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Evaluation of the "Shared Community Follow-up" after a germ cell tumour—A novel initiative for remote cancer follow-up enhanced by online patient-reported outcome measures

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Abstract

Objective: Replying to germ cell tumour patients' needs, we implemented "Shared Community Follow-up"—a collaborative initiative, enabling remote delivery of specialist cancer care across large geographical areas. Blood, radiological investigations and patient-reported outcome measures (PROMs) are completed remotely and integrated within the electronic patient records for specialist review without patients requiring appointments. We describe the service evaluation estimating the feasibility, safety and acceptability of this initiative versus traditional Standard Follow-up.

Methods: This cross-sectional evaluation estimated feasibility (uptake, adherence) and safety (via missed appointments, timeliness, cancellations) using routinely collected service process data. An acceptability questionnaire, evaluating patient satisfaction, was administered to 91 patients.

Results: The new service is feasible. Across 2 years (2014–2016), uptake increased 54% (*N* = 123 to *N* = 270) and only 4.8% (*N* = 13) of patients were non-adherent. Fewer missed/cancelled investigations (*N* = 39, 5.9% vs. *N* = 566, 85.5%), timelier investigations (seven vs. 14 timely investigations) and equal relapse detection suggest its safety. PROMs replaced 3 appointments/patient. Patients were as satisfied with both services (3.4/4 vs. 3.6/4).

Conclusion: New follow-up services, with investigations completed remotely and shared between community providers and cancer centres, offer an alternative to traditional appointments with advantages for patients and the National Health Service.

KEYWORDS

cancer follow-up, germ cell tumours, patient-reported outcome measures, service evaluation

1 | INTRODUCTION

The aim of cancer follow-up is to detect relapses early, to monitor and manage early and late treatment toxicities, and to offer holistic post-treatment support (Heathcote et al., 2018). As more people live beyond cancer, the demand for follow-up monitoring increases (Maddams, Utley, & Møller, 2012; Stark et al., 2015). The problem is that cancer services will be unable to cater for the projected 4

million people living with and beyond cancer by 2030 without detracting from the treatment of new cancers (Maddams et al., 2012). Patients' return to normal everyday life is also disrupted by the necessary follow-up process (Grinyer, 2009; Laxton, Darragh, Malik, & Hawkins, 2016), although many are willing to utilise self-management and electronic symptom monitoring (Basch et al., 2017). Therefore, where modern systems can deliver this safely and acceptably, some cancer follow-up activities (e.g. performing investigations, collecting patient-reported outcomes, providing telephonic reassurance) could be performed remotely and be shared with community services (i.e. smaller local hospitals, pharmacies, primary care), while specialist outpatient clinics can focus on those who need them most (Naylor et al., 2013).

Failure to detect cancer relapses promptly results in greater disease and intensive treatments (Albers et al., 2015; Ferrari et al., 2016). In curable cancers, this increases late effects of risk, such as second malignant neoplasms and cardiovascular comorbidities (Cappuccio et al., 2018). Anxiety regarding recurrence, late effects and psychosocial problems are also prominent, warranting appropriate management (Jarrett et al., 2013).

Germ cell tumours (GCTs) have a 95% five-year survival rate, and 85% occur in working-age patients. As GCTs are rare, in the United Kingdom National Health Service (UK NHS) their management through multidisciplinary specialist services in large regional hospitals improves patient outcomes (Albers et al., 2015; Woldu et al., 2017).

Based on international clinical risk stratification guidelines (Albers et al., 2015; Honecker et al., 2018; Kollmannsberger et al., 2015), patients with advanced GCT undergo intensive curative chemotherapy with an approximate 20% relapse rate. Patients with localised GCT undergo surgery and surveillance which minimises the risk of post-treatment toxicities, with around 30% requiring relapse treatment. As relapses in localised disease are curable, surveillance is standard management. In advanced disease, systemic treatment is paramount for survival. Relapses are still curable, but prognosis is poorer; therefore, treatment choices require a lower relapse rate than in localised disease. After treatment, all patients undertake follow-up to ensure rapid access to further curative treatment if necessary.

Standard Follow-up (SF) is an intensive programme of scheduled clinical investigations (blood markers, chest X-rays and computed tomography [CT] scans) and consultations, stratified in frequency and length for risk of relapse and pursued in specialist regional cancer centres (Albers et al., 2015; Kollmannsberger et al., 2015). Consultations to promptly detect relapses do not require clinician-led physical examinations in asymptomatic patients (Cunniffe, Robson, Mazhar, & Williams, 2012). However, specialist consultations are still needed for abnormal result, to identify/manage patients' concerns, symptoms, late effects, psychosocial problems and reduce adverse health behaviours which may increase cancer risks.

The delivery of tailored but holistic follow-up care requires integrated, collaborative services that are also risk-stratified, patient-centred and delivered by specialists (Howell et al., 2012; Naylor et al., 2013). Within traditional SF, to have these investigations, consultations and receive care, many patients will travel long distances to regional specialist centres for their frequent scheduled appointments. This is particularly the case for large regional specialist centres such as the Yorkshire Cancer Centre. As an alternative, our centre developed and implemented a new initiative for people living after GCT—Shared Community Follow-up (CF). Within CF patients have their blood tests and chest X-rays remotely, these activities being the "shared" component of the service whereby these investigations are requested by the specialist centre, delivered by community-based providers, and results transferred and integrated in the electronic patient record (EPR) within the specialist centre. Face-to-face consultations for symptoms and concerns are replaced by remote completion of patient-reported outcome measures (PROMs) which are, again, integrated automatically into the EPR. The findings are then reviewed by clinicians in the specialist centre and communicated to patients and their primary healthcare providers. Our aim was to estimate the comparative feasibility, safety and acceptability of CF and SF.

2 | METHODS

2.1 | Context and content of the CF service

We developed and implemented CF alongside SF in the Yorkshire Cancer Centre. The centre delivers GCT specialist care for a supra-network covering West and North Yorkshire in England, a population in excess of 3.6 million patients over an area of over 2,000 km^2 (West Yorkshire & Harrogate Cancer Alliance, 2017). From January 2015, a subgroup of consecutive eligible patients was offered CF as an alternative to SF. Patients were eligible for CF if they were within 12 months post-treatment, had Internet access, felt they could arrange investigations closer to home and were English speakers. All patients provided informed written consent to enter CF given the need for online/telephonic patient contact for reminders. Upon choosing CF, patients had a nurse-led appointment providing information on self-examinations, potential symptoms, self-care options, a personalised appointments schedule and contact details for problems.

In both services, patients follow the same risk-stratified schedule or care pathway. The evidence-based clinical risk-stratified pathways define the frequency and content of follow-up investigations which could last either 3, 5 or 10 years from the last cancer treatment (Figures A1 and A2). This stratification is based on extensive clinical trials comparing recurrence detection by using specific investigations, at certain times, depending on the patients' prognosis (Albers et al., 2015; Honecker et al., 2018; West Yorkshire & Harrogate Cancer Alliance, 2017).

In SF, symptoms and concerns are identified and discussed in face-to-face outpatient appointments, followed by blood tests and radiological examinations in the regional centre. In CF, patients record their symptoms and concerns remotely using a

bespoke online PROM system named "QTool" (Holch et al., 2017); blood and radiological examinations are undertaken by local hospitals or community services who then share this information with the specialist centre. Blood, radiological examinations and PROMs are then integrated into the EPR of the regional centre, for review (Table A1). Electronic PROMs ensure consistent, disease-specific symptom reporting and have been demonstrated to improve patient well-being and survival (Basch et al., 2017; Velikova et al., 2004). The PROMs in CF cover aspects relevant to post-treatment patients' quality of life—symptoms, emotional distress and psychosocial support needs. They are tailored to symptoms suggestive of GCT (i.e. back pain, testicular self-examination) and survivorship issues through the distress thermometer (Recklitis, Blackmon, & Chang, 2016) and the Holistic Needs Assessment (Macmillan Cancer Support, 2017).

The scheduling, requesting, tracking and integration of investigations are supported by electronic workflow systems (Figure A3) and a part-time administrative team member reminding patients to arrange blood and radiology tests in the community (e.g. primary care practices, supermarket pharmacies) using the request forms from the specialist centre. Within a 14-day "window," patients undertake tests and complete the PROMs. Just as in SF, the same clinical team reviews the findings, acts upon concerns and informs patients and general practitioners of their conclusions. The specialist team remains the patients' first point of contact that patients still meet face-to-face once a year for their CT scan results or on the anniversary of their last treatment. This face-to-face appointment is maintained to reassure patients of the continuity of care with the same team, important in the early stage of implementing this initiative. Figure 1 below summarises the differences between SF and CF, including the proportion of yearly patient visits to the regional centre, based on the risk-stratified follow-up schedule.

2.2 | Evaluation of the initiative: Feasibility

We defined feasibility as the long-term uptake and adherence to both services (Arain, Campbell, Cooper, & Lancaster, 2010). Uptake was explored using anonymised routine sequential process data on the number of patients attending appointments across time in the entire GCT service—new diagnoses, patients on treatment or in the two follow-up services. Patients in SF represent the cumulative number of patients seen in this service historically—those achieving remission during 2014–2016 and those who would have been on SF previously. The number of patients in CF represents the patients progressively entering and staying on CF, once introduced in January 2015. Adherence was evaluated in patients who consented to the evaluation given the non-anonymised nature of the data. We explored how many patients initially choosing CF requested to return to SF and their reasons.

2.3 | Evaluation of the initiative: safety

We estimated safety in three ways. First, through the cancelled and missed appointments within the GCT service using anonymised routine process data. Second, by examining the timeliness of individual investigations from the last treatment to the end

Standard Follow-up (SF)	Shared Community Follow-up (CF)
Blood tests (tumour markers) **Pursued in Cancer Centre (face-to-face)**	**Run** and **uploaded** onto shared systems by **phlebotomy** staff. Results discussed face-to-face with patient
Chest X-ray **Pursued in Cancer Centre (face-to-face)**	**Run** and **uploaded** onto shared systems by **radiology** staff. Results discussed face-to-face with patient
CT scans **Pursued in Cancer Centre (face-to-face)**	**Run** and **uploaded** onto shared systems by **radiology** staff. Results discussed face-to-face
Self-report status (i.e. patients' symptoms and concerns) **Face-to-face appointment in Cancer Centre**	Patients **receive their test results AND discuss concerns/symptoms** with a nurse or consultant
Summary of Activities in Standard Follow-up (SF) • All investigations and discussions pursued in Cancer Centre • Results interpreted by local treatment team • Results communicated to patients in 10-minute outpatient face-to-face appointment • Concerns and symptoms discussed in the same 10-minute outpatient face-to-face appointment • Outpatient appointments led by consultants or nurse specialists	Blood tests (tumour markers) **Pursued in Primary care/District hospital (remote)** — **Chased** and **uploaded** onto shared systems by **administrator** (unless automatic). Patients receive results via post/email Chest X-ray **Pursued in Primary care/District hospital (remote)** — **Chased** and **uploaded** onto shared systems by **administrator** (unless automatic). Patients receive results via post/email CT scans **Pursued in Cancer Centre (face-to-face)** — **Run** and **uploaded** onto shared systems by **radiology** staff. Result discussed face-to-face Self-report status **Online electronic patient-reported outcome measures (QTool system, remote)** — Patients report their **concerns/symptoms** online. A nurse calls them **if** there are concerns. **Summary of Activities in Shared Community Follow-up (CF)** • All tests apart from CT scans, pursued by primary care/district hospitals • Results chased and uploaded by administrator in Cancer Centre • Results interpreted by local treatment team • Patient recalled to Cancer Centre if tests/self-reports suggest concerns • Otherwise, patients received results via telephone/post/email • Patients seen in Cancer Centre maximum once per year or when given CT result

Clinical Stratified Pathway/ Proportion outpatient visits	A1	A2	A3	B	C	D	E	F	G	H	J	K	L
Total visits in SF/years of follow-up = proportion of Cancer Centre visits per year	12 visits/5 years = 2.4/year	13 visits/5 years= 2.6/year	15 visits/5 years= 3/year	15 visits/5 years= 3/year	26 visits/5 years = 5.2/year	10 visits/3 years = 3.3/year	17 visits/10 years = 1.7/year	14 visits/5 years = 2.8/year	2visits/10 years = 2.3/year	33 visits/10 years = 3.3/year	21 visits/10 years = 2.1/year	7 visits/3 years = 2.3/year	7 visits/3 years = 2.3/year
Total visits in CF/years of follow-up = proportion of Cancer Centre visits (max. number CT scans/year)†	1 visit/5 years = 0.2/year	3 visits/5years = 0.6/year	7 visits/5 years = 1.4/year	4 visits/5 years = 0.8/year	6 visits/5 years= 1.2/year	3 visits/3 years = 1/year	2 visits/10 years = 0.2/year	4 visits/5 years = 0.8/year	6 visits/10 years = 0.6/year	7 visits/10 years = 0.7/year	6 visits/10 years = 0.6/year	2 visits/3 years = 0.6/year	3 visits/3 years = 1/year

FIGURE 1 Summary of activities and visits in Standard versus Shared Community Follow-up: what, when and where are investigations pursued. †The total number of visits to the Cancer Centre in CF is based on the number of CT scans

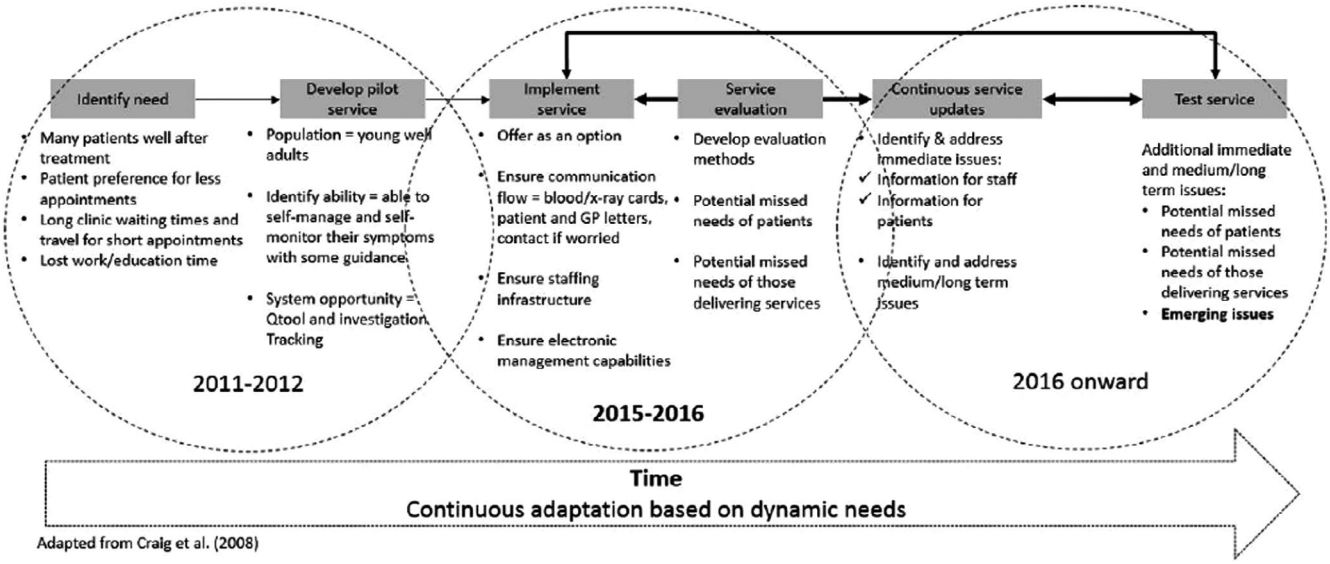

FIGURE 2 Timeline of the implementation and evaluation of the Shared Community Follow-up service for germ cell tumour patients

of evaluation for each consenting patient. Finally, for this group we also extracted the number of relapses and time to diagnosis and treatment.

2.4 | Evaluation of the initiative: acceptability

Our evaluation pragmatically synthesised elements of service implementation and behavioural change theories (Greenhalgh, Robert, Macfarlane, Bate, & Kyriakidou, 2004; Michie, van Stralen, & West, 2011; Venkatesh, Morris, Davis, & Davis, 2003) within a bespoke questionnaire. To explore factors associated with the diffusion of innovations model (Greenhalgh et al., 2004), we recorded demographic characteristics that may influence service acceptability (age, education, work, close relationships, living status). We evaluated the service users' ability to adopt the initiative based on the behavioural change wheel (Michie et al., 2011) and patients' comfort with electronic PROMs based on the unified theory of acceptance and use of technology (Venkatesh et al., 2003). The questionnaire included items on satisfaction with cancer-related information from the European Organization of the Research and Treatment of Cancer (EORTC) QLQ-INFO25 (Arraras et al., 2007), patients' confidence in managing symptoms from the Perceived usefulness scale of the Patient Acceptance Survey (Horne et al., 2013), general service satisfaction using items from the National Cancer Patient Experience Survey (NHS England, 2015) and satisfaction with communication with the responsible healthcare professional (Shilling, Jenkins, & Fallowfield, 2003). Patients also completed questions on their computer use and the System Usability Scale to evaluate their satisfaction with QTool (Lewis & Sauro, 2009). We explored patients' costs associated with consultations in the regional centre if the CF initiative were not implemented.

To further explore barriers/facilitators in adopting the new service, we used a range of validated measures (see "Other patient-reported factors"). We explored whether patients felt they had social support through individual items pertaining to testicular cancer from the EORTC Library (EORTC, 2015). We evaluated patients' health using the EQ-5D where patients rate their functioning on five dimensions on a 3-point Likert scale and general health on a visual analogue scale (EuroQoL Group, 2019). Emotional distress was evaluated through the distress thermometer (Recklitis et al., 2016) measuring the intensity of specific feelings on a scale of 0 (none) to 10 (extreme); cancer self-efficacy through the brief Cancer Behaviour Inventory (Heitzmann et al., 2011) comprising 12 questions rated on a 9-point Likert scale; health-related anxiety through the Health Anxiety Questionnaire (Lucock & Morley, 1996) comprising 21 items rated on a 4-point Likert scale; and the Brief Illness Perceptions Questionnaire (Broadbent, Petrie, Main, & Weinman, 2006), consisting of 8 questions rated on a 11-point scale. The questionnaire (see Supporting information) used in evaluation took patients up to 30 min to complete.

2.5 | Participants

Patients were recruited either by post/email, if they consented to such communications, or by clinicians approaching all patients, consecutively, during outpatient appointments. SF patients were approached if they met the eligibility criteria for the initiative but had not yet adopted it. Patients entering the evaluation provided written informed consent to data extraction pertaining to adherence, timeliness and relapses. These data were extracted between May and December 2016. Our service evaluation did not require NHS ethical approval, but for the purpose of dissemination we obtained local university ethical approval (MREC15-100) and NHS Trust approval

as a service evaluation (MO16_078). We aimed to sample 54 patients/service (Billingham, Whitehead, & Julious, 2013).

2.6 | Analyses

Service process data (uptake, cancellations, missed appointments) were summarised descriptively and analysed using repeated analysis of variance (rANOVAs). Timeliness was evaluated using rANOVAs, within patients and across time, for the overlap with the pre-defined stratified schedule. We summarised patients' characteristics, adherence, relapses and questionnaire responses descriptively. We performed chi-square, Mann–Whitney or *t* tests, as appropriate, with Bonferroni corrections to explore potential differences between services. Significance testing was important in the context of the first evaluation of a novel initiative.

3 | RESULTS

Figure 2 depicts the process of CF development, implementation and evaluation, displayed commensurate with the principles of complex intervention development and evaluation (Craig, et al., 2008). It was developed as a pilot service between 2011 and 2012, implemented from 2015 and evaluated in 2016.

3.1 | Evaluation of the initiative: feasibility

Between 1 January 2014 and 31 December 2016, the GCT outpatient service saw 4,593 patients (Table 1), comprising new diagnoses (N = 336), patients on treatment (N = 487) and patients in follow-up (N = 3,770). The latter includes SF patients who had finished treatment under the care of the centre in the preceding 10 years (N = 3,377) and all people entering CF from January 2015 (N = 393). There was a significant change in the number of patients in both services across time ($F_{2,151}$ = 20.9, p < .0001). The number of people in SF decreased between 2014 and 2016 (mean difference = −5.6, p < .01), the number people in CF increased (mean difference = 5.2, p < .0001), while the total number of patients in follow-up remained constant ($F_{2,151}$ = 0.5, p = .6).

Between 2014 and 2016, 823 patients were new diagnoses or on treatment. From January 2015, eligible patients in this group who would have finished treatment in the past 12 months could choose CF. By the end of December 2016, 270 patients of the potential 823 (32%) chose CF (Table 1). Patients were highly adherent to CF—out of 270 patients, 35 (12.9%) chose to return to SF. For 13 (4.8%), this was a clinical decision due to general non-adherence to follow-up, five chose to return to SF due to problems organising tests in the community (1.8%), five were recorded as patient preference (1.8%), for four the causes were not recorded (1.48%), three were not registered with primary care (1.11%), for three it was due to a pre-evaluation relapse (1.11%), and for two it was country relocation (0.74%).

3.2 | Evaluation of the initiative: safety

Missed appointments peaked in 2014; from 1,527 planned appointments, 236 (15.4%) were missed (Table 2). rANOVAs across 2014–2016 demonstrated a significant difference between the two services ($F_{2,151}$ = 221.45, p < .0001) and a significant interaction with time ($F_{2,151}$ = 11.72, p < .0001). Bonferroni-corrected post hoc tests revealed a fewer missed appointments in CF versus SF (mean difference = −3.01, p < .0001), a decrease between 2014–2015 (mean difference = −1.05, p < .0001) and 2015–2016 (mean difference = −0.64, p < .05). Cancelled appointment numbers differed significantly between services ($F_{2,151}$ = 307.3, p < .0001), and there was a significant interaction between services and time ($F_{2,151}$ = 3.11, p < .05). Post hoc analyses indicated fewer cancellations in CF versus SF (mean difference = −3.02, p<.0001), independent of time ($F_{2,151}$ = 1.43, p = .24).

Figure 3 details the patient recruitment to evaluate safety and acceptability, where consent was necessary. We approached 52 SF patients during outpatient clinics, 44 consented and 37 returned the completed questionnaire to the team (84%). Sixty-two CF patients consented, and 54 returned the questionnaire (87%). Our final sample consisted of 91 participants.

Patients choosing SF had mostly finalised secondary education or college (45.9%), many were married/cohabiting (62.1%) and working full-time (70.3%). Patients choosing CF had at least university education (57.4%), more were married/cohabiting (75.9%), and 83% worked full-time. The demographic characteristics and risk stratification of the 91 patients who consented to the evaluation are described in Table 3.

There was one relapse in CF (1.6%) and one in SF (2.3%). The CF patient had timely blood and radiological investigations in the community which indicated increased tumour markers. The patient was recalled to the outpatient clinic where the diagnosis was confirmed,

TABLE 1 Number and proportion of germ cell tumour patients (GCT) attending outpatient appointments between 1 January 2014 and 31 December 2016

Total GCT appointments	2014	2015	2016
Shared community follow-up	0	123 (8.1%)	270 (17.5%)
Standard follow-up	1,286 (84.2%)	1,072 (70.5)	1,019 (65.9%)
On treatment	144 (9.4%)	212 (13.9%)	131 (8.5%)
New referrals	97 (6.4%)	114 (7.5%)	125 (8.1%)
Total patients	1,527	1,521	1,545

TABLE 2 Total number and proportion of patients who missed or cancelled their germ cell tumour appointments/investigations between 1 January 2014 and 31 December 2016

	2014		2015		2016	
Missed or cancelled appointments	Missed	Cancelled	Missed	Cancelled	Missed	Cancelled
Shared Community Follow-up	0	0	7 (5.2%)	11 (6.4%)	16 (7.1%)	5 (3.2%)
Standard Follow-up	219 (92.8%)	185 (91.1%)	104 (77%)	147 (85.5%)	164 (83.2%)	149 (94.3%)
On treatment	4 (1.7%)	5 (2.5%)	4 (2.9%)	6 (3.5%)	3 (1.5%)	2 (1.3%)
New referrals	13 (5.5%)	13 (6.4%)	20 (14.8%)	8 (4.6%)	14 (7%)	2 (1.3%)
Total patients	236	203	135	172	197	158

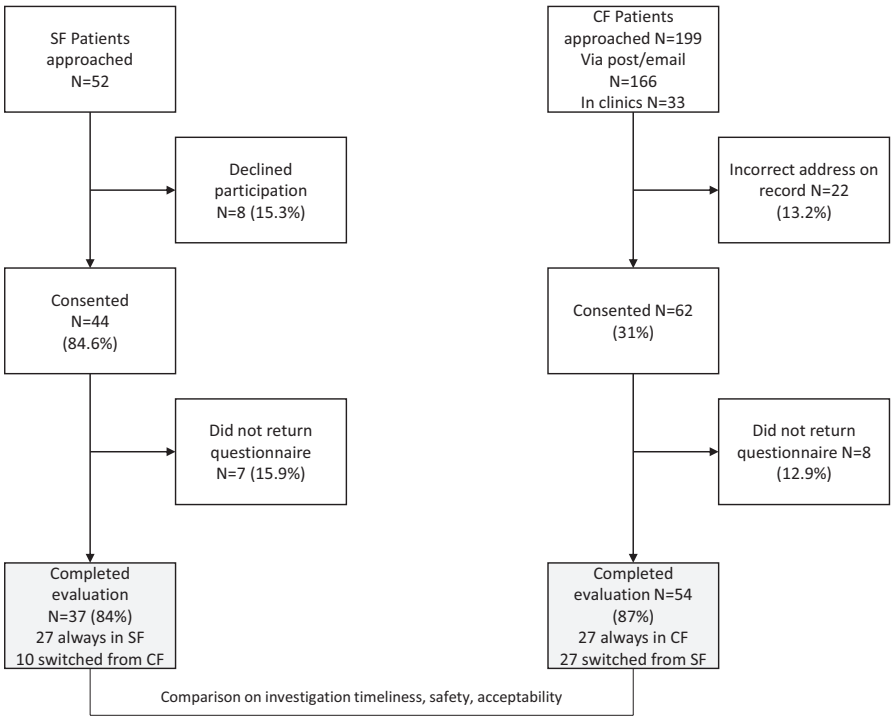

FIGURE 3 Service evaluation—patient recruitment flow chart. CF, Shared Community Follow-up; SF: Standard Follow-up

and treatment started within 7 days of their investigation in the community. In SF, the patient self-referred to the service before their scheduled contact with concerns related to self-examination. Within 24 hr, the patient was recalled to clinic where investigations confirmed relapse and treatment started within 7 days. We also explored the timeliness of investigations versus their expected timing (Table 4). In SF, more investigations were missed ($F_{1,89}$ = 10.8, p = .001) and performed outside schedule ($F_{1,89}$ = 6.57, p = .01); more investigations were performed on time in CF versus SF ($F_{1,89}$ = 4.33, p < .05).

3.3 | Evaluation of the initiative: acceptability

After Bonferroni corrections, there were no group differences on most aspects covered by the service evaluation questionnaire (Table A2). Patients in SF and CF felt that their information needs were met, and they were satisfied with their care, communication with healthcare professionals, and with the symptom management. Patients in CF were satisfied with the use of online PROMs. Patients in SF perceived the responsible practitioner as more sympathetic than those in CF (U = 53, p = .001).

We asked patients to estimate the costs incurred when travelling for follow-up to the regional centre prior to the service being initiated and when travelling for annual reviews. Patients who chose CF perceived that travel to the centre involved more time and financial expense than patients who chose SF. To have their investigations and consultations within the regional centre, rather than remotely, CF patients used multiple modes of transport (19.6% in CF; 17.1% in SF), travelled for longer (on average 96 min (SD = 22.31) versus 40 min (SD = 23.05) in SF), took more time off work (m = 8.85 hr, SD = 2.83) than SF patients (m = 5.56 hr, SD = 3.11) and spent more to reach their appointment (m = £16.26 (SD = 6.76) vs. m = £10.55 (SD = 17.7)).

3.4 | Other patient-related factors

General health was rated higher by CF patients compared with those in SF (t_{81} = 2.61, p = .01). There were no differences on other measures (Table A3).

TABLE 3 Socio-demographic characteristics and clinical risk-stratified pathways of patients included in the service evaluation

Characteristics/ group	Shared Community Follow-up (*N* = 54)	Standard Follow-up (*N* = 37)
Age *M* (*SD*)	38.3 (10. 9)	37.3 (14.1)
Sex (*N*, %)	53 male (98%); 1 female (1.8%)	37 male (100%)
Education (*N*, %)	Post-graduate: 8 (14.8%); university: 23 (42.6%); college: 10 (18.5%); secondary: 9 (16.6%); N/A: 4 (7.4%)	Post-graduate: 4 (10.8%); university: 2 (5.4%); college: 5 (13.5%); secondary: 12 (32.4%); N/A: 14 (37.8%)
Relationship status (*N*, %)	Married/civil partnership: 29 (53.7%); cohabiting (12, 22.2%); single: 9 (16.6%); separated/divorced: 2 (3.7%); N/A: 2 (3.7%)	Married/civil partnership: 14 (37.8%); cohabiting: 9 (24.3%); single: 13 (35.1%); N/A: 1 (2.7%)
Work schedule (*N*, %)	Full-time: 45 (83.3%); part-time/ student: 2 (3.7%); unemployed, not looking: 2 (3.7%); retired: 2 (3.7%); unemployed, looking: 1 (1.9%), self-employed: 1 (1.9%); N/A: 1 (1.9%)	Full-time: 26 (70.3%); part-time/student: 5 (13.5%); unemployed, not looking: 3 (8.1%); retired: 1 (2.7%); N/A: 2 (5.4%)
Risk-stratified pathway (*N*, %)	A2: 7 (13%); A3: 17 (31.5%); C: 10 (18.5%); E: 6 (11.1%); F: 9 (16.7%); H: 1 (1.9%); J: 3 (5.6%); L: 1 (1.9%)	A2: 5 (13.5%); A3: 5 (13.5%); C: 8 (21.6%); D: 1 (2.7%); F: 8 (21.6%); G: 2 (5.4%); J: 5 (13.5%); L: 3 (8.1%)

Note: Path A2: Stage I seminoma treated with adjuvant carboplatin; A3: Stage I seminoma in surveillance; C: Stage I non-seminomatous germ cell tumour (NSGCT) in surveillance, except teratoma differentiated; D: Stage I NSGCT, teratoma differentiated, in surveillance; E: Stage II seminoma treated with radiotherapy; F: Stage II seminoma treated with chemotherapy or metastatic disease with no disease on CT, good prognosis; G: metastatic disease with no disease on CT or necrotic tumour in resection specimen, treated with chemotherapy, intermediate/poor prognosis; H: metastatic disease with residual mass on CT after chemotherapy and viable tumour in resection, except teratoma differentiated; J: metastatic disease with residual mass on CT after chemotherapy and viable tumour in resection, teratoma differentiated; L: rare testicular tumours (Sertoli and Leydig cell tumours).

TABLE 4 Timeliness of investigations in Standard Follow-up (SF) and Shared Community Follow-up (CF), in 91 patients, from the first appointment recorded for any given consenting patient (September 2007) to the end of evaluation at the end of December 2016

Investigations pursued per patient between September 2007 and end of December 2016	Standard Follow-up (SF) *N*, *M* (*SD*)	Community Follow-up (CF) *N*, *M* (*SD*)	Total investigations *N*, *M* (*SD*)	Difference between services *F*, *p*
Total investigations *N*, *M* (*SD*)	4,356, 117.7 (79.5)	5,321, 98.5 (55.01)	9,677, 106.3 (66.3)	$F_{1,89} = 1.8$, $p = .2$
Missed investigation *N*, *M* (*SD*)	529, 14.3 (10.6)	437, 8.09 (7.4)	966, 10.6 (9.3)	$F_{1,89} = 10.8$, $p = .001$
Investigation on time *N*, *M* (*SD*)	457, 12.3 (7.9)	844, 15.6 (7)	1,301, 14.3 (7.5)	$F_{1,89} = 4.3$, $p = .04$
Investigations outside of schedule *N*, *M* (*SD*)	470, 78.4 (59.7)	458, 8.5 (6.4)	928, 10.3 (7.9)	$F_{1,89} = 6.6$, $p = .01$

4 | DISCUSSION

To our knowledge, this is the first implementation in routine practice of a cancer follow-up initiative where clinical investigations are performed remotely by community services and patients are remotely monitored using electronic PROMs, while EPR-integrated clinical findings are still reviewed by the specialist team.

CF is feasible—once available, patients opted for it in progressively greater numbers and the proportion of missed appointments and cancellations decreased. This suggests that CF is attractive to patients and meets their needs (Naylor et al., 2013). Thirteen patients who initially chose CF returned to SF due to general non-adherence to follow-up. While missed and cancelled follow-up appointments are generally an issue in younger groups (Grinyer, 2009), their decrease during the CF is encouraging. Future studies could explore whether the administrative role required for patient communications/reminders may have also influenced the lower non-attendance.

While longitudinal evaluations will replicate and extend our findings, in this cross-sectional evaluation, CF was acceptable—patients felt equally satisfied with both services. In the future, we should evaluate whether the decision for an annual face-to-face appointment minimised loss to follow-up and helped maintain our patient relationship (Grinyer, 2009). In CF, online PROMs for symptoms and concerns were more likely to be on time and replaced 244 face-to-face appointments over 2 years, roughly three appointments/patient. The timely completion of investigations and rapid detection of relapses suggest that CF is safe, although a more strongly powered study is needed to examine safety. Other studies have demonstrated that the use of PROMs (Heathcote et al., 2018) and tracking patients' schedules through administrative teams or electronically can increase safety. PROMs are known to enhance patient outcomes within traditional cancer follow-up, as evidenced by multiple trials implementing them in waiting areas prior to face-to-face appointments (Basch et al., 2017; Velikova et al., 2004). Here, we successfully implemented the use of online PROMs as a routine method of monitoring patients' symptoms remotely. The feasibility of using them in routine care within CF encourages their implementation in SF more widely.

Our study has some clear limitations. The number of patients entering CF versus SF is based on anonymised service process data. Without access to de-anonymised data, we cannot estimate how many patients entered SF from January 2014 as opposed to having been in the service for many years. Similarly, we cannot know how many of these patients were not offered CF due to ineligibility. However, the number of patients in SF decreased, the number of patients in CF increased, while the number of patients in follow-up remained constant. Similarly, the feasibility definition for the implementation of the initiative focused on the routinely collected appointment data within the regional centre, as estimating primary care appointments and other contacts to the centre (i.e. phone calls) would have required additional study resources. These elements could be included in future replications, now motivated by this evaluation.

This is an evaluation of an ongoing initiative. It was neither designed nor tested as an intervention within a randomised clinical trial because it sought to pragmatically evaluate a new service, where some investigations (i.e. blood and radiological examinations) are performed remotely and with clinical results shared between specialist regional and local community healthcare providers, and electronic PROMs replacing face-to-face appointments. Our initiative allowed patients to make an informed decision regarding their care (Heathcote et al., 2018). Consequently, patients in CF are a self-selected sample. This enabled us to characterise patients who prefer remote follow-up methods, which may respond to the needs of a different population, previously demonstrated to appreciate a more flexible approach to frequent outpatient appointments (Grinyer, 2009). Patients choosing CF self-reported better general health were more likely to have completed higher education, be in full-time work and in long-term relationships. A larger proportion of patients in CF perceived standard appointments as burdensome, travelling for longer distances and at greater expense. Future longitudinal evaluations could explore whether different support mechanisms and education at post-treatment may empower more patients to choose CF.

Finally, despite known recruitment difficulties in young adult patients (Kenten et al., 2017) through our recruitment strategy the questionnaire return rate was over 80% despite differences in consent rates. The latter were due to the method of approaching patients, whereby more SF patients were approached face-to-face and more CF patients approached via post. Differences in the number of patients included in specific data extractions are due to the active number of patients available in the continuously growing CF service.

Providing the CF service required commissioning support, agreement between community investigation providers, the support of a part-time administrative team member (2 hr/week) and a nurse (6 hr/week) to help manage patient scheduling, investigation request forms and reminders. No other resources were needed as professionals who request medical tests are obliged to review these and correspond with patients and GPs. We did not pursue a formal economic evaluation of the services; future studies should explore their long-term cost-effectiveness.

There are known gaps between the evidence for the benefits of interventions and their implementation and adoption (Greenhalgh et al., 2004). Our study is among the first to bridge this gap for GCT patients, suggesting that patient-centred, integrated, collaborative, remote cancer follow-up care is feasible, acceptable for specific patients and likely to be safe. If replicated, our findings may enable specialist care with reduced disruption to patients' lives and fewer appointments. When considering whether to generalise these results to other cancers, we note that up to 70% of GCTs secrete sensitive and specific biomarkers (AFP, β-hCG); hence, blood testing can detect disease. Physical examination adds little to follow-up care in GCT (Cunniffe et al., 2012). As new circulating biomarkers are established, the implementation of similar initiatives will be increasingly feasible in other specialties, such as breast, colorectal or prostate cancer (Teagle & Gilbert, 2014). These are also specialties where cancer-specific PROMs are already available and could easily replace face-to-face appointments (EORTC, 2015).

Some elements of the CF service are replicable—the clinical risk stratification method, the structure of the online PROMs and its EPR linkage. Other elements will require localised solutions—the content of PROMs and the interaction between specialist centres and community services to enable remote clinical testing and result sharing. Follow-up schedules will vary over time, diagnosis and place, but the challenges of patients travelling to receive specialist care will remain. Hence, while one model of follow-up may not be applicable to all settings, this Shared Community Follow-up initiative may suit the clinical needs of cancer patients currently receiving care in large regional centres.

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CONFLICT OF INTEREST

The authors have declared no conflict of interest.

ETHICAL APPROVAL

All procedures performed in this study with human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments. The study received local university ethical approval (MREC15-100) and NHS Trust approval as a service evaluation (MO16_078). All patients offered informed consent to participate in the service evaluation.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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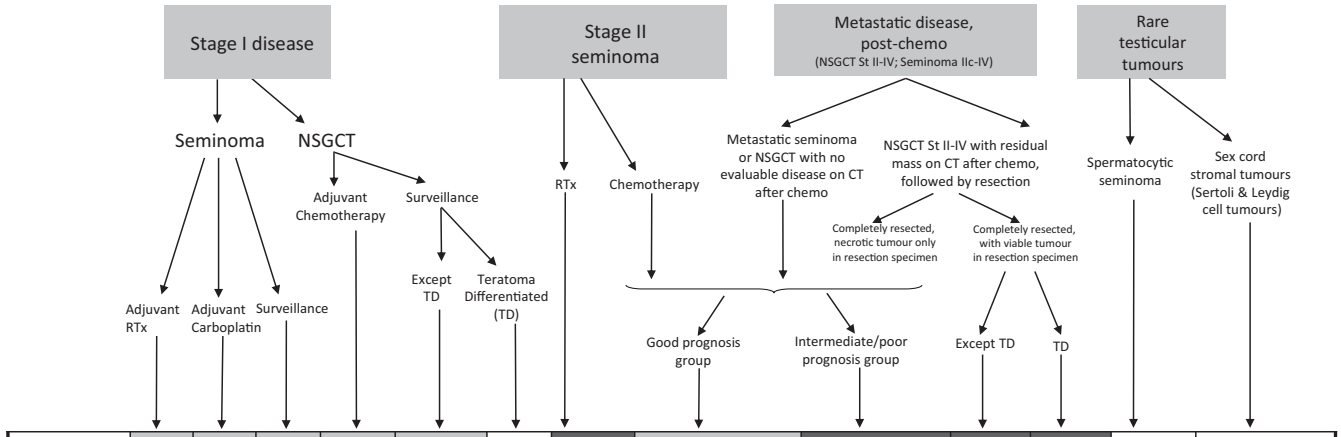
APPENDIX



Pathway/ Investigation	A1	A2	A3	B	C	D	E	F	G	H	J	K	L
Outpatient appointment (OPA) & Tumour Markers	12	13	15	15	26	10	17	14	23	33	21	7	7
CT scans	1	3	7	4	6	3	2	4	6	7	6	2	3
CXRs	12	9	6	6	8	2	16	11	13	13	11	2	3
Years	5	5	5	5	5	3	10	5	10	10	10	3	3

FIGURE A1 Clinically informed risk-stratified care pathways (A1-L) for the follow-up of germ cell tumour patients. Based on patients' diagnosis and tumour histology (e.g. Stage 1 seminoma) and treatment (e.g. adjuvant radiotherapy), each arrow defines the *stratified care pathway* which is associated with a particular number (in the boxes) of consultations and investigations (blood tests, X-ray and CT scans) and number of years of follow-up (3, 5 or 10 years). Dark—high risk of relapse; light—medium risk of relapse; white—low risk of relapse. CT, computer tomography; CXR, chest X-ray; NSGCT, non-seminomatous germ cell tumours; RTx, radiotherapy; TD, teratoma differentiated

C

Follow-up protocol for low-risk Stage I NSGCT (intense surveillance programme)

Note: modified from 5-scan schedule to 2-scan schedule, following publication of MRC TE08 trial data, Rustin et al., 2007.

Enter month of completion of most recent treatment in red box below, in the format Month-Year

	Last treatment date: (e.g. Jul-15)		
Patient name:			
Date of birth:			
Hospital number:			
Interval of appointments (months since last treatment)	**Outpatient appointment date**		**Investigations required**
1	*Insert date above to automatically calculate the dates of each appointment*		AFP, hCG, LDH
2			AFP, hCG, LDH; CXR
3	3-month follow-up		AFP, hCG, LDH; CT scan
4			AFP, hCG, LDH; CXR
5			AFP, hCG, LDH
6	6-month follow-up		AFP, hCG, LDH; CXR
7			AFP, hCG, LDH
8			AFP, hCG, LDH; CXR
9			AFP, hCG, LDH
10			AFP, hCG, LDH; CXR
11			AFP, hCG, LDH
12	12-month follow-up		AFP, hCG, LDH; CT scan
14		Nurse-led	AFP, hCG, LDH
16		Nurse-led	AFP, hCG, LDH; CXR
18	18-month follow-up	Nurse-led	AFP, hCG, LDH
20		Nurse-led	AFP, hCG, LDH; CXR
22		Nurse-led	AFP, hCG, LDH
24	24-month follow-up	Nurse-led	AFP, hCG, LDH; CXR
27		Nurse-led	AFP, hCG, LDH
30		Nurse-led	AFP, hCG, LDH; CXR
33		Nurse-led	AFP, hCG, LDH
36	36-month follow-up	Nurse-led	AFP, hCG, LDH; CXR
42		Nurse-led	AFP, hCG, LDH; CXR
48	48-month follow-up	Nurse-led	AFP, hCG, LDH; CXR
54		Nurse-led	AFP, hCG, LDH
60	60 month follow-up	Nurse-led	AFP, hCG, LDH; CXR
Discharge at 5 years, or to long term follow-up if were aged up to their 30th birthday at the point of diagnosis (unless a trial or protocol dictates otherwise)			

FIGURE A2 Example of an investigation schedule for a patient on intensive surveillance pathway C for Stage 1 non-seminomatous germ cell tumour (NSGCT). Starting with the 13th month of follow-up, appointments change from being led by a consultant to being led by the clinical nurse specialist—this timing is decided upon clinically and will differ between surveillance pathways. AFP, alpha-fetoprotein; CT, computer tomography; CXR, chest X-ray; hCG, human chorionic gonadotropin; LDH, lactate dehydrogenase

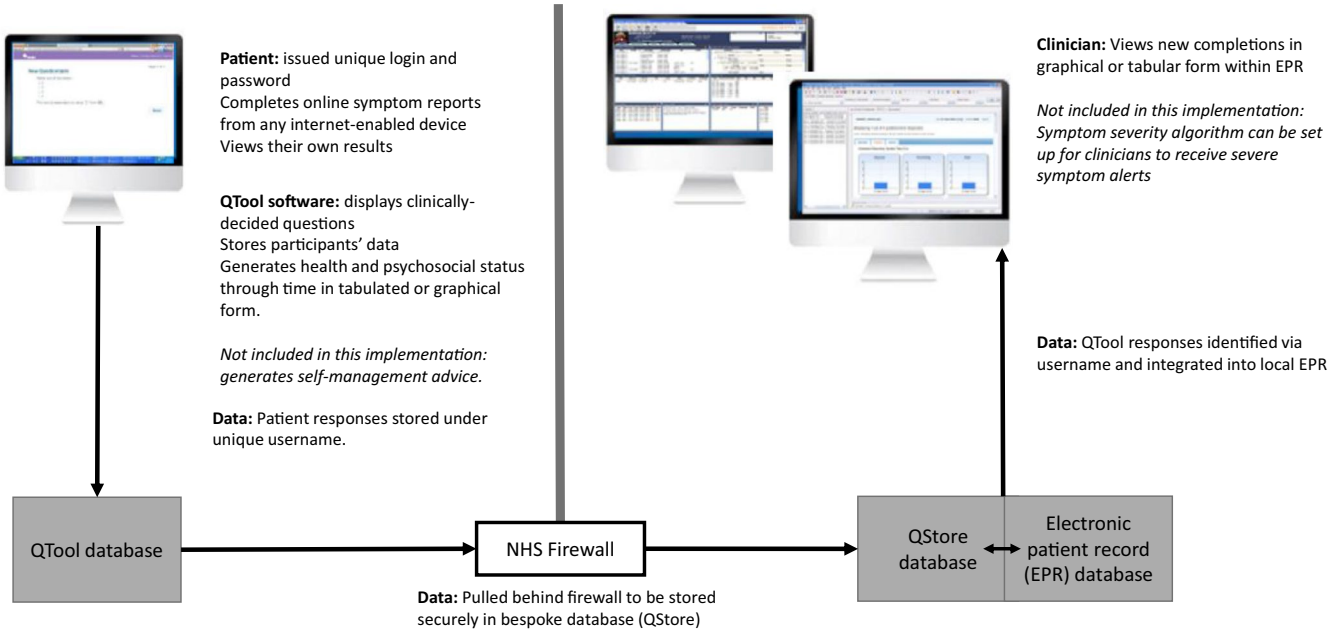


FIGURE A3 Online patient-reported outcome measures collection via QTool—overview of integration within the hospital electronic patient record (EPR) system

TABLE A1 A list of similarities and differences between the two follow-up cancer services [Standard Follow-up (SF) versus Shared Community Follow-up (CF)] detailing where investigations are performed, the frequency of appointments, how symptoms are reported, communication and method of symptom review

Activities within follow-up services	Standard Follow-up (SF)	Shared Community Follow-up (CF)
Blood investigations (tumour markers)	In the regional centre	In the community by any competent centre, but result interpreted by the regional centre
X-ray investigations	In the regional centre	In the community by any competent centre, but result interpreted by the regional centre
CT scan	In the regional centre.	In the regional centre
Symptom and concern self-report	Face-to-face assessment with clinician or nurse during a 10-min appointment	Online QTool—nurse telephones patient if issues are identified
Communication with healthcare professionals	Discussion with key worker for 5–10 min at every face-to-face appointment	Patients seen for a face-to-face discussion when receiving their CT result OR at the anniversary of their last treatment. If patients are worried, they can contact their key worker or the key worker will contact the patient for any concerns
Frequency of investigations	Patient-specific, based on the risk stratification guidelines.	Patient-specific, based on the risk stratification guidelines
Frequency of outpatient appointments	Between 7 and 33 over 3–10 years	Between 3 and 10 over 3–10 years
Review and communication of clinical results	The patients' care team in the regional centre	The patients' care team in the regional centre

TABLE A2 Summary of patients' perceived acceptability of the service on the Service Evaluation Questionnaire

Results on the individual items and areas covered by the service evaluation questionnaire		
Information satisfaction (Bonferroni correction for 13 tests and 1 *df*, $p = .004$)		
	CF ($N = 54$) *M* (*SD*)	**SF ($N = 37$) *M* (*SD*)**
To what extent do you feel you received enough information regarding your GCT FU? (0–6)	4.62 (1.45)	5.17 (1.2)
Mann–Whitney $U = 700$, $p = .03$		
To what extent do you understand how to care for yourself following your GCT (0–6)	4.92 (1.24)	5.05 (1.36)
Mann–Whitney $U = 836$, $p = .46$		
How much information did you receive on: If your cancer is under control? (1–4)	3.51 (0.89)	3.63 (0.59)
Mann–Whitney $U = 850$, $p = .31$		
Purpose of any planned tests (1–4)	3.20 (1.77)	3.44 (0.65)
Mann–Whitney $U = 798$, $p = .15$		
Procedures involved in any planned tests (1–4)	3.07 (0.85)	3.38 (0.68)
Mann–Whitney $U = 766$, $p = .09$		
The results of any planned tests (1–4)	3.66 (0.64)	3.55 (0.65)
Mann–Whitney $U = 856$, $p = .31$		
The expected benefit of your follow-up (1–4)	2.96 (0.92)	3.15 (0.66)
Mann–Whitney $U = 777$, $p = .44$		
The possible side effects of your treatment and cancer (1–4)	3.13 (0.96)	3.41 (0.74)
Mann–Whitney $U = 771$, $p = .22$		
The possible side effects of your treatment on social and family life (1–4)	2.59 (1.01)	3.11 (1.01)
Mann–Whitney $U = 670$, $p = .02$		
The effects of your treatment on your sexual activity (1–4)	2.72 (0.95)	2.94 (1.06)
Mann–Whitney $U = 812$, $p = .21$		
Additional help outside the main treatment centre (1–4)	2.11 (0.93)	2.72 (1.14)
Mann–Whitney $U = 654$, $p = .009$		
Managing any symptoms or side effects at home (1–4)	2.49 (0.91)	2.94 (0.98)
Mann–Whitney $U = 703$, $p = .03$		
Possible professional psychological support (1–4)	2.13 (0.96)	2.66 (1.19)
Mann–Whitney $U = 693$, $p = .02$		
Satisfaction with service and communication (Bonferroni correction for 15 tests and 1 *df*, $p = .003$)		
	CF *M* (*SD*)	SF *M* (*SD*)
How satisfied are you with the GCT service at present? (1–4)	3.39 (0.79)	3.57 (0.74)
Mann–Whitney $U = 809$, $p = .24$		
To what extent are your concerns addressed? (1–4)	3.14 (0.94)	3.34 (0.97)
Mann–Whitney $U = 746$, $p = .21$		
Who has the responsibility of your care?		
Oncology consultant	36 (66.7%)	29 (78.4%)
General practitioner	7 (13%)	4 (10.8%)
Clinical nurse specialist	4 (7.4%)	0
N/A or blank	2 (3.9%)	2 (5.4%)
Other: not sure or community	2 (3.9%)	2 (5.4%)
$\chi^2 = 1.50$, $p = .82$		

(Continues)

TABLE A2 (Continued)

Results on the individual items and areas covered by the service evaluation questionnaire		
Information satisfaction (Bonferroni correction for 13 tests and 1 *df*, $p = .004$)		
	CF ($N = 54$) *M* (*SD*)	**SF ($N = 37$) *M* (*SD*)**
How satisfied are you with the communication with this person? (1–4)	3.25 (0.86)	3.67 (0.58)
Mann–Whitney $U = 633$, $p = .02$		
To what extent do they have the right information about your diagnosis and treatment? (1–4)	3.53 (0.73)	3.82 (0.46)
Mann–Whitney $U = 684$, $p = .03$		
To what extent do they have experience with your problems? (1–4)	3.49 (0.83)	3.85 (0.36)
Mann–Whitney $U = 676$, $p = .03$		
To what extent do they listen to what you have to say? (1–4)	3.47 (0.81)	3.64 (0.64)
Mann–Whitney $U = 780$, $p = .34$		
Did you get to discuss personal or family issues that might affect your health? (1–4)	2.61 (1.03)	3.21 (0.89)
Mann–Whitney $U = 581$, $p = .009$		
This person uses medical terms I don't understand (1–4)	1.92 (1.01)	1.47 (0.82)
Mann–Whitney $U = 681$, $p = .05$		
They told me what I wanted to know (1–4)	3.13 (0.97)	3.58 (0.74)
Mann–Whitney $U = 645$, $p = .02$		
The practitioner I saw seemed sympathetic (1–4)	**2.71 (1.17)**	**3.85 (1.77)**
Mann–Whitney $U = 537$, $p = .001$		
Is empathic communicating changes in my results (1–4)	3.08 (0.94)	3.53 (0.63)
Mann–Whitney $U = 532$, $p = .04$		
I frequently feel unclear about things they tell me (1–4)	1.25 (0.56)	1.33 (0.70)
Mann–Whitney $U = 812$, $p = .71$		
To what extent did they explain how manageable would the follow-up be? (1–4)	3.13 (1.00)	3.4 (0.72)
Mann–Whitney $U = 680$, $p = .37$		
How reassured after the outpatient appointment? (1–4)	3.29 (0.85)	3.63 (0.62)
Mann–Whitney $U = 647$, $p = .04$		
How reassured before the outpatient appointment? (1–4)	2.98 (0.90)	3.12 (1.01)
Mann–Whitney $U = 719$t, $p = .34$		
Confidence in symptom management (Bonferroni correction for 7 tests and 1 *df*, $p = .007$)		
How confident are you in determining if a physical symptom is related to your GCT or treatment? (1–4)	2.78 (0.89)	2.80 (0.88)
Mann–Whitney $U = 883$, $p = .88$		
How often self-examine (/month)?		
Daily	10	5
Weekly	13	6
Monthly	6	5
N/A	25	45
Not anymore	0	1
$\chi^2 = 9.66$, $p = .04$		
Does it improve your ability to manage your own symptoms? (0–6)	4.23 (1.85)	4.40 (1.49)
Mann–Whitney $U = 691$, $p = .68$		
Does it help you save time managing them? (0–6)	3.84 (2.08)	4.25 (1.73)

(Continues)

TABLE A2 (Continued)

Results on the individual items and areas covered by the service evaluation questionnaire		
Information satisfaction (Bonferroni correction for 13 tests and 1 *df*, $p = .004$)		
	CF (*N* = 54) *M* (*SD*)	**SF (*N* = 37) *M* (*SD*)**
Mann–Whitney $U = 745$, $p = .98$		
Does it enhance your effectiveness in managing them? (0–6)	4 (2.1)	4.64 (1.66)
Mann–Whitney $U = 696$, $p = .59$		
Do you find it useful in managing your symptoms? (0–6)	3.83 (2.16)	4.87 (1.43)
Mann–Whitney $U = 611$, $p = .21$		
Is it easy for you to manage the tasks needed? (0–6)	4.48 (1.73)	4.90 (1.32)
Mann–Whitney $U = 723$, $p = .71$		
Is it easy to get each person involved to do what you need? (0–6)	4.66 (1.40)	4.78 (1.67)
Mann–Whitney $U = 761$, $p = .59$		
System Usability Scale (Satisfaction with online PROM software, QTool) (Bonferroni correction for 10 tests and 1 *df*, $p = .005$)		
	CF *N* = 51 *M* (*SD*)	**SF *N* = 8 *M* (*SD*)**
I think I would like to use QTool frequently	3.58 (1.18)	1.87 (1.64)
Mann–Whitney $U = 79$, $p = .007$		
I found QTool unnecessarily complex	1.59 (0.91)	1.71 (1.49)
Mann–Whitney $U = 162$, $p = .83$		
I think QTool was easy to use	4.37 (0.73)	3.28 (1.88)
Mann–Whitney $U = 121$, $p = .25$		
I think I would need the support of a technical person to be able to use QTool	1.34 (0.75)	1 (0.00)
Mann–Whitney $U = 29$, $p = .30$		
I found the various pages in QTool were well integrated	4.04 (0.95)	4.40 (0.89)
Mann–Whitney $U = 96$, $p = .45$		
I thought there was too much inconsistency in QTool	1.67 (0.82)	2.16 (1.60)
Mann–Whitney $U = 128$, $p = .63$		
I imagine that most people would learn to use QTool very quickly	4.31 (0.86)	4.16 (0.98)
Mann–Whitney $U = 140$, $p = .75$		
I found QTool very cumbersome to use	1.7 (0.97)	2.42 (1.61)
Mann–Whitney $U = 133$, $p = .32$		
I felt very confident using QTool	4.5 (0.78)	4.33 (1.21)
Mann–Whitney $U = 145$, $p = .99$		
I needed to learn a lot of things before I could get going with QTool	1.36 (0.75)	1.14 (0.37)
Mann–Whitney $U = 153$, $p = .61$		

Note: Light grey: result significant before Bonferroni correction; **Bold**: result significant after Bonferroni correction.

Abbreviations: CF, Shared Community Follow-up; *df*, degrees of freedom; FU, follow-up; GCT, germ cell tumour; M, mean; *SD*, standard deviation; SF, Standard Follow-up.

TABLE A3 Other patient-related factors measured through patient-reported outcome measures (PROMs)

Results on individual items and scales covered by questionnaires on other patient-related factors		
EORTC Individual items (Bonferroni correction for 9 tests and 1 *df*, $p = .005$)		
	CF *M* (*SD*) (*N* = 50)	**SF *M* (*SD*) (*N* = 35)**
Can you talk about cancer with your partner of the person closest to you?	3.6 (0.83)	3.68 (0.72)
Mann–Whitney $U = 850$, $p = .75$		
Can you talk about your sexuality with your partner or person closest to you?	3.52 (0.86)	3.6 (0.91)
Mann–Whitney $U = 813$, $p = .46$		
Have you felt less masculine as a result of your cancer or treatment?	1.68 (0.83)	1.83 (0.95)
Mann–Whitney $U = 783$, $p = .57$		
Have you been tired?	2.24 (0.97)	2.4 (1.06)
Mann–Whitney $U = 819$, $p = .59$		
What was the severity of your tiredness in the last 7 days?	1.76 (0.89)	2.11 (1.10)
Mann–Whitney $U = 725$, $p = .15$		
Have you had difficulty concentrating on things?	1.52 (0.78)	1.82 (0.92)
Mann–Whitney $U = 706$, $p = .09$		
What was the severity?	1.46 (0.76)	1.91 (0.91)
Mann–Whitney $U = 619$, $p = .01$		
Have you had difficulty remembering things?	1.62 (0.83)	1.91 (0.98)
Mann–Whitney $U = 729$, $p = .15$		
What was the severity?	1.5 (0.76)	1.77 (0.84)
Mann–Whitney $U = 709$, $p = .09$		
EQ-5D		
General health state	**82.92 (13.61)**	**73.78 (18.21)**
Mann–Whitney $U = 568$, $p = .02$		
Distress thermometer (Bonferroni correction for 4 tests and 1 *df*, $p = .01$)		
Anxiety	2.6 (2.88)	3.09 (3.71)
Mann–Whitney $U = 777$, $p = .82$		
Depression	1.44 (2.18)	2.12 (3.09)
Mann–Whitney $U = 689$, $p = .24$		
Anger	1.58 (2.73)	2.72 (3.48)
Mann–Whitney $U = 649$, $p = .11$		
Wanting help	1.18 (2.34)	1.5 (2.73)
Mann–Whitney $U = 673$, $p = .73$		
Health Anxiety Questionnaire (Bonferroni correction for 4 tests and 1 *df*, $p = .01$)		
Total	0.86 (0.48)	1.04 (0.69)
$t_{83} = -1.28$, $p = .20$		
Worry	0.86 (0.56)	1.03 (0.79)
$t_{83} = -1.14$, $p = .25$		
Fear	1.04 (0.60)	1.15 (0.85)
$t_{83} = -0.66$, $p = .51$		
Reassurance seeking	1.07 (0.58)	1.06 (0.57)
$t_{83} = 0.05$, $p = .96$		

(Continues)

TABLE A3 (Continued)

Results on individual items and scales covered by questionnaires on other patient-related factors		
EORTC Individual items (Bonferroni correction for 9 tests and 1 *df*, $p = .005$)		
	CF *M* (*SD*) (*N* = 50)	**SF *M* (*SD*) (*N* = 35)**
Interference due to health anxiety	0.24 (0.47)	0.81 (0.98)
Mann–Whitney $U = 634$, $p = .02$		
Brief Cancer Behaviour Inventory (Bonferroni correction 11 tests and 1 *df*, $p = .004$)		
Total	7.72 (1.11)	7.23 (1.48)
$t_{83} = 1.73$, $p = .08$		
Maintain independence	8.48 (1.05)	7.71 (2.01)
Mann–Whitney $U = 744$, $p = .17$		
Maintain a positive attitude	7.48 (1.54)	6.77 (2.46)
Mann–Whitney $U = 774$, $p = .35$		
Maintain a sense of humour	8.10 (1.40)	7.77 (1.81)
Mann–Whitney $U = 848$, $p = .79$		
Expressing negative feelings about cancer	6.54 (2.44)	6.20 (2.75)
Mann–Whitney $U = 829$, $p = .68$		
Maintaining activities (work, home, hobbies, social)	8.2 (1.35)	7.23 (2.64)
Mann–Whitney $U = 760$, $p = .25$		
Remaining relaxed throughout treatments and not allowing scary thoughts to upset me	7.32 (2.05)	6.97 (2.34)
Mann–Whitney $U = 818$, $p = .60$		
Actively participating in treatment decisions	8.06 (1.75)	8.02 (1.38)
Mann–Whitney $U = 837$, $p = .70$		
Asking physician questions	8.06 (1.55)	7.6 (2.38)
Mann–Whitney $U = 833$, $p = .68$		
Seeking consolation (support)	7.24 (2.39)	6.94 (2.56)
Mann–Whitney $U = 830$, $p = .67$		
Sharing feelings of concern	7.68 (1.97)	7.25 (2.14)
Mann–Whitney $U = 782$, $p = .38$		
Managing nausea and vomiting	8.06 (1.22)	7.51 (1.72)
Mann–Whitney $U = 747$, $p = .22$		
Coping with physical changes	7.42 (1.85)	6.77 (2.43)
Mann–Whitney $U = 769$, $p = .33$		
Brief Illness Perception Questionnaire (Bonferroni correction for 11 tests and 1 *df*, $p = .005$)		
How much does your illness affect your life (0–10)?	2.90 (2.06)	3.45 (2.50)
Mann–Whitney $U = 776$, $p = .37$		
How long do you think your illness will continue?	3.48 (3.02)	4.61 (3.12)
Mann–Whitney $U = 592$, $p = .07$		
How much control do you feel you have over your illness?	5.54 (3.62)	6.11 (3.30)
Mann–Whitney $U = 767$, $p = .33$		
How much do you think your treatment can help your illness?	7.6 (3.12)	8.65 (1.98)
Mann–Whitney $U = 736$, $p = .19$		
How much do you experience symptoms from your illness?	2.10 (1.89)	3.08 (2.82)

(Continues)

TABLE A3 (Continued)

Results on individual items and scales covered by questionnaires on other patient-related factors		
EORTC Individual items (Bonferroni correction for 9 tests and 1 *df*, $p = .005$)		
	CF *M* (*SD*) (*N* = 50)	**SF *M* (*SD*) (*N* = 35)**
Mann–Whitney $U = 683$, $p = .09$		
How concerned are you about your illness?	2.58 (2.13)	3.64 (2.52)
Mann–Whitney $U = 617$, $p = .03$		
How well do you understand your illness?	7.58 (2.72)	7.50 (2.77)
Mann–Whitney $U = 837$, $p = .91$		
How much does your illness affect you emotionally (e.g. does it make you angry, scared, upset or depressed)?	3.38 (2.39)	4.73 (3.13)
Mann–Whitney $U = 635$, $p = .05$		

Note: Light grey: result significant before Bonferroni correction; **Bold**: result significant after Bonferroni correction.

Abbreviations: CF, Shared Community Follow-up; *df*, degrees of freedom; EORTC, European Organisation for the Research and Treatment of Cancer; *M*, mean; *SD*, standard deviation; SF, Standard Follow-up.