may cause. It allows you (the patient) to take control – you can quickly gain access to the team when you need to.

At your appointment with the CNS you will have the opportunity to complete a Personalised Care and Support Plan (PCSP) using an electronic Holistic Needs Assessment (eHNA) and have your nutritional needs assessed.

Which symptoms should I get advice about?

Everyone has aches and pains, but when you have had an ovarian cancer, you may be more aware of them and may be concerned that any pain is related to cancer. This leaflet gives you a summary of symptoms that you may want to report to your CNS if they develop.

If you feel you have any of these symptoms it does not necessarily mean that you cancer has come back, as they can be caused by many other common conditions, but we would recommend that you telephone to discuss these symptoms with the CNS.

If you get any of the following symptoms for no apparent reason, please contact the CNS team for further advice:

- Vaginal bleeding
- Vaginal discharge that does not go away
- New abdominal pain, bloating or discomfort which lasts for two weeks or more
- New leg swelling in one or both legs
- Reduced appetite, feeling full after only eating a small amount
- Change in bowel or bladder habit which lasts for two weeks or more
- New breathlessness that does not go away
- New back pain which lasts or gets worse over two weeks or more

Monitoring tests

Blood test monitoring detects changes that could indicate recurrence of granulosa cell ovarian cancer in the majority of patients. The blood tests that currently recommended are inhibin B and Anti-Mullerian Hormone (AMH), and are sent to a specialist centre for testing, which can sometimes result in delays in receiving results.

You will be sent a form to have blood tests performed through your GP surgery, either every 6 or 12 months, depending how long it has been since your treatment. The blood test result will be reviewed by the RMS team who will contact you with the results. If you do not have the blood test taken, you will receive a reminder letter from the RMS team.

If one of your ovaries was not removed at surgery, you may be asked to have an ultrasound scan as part of your follow-up pathway. An appointment for a scan will be organised through the RMS team and they will write to you with the results.

Should a blood test be raised or the scan identify an abnormality, you will be contacted by the CNS, usually a telephone call, to explain the next step. This will usually be a scan, often a CT or MRI scan, or it may be a clinic appointment.

Feelings and emotions

Everyone will have different feelings when they no longer need to see their medical team regularly. Some people feel relieved that they can start to get their lives back to normal, others may be concerned about what can happen in the future and anxious about losing contact with the hospital where they received their treatment. Most people worry about the cancer coming back. This is very normal and usually these anxieties lessen with time. Realising that there is a problem and getting help is the most important thing to do. While it is normal to feel low from time to time, sometimes you may find the way you are feeling is interfering with your enjoyment of life.

If you are finding it difficult, please do not hesitate to contact the CNS team.

Our commitment to you

If the CNS teams feels that you should be seen in one of our clinics because of any symptoms you are experiencing, we will make sure that you are offered an appointment within 14 days of telephoning us. If the team feel that you do not need to come to clinic, they will advise you to contact your GP as your symptoms may not be due to your previously treated ovarian cancer or reassure you that no further action is needed.

After your treatment has finished

Once treatment is over, people often want to know what they can do to stay healthy. You may have questions about your diet, exercise and general wellbeing which we will be happy to talk about. We also offer advice on:

- Menopausal symptoms
- Your body image and sexuality
- Self-help courses after completion of treatment
- Financial support
- Counselling and support

Information about remote monitoring after treatment for borderline ovarian cancer

What is remote monitoring?

Now that you have completed treatment for a borderline ovarian cancer you have been referred to a remote monitoring scheme (RMS). This provides you with long-term follow-up after treatment by offering you support and education to help manage your health and wellbeing.

We hope you will find the information in this booklet useful. The aim of the leaflet is to explain the remote monitoring scheme and help you decide when (or if) you need to contact the Macmillan Gynaecological Oncology Clinical Nurse Specialist team (CNS) at the University Hospitals of Leicester NHS Trust. We have included information about how to get support and advice about your health.

What are the benefits of remote monitoring?

Routine clinic visits often cause anxiety and stress for individuals who are well following their treatment. Other hospitals have found that remote monitoring allows patients to put their experience behind them and focus on getting back to their normal lives. They tend to worry less about results and clinic appointments and also avoid the inconvenience that these visits may cause. It allows you (the patient) to take control – you can quickly gain access to the team when you need to.

At your appointment with the CNS you will have the opportunity to complete a Personalised Care and Support Plan (PCSP) using an electronic Holistic Needs Assessment (eHNA) and have your nutritional needs assessed.

Which symptoms should I get advice about?

Everyone has aches and pains, but when you have had a borderline ovarian cancer, you may be more aware of them and may be concerned that any pain is related to your previous treatment. This leaflet gives you a summary of symptoms that you may want to report to your CNS if they develop.

If you feel you have any of these symptoms it does not necessarily mean that there is an abnormality related to your previous treatment, as they can be caused by many other common conditions, but we would recommend that you telephone to discuss these symptoms with the CNS.

If you get any of the following symptoms for no apparent reason, please contact the CNS team for further advice:

- Vaginal bleeding
- Vaginal discharge that does not go away
- New abdominal pain, bloating or discomfort which lasts for two weeks or more
- New leg swelling in one or both legs
- Reduced appetite, feeling full after only eating a small amount
- Change in bowel or bladder habit which lasts for two weeks or more
- New breathlessness that does not go away
- New back pain which lasts or gets worse over two weeks or more

Borderline Ovarian Cancer

Monitoring tests

Blood test monitoring is not advised after treatment for a borderline tumour however, if only one or both of your ovaries have not been removed then the British gynaecological Cancer Society recommend ultrasound scan monitoring as part of your follow-up pathway. An appointment for a scan will be organised through the RMS team and they will write to you with the results.

Should the scan identify an abnormality, you will be contacted by the CNS, usually a telephone call, to explain the next step. This will usually be a scan, often a CT or MRI scan, or it may be a clinic appointment.

Feelings and emotions

Everyone will have different feelings when they no longer need to see their medical team regularly. Some people feel relieved that they can start to get their lives back to normal, others may be concerned about what can happen in the future and anxious about losing contact with the hospital where they received their treatment. Most people worry about having an abnormality related to the borderline tumour. This is very normal and usually these anxieties lessen with time. Realising that there is a problem and getting help is the most important thing to do. While it is normal to feel low from time to time, sometimes you may find the way you are feeling is interfering with your enjoyment of life.

If you are finding it difficult, please do not hesitate to contact the CNS team.

Our commitment to you

If the CNS teams feels that you should be seen in one of our clinics because of any symptoms you are experiencing, we will make sure that you are offered an appointment within 14 days of telephoning us. If the team feel that you do not need to come to clinic, they will advise you to contact your GP as your symptoms may not be due to your previously treated ovarian cancer or reassure you that no further action is needed.

After your treatment has finished

Once treatment is over, people often want to know what they can do to stay healthy. You may have questions about your diet, exercise and general wellbeing which we will be happy to talk about. We also offer advice on:

- Menopausal symptoms
- Your body image and sexuality
- Self-help courses after completion of treatment
- Financial support
- Counselling and support

The CNS team would rather help you with something that turns out to be nothing, than for you to be at home worrying. They are here to help you, so please telephone if you have questions or concerns.

Please note, this service is not for acutely unwell patients, so if you suddenly feel unwell, please seek urgent medical attention through your GP, the Emergency Department or the 111/999 services.

Appendix C: RMS Reminder Letter

Ovarian Cancer - CA125 Reminder Letter

Hospital Number: <<HospitalNumber>>

University Hospitals of Leicester NHS
NHS Trust
Caring at its best

Gynaecology Department

Date: 03/06/2024

<<PtGivenName>> <<PtFamilyName>>
<<PtAddress>>

Dear <<PtTitle>> <<PtFamilyName>>

As part of your follow-up after your ovarian cancer treatment you are due to have a CA125 blood test.

Could you please arrange a blood test with your GP practice within the next two weeks and take the enclosed blood test form with you.

Alternatively, if you are already due to have a blood test in the next couple of weeks for any other reason, either with your GP or at the hospital, please take the enclosed form with you so that this test can be taken at the same time.

Your Gynaecology Nurse will advise you of the results.

Contact details

Gynaecology Nurse Specialists (key workers):

0116 258 4840

Kind Regards

Gynaecology Cancer Remote Monitoring Team

Granulosa Cell Tumour - Blood Tests (Inhibin B and Anti-Mullerian Hormone) Reminder Letter

Hospital Number: <<HospitalNumber>>

University Hospitals of Leicester NHS
NHS Trust
Caring at its best

Gynaecology Department

Date: 30/05/2024

<<PtGivenName>> <<PtFamilyName>>
<<PtAddress>>

Dear <<PtTitle>> <<PtFamilyName>>

As part of your follow-up after your granulosa cell ovarian cancer treatment you are due to have a blood test (Inhibin B and Anti-Mullerian Hormone)

Could you please arrange a blood test with your GP practice within the next two weeks and take the enclosed blood test form with you. Alternatively if you are already due to have a blood test in the next couple of weeks for any other reason, either with your GP or at the hospital, please take the enclosed form with you so that this test can be done at the same time.

Your Gynaecology Nurse will advise you of the results.

Contact details

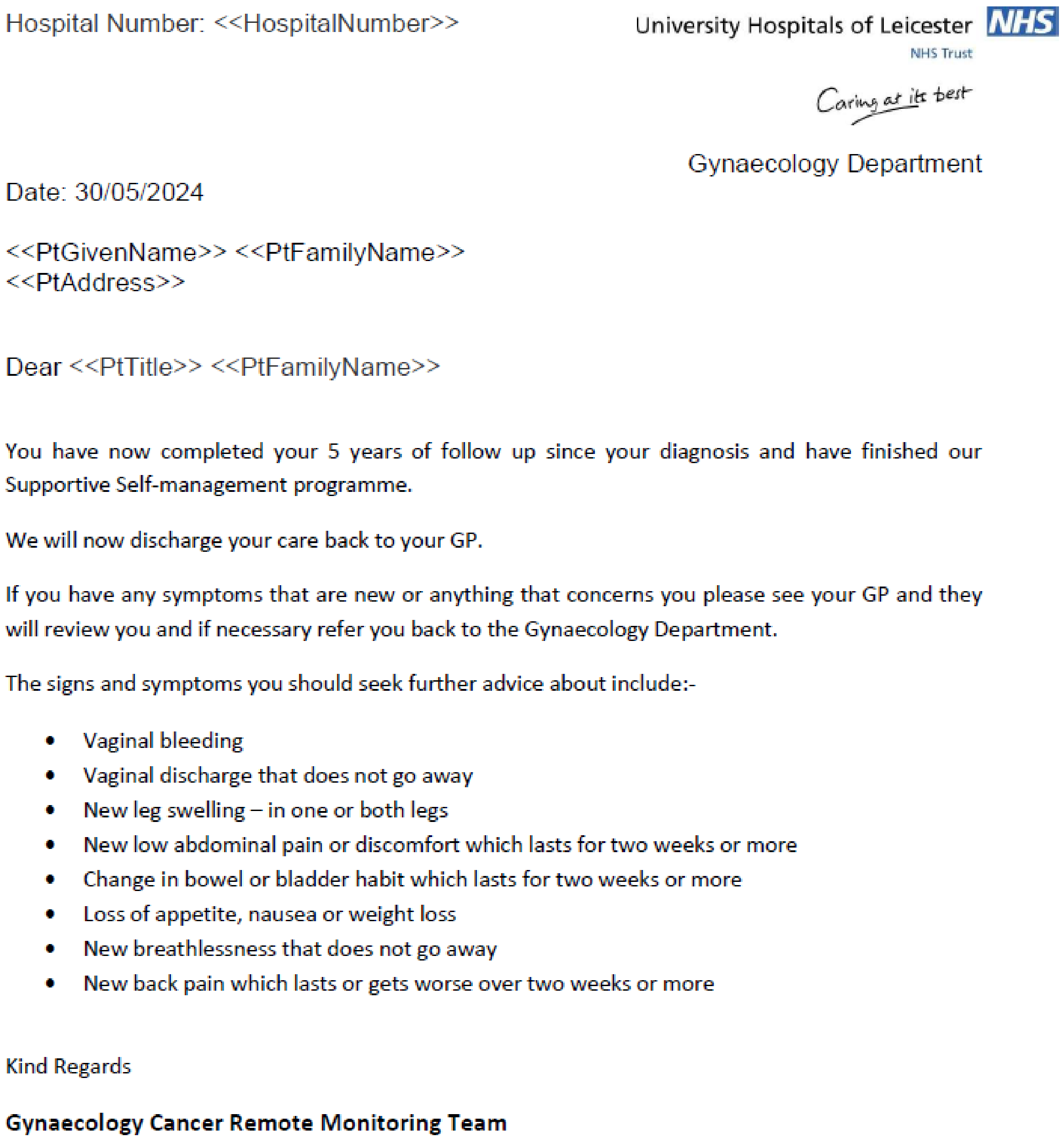
Gynaecology Nurse Specialists (key workers):

0116 258 4840

Kind Regards

Gynaecology Cancer Remote Monitoring Team

Appendix D: RMS Discharge Letter (excluding granulosa cell tumours)



Hospital Number: <<HospitalNumber>>

University Hospitals of Leicester NHS
NHS Trust
Caring at its best

Gynaecology Department

Date: 30/05/2024

<<PtGivenName>> <<PtFamilyName>>
<<PtAddress>>

Dear <<PtTitle>> <<PtFamilyName>>

You have now completed your 5 years of follow up since your diagnosis and have finished our Supportive Self-management programme.

We will now discharge your care back to your GP.

If you have any symptoms that are new or anything that concerns you please see your GP and they will review you and if necessary refer you back to the Gynaecology Department.

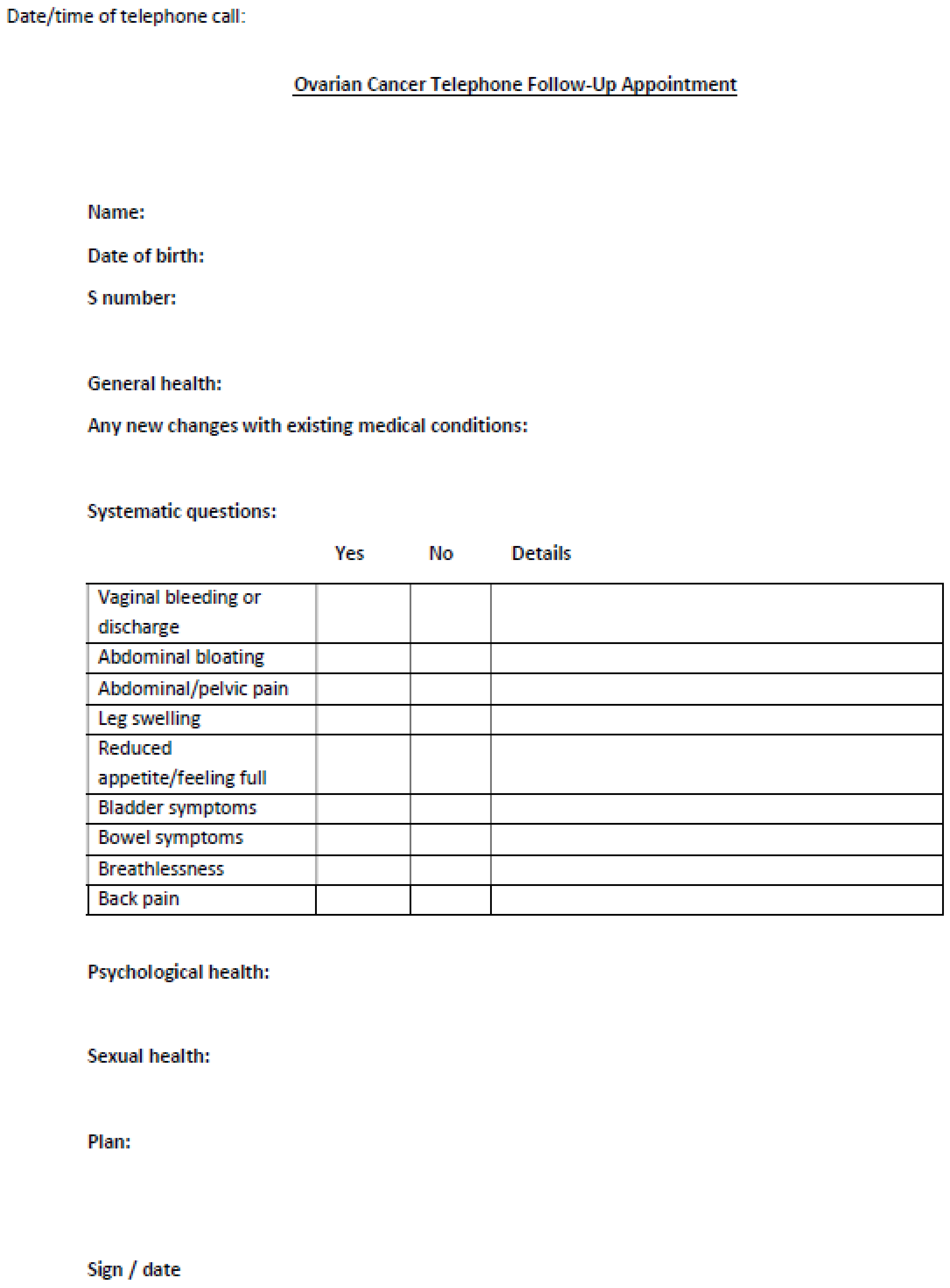
The signs and symptoms you should seek further advice about include:-

- Vaginal bleeding
- Vaginal discharge that does not go away
- New leg swelling – in one or both legs
- New low abdominal pain or discomfort which lasts for two weeks or more
- Change in bowel or bladder habit which lasts for two weeks or more
- Loss of appetite, nausea or weight loss
- New breathlessness that does not go away
- New back pain which lasts or gets worse over two weeks or more

Kind Regards

Gynaecology Cancer Remote Monitoring Team

Appendix E: CNS TFU Question List



Date/time of telephone call:

Ovarian Cancer Telephone Follow-Up Appointment

Name:

Date of birth:

S number:

General health:

Any new changes with existing medical conditions:

Systematic questions:

	Yes	No	Details
Vaginal bleeding or discharge			
Abdominal bloating			
Abdominal/pelvic pain			
Leg swelling			
Reduced appetite/feeling full			
Bladder symptoms			
Bowel symptoms			
Breathlessness			
Back pain			

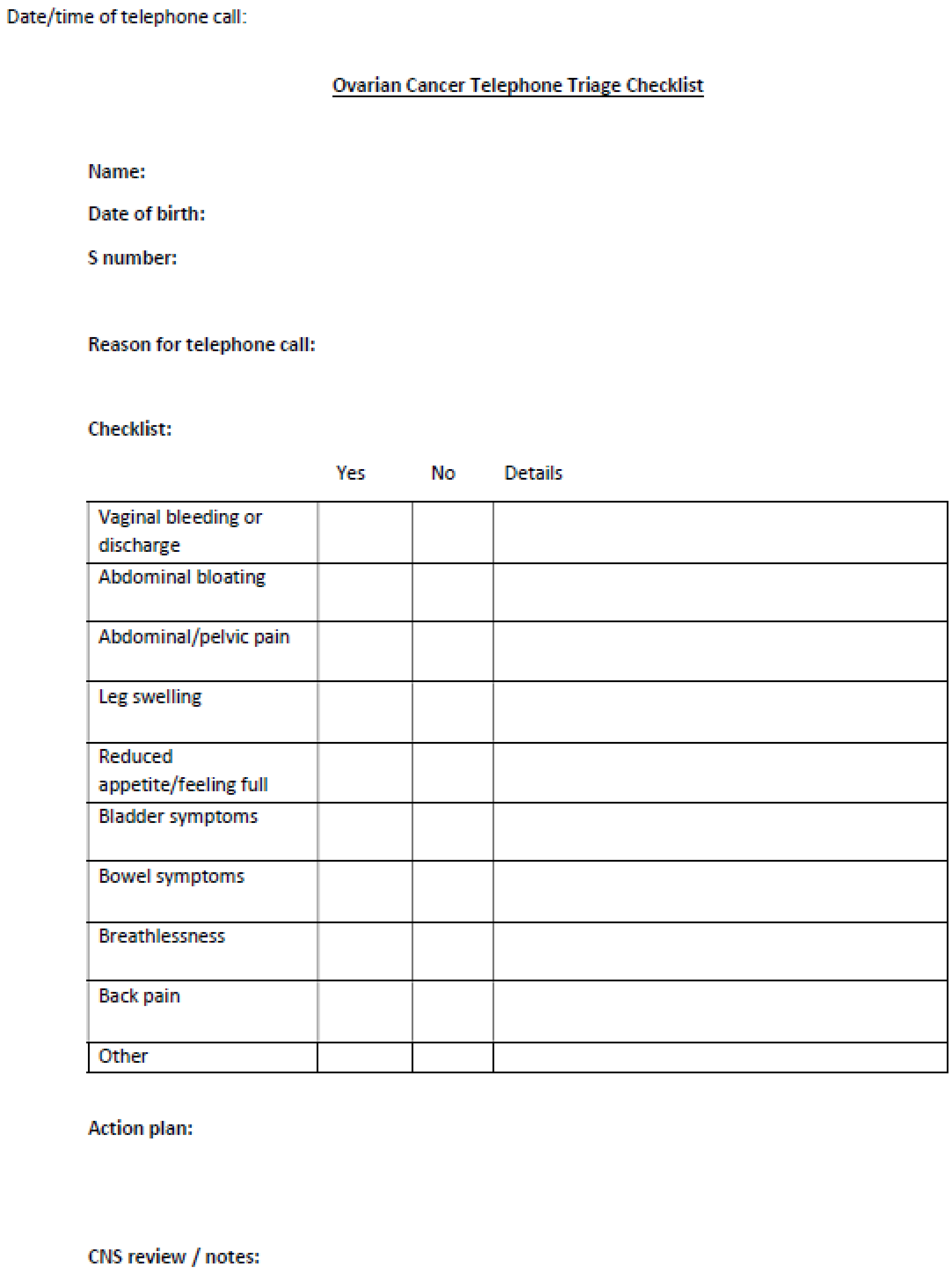
Psychological health:

Sexual health:

Plan:

Sign / date

Appendix F: Triage Question Sheet



Date/time of telephone call:

Ovarian Cancer Telephone Triage Checklist

Name:

Date of birth:

S number:

Reason for telephone call:

Checklist:

	Yes	No	Details
Vaginal bleeding or discharge			
Abdominal bloating			
Abdominal/pelvic pain			
Leg swelling			
Reduced appetite/feeling full			
Bladder symptoms			
Bowel symptoms			
Breathlessness			
Back pain			
Other			

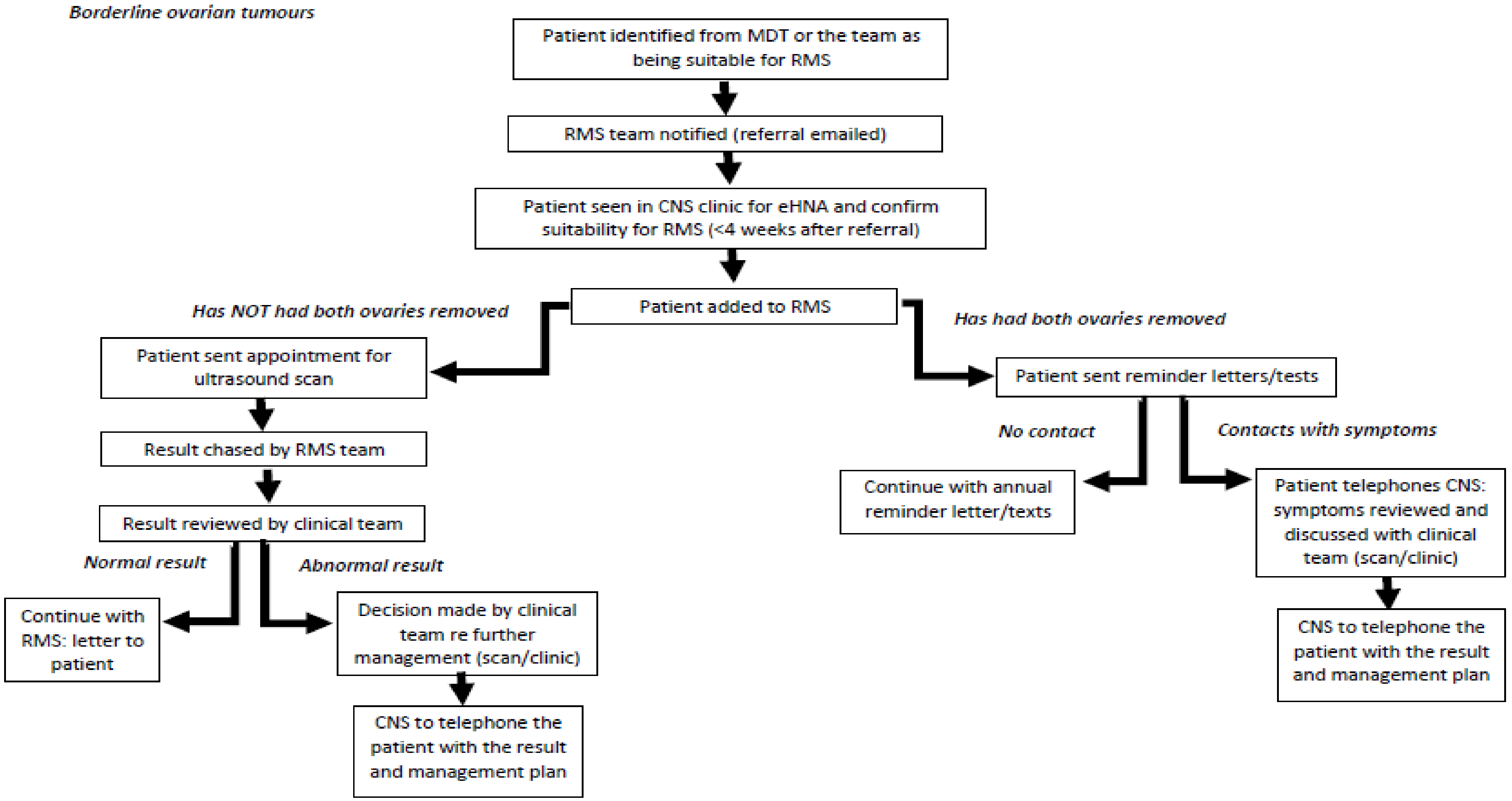
Action plan:

CNS review / notes:

Appendix G: Flow Charts

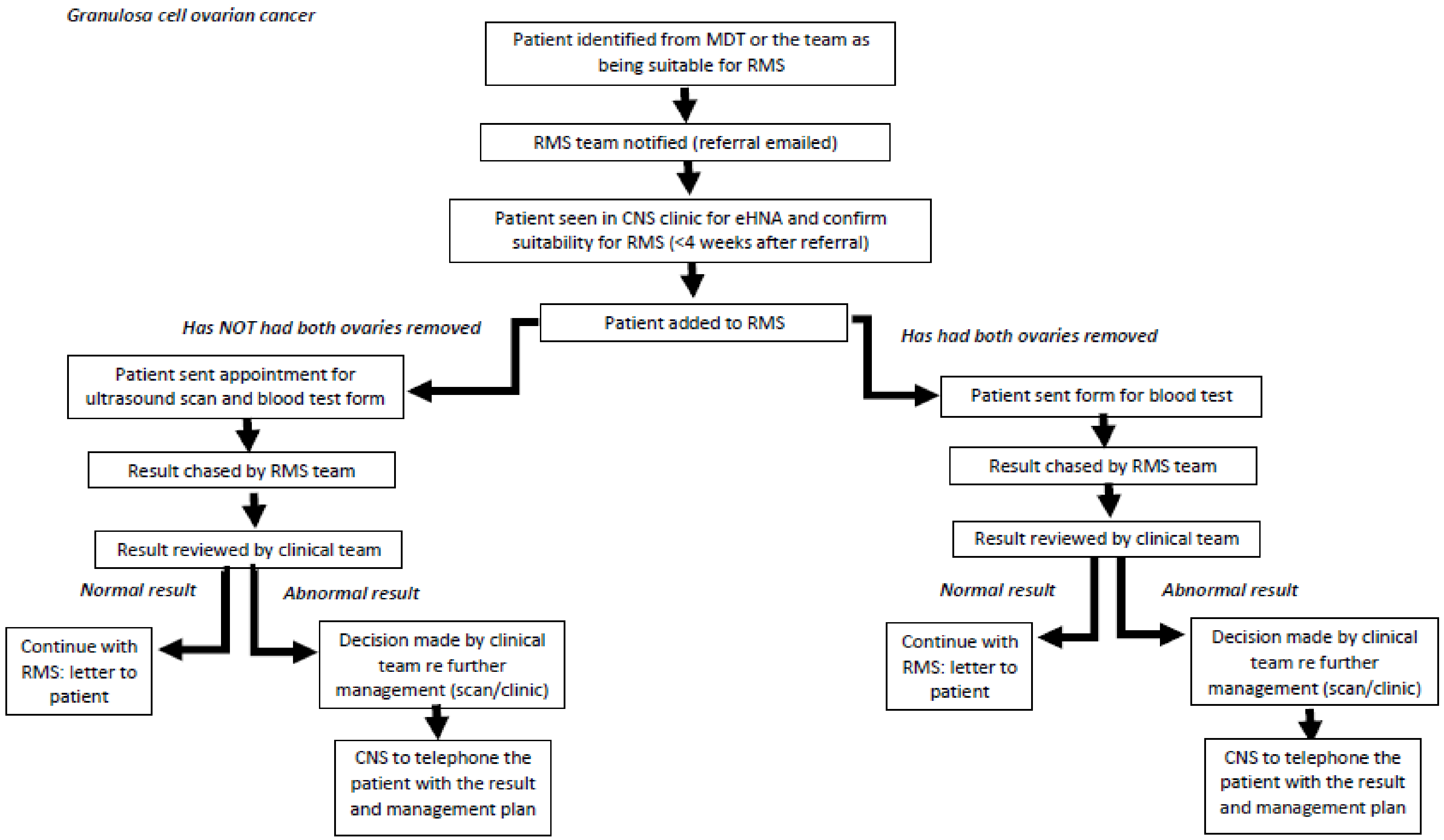
Borderline tumours

Flow diagram for the management of ovarian cancer patients on the remote monitoring scheme



Granulosa cell tumours

Flow diagram for the management of ovarian cancer patients on the remote monitoring scheme



Epithelial ovarian cancers

Flow diagram for the management of ovarian cancer patients on the remote monitoring scheme