1 **ACCEPTABILITY AND UTILISATION OF PATIENT-INITIATED FOLLOW-UP**

2 **(PIFU) FOR ENDOMETRIAL CANCER AMONGST WOMEN FROM DIVERSE**

3 **ETHNIC AND SOCIAL BACKGROUNDS: A MIXED METHODS STUDY**

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24 **CONFLICT OF INTEREST STATEMENT**

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26 None of the authors report conflict of interest.

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28 **ABSTRACT**

29 **Introduction**

30 A shift in focus towards risk stratification and survivorship in early stage endometrial cancer

31 (EC) has led to the replacement of hospital follow-up (HFU) with patient-initiated follow-up

32 (PIFU) schemes.

33 **Methods**

34 A mixed-methods study was undertaken prospectively to investigate utility and patient

35 satisfaction with a newly introduced PIFU scheme.

36 **Results**

37 228 women were enrolled onto PIFU in the first 18 months, median age 65 years (range 42-90

38 years). Twenty-four (10.5%) women were non British-White ethnicity. Forty-five women

39 contacted the Clinical Nurse Specialist (CNS) at least once (19.7%), the primary reason being

40 vaginal bleeding/discharge (42%). Contact was greater in first six months on the scheme

41 compared to the second six months, and women who made contact were significantly younger

42 than those who did not (57 years versus 65 years, p<0.001).

43 **Conclusions**

44 PIFU appears to be well received by the majority of women. Although many of the CNS

45 contacts were due to physical symptoms, a number were for psychological support or

46 reassurance. Younger women had greater CNS contact indicating that they may benefit from a

47 greater level support. Patient feedback of the PIFU scheme was positive, with many women

48 reporting that it enabled them to have more control over their own health.

49

50 **KEYWORDS:** Endometrial cancer; follow up; patient-initiated; quality of life; patient

51 satisfaction

52

INTRODUCTION

The incidence of endometrial cancer (EC) in the UK has increased by 65% over the past 40 years making it not only the most common gynaecological cancer but the fourth most common malignancy in women, accounting for 3% of all new cancer diagnoses (UK). The majority of cases are diagnosed with early stage disease, which carries a good long-term prognosis with 5-year disease-specific survivals in excess of 95% (Amant et al., 2005; UK). It is a disease typically affecting older women with the majority being over the age of 70 years at diagnosis and having co-morbidities, in particular obesity, diabetes and cardio-vascular disease (Parkin, Boyd, & Walker, 2011).

Women diagnosed with an endometrial cancer have been traditionally followed-up through regular hospital review by a specialist gynaecological oncologist after completing their treatment (Colombo et al., 2011). Hospital follow-up (HFU) typically involves women being reviewed routinely by doctors and/or nurses who conduct a physical examination. The rationale for attending HFU is surveillance for cancer recurrence thus enabling early detection, prompt management and as a result a better long-term prognosis. The period of review has historically been for a minimum of five years since the majority of cancer recurrences occur within three years post treatment (Colombo et al., 2011). The role of routine follow-up in early stage, low-risk endometrial cancer (EC) however has been questioned since it does not appear to have an impact of long-term survival (Gadducci, Cosio, Fanucchi, Cristofani, & Genazzani, 2000; Owen & Duncan, 1996; Yoshiba et al., 2016). In light of the rising incidence, low recurrence rate, population demographics and the lack clear clinical benefit of hospital follow-up in such cases, alternative follow-up schedules (Salani et al., 2011) and models have been developed, for example telephone follow-up (TFU) (Beaver et al., 2016) and patient-initiated follow-up (PIFU).

78

79   PIFU, as the name suggests, is where patients are not routinely seen in hospital but instead have

80   open access to Clinical Nurse Specialists (CNS) whom they can contact should they have

81   concerns or if/when symptoms arise. The first UK national survey on the follow-up of

82   gynaecological cancer patients reported that out of all the available follow-up schemes, PIFU

83   was used instead of or as an adjunct to existing follow up models by 32% of the centres that

84   responded (Leeson, Stuart, Sylvestre, Hall, & Whitaker, 2013). Despite the wide spread use of

85   PIFU there are very few reports in the literature examining patient views or satisfaction with

86   such schemes.

87

88   A PIFU scheme was introduced in September 2014 at University Hospitals of Leicester (UHL)

89   for early stage EC. Women who had received a diagnosis of early stage EC in the previous 5

90   years and were under HFU were offered transfer to the PIFU scheme. Women with a new

91   diagnosis were started on PIFU immediately following completion of their treatment. PIFU

92   was led by the CNSs who would have an end of treatment appointment with the patient where

93   they would provide them with their contact details and written information on the

94   signs/symptoms that should prompt a medical review. A telephone call by the CNS to the

95   patient was scheduled for 6 and 12 months to ensure that the patient was still happy to continue

96   on the PIFU scheme and had the contact details should symptoms arise. No other contact with

97   the medical team was organised.

98

99   In order to ensure patient satisfaction with the scheme a prospective study was conducted

100 investigating patients' utilisation, personal opinions and attitudes towards the PIFU scheme.

101

102

METHODS

A mixed methods study was undertaken following guidelines for qualitative research in order to ensure reliability and validity (BMJ, 2016). Mixed methods studies are increasingly used within health research to increase our understanding of health problems (Plano Clark & Creswell, 2010). This study utilized a sequential explanatory approach (Terrell, 2012) whereby the results from the distributed questionnaires informed the development of the semi-structured interview schedule. In addition, qualitative data added depth and understanding to the questionnaire findings.

The introduction of the PIFU scheme at UHL was supported by the East Midlands Gynaecological Oncology Clinical Advisory Group (ECAG) and the UHL Cancer Board. The prospective audit of patient utility and satisfaction of the scheme was approved by the University Hospitals of Leicester audit team. Ethical approval was granted for the patient interviews (15/WM/0239). Women with a diagnosis of early stage low-risk EC and early stage intermediate risk EC who had completed adjuvant treatment, were enrolled onto the PIFU scheme in its first 18 months (September 2014 to March 2016) and were included in the study.

Scheme utilisation

Information was collated on the demographics of the patients, including age at diagnosis and ethnicity. The contemporaneous call log and individual patient records kept by the CNSs were reviewed and classified by primary reported reason for telephone contact: physical; psychological; practical. The data were analysed using GraphPad Prism (GraphPad Software, Inc, La Jolla, USA).

128 *Patient satisfaction*

129 Quality of Life (EORTC QLQ-C30) and patient satisfaction questionnaires (Appendix 1) were

130 posted to the women on the scheme at 6 and 12 months following enrolment. The QLQ-C30

131 results were analysed using the EORTC QLQ-C30 scoring manual (Fayers & Bjordal, 2001)

132 in order to give a score for Functioning, Symptoms and Global Health Status and were

133 compared against the references values (Scott & Aaronson, 2008).

134

135 *Semi-Structured interviews*

136 Women enrolled on the PIFU scheme were invited to attend a face-to-face semi-structured

137 interview with two female members of the research team (PK and EM) to discuss their views

138 and opinions on PIFU. Both PK and EM are trained in interview techniques. One of the

139 interviewers was a member of the clinical gynaecological oncology team at the University

140 Hospitals of Leicester. In order to achieve a wide sampling frame women were grouped in to

141 British White (BW) (Group a) and non British White (non BW) (Group b) and then subdivided

142 into women who transferred onto the PIFU scheme from HFU (Group A) and those who were

143 started directly onto the PIFU scheme following their diagnosis (Group B). Women were

144 selected randomly from each of the four groups (Aa, Ab, Ba, Bb) by hospital unit number and

145 a written invitation was posted to their home address. Invitations were sent out and interviews

146 were conducted in an outpatients clinic room, until data saturation was achieved. An interview

147 guide was used asking questions on their treatment journey, experiences and views on different

148 follow up schemes and views of the future. Interviews were recorded with the knowledge and

149 consent of the participants and subsequently transcribed verbatim. Due to the interviews being

150 fully transcribed, field notes were not undertaken by either interviewer.

151

152 The interview data were analysed using the six-stage process of Thematic Analysis described

153 by Braun & Clarke (2006) and managed using Nvivo software. Initially, the analysis was

154 deductive but as the analysis progressed it became more inductive as new themes were

155 identified in the data. The data transcripts were read and re-read to facilitate familiarisation

156 with the data, and then coded line-by-line by the researchers (PK and HM). Repeated reading

157 of the data allowed codes to be developed, which were subsequently grouped into themes. As

158 the analysis progressed key themes were selected and further sub-themes were subsequently

159 developed. A thematic map incorporating the identified codes was created in order to identify

160 trends and associations. To ensure the trustworthiness of the coding the two researchers (PK

161 and HM) independently coded the data and during discussions similar codes and interpretations

162 were found to have been applied to the cross checked sections of data. All experiences reported

163 by participants were included in the analysis and represented in the manuscript. Triangulation

164 was used at the interpretation stage of the study in order to consider the findings from the

165 quantitative and qualitative aspects and determine their agreement or dissonance (Erzberger &

166 Prein, 1997).

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168

169 **RESULTS**

170 Over the 18-month study period 228 women with a diagnosis of an early stage EC were

171 enrolled onto the PIFU scheme. The median age was 65 (range 42 - 90 years). The majority of

172 women, 204 (89.5%), were BW and 24 (10.5%) were non BW (22 British South Asian (BSA)

173 and 2 African/AfroCaribbean (AA)). One hundred and three women were diagnosed pre-

174 September 2014 and were transferred from routine hospital follow-up (HFU) onto the PIFU

175 scheme. There were 125 women diagnosed post-September 2014 that were directly transferred

176 onto the PIFU scheme. The median time on the PIFU scheme was 14 months (95% CI 12.9-

177   14.3 months). The total number of women in follow-up prior to September 2014 or who had

178   completed adjuvant therapy was not known and therefore it was not possible to calculate the

179   proportion of patients who moved to PIFU. Women in these groups were given the choice of

180   PIFU rather than HFU by their supervising clinicians. Of the women diagnosed post-September

181   2014 with early stage low-risk EC less than 5% were deemed not suitable for recruitment to

182   PIFU, primarily due to mental health issues.

183

184   ***Patient-Initiated Contact***

185   Forty-five women (19.7%) contacted the Clinical Nurse Specialists (CNS) at least once.

186   Significantly more contact was made in the first six months of being entered onto the scheme

187   as compared to the second six months (37/45 versus 8/45, Chi squared p<0.001). Women who

188   were transferred onto PIFU directly also were more likely to make contact compared to women

189   who had been under routine HFU and then transferred (30/125 women versus 15/103 women,

190   Chi square p=0.075) and were significantly younger than women who did not contact (median

191   age 57 years compared to 65 years, Mann Whitney p<0.001). Although women of non BW

192   ethnicity were more likely to contact (6/24, 33.3%) compared to BW women (39/204, 19.1%)

193   the difference was not statistically significant. Four women were transferred from PIFU back

194   to HFU due to patient anxiety and multiple symptomatology.

195

196   The primary reason for contacting the CNS were mainly due to physical symptoms (62%), such

197   as vaginal bleeding/discharge or abdominal pain, however, 20% of the calls were for

198   psychological support or reassurance. Another 2 calls were for practical assistance, for example

199   help claiming benefits.

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Quality of Life

In total, 153 6-month and 109 12-month Quality of Life (QLQ) and Patient Satisfaction (PSQ) questionnaires were returned. There was no significant difference in Functioning Scale Scores (FSS) between the six-month and 12-month QLQs (Figure 1). For all of the functioning subscales, the scores from both 6 and 12 months were higher than the references values, indicating that the women on the PIFU scheme had a higher level of functioning than the reference populations 'all cancer patients: female' and 'all cancer patients: stage 1-II'. The scores were also lower than the reference values for the symptoms scale score (SSS) (Figure 2) and for the global health status score (GHSS) (Figure 3). There was no difference in the GHSS score between the 6- and 12-month QLQs, Mann Whitney p=0.564.

Patient Satisfaction

Patient feedback regarding the PIFU scheme was positive, with 62% of women in the 6-month PSQ reported they found it useful (very much/quite a bit) and only one patient (0.6%) reporting that they did not find the scheme useful at all. Dissatisfaction increased slightly at the 12-month PSQ with 4 women (3.6%) giving the response 'not at all' to the question 'Overall how reassured are you by PIFU?' but this contrasted with 63% of women who responded very much/quite a bit. In the PSQs 25 women (six-month PSQ) and 12 women (12-month PSQ) reported contacting the CNS with the most common reason being that they were worried about a symptom they had developed. The next most commonly reported reason was that they wanted to speak about worries and feelings that they were having.

Patient Attitudes

Of the 51 women contacted, 21 women agreed to (13 BW and 8 non BW) participate in a semi-structured interview. Non BW women were offered translators, which two accepted and two

227 women brought a family member with them to translate. Interview times ranged from 20 to 58

228 minutes.

229

230 PIFU was reported as being the preferred follow-up model by nine women. Four women

231 preferred HFU and five suggested a combination of HFU initially following treatment with

232 transfer to PIFU after a short period of time, for example 12 months, would be better. Women

233 that preferred the PIFU scheme commented on the importance of being able to carry on with

234 their lives and being able to have more control over their own health whilst having the

235 reassurance of direct access to the CNS if needed. For example, one 53-year-old non BW

236 female stated; *"It stops me having to worry about 'I've got an appointment here to come and*

237 *see this person'. I'm looking out for my own symptoms and know that if I ring up the secretary*

238 *or the clinic and say 'I have this issue, can I come and see somebody?' I can come in. I don't*

239 *have to go via the GP is what I'm saying."* The main reason given for preferring hospital

240 follow-up (HFU) was the reassurance of seeing somebody face-to-face as it was thought to be

241 more personal. A 51-year-old BW female said; *"I think I would have preferred to come back*

242 *and seen, physically seen someone… I think it's more just reassurance to meet somebody face*

243 *to face about it. It's a bit more personal."* No participants reported that they would have

244 preferred to be seen by their general practitioner (GP) for follow-up.

245

246 The majority of women on the PIFU scheme understood how to use the scheme. The overall

247 feeling reported by participants was that it was easier and quicker to contact the CNS and they

248 reported that they had confidence that the CNS would instigate any necessary investigations or

249 appointments, rather than being seen in primary care for symptoms. The majority of the non

250 BW women interviewed were of BSA ethnicity and they felt particularly reassured that they

251 could communicate with a Gujarati/Hindi speaking CNS. A 59-year old non BW female said;

252   *'Yes. It's very helpful because it's in our language, whatever the problem is I can communicate*

253   *it very well and I'm happy".*

254

255   The main reason participants reported for not utilising the scheme was the fear of wasting the

256   CNS' time. For example, a 63 year-old BW female stated; *"It's too easy to think 'I won't*

257   *bother' because it, I don't know, you feel like you're bothering somebody."* Other reported

258   reasons included either worrying about or ignoring symptoms participants thought might have

259   been related to their endometrial cancer diagnosis. For example, a 53-year old non BW female

260   said; *"The only barrier that I think would stop them ringing in is if they worried that it has*

261   *come back. Because you've got to get your mind around that one first before you go and ring".*

262

263   'Wasting the doctor's time' and the 'unnecessary journey' to a HFU appointment if women

264   were asymptomatic were commonly reported barriers to attending HFU. A 63 year-old BW

265   female said; *'It becomes a bit of a pain coming in every 4 months, every 6 months, when actually*

266   *there's not anything wrong with you and it's a waste of your time, bus money, petrol money,*

267   *whatever the consultant's time, when there's actually nothing wrong with you.'*

268

269   **DISCUSSION**

270   Risk stratification with regard to patient follow-up is not a new concept in oncology. PIFU

271   schemes have been developed for low-risk disease for several reasons, both patient and

272   economic, across a range of specialties and diseases (Taneja, Su'a, & Hill, 2014). However,

273   ensuring patient safety and satisfaction has to be the central goal when evaluating such

274   schemes. In this mixed methods study we have used both quantitative and qualitative methods

275   to ensure women are utilising PIFU and are accessing the CNSs when needed. The results of

276   the two investigative methods have given complimentary information, with the quantitative

277   aspect determining the frequency/indication for contact and the interviews exploring women's

278   rationale for their behavior. Leeson et al., (Leeson et al., 2013) identified that there are a wide

279   range of follow-up models currently in use in the UK for women who have been diagnosed

280   with a gynaecological malignancy. Many centres reported using telephone (25%) or patient-

281   initiated (32%) follow up schemes, in contrast to ESMO guidance (Colombo et al., 2011),

282   which supports a policy of regular follow up for all patients for 5 years.

283

284   We have demonstrated that early stage EC patients experience a good quality of life post

285   treatment, noticeably higher than the reference populations 'all cancer patients: female' and

286   'all cancer patients: stage I-II' used for the EORTC-QLQ30. A strong theme that emerged in

287   the interviews was that women understood that their risk of recurrence was low and did not

288   want to keep being reminded of their diagnosis by attending HFU. This may be interpreted as

289   a self-management coping mechanism whereby the participants tried to leave their cancer

290   experiences behind them in an attempt to adopt some form of normality. Indeed, reminders of

291   cancer have been found to induce fear and increased insecurity of cancer recurrence in breast

292   cancer survivors (Drageset, Lindstrom, & Underlid, 2016).

293

294   The fear of cancer recurrence can lead to cancer survivors employing specific self-management

295   strategies to forget their cancer diagnosis. Howard et al., (Howard et al., 2016) identified that

296   adult childhood cancer survivors' employed strategies such as avoiding contact with medical

297   personnel and not attending hospital/clinic appointments in an attempt to forget their previous

298   diagnosis. In a further study by Zelman et al., (Zelman et al., 2004) participants reported that

299   being able to forget about their cancer diagnosis, even for a short while, was an important

300   determinant of a 'desirable day'. Returning to normal life has been identified as a highly

301   motivating factor for recovery (Howard et al., 2016) and an important factor in coping with a

302   cancer diagnosis (Drageset, Lindstrom, & Underlid, 2010). PIFU removes the need for patients

303   to attend hospital appointments and it may be argued that this can facilitate their 'return to

304   normal'. The good long-term prognosis of early stage EC and PIFU can help to change

305   people's perception that cancer is not necessarily a fatal disease but that they can have a life

306   beyond their diagnosis. The change in focus toward patient survivorship is increasingly

307   necessary and the importance of developing supported self-management pathways, helping

308   patients to manage their own health and wellbeing can not only address unmet needs but can

309   reduce the demand on support services.

310

311   We have shown that PIFU for early stage EC is well received by our population. A recent

312   randomised trial evaluating the effectiveness of nurse-led telephone follow-up (NTFU),

313   compared to HFU, also reported high levels of patient satisfaction, with no detrimental physical

314   or psychological effects (Beaver et al., 2016). Our scheme was not classified as a NTFU since

315   the 6-monthly calls were not structured and did not ask questions on symptoms or wellbeing,

316   merely ensured that the patient understood the purpose of the PIFU scheme and was happy to

317   remain on it. We did identify that younger women and women from a non BW ethnicity were

318   more likely to initiate contact, suggesting that they were in greater need of support from the

319   CNS. A reason for this finding could be that psychological unmet needs have been shown to

320   be significantly associated with age at diagnosis (Boyes, Girgis, D'Este, & Zucca, 2012). BSA

321   cancer patients are reported to have twice the rate of self-reported depressive symptoms and

322   five times the incidence of severe depression as compared to BW cancer patients (Lord et al.,

323   2013). Lord et al., (Lord et al., 2013) also reported that BSA patients used more maladaptive

324   coping strategies, such as helplessness/hopelessness and fatalism, and experienced a heavier

325   physical symptom burden as compared to BW patients. In our study the BSA women reported

326   that they were very supportive of PIFU preferring not to attend the hospital, since this was felt

327 to be a sign of ongoing active disease rather than surveillance for disease that had been treated.

328 It is essential when designing a PIFU scheme to ensure that the women who are enrolled have

329 the capacity and insight to contact the CNS should an issue arise. Women who are non-English

330 speakers are at particular risk of being disenfranchised and education sessions with their

331 family/carers and the availability of interpreting services can enable women to participate in

332 PIFU. Knowledge of the local community and its demographics can be helpful in planning

333 services, for example Leicester has a high BSA population who are predominantly Gujarati

334 speaking. An advantage of the Leicester PIFU scheme therefore is that one of the CNSs is a

335 fluent Gujarati/Hindi speaker thereby enabling non-English speakers to access the scheme,

336 another positive factor reported by the non BW women who were interviewed.

337

338 **CONCLUSION**

339 PIFU for early stage EC appears to be well received by the majority of women. Although many

340 of the CNS contacts were related to physical symptoms, many were for psychological support

341 or reassurance. Younger women had greater CNS contact indicating that they may benefit from

342 a greater level of CNS support. Women from a non WB ethnicity are also supportive of PIFU,

343 although consideration should be made to ensure non-fluent English speakers are able to access

344 the scheme.

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Figure 1.

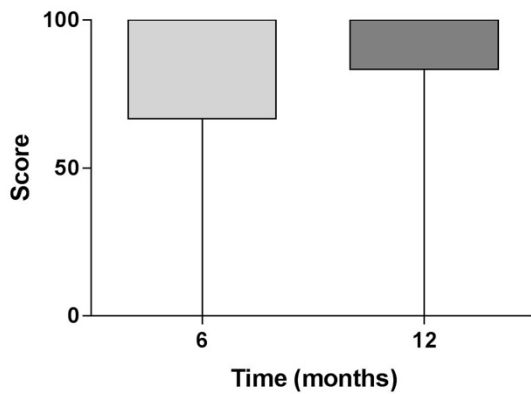EORTC Functioning Scale Scores (FSS).

A) Physical functioning.
6 months n=138, 12 months n= 104. Mann Whitney p=0.938.

B) Emotional functioning.
6 months n=143, 12 months n=101. Mann Whitney p=0.813.

C) Role functioning
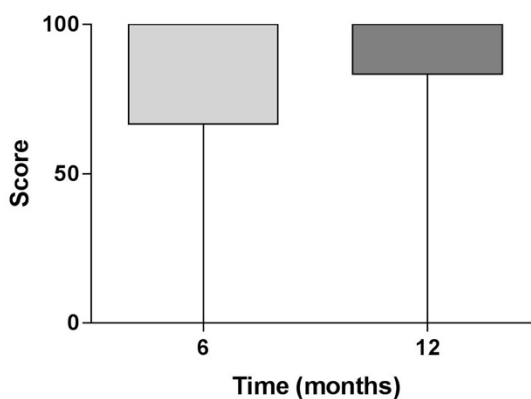6 months n=147, 12 months n=104. Mann Whitney p=0.563

495   **Figure 2.** Symptoms scale score (SSS).
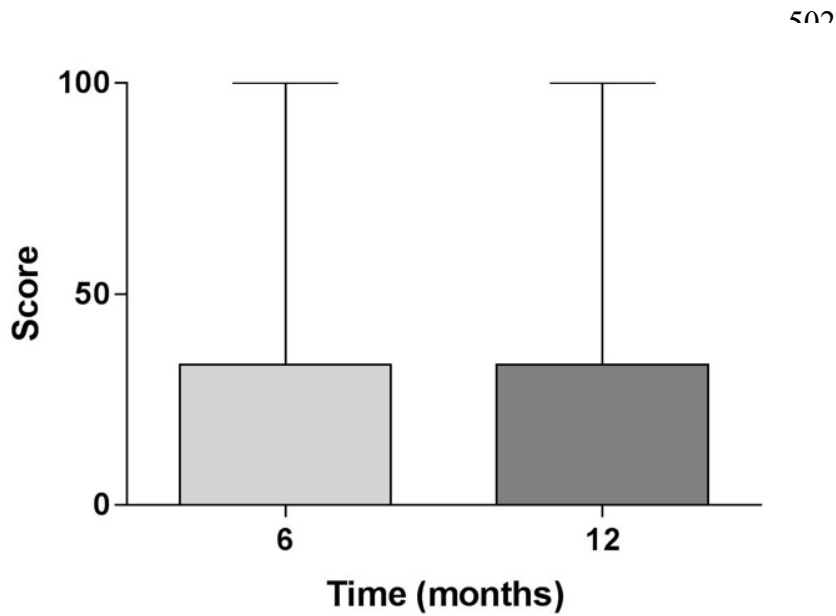496
497
498   **A) Pain**
499   6 months n=145, 12 months n=105. Mann Whitney p=0.429
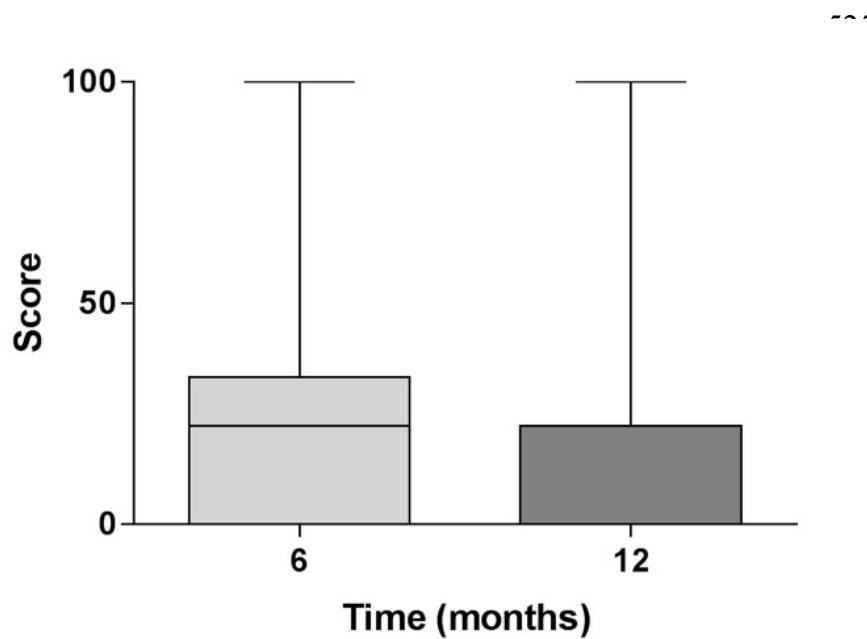500
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521   **B) Fatigue**
522   6 months n=146, 12 months n=104. Mann Whitney p=0.250
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539   **Figure 3.** EORTC Global Health Status Scores (GHSS). Range from 0-100 with a high score

540   indicating a high quality of life. 6 months n=146, 12 months n=106. Mann Whitney p=0.564.

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