NHS England

Engagement Report for *Specialist Cancer Services (adults), Specialist Gynaecological Cancer Service Specification*

28 July 2023, Version 1

Topic details

Programme of Care	Cancer Programme of Care
Clinical Reference Group	Cancer Clinical Advisory Group
Unique Reference Number (URN)	2228

1. Summary

This report summarises the feedback NHS England received from engagement during the development of the Specialist Cancer Services (adults), Specialist Gynaecological Cancer Service Specification, and how this feedback has been considered. The service specification proposition was circulated to key stakeholders for a 2-week period for testing in line with the standard stakeholder engagement method. Ten responses were received from stakeholder groups, including those signed up for one of more of the Clinical Reference Groups (CRGs) stakeholder lists that may retain an interest in this area, and relevant patient and professional groups: The British Gynaecological Cancer Society, The Royal College of Obstetricians and Gynaecologists, Ovacome, Eveappeal and Jo’s Cervical Cancer Trust.

Feedback was positive overall, with stakeholders registering their broad support for the service specification requirements, standards, and outcomes proposed.

2. Background

There are five diagnostic groups of gynaecological cancer: ovarian, cervical, vulvar, endometrial, and uterine. In 2022 there were approximately 18,941 new diagnoses of gynaecological cancer recorded in England (CancerStats). Gynaecological cancer accounted for around 12% of all cancer diagnoses, and approximately 10% of cancer deaths amongst females the England (BMA).

The proposed Service Specification has been formed from the current Specialist Gynaecological Cancers Service Specification (2013).

The service specification has been developed to set out the must-do requirements for providers and:

- Reflect current care pathways and the role of Cancer Alliances;
- Reference up to date national guidance and guidelines, as well as appropriate national policy, for example Faster Diagnosis and elective recovery;
- Incorporate meaningful quality outcome measures which will support improved outcomes and experiences of care; and
- Avoid duplication with other schedules within the NHS Standard Contract.

It is expected that the updated Service Specification will support Integrated Care Boards (ICBs) to take responsibility for the commissioning of gynaecological cancer services when delegated. It is expected that the service will be delegated to ICBs from April 2024, subject to the final approval of NHS England's Board.

The new Service Specification is not expected to change the provider landscape or overall service delivery. As a result, it is expected to be cost neutral to NHS England and other parts of the NHS.

In accordance with usual NHS England processes, the Service Specification was developed with the support and input of a Specification Working Group (SWG), comprising representation from gynaecological cancer clinical experts and patient and public voice representatives.

3. Engagement Results

NHS England has a duty under Section 13Q of the NHS Act 2006 (as amended) to 'make arrangements' to involve the public in commissioning. Full guidance is available in the Statement of Arrangements and Guidance on Patient and Public Participation in Commissioning. In addition, NHS England has a legal duty to promote equality under the Equality Act (2010) and reduce health inequalities under the Health and Social Care Act (2012).

The proposed Service Specification was sent for stakeholder testing for two weeks from July 14th to July 28th, 2023. Effort was made to review and update the stakeholder engagement list to ensure that relevant professional societies and patient groups were

contacted and asked to comment. The feedback received has been reviewed by the Specification Working Group Chair and the Cancer Programme of Care (PoC) to enable consideration of feedback and to support a decision on whether any changes to the specification might be recommended.

3.1 Stakeholder Testing

The Service Specification was sent for stakeholder testing for two weeks from July 10th to July 14th. The comments have then been shared with the Specification Working Group to enable full consideration of feedback and to support a decision on whether any changes to the specification might be recommended.

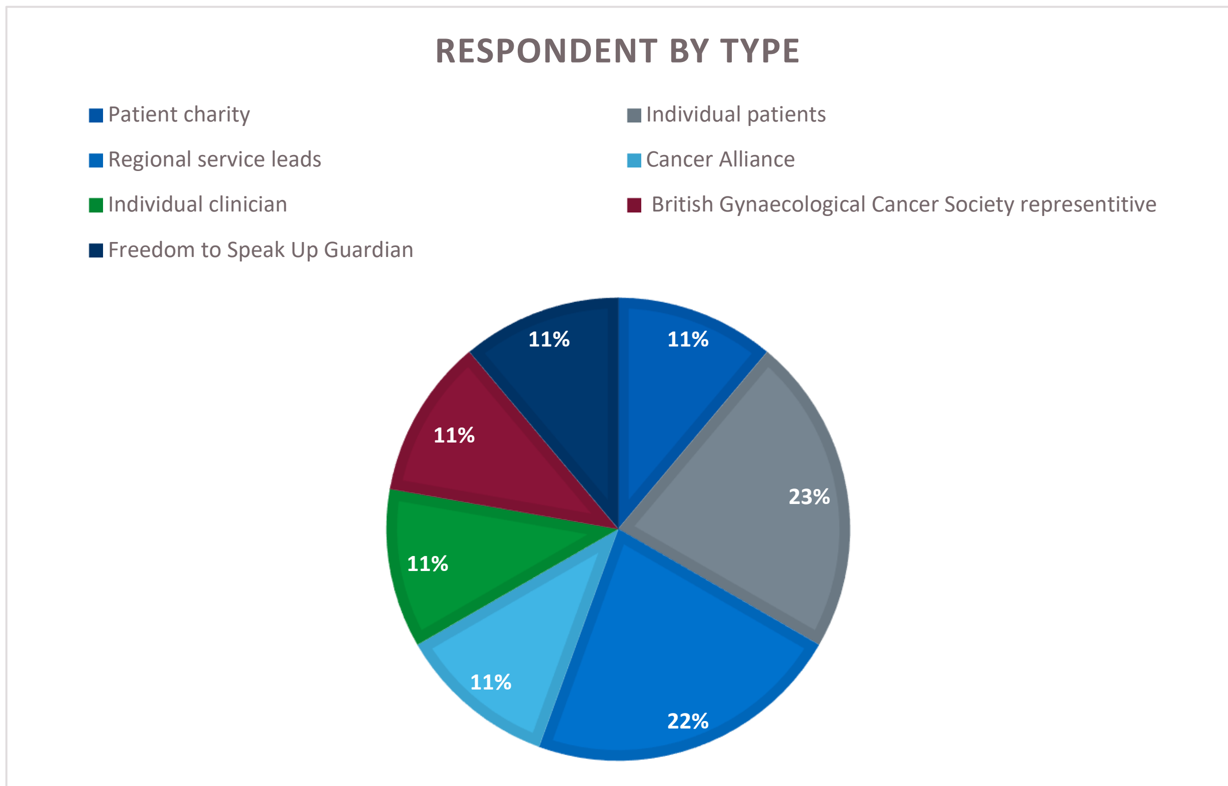
Respondents were asked the following questions:

- Do you have any comments on the proposal?
- If Yes, please describe below, in no more than 500 words, any further comments on the proposal as part of this initial 'sense check'
- Are the service quality outcomes appropriate to the service specification?
- If no, what quality outcome measures would you want to see included in the service specification?
- Do you support the Equalities and Health Inequalities Impact Assessment?
- Please declare any conflicts of interest.

3.2 Stakeholder testing results and summary of participants

10 responses were received:

- 1 NHS Provider Trust
- 1 Patient charity
- 2 Individual patients
- 2 Regional service leads
- 1 Cancer Alliance
- 1 Individual clinician
- 1 member of the British Gynaecological Cancer Society
- 1 Freedom to Speak Up Guardian



Overall, the feedback received was positive, with stakeholders registering their broad support for the service specification requirements, standards, and outcomes proposed.

In terms of specific questions asked; seven out of the ten respondents considered the service quality outcomes relevant to the service specification. One regional lead commented that the ovarian cancer quality performance indicators from the European Society of Gynaecological Cancer could be considered for inclusion, however the data for these indicators are not as yet available for collection, meaning including these would not align with the projected timescales for publication of the service specification. The other regional lead commented that the outcomes could include participation in NPCES and quality of life surveys, as well as rates of minimal access hysterectomy for endometrial cancer. It is noted that the wider set of quality metrics developed to support the service specification includes a metric around both patient experience and rates of minimal access hysterectomy for endometrial cancer. The BGCS representative commented that the quality outcomes focused on ovarian cancer, and could have included quality outcomes that represented each of the five subtypes of gynaecological cancer. As the overall set of proposed quality metrics includes indicators for each of these subtypes, it was deemed unnecessary to make any changes to the quality outcomes for this reason alone.

On the question of additional any comments related to the Service Specification; two of the ten participants included comments relating to the population size, specifically around the number of ovarian cancer surgeries performed by a subspecialist gynaecological cancer clinician. The BGCS representative suggested that criteria changed reflect that those treating ovarian cancer are involved in 15 gynaecological cases per year, whilst one of the regional clinical gynaecological cancer leads sighted the European Society for

Gynaecological Cancer (ESGO) ovarian cancer quality performance indicators (QPI) setting >20 cases as the minimum standard.

However, the Improving Outcomes Guidance for Gynaecological Cancer outlines that the number should be >15, and noting the ESGO standard is a European standard rather than one that reflects the minimum standard for England, meaning that the specification remains unchanged in the minimum population section.

Two respondents noted that the guidance section should contain the most up-to-date NICE guidance on maximal cytoreductive surgery for advanced ovarian cancer. The specification was amended to include this guidance.

On the question of supporting the Equalities and Health Inequalities Impact Assessment (EHIA), eight out of the ten respondents fully supported the proposed assessment, with the Cancer Alliance lead commenting that a reference to an interpreter for those that need it should be included. The EHIA was amended to include this change. One of the regional leads generally supported the proposal but commented that the age of patients with vulval and vaginal cancers was incorrect. This was amended in the EHIA.

The review of stakeholder responses to engagement, and subsequent decisions on whether any changes to the specification might be recommended are outlined in Section 4 below.

A 13Q assessment has been completed following stakeholder testing. The Programme of Care has decided that the service specification and proposed amendments does not constitute material changes to the way in which services are delivered or the range of services available and therefore further public consultation was not required. This decision has been assured by the Patient Public Voice Advisory Group.

4 How has feedback been considered

Responses to engagement have been reviewed by the Specification Working Group and the Cancer PoC. The following themes were raised during engagement:

Engagement activity theme identified in e.g. stakeholder testing, public consultation	Key themes in feedback	NHS England Response
	Relevant Evidence	
Cancer Alliance	Open 24 hours a day, 365 days a year is not a reasonable statement. Services are not staffed for this level of cover form the individual specialists, but the service should be situated in a location where patients could receive care at all times.	Level 2. A 24/7-hour 365 day a year service is the minimum requirement set out in the Improving Outcomes Guidance for providing specialist gynaecological cancer services. **No change.**
BGCS Representative	**Minimum population size -** Gynaecological oncologists treat 4 main cancers - Cervix, endometrial, vulval and ovarian (including fallopian tube, peritoneal). Most Gynaecological oncologists are splitting between Robotic & Vulval (laparoscopic endometrial) cervical and vulval cancer and Ovarian debulkers. Such surgery is often collaborative with ovarian debulkers working together. As such a criterion of 15 ovarian cancers per year - is meaning less for those who do vulval and endometrial cancer and potentially pushes surgeons who are not experienced in cytoreductive surgery into an area that is highly specialist. I suggest that your criteria changes to - for those treating ovarian cancer they are involved in 15 cases per year - you could argue that gynaecological oncologists doing higher risk staging laparotomies should do at least 15 a year.	Level 2. Improving Outcomes Guidance for Gynaecological Cancer states that Subspecialist gynaecological oncology surgeons to perform >15 operations for ovarian cancer per year. **No change.**

	Minimum cut offs for vulva and cervical cancer as there are minimum cases across all centres	
Regional Lead	I am concerned that some specialist gynaecological oncology centres have struggled since the COVID pandemic to retain a dedicated specialist gynaecological oncology / gynaecology ward within the acute hospital setting. If gynae oncology patients are dispersed throughout the hospital this is deleterious to care and prevents the development of a specialist gynae oncology nursing workforce. Therefore, I suggest that this bullet point mandatory requirement is amended to "specialist dedicated ward with appropriate bed capacity"	Level 2. The service specification states that appropriate ward/bed capacity is an essential facility in section 7.5. **No change.**
Regional Lead	**5.2 Minimum population size** ESGO QPI 2 suggests subspecialist gynaecological oncology surgeons to perform >20 operations for ovarian cancer per year, not 15 (Fotopoulou C, Concin N, Planchamp F, et al. Int J Gynecol Cancer Published Online First: 24 Jan 2020. doi:10.1136/ ijgc-2020-001248)	Level 2. Improving Outcomes Guidance for Gynaecological Cancer states that Subspecialist gynaecological oncology surgeons to perform >15 operations for ovarian cancer per year. **No change.**
	Impact Assessment	
Patient Charity	Participation in and reporting results of NCPES and cancer patient's quality of life surveys.	Level 2. Quality metrics developed to support the service specification include a metric from the Cancer Patient Experience Survey. **No change.**
Regional Lead	Consider use of ESGO Ovarian QPIs (Fotopoulou C, Concin N, Planchamp F, et al. Int J Gynecol Cancer Published Online First: 24 Jan 2020. doi:10.1136/ ijgc-2020-001248)	Level 2. ESGO Ovarian quality performance indicators are currently in development, and not routinely collected or published. Unlikely that these indicators will be published within suitable timescales for publication of the service specification. **No change.**
BGCS Representative	Outcomes are limited and are again very ovarian cancer focused. If you want a short list of metrics you could use: Ovarian cancer: Rate of surgery in	Level 2. Proposed quality metrics developed to support the service specification include

	stage 2-4 ovarian cancer and rate of complete resection in stage 2-4 ovarian cancer: Endometrial cancer: Rate of surgery, Cervical cancer: Rate of surgery for stage 1b1-2, Vulval cancer: Rate of sentinel node assessment in patients undergoing lymph node surgery.	measures relating to all subtypes of gynaecological cancer. **No change.**
	Current Patient Pathway	
Patient Charity	With regards to point 7.4 (Essential Staff Groups), we would encourage the involvement of a psychologist who has experience in cancer and psychosexual problems. If a specialist psychologist is not always available, we would encourage specialist training for the other members of the sMDT and sharing of best practice and specialist resources.	Level 2. The service specification already mentions Psychologist / Psychiatrist / Counsellor with experience in cancer and psychosexual problems. **No change.**
Cancer Alliance	**Ensures relevant surgeon joins the sMDT to discuss the case pre-referral when exenterative surgery is provided elsewhere.** Unnecessary as the case should be discussed at the MDT in the exenterative surgery provider.	Level 2. Section 7.1 states that the Service Provider must be a member of a Cancer Alliance and ensure that the service enables prompt referral to exenterative surgery providers, where the treatment is not provided locally by the Service. This must also set out a mechanism through which the sMDT will receive a report of Service User outcomes and for Service Users to be referred back to the Service for onward care. **No change.**
Cancer Alliance	**A minimum of two surgical gynaecological oncologists (subspecialist gynaecologists who specialise in surgery for gynaecological cancer)** To make this the minimum requirement for quoracy would mean that the centres need 4 surgeons in post to cover 52 weeks a year which is not possible in most centres in the country and increasing	Level 2. The Specification Working Group initially prompted that a minimum of three surgical oncologists attend the sMDT, however the current service specification mandates a minimum of two surgical gynaecological oncologists. **No change.**

	numbers are not possible as the number of trainees is less than needed for replacement jobs.	
Cancer Alliance	All sMDTs should have agreed some standard care pathways and demonstrate that they have adopted way to modernise their MDT for most effective use of the team's time. **https://www.england.nhs.uk/wp-content/uploads/2020/01/multi-disciplinary-team-streamlining-guidance.pdf**	Level 2. The proposed service specification is reduced in size and content specifically to avoid duplication with relevant NHS guidance. **No change.**
	Potential impact on equality and health inequalities	
Patient Charity	For the Equalities and Health Inequalities Impact Assessment, we would suggest including an additional consideration for disabled women. For disabled women with reduced or no physical sensation in areas of their body, there must be clear guidelines and advice given on how to recognise adverse outcomes following cancer treatment. For example, a patient may generally be expected to experience pain if there is an infection following surgery, but healthcare professionals should ensure that other identifiers are made clear to the patient and their ongoing care team.	Level 1. Equalities and Health Inequalities Impact Assessment section on disability amended to include section on patients with disabilities that include reduced or no physical sensation. **Amended.**
Regional Lead	There should be reference to access to interpreter services for those who need it.	Level 2. This is covered in section 13.2 of the standard contract which states: *"The Provider must provide appropriate assistance and make reasonable adjustments for Service Users, Carers and Legal Guardians who do not speak, read, or write English or who have communication difficulties (including hearing, oral or learning impairments). The Provider must carry out an annual audit of its compliance with this obligation and must demonstrate at Review Meetings the extent to*

		which Service improvements have been made as a result." **No change.**
Regional Lead	Race and ethnicity: Consideration to be given to make available patient information resources in multiple languages. Where religious beliefs or cultural norms mean that women would prefer to see a female clinician.	Level 2. This is covered in section 13.2 of the standard contract which states: *"The Provider must provide appropriate assistance and make reasonable adjustments for Service Users, Carers and Legal Guardians who do not speak, read, or write English or who have communication difficulties (including hearing, oral or learning impairments). The Provider must carry out an annual audit of its compliance with this obligation and must demonstrate at Review Meetings the extent to which Service improvements have been made as a result."* **No change.**
Regional Lead	With regard to younger people, Teenagers & Young Adults (TYA) Multidisciplinary teams help address psychological and reproductive needs. Also, many tumours within this age group may be more chemosensitive, such as germ cell tumours.	Level 2. TYA cancer falls under separate service specification. **No change.**
Regional Lead	Gender re-assignment: Should read 'Individuals who are born female and have female reproductive organs…'	Level 1. EHIA amended to reflect correct wording for gender re-assignment. **Amended.**
Regional Lead	Looked after children and young people: Women aged 18-24years (young adults) should be specifically mentioned here as the TYA MDT forum provides psychological, reproductive, and nursing supports for these women.	Level 2. TYA cancer falls under separate service specification. **No change.**
Regional Lead	**Age:** Peak age prevalence for vulva cancer is incorrect as there has been a rise in vulva cancer incidence in	Level 1. EHIA amended to include updated peak age for vulva cancer and vaginal cancer. **Amended.**

	50-69year olds and a decrease in the incidence for younger and older populations (Int J Public health 2022; 67:1605021 PMID 36105176) Peak prevalence for vaginal cancer is incorrect as average age is 67years (cancer.net).	
Cancer Alliance	Rurality is important as patients in more isolated communities are less likely to have treatments such as radiotherapy and assess to accommodation and transport for patients living at distance from the treatment centre should be essential.	Level 2. EHIA addresses issues around remote access to care in the section on people living in remote, rural and island locations. **No change.**
Freedom to Speak Up Guardian	Health passport model to include written and visual material for those with learning disabilities, or psychological ill health. The voice of the patient in the care pathway - How will this be included? The Impact Assessment has high relevance to the duty to eliminate discrimination. Have Health Passport models for patients been considered and feedback mechanisms to ensure the voice of the patient is heard throughout the treatment pathway.	Level 4. Falls outside the remit of the service specification. Falls under the responsibility of the local Trust. **No action required.**
	Changes/addition to specification.	
Regional Lead	There is a more up-to-date NICE Guideline replacing Ultra radical surgery Maximal cytoreductive surgery for advanced ovarian cancer (nice.org.uk).	Level 1. Guidance section changed to incorporate updated NICE guidance. **Amended.**
Regional Lead	**Relevant NICE Guidance** Interventional Procedures Guidance Ultraradical surgery 2023, not 2013.	Level 1. Guidance section changed to incorporate updated NICE guidance. **Amended.**

5 Has anything changed in the service specification as a result of the stakeholder testing and consultation?

The following change based on the engagement responses has been made to the service specification:

- Amendment in guidance section to include most recent recommended guidance on ultraradical surgery.

The following changes based on the engagement responses have been made to the Equalities and Health Inequalities Impact Assessment:

- Amendment in the disability section to include statement regarding patients with disabilities that include reduced or no physical sensation.
- Amendment in the gender reassignment section to reflect correct wording for gender re-assignment.
- Amendment in the section on age to include updated peak age for vulva cancer and vaginal cancer.

6 Are there any remaining concerns outstanding following the consultation that have not been resolved in the final service specification?

The 13Q assessment has been completed following stakeholder testing. The proposition and the 13Q will be reviewed at the PPVAG meeting on 17th August 2023.

Confirmation has been received that public consultation is not required.

7 What are the next steps including how interested stakeholders will be kept informed of progress?

A summary of the feedback from stakeholder engagement will be made available to the registered and relevant stakeholders.