

# Supported self-management of testicular cancer patients in Wessex

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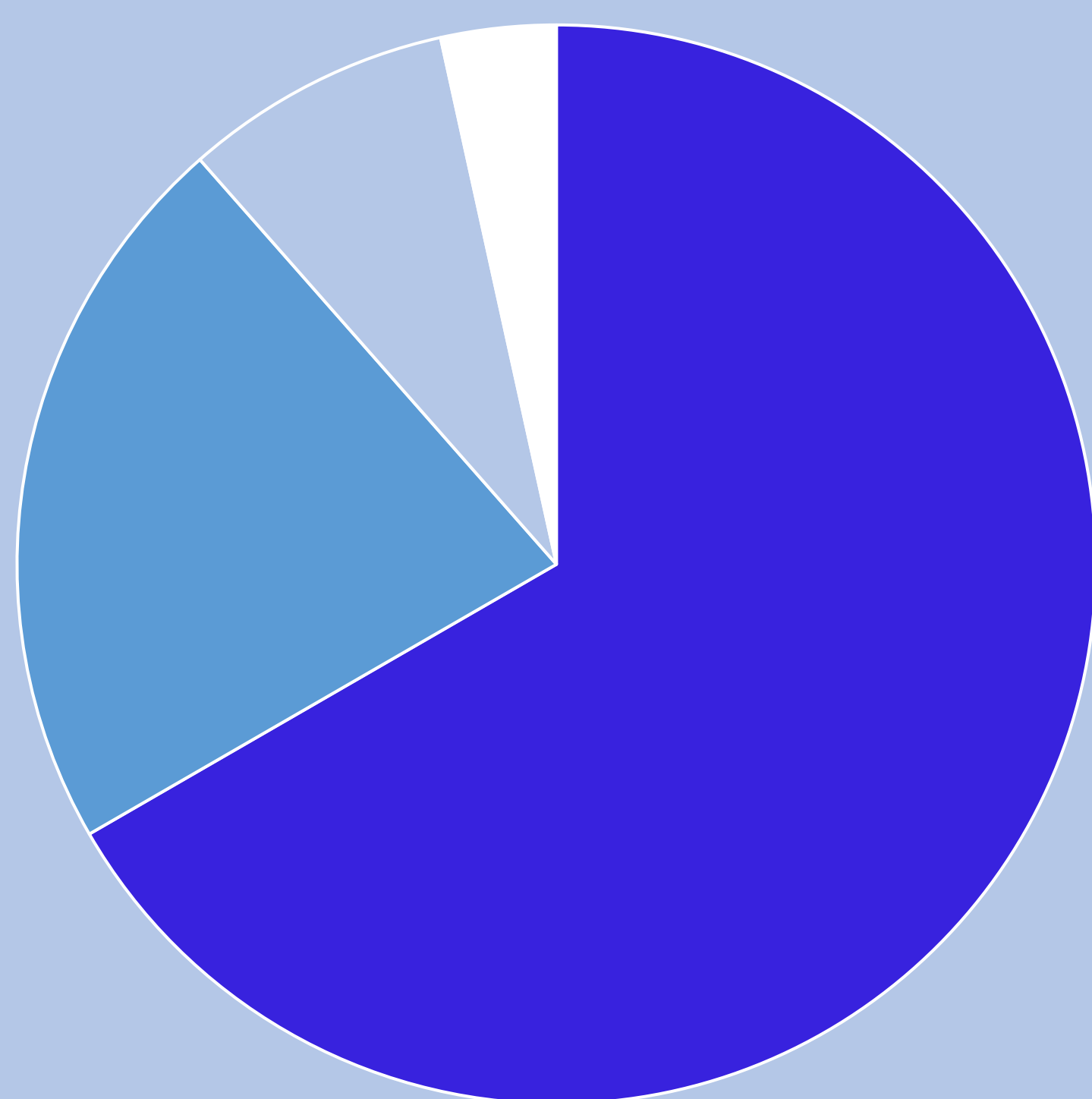
## Background

Since 2018, testicular cancer patients have had the option to enter Patient Initiated Follow Up (PIFU) following completion of treatment. PIFU empowers patients to manage their own follow-up remotely, access their surveillance protocol and view their results through use of MyMedicalRecord (MyMR), a digital platform developed at University Hospital Southampton.

## Methods

Eligible patients are those with stage 1 disease or good prognosis metastatic disease (must have complete response or fully resected if NSGCT). Those with metastatic NSGCT with unresectable residual masses, and those with intermediate or poor prognosis disease are not routinely entered into PIFU but can be at the consultants discretion. Patients are introduced to PIFU via a workshop which provides education on supported self-management, use of MyMR, signs of recurrence, health and well-being information and holistic needs assessment. Patients are managed by a specific PIFU support worker according to protocols and overseen by the germ cell cancer clinical nurse specialist (CNS). Patients are reviewed by an oncologist or germ cell CNS after each CT, if they develop symptoms or test results suggestive of recurrence and prior to discharge.

Discharges and recalls from follow-up since 2018



- End of follow-up
- Back to clinical follow-up (non-compliance)
- Back to clinical follow-up (recurrence)
- Referred out of area

## Conclusion

Benefits of PIFU include promoting patient autonomy, time saving for patients, consultants and CNS', financial savings for patients and reduced environmental impact. Potential negatives could include the risk that reduced face-to-face interactions could reduce patient engagement, we have tried to mitigate this by ensuring patients have a clinic consultation after each scan and can easily access the team via text, email or phone call.

Current Protocol: 03-NSGCT Metastatic-Chemo (NoTD) started on 13/02/2019 Add Event

Protocol	Event	Date	Tasks
03-NSGCT Metastatic-Chemo (NoTD)	Annual	14/02/2022	aFP HCG CXR HNA
03-NSGCT Metastatic-Chemo (NoTD)	Annual	13/02/2023	aFP HCG CXR HNA Serum lipids
03-NSGCT Metastatic-Chemo (NoTD)	Annual	13/02/2024	aFP HCG BP CT C/IA/P CXR HNA Late Tox. Itr OP Appt Renal profile

[Protocol example on MyMR for metastatic NSGCT follow-up]

## Results

Since 2018, 299 patients have been enrolled in PIFU, 87 of these have been discharged.

Of those 87 patients, 67% have completed their surveillance under PIFU and 8% have been referred back to clinical follow-up as a result of cancer recurrence. 22% of patients were discharged back to their consultant for ongoing face-to-face appointments due to lack of patient engagement with follow-up.

Review of the 12 month period from April 2021 to March 2022 revealed:

- 507 virtual reviews undertaken by PIFU team
- Assuming each virtual review replaces a 20 minute clinic appt, this saved 169 hours of consultant time
- 161 messages were sent between the PIFU team and patients
- Assuming each message replaces a 10 minute phone call this saved 27 hours of CNS time
- By patients not travelling to hospital £2625 was saved in travel expenses and nearly 3140 kilos of carbon was avoided

### Patient feedback

*"There is a significant advantage in terms of being able to access both my schedule and results online. I'm safe in the knowledge that if I do have any concerns, I can immediately escalate them"*

*"I found the service to be excellent. My appointments came through exactly when I expected them based on the follow-up plan I was given years before. I have full confidence in the service"*



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