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Title	British Gynaecological Cancer Society recommendations and guidance on patient-initiated follow-up (PIFU)
Type	Article
URL	https://clock.uclan.ac.uk/id/eprint/33173/
DOI	https://doi.org/10.1136/ijgc-2019-001176
Date	2020
Citation	Newton, Claire, Nordin, Andy, Rolland, Philip, Ind, Thomas, Larsen-Disney, Peter, Martin-Hirsch, Pierre, Beaver, Kinta, Bolton, Helen, Peevor, Richard et al (2020) British Gynaecological Cancer Society recommendations and guidance on patient-initiated follow-up (PIFU). <i>International Journal Of Gynecological Cancer</i> , 30 (5). pp. 695-700. ISSN 1048-891X
Creators	Newton, Claire, Nordin, Andy, Rolland, Philip, Ind, Thomas, Larsen-Disney, Peter, Martin-Hirsch, Pierre, Beaver, Kinta, Bolton, Helen, Peevor, Richard, Fernandes, Andrea, Kew, Fiona, Sengupta, Partha, Miles, Tracie, Buckley, Lynn, Manderville, Helen, Gajjar, Ketan, Morrison, Jo, Ledermann, Jonathan, Frost, Jonathan, Lawrence, Alexandra, Sundar, Sudha and Fotopoulou, Christina

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<https://doi.org/10.1136/ijgc-2019-001176>

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1 **ABSTRACT**

2 The National Cancer Survivorship Initiative through the National Health Service (NHS)
3 improvement in the United Kingdom (UK) started the implementation of stratified pathways
4 of patient-initiated follow-up (PIFU) across various tumour types. Now the initiative is
5 continued through Living With and Beyond Cancer programme by NHS England.

6 Evidence from non-randomised studies and systematic reviews does not demonstrate a
7 survival advantage to the long-established practice of hospital-based follow-up (~~FU~~)
8 regimens, traditionally over 5 years. Evidence shows that patient needs are inadequately
9 met under the traditional hospital-based follow-up ~~FU~~ programmes and there is ~~therefore~~
10 an urgent need-necessity to adapt pathways to the needs of patients. The assumption that
11 ~~hospital-based~~ hospital-based follow-up ~~FU~~ is able to detect cancer recurrences early and
12 hence improve patients' prognosis has not been validated. A recent survey demonstrates
13 that hospital-based follow-up ~~FU~~ practice across the UK varies widely, with telephone follow-
14 up ~~FU~~ clinics, nurse-led clinics, and PIFU becoming increasingly common.

15 There are currently no completed randomised controlled trials in ~~-PIFU~~ in gGynaecological
16 malignancies, although there is a drive towards implementing PIFU ~~it~~. PIFU aims to
17 individualise patient care, based on risk of recurrence and holistic needs, and optimising
18 resources. The British Gynaecology Cancer Society (BGCS) wishes to provide the
19 gynaecological oncology community with guidance and a recommendations' statement
20 regarding the value, indications and limitations of PIFU in endometrial, cervical, ovarian and
21 vulva cancers in an effort to standardise practice and improve patient care.

22 Key words: Patient initiated follow-up (PIFU), gGynaecology oOncology, ~~follow-up (FU)~~,
23 gGynaecological malignancies.

24 **Precis:** British Gynaecology Cancer Society (BGCS) recommendations' statement regarding
25 the value, indications and limitations of PIFU in endometrial, cervical, ovarian and vulvar
26 carcinoma

27

28 **INTRODUCTION**

29 The British Gynaecology Cancer Society (BGCS) has issued a number of guidelines to
30 improve the quality of care and standardise treatment and follow-up pathways for
31 patients with gynaecological cancer. As the practice of follow up varies widely¹
32 and is continuously evolving, the BGCS wished to implement strategies for a UK-wide
33 implementation of patient initiated follow-up (PIFU), addressing its indications, value and
34 limitations across all different gynaecological cancer sites. The National Cancer Survivorship
35 Initiative, through NHS improvement, has already implemented stratified pathways
36 (including some patient initiated) for follow up in breast, colorectal, and prostate
37 cancer². Patients with early stage cancer of breast, colorectal and prostate may be
38 offered remote surveillance and at the present time no surveillance techniques have been
39 deemed to be effective in gynaecological cancers.

40 Historically, patients have been kept on hospital-based follow up in dedicated outpatient
41 clinics for 5-10 years following diagnosis and treatment for gynaecological cancer^{3,4}.
42 The main aims of follow-up include: detection of asymptomatic recurrences, with the
43 assumption that this will improve prognosis; detection and management of side effects of
44 treatment; improvement in quality of life; identification and treatment of patient concerns
45 and anxieties around their cancer diagnosis^{5,6}. However, there is no evidence that
46 intensive follow-up improves survival⁷⁻¹³ and women often find clinical examination
47 uncomfortable (especially vaginal examination) with 54% (48/89) experiencing increased
48 anxiety prior to their follow up appointments⁶.

49 There is evidence that the current hospital-based follow-up does not necessarily meet
50 cancer survivors needs, failing to provide emotional support and information needs¹⁴
51 due to limited time, resources and lack of focus on a holistic approach of the patients'
52 needs. A holistic approach will take account of mental and social factors as well as
53 symptoms of the disease. In 2010 the National Cancer Survivorship Initiative (NCSI) was
54 launched by the Department Of Health in England in collaboration with one of the UK's
55 largest charitable organisations, Macmillan Cancer Support, to improve the long term
56 consequences of surviving cancer¹⁵. In more recent years, the Living With and Beyond
57 Cancer programme¹⁶ has advocated a shift in care and support towards self-
58 management, based on individual needs and preferences, and away from the traditional
59 single model of clinical follow-up. This approach empowers individuals to take responsibility

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60 for their condition, supported by clinical assessment to enable early recognition of
61 symptoms of recurrence or consequences of their treatment and a 'Recovery Package' that
62 includes holistic needs assessments (performed after completion of treatment for cancer),
63 treatment summaries, health and well-being events and cancer care reviews in primary
64 care¹⁶.

65 There are different [follow up](#) methods currently utilised in the UK which include hospital
66 [follow up](#), telephone [follow up](#) and PIFU. Hospital [follow up](#) involves seeing
67 patients in clinics at regular intervals, whereas telephone [follow up](#) involves calling
68 patients at a specified time at pre-determined intervals. PIFU involves educating patients
69 about concerning symptoms, such as vaginal bleeding, unintentional weight loss, and
70 worsening abdominal pain or bowel/bladder symptoms. In patient-initiated [follow up](#),
71 patients are not given routine [follow up](#) appointments (hospital, telephone or with [the](#)
72 [General practitioner](#)), but instead are empowered to call the gynaecological oncology
73 team directly (often via the clinical nurse specialist with specialist cancer knowledge) if they
74 have these symptoms and then they are fast-tracked back into the specialist care system. It
75 is very important that patients are given written information about PIFU, which includes the
76 contact details should they need them. Most patients find PIFU acceptable¹⁷, although
77 younger patients and those who struggle to access healthcare (due to socio-demographic
78 factors) may require the additional support¹⁸ of routine contact, either via hospital
79 [follow up](#) or telephone [follow up](#).

80 **METHODS**

81 The BGCS PIFU meeting was held on 14th March 2019 in London, UK. Experts from clinical
82 practice (including medicine and nursing) and academia with specialist knowledge and
83 expertise in [gynaecology](#) [oncology](#) and alternative [follow up](#) strategies reviewed
84 available evidence from a systematic literature search in Medline, Embase CINAHL, AMED,
85 BNI, HBE, HMIC, PsycINFO that aimed to identify significant evidence on alternatives to
86 hospital-based follow-up. These data were presented, discussed and evaluated by the key
87 opinion leaders. Additionally, data from a national survey of follow-up practice across the
88 UK in gynaecological malignancies were presented. All experts agreed the consensus

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89 guidelines for each gynaecological tumour site (cervical, ovarian, endometrial and
90 vulva).

91 Although there was no patient representative at the BGCS PIFU meeting, there has been
92 positive feedback from patients within the hospitals that have already implemented the
93 guidelines and in studies that looked at patient acceptability¹⁷⁻¹⁹

94 .

95

96 **DISCLAIMER**

97 Clinicians should always use their clinical judgement to determine if an individual patient is
98 suitable for PIFU. These consensus recommendations have been produced as guidance for
99 follow up pathways and are based on available evidence. Where little evidence existed,
100 expert consensus was agreed.

101 **RESULTS**

102 PIFU guidance for each cancer type will be presented separately under the general umbrella
103 and recommendation that only those patients who fit all of the criteria below are eligible
104 and safe to be offered PIFU:

105

General eligibility criteria for PIFU
Completed primary treatment for a gynaecological malignancy and are clinically well
Patients should be willing and able to access healthcare if on PIFU
They should be without significant treatment related side-effects that need ongoing management
They should not have recurrent disease
They should not be on active or maintenance treatment
They should not be on a clinical trial where follow-up schemes are defined and limited to hospital-based <u>follow upFU</u>
They should not have a rare tumour with uncertain risk of recurrence and need for ongoing management They must be able to communicate their concerns without a significant language barrier or psychological comorbidity and have competence to agree to PIFU

106

107 At the clinic visit prior to offering PIFU, patients should be provided with a careful
108 explanation on the lack of evidence for benefit from regular follow-up visits to the hospital
109 and the rationale for implementing a supported self-management approach (PIFU).
110 However, for patients with significant iatrogenic side effects, which impair their quality of
111 life and need active management, it is important that those are addressed and managed
112 within in the clinic setting with sufficient access to other health professionals, such as
113 gastroenterologists, urologists, endocrinologists, and psychologists. PIFU should be offered
114 on a case-by-case basis, ensuring there are no existing unmet needs and according to their
115 cancer type.

116 **ENDOMETRIAL CANCER**

117 There are approximately 9,300 new cases of endometrial cancer in the UK and it is the 4th
118 most common cancer in women²⁰. There has been an increase of nearly 20% in the last
119 10 years²⁰, which is thought to be largely due to the sharp increase in obesity, although
120 rarer tumours, not associated with obesity have also increased.

121 Low risk endometrial cancer is defined by the (European Society of Medical Oncology-
122 European Society of Gynecological Oncology) ESMO-ESGO guidelines²¹ as stage I
123 endometrioid, grade 1-2 histology, with ≤50% myometrial invasion, negative for
124 lymphovascular space invasion and hence not in need of adjuvant treatment²¹.

125 Following hysterectomy and bilateral salpingo-oophorectomy, patients have their
126 holistic needs assessment and the next steps of their journey discussed with their
127 dedicated cancer support workers, under the coordination and guidance of the clinical nurse
128 specialists. They can also be referred to psycho-oncological counselling services, if required
129 and accepted by the patient. Patients are educated about symptoms that would be
130 concerning for a recurrence, such as vaginal bleeding, worsening or persistent abdominal
131 pain, or bladder/bowel symptoms. A population study by Salvesen over 10 years
132 demonstrated that 653 patient consultations were needed to pick up one asymptomatic low
133 risk endometrial cancer patient with recurrent disease^{12,13}. Based on a very low risk
134 of relapse without adjuvant treatment, these patients could be offered PIFU after they have

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Commented [NC6]: Apologies, I have changed it as its reference 12 and 13.

135 completed treatment at, or shortly after, the time of their [holistic needs assessment](#)
136 appointment ([Figure 1](#)).

137 Intermediate risk endometrial cancer is defined by the ESMO-ESGO guidelines²¹ as
138 stage I endometrioid, grade 1–2, ≥50% myometrial invasion, [lymphovascular space invasion](#)
139 negative. These patients are commonly offered vaginal brachytherapy, without external
140 beam radiotherapy, following their hysterectomy²¹. Their risk of recurrence is relatively
141 low. Patients could be offered PIFU at the 3-month review after treatment or anytime
142 during the first 2 years of hospital [follow up](#). It is important for patients to be aware that
143 they may develop late onset toxicity following brachytherapy that may not be apparent
144 shortly after finishing their treatment. For that reason, it should be explained that they can
145 be seen back in clinic, if their have concerns related to toxicity, as well as if they have
146 symptoms concerning for recurrence, if they are on PIFU. Another option for these patients
147 is telephone [follow up](#) with [randomised controlled trial](#) level data of no physical or
148 psychological detriment, compared to hospital follow-up, in stage I endometrial cancer²²
149 Telephone follow-up could be seen as a useful transition between face to face hospital-
150 based appointments and PIFU.

151 High-intermediate risk endometrial cancer is defined by the ESMO-ESGO guidelines²¹ as
152 patients with grade 1–2 tumours with deep (≥50%) myometrial invasion and unequivocally
153 positive (substantial, not focal) [lymphovascular space invasion](#), and those with grade 3
154 tumours with <50% myometrial invasion regardless of [lymphovascular space invasion](#)
155 status. These patients are treated as high risk for the purpose of these guidelines, due to
156 their higher risk of recurrent disease. High-intermediate risk endometrial cancer represents
157 a heterogeneous group of patients, including both endometrioid and non-endometrioid
158 tumour types, such as serous and clear cell, and ranges from stage IB grade 3 (with or
159 without [lymphovascular space invasion](#) and with or without nodal staging) to more
160 advanced FIGO stages²¹. The risk of recurrence is higher for these patients (>20%)
161 and therefore it is suggested that they should be seen in the clinic for at least the first 2
162 years, as this is the most frequent time for recurrence^{23,24}. After 2 years patients
163 could be offered PIFU for the remaining 3 years ([Figure 1](#)). Again, another alternative is
164 telephone [follow up](#) for the remaining 3 years.

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165 **CERVICAL CANCER**

166 There are approximately 3,200 new cases of cervical cancer every year, with an
167 incidence of 12 per 100,000 in the UK²⁵.

168 In patients with a FIGO stage **IA1** cervical cancer the British Society of Colposcopy and
169 Cervical Pathology (BSCCP) recommend cervical cytology should be taken 6 and 12 months
170 after treatment (hysterectomy or LLETZ) followed by annual cytology for a further 9 years
171 before returning to routine recall until the age of 65 for those treated with LLETZ and still
172 have a cervix²⁷. If patients have had a hysterectomy for stage **IA1** cervical cancer
173 there are specific guidelines on cytology follow-up depending on histology of the
174 hysterectomy specimen²⁷. Patients who have had a hysterectomy for stage **IA1** are
175 also excluded from PIFU.

176 In low risk patients (FIGO stage **IB1**) who have undergone a radical hysterectomy for
177 treatment of cervical cancer the BGCS recommends follow-up in the clinic setting every 3-4
178 months in the first 2 years, and then PIFU can be offered (Figure 2). It should be noted
179 that the BSCCP recommends vault smears at 6 and 18 months after a hysterectomy for
180 cervical intraepithelial neoplasia (CIN)²⁷ if margins are free of CIN. However, vaginal
181 vault cytology should not be performed following treatment for FIGO stage **≥IA2** as it
182 does not add significantly to the detection of recurrent disease^{25, 27-28}. These
183 patients have a 5-year risk of recurrence of 5.8-8%^{27, 29-31}. However only 4-5%
184 will have pelvic recurrences and only 1-2% can be salvaged^{28, 31, 32}, although this
185 has increased slightly with cyberknife and other techniques. In a large Danish national
186 cohort study of 1523 patients with low-risk cervical cancer, of those with recurrent
187 disease, 67.5% experienced a symptomatic recurrence³⁰. Other studies have shown
188 similar rates of symptomatic recurrent cervical cancer²⁴. Therefore, as the majority
189 present with symptoms, PIFU appears to be reasonable for low-risk patients. As surgery for
190 early stage cervical cancer may cause morbidity, such as bladder dysfunction and
191 lymphoedema, hospital **follow up** for the first 2 years was thought to be preferable to
192 telephone **follow up** (BGCS consensus agreement).

193 In patients with intermediate (risk of recurrence 10-20%) or high risk (risk of recurrence
194 >20%) disease, hospital **follow up**, to include taking an appropriate history and clinical

195 examination at each visit, should be undertaken to try and detect recurrent disease. This
196 group of patients usually have FIGO stage \geq IB₂, although there are other factors that play
197 a role in the likelihood of recurrence, such as lymph node status and [lymphovascular space](#)
198 [invasion](#)³⁰. Hospital [follow up](#) should be undertaken for 5 years, particularly as
199 these patients may have significant treatment-related toxicity (Figure 2). However, it
200 should be noted that the majority of recurrences occur within 2 years; a Norwegian national
201 prospective observational study by Vistad et al. in 2017, which included 680 patients with
202 gynaecological cancer recurrence, showed a mean annual incidence rate from years 3-5 of
203 only <7%³⁰.

204 **OVARIAN CANCER**

205 There were 7,500 women who developed tubo-ovarian/primary peritoneal cancer in the UK
206 in 2016 making it the 6th most common cancer in women³⁴. The majority of those who
207 developed tubo-ovarian/primary peritoneal cancer had epithelial ovarian cancer,
208 which relates to these guidelines. Non-epithelial ovarian cancers, such as granulosa cell
209 tumours or germ cell tumours of the ovary, are not included in these guidelines, as they
210 have their own distinct pathogenesis and behave differently [from epithelial ovarian](#)
211 [cancer](#). Fertility-preserving surgery, that includes a unilateral salpingo-oophorectomy
212 and full surgical staging, is acceptable in young patients with stage IA (grade 1 and 2), and
213 stage IC (grade 1) disease, as they have similar recurrence rates and overall survival to
214 those undergoing conventional treatment³⁵. However, these patients should be seen
215 regularly for hospital [follow up](#) and ultrasound scans of the contralateral ovary and
216 are excluded from PIFU.

217 Only patients who have been adequately staged, with pelvic and para-aortic
218 lymphadenectomy and peritoneal biopsies for an apparent stage I ovarian cancer, should
219 be offered PIFU, so that occult higher stage cancers with higher risk of relapse, are not
220 included³⁶. Patients with fully staged IA/B ovarian cancer (of any grade) have a low
221 risk of recurrence and therefore could be offered PIFU after they have completed their
222 treatment (Figure 3). Evidence does not suggest that routine follow-up of patients with
223 ovarian cancer improves survival³⁷⁻⁴⁰. A randomised phase III study OV05-EORTC
224 55955⁴⁰, which compared initiation of chemotherapy on development of elevated

225 CA125 versus initiation of chemotherapy on clinical/symptomatic evidence of relapse
226 showed treatment was delayed by a median of 4.8 months in the latter group with no
227 detriment to overall survival (HR 1.01; 95% CI 0.82–1.25; P = 0.91). Moreover, quality of
228 life was lower in the patients that had initiation of chemotherapy on CA125 rise. However,
229 this study took place outside the possibility of secondary cytoreductive surgery for recurrent
230 ovarian cancer and also before the establishment of targeted and maintenance agents at
231 relapsed disease and it is unclear whether we can translate its findings to the modern era of
232 ovarian cancer management^{36,42}.

233 At the follow-up appointment, symptoms should be assessed and a physical examination
234 should be carried out in the first 3 years from completing treatment in patients with FIGO
235 stage 2-4, as this is the most common time period in which recurrent disease develops³⁰
236 . In years 4 and 5, in the absence of recurrent disease, patients could have the option of
237 moving to a combination of telephone [follow up](#) with CA125 serial measurements, if
238 deemed suitable by their clinician. There is evidence that telephone [follow up](#) in ovarian
239 cancer is well received and the majority preferred it to hospital [follow up](#)⁴³. If
240 patients are not suitable for telephone [follow up](#) and remote CA125 measurements,
241 patients should continue hospital [follow up](#) for a minimum of 5 years after completing
242 treatment.

243 VULVAR CANCER

244 Vulvar cancer is rare with only 1,300 new cases in 2015 in the UK, which is less than 1% of all
245 cancers in women⁴⁴. Cancer of the vulva primarily affects older women with the
246 highest incidence of women aged 90 or over⁴⁴. The difficulty of self-examination and
247 the increased numbers of cases in deprived areas⁴⁴ leads to a greater number of
248 vulnerable women. Therefore, the BGCS recommends that women with vulvar cancer are
249 not suitable for PIFU (Figure 4) and should follow the traditional [follow up](#) schemes
250 involving careful clinical examination. This should be performed by clinicians with
251 appropriate experience, which would usually be in the hospital setting.

252 There is no evidence for the recommendations of frequency of examinations. The ESGO
253 expert consensus guidelines and RCOG guidelines on vulvar cancer⁴⁵ recommend 3-4
254 monthly follow-up in the first 2 years, biannually for years 3 and 4 and then [annual](#) [life-long](#)

255 **follow-up.** This is supported by a retrospective analysis of 330 patients with primary vulvar
256 carcinoma treated at the Mayo clinic, which showed 35% of recurrences occurred more
257 than 5 years after diagnosis with both distant and local disease⁴⁶. The BGCS
258 recommends **follow up** of patients with vulval cancer for at least 5 years, with longer
259 follow-up at the discretion of the treating clinician. Patients with multi-focal vulvar
260 intraepithelial neoplasia (VIN) or lichen sclerosis with VIN (differentiated VIN) are at high
261 risk of multi-focal disease and more intensive follow-up may be warranted^{45, 47}.

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Commented [NC11]: Yes. I have added in 'annual'

263 **ACKNOWLEDGMENTS**

264 We would like to thank Debbie Lewis for her help in organising the BGCS PIFU meeting.

265 **COMPETING INTERESTS**

266 None

267 **ETHICS**

268 No ethical review was necessary as this is a review article and therefore we did not use any
269 human participants for this piece of research.

270

271 **FUNDING**

272 All costs relating to the BGCS guideline meeting on patient-initiated follow-up were covered
273 by BGCS funds.

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Endometrial Cancer	Clinic-based FU	Telephone FU +/- blood test	PIFU
Low risk (<10% risk of recurrence ROR)	If patient declines PIFU (for maximum of 2 years from end of treatment)	If patient declines PIFU (for maximum of 2 years from end of treatment)	Offer from end of treatment (after Holistic needs assessment at 3 months)
Intermediate risk	Can be offered if declines PIFU for 2 years from end of treatment	Can be offered if declines PIFU for 2 years from end of treatment	offer from end of treatment or after 2 years for all
High -intermediate risk	For 5 years (either telephone FU or clinic FU)	For 5 years (either telephone FU or clinic FU)	offer from 2 years from end of treatment in place of telephone FU or clinic FU.
High-risk	For 5 years (either telephone FU or clinic FU)	For 5 years (either telephone FU or clinic FU)	offer from 2 years from end of treatment in place of telephone FU or clinic FU.

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Figure 1: Guidelines for follow-up in eEndometrial cancer
(ROR=risk of recurrence, PIFU= patient initiated follow-up, FU=follow-up)

281

Cervical Cancer	Clinic-based FU	Telephone FU +/- blood test	PIFU
Low risk (<10% risk of recurrence ROR) excluding fertility sparing surgery/ LLETZ	For 5 years post completion of treatment	Not suitable	Offer from 2 years from end of treatment
Intermediate risk	For 5 years post completion of treatment	Not suitable	Not suitable
High risk	For 5 years post completion of treatment	Not suitable	Not suitable

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Figure 2: Guidelines for follow-up in cervical cancer (ROR=risk of recurrence, PIFU= patient initiated follow-up, LLETZ= large loop excision of transformation zone, FU=follow-up).)

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Ovarian Cancer	Clinic-based FU	Telephone FU +/- blood test	PIFU
Low risk (<10% risk of recurrence ROR, stage 1a/b fully staged) from end of treatment (surgery +/-chemo). Excluding fertility sparing surgery	Can be offered if declines PIFU for 2 years from end of treatment	Can be offered if declines PIFU for 2 years from end of treatment	Offer from end of treatment (after Holistic needs assessment at 3 months)
FIGO stages 1c-4	For 3 years from end of treatment	Can be offered for years 4+5 from end of treatment	Not suitable

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Figure 3: Guidelines for follow-up in govarian cancer

(ROR=risk of recurrence, PIFU= patient initiated follow-up, FU=follow-up)

Options for follow-up	Vulval Cancer
PIFU for 5 years from treatment	Not suitable
Remote/telephone +/- bloods	Not suitable
Clinic-based FU	Follow-up including clinical inspection for at least 5 years from from end of treatment

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**Figure 4: Guidelines for follow-up in vulvar lcancer
(FU=follow-up, PIFU= patient initiated follow-up)**

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