1. Introduction

Kidney cancer is the 7th most common cancer in the UK. Around 13.300 kidney cancers are diagnosed in the UK.

In females in the UK, kidney cancer is the 10th most common cancer, with around 4,900 new cases every year (2016-2018).

In males in the UK, kidney cancer is the 5th most common cancer, with around 8,400 new cases every year (2016-2018).

Incidence rates for kidney cancer in the UK are highest in people aged 85 to 89 (2016-2018).

Each year around a third (34%) of all new kidney cancer cases in the UK are diagnosed in people aged 75 and over (2016-2018).

Since the early 1990s, kidney cancer incidence rates have increased by almost nine-tenths (88%) in the UK. Rates in females have increased by more than nine-tenths (94%), and rates in males have increased by more than three-quarters (77%) (2016-2018).

Cancer Research UK - Kidney cancer incidence statistics | Cancer Research UK

This has undoubtedly had a vast impact on secondary care and Urology departments across the country are required to develop smarter pathways to enable faster diagnosis and access to treatment.

Personalised Stratified Follow Up (PSFU) is an effective way of adapting care to the needs of patients after cancer treatment, to ensure that we are providing world class services.

The implementation of PSFU pathways tailored to individual needs offers huge benefits to patients and the NHS. Stratified follow up improves patient experience and quality of life for people following treatment for cancer, as well as making services more efficient and cost-effective.

Remote monitoring will be managed through the Somerset RMS cancer information system ensuring there are system processes in place to deliver efficient and safe monitoring.

This document outlines the arrangements for the management of patients with kidney cancer that have been clinically risk stratified via the multidisciplinary team for remote monitoring and the patient has consented to this service.

2. Scope

This document applies to all consultants, junior medical staff, nursing staff and administration staff responsible for the care of kidney cancer patients within the University Hospitals of Leicester NHS Trust (UHL).

3. Recommendations, Standards and Procedural Statements

3.1. Aims of the Service

PSFU provides safe remote monitoring follow up for patients that have been treated for kidney cancer who fulfil the criteria for this service.

PSFU pathway patients are followed up remotely via the Somerset RMS system reducing cost and time to patients and the service (thus improving the patient experience).

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PSFU will enhance continuity of care, better triage of queries by support staff, more responsive access to specialist teams if problems occur.

PSFU will improve communication and links with primary care teams (e.g. via End of Treatment Summaries) and improves knowledge of pathways for referral/ signposting to services and third sector support.

3.2. Profile of Remote Monitoring Service

3.2.1. Inclusion Criteria

Patients can be referred to the PSFU pathway by a Consultant, Registrar or Associate Specialist, at MDT. The referring clinician is responsible for ensuring that the patient meets the inclusion criteria, explaining PSFU follow-up to the patient and getting the consent of the patient in clinic.

- Patients that have been diagnose with renal cell carcinoma only, on their histopathology results, based on the TNM system.

- Patients discussed on Urology MDT and have had a multidisciplinary discussion about their imaging reports and histopathology results, being established their risk profile follow up (low, intermediate and high risk), by consultants agreement.

- Patients that have completed treatment for their kidney cancer (surgery) and they have been told their histopathology results, by a Consultant in clinic.

- Patients with no presence of metastatic disease.

- Local patients from Leicester.

- Kidney Cancer Follow up based on risk profile assigned at the MDT discussion.
  Following GIRFT guidelines, Leibovich score will be used to define risk profile on ccRCC (clear cell renal cell carcinoma), and VENUSS score on PRCC (papillary renal cell carcinoma).

    1. Low risk requires CT CAP at 1,3,5 years post-surgery, then discharge;
    2. Intermediate risk requires CT CAP at 6 months,1,2,3,4,5,7,9 years post-surgery, then discharge;
    3. High risk requires CT CAP at 3 months, 6 months,12 months,18 months, 2,3,4,5,7,9 years post-surgery, then discharge.

3.2.2. Process Summary

1. The Urology MDT outcome will reflect that the patient is suitable for PSFU.
2. The patient will be seen in clinic to discuss the results of their surgery and advised of the PSFU pathway for their follow up, being offered a personalized care and support plan using an eHNA.
3. Patients will be given the choice, at this moment, if PSFU team will initiate contact with them at (18 months, 5 years and at 9 years post treatment) and offer wellbeing strategies or the communication will be started by them with the PSFU service.
4. The next steps coordinators send the patient referral details electronically to the RMS mailbox to add the patient to RMS

5. On approval of referral, the clinical nurse specialist will generate an end of treatment summary in RMS. The remote monitoring administrator will input details from Somerset into RMS and will send to the patient:
    - PSFU introduction letter
    - Blood form (UE's completed by CNS or Consultant)

The PSFU letter will provide details of the service as well as alert symptoms for the patient and patient's GP to be aware of. On appendix 1.

Key data items inputted into Somerset RMS include:

- Next CT scan test due.
- Next blood test due.
- Referring clinician.
- PSFU team contacts via Accurex.

6. The patient will attend to his surveillance CT chest, abdomen and pelvis (CAP). To be able to have their CT staging patients need to have a recent U&E's blood test. Blood forms for UE's can be posted with the clinic letter, with instruction to complete their blood test on a specific time (usually one month before scan due).
7. The remote monitoring administrator will check Somerset worklists every working day. The worklists will show:
    - Patients who have had their U&E's in time.
    - Patients who have had their CT CAP.
    - Patients who have had their CT CAP reported, a VIRTUAL KCAFU appointment can be booked, as soon as possible, via the next step coordinators.
8. If the patient has not attended their UE's result by the due date, the administrator will send a reminder letter to the patient with a copy sent to the patient's GP. If the patient has still not attended a blood test within 2 weeks of sending the reminder letter, then the clinical nurse specialist/administrator will contact the patient/patient's GP practice. The clinical nurse specialist/administrator will record all intervention on the Somerset system.
9. If the patient has not attended their CT CAP scan by the due date, the administrator will send a reminder Accurex text to the patient and organize a new date for the patient with radiology. If the patient has still not attended his CT CAP scan, then the clinical nurse specialist/administrator will contact the patient/patient's GP practice. The clinical nurse specialist/administrator will record all intervention on the Somerset system.
10. If CT CAP scan shows no metastatic disease, the patient will be booked a KCAFU VIRTUAL appointment for responsible clinician (Mr Butterworth) and CNS to review scan and write to patient the results and future plans.
11. If CT CAP scan shows metastatic disease patient should be discussed in the next MDT and a face to face appointment will be arranged to discuss the recommendations from that meeting.
12. CT CAP scan findings could lead to further investigations or referrals to different MDT to initiate those investigations, these should be completed by the responsible clinician.
13. The clinical nurse specialist/administrator will record on the RMS system details of all action taken and any communication relating to the care of the patient, if not recorded by the responsible clinician on Dit3.
14. In the absence of the CNS due to annual leave or sickness, the service will be overseen by the Clinical Lead and Urology CNS team.

3.2.3. Discharge

At the end of post treatment follow up, stable patients will be discharged for management within Primary Care. The clinical nurse specialist will generate an end of treatment summary and the administrator will send the treatment summary and discharge letter to the patient and the patient's GP. Discharge will be recorded in the Somerset system.

Where patients are discharged before the end of the standard follow up period (e.g. for clinical reasons), this will be recorded in the Somerset system and where appropriate (e.g. where the patient has died), the clinical nurse specialist will generate an end of treatment summary and letter for the patient and GP.

3.2.4. Trigger points for clinical intervention

The below are guidelines and any clinical intervention by clinical nurse specialist and doctor may be appropriate outside of these triggers.

New symptoms

- Blood in the urine.
- Acute back or flank pain.
- Unexplained weight loss (persistent and unintentional weight loss more than 10% over the last 6 to 12 months).

4. Education and Training

It is the responsibility of the clinical nurse specialist to ensure they regularly update their knowledge and skills in line with continuing professional development. The CNS has undergone adequate preparation for the development of this practice, supported by the Clinical Lead.

Nurse specialist competencies – appendix 2.

5. Monitoring and Audit Criteria

Key Performance Indicator	Method of Assessment	Frequency	Lead
Patient experience	Patient survey	Annually	Clinical Nurse Specialist
Number of days between CT scan result and review/sending results letter.	Analysis from RMS	Quaterly	Clinical Nurse Specialist
Number of patients that do not attend blood test.	Analysis from RMS	Quaterly	Clinical Nurse Specialist
Number of patients that do not attend CT scan.	Analysis from RMS	Quaterly	Clinical Nurse Specialist

6. Legal Liability Guideline Statement

The University Hospital of Leicester NHS Trust as an employer will assume vicarious responsibility for the nurse providing that

7. Supporting Documents and Key References

The guideline is to be used in-conjunction with the following document

Appendix I - Remote Monitoring Referral Form

8. Key Words

RM	Remote Monitoring
CNS	Clinical Nurse Specialist
GP	General Practitioner
UE's	Urea and Electrolytes (kidney function test)
CT	Computerised Tomography

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This table is used to track the development and approval and dissemination of the document and any changes made on revised / reviewed versions

DEVELOPMENT AND APPROVAL RECORD FOR THIS DOCUMENT		
Author / Lead Officer:	Hugo Escabelado	**Job Title:** Macmillan Urology Oncology CNS
Reviewed by:	Paul Butterworth – Consultant Urologist	
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Date	**Name**	**Dept**	**Received**

APPENDIX 1:

University Hospitals of Leicester NHS
NHS Trust

Hospital Number: <<HospitalNumber>>

Caring at its best

Urology Department

Direct Dial: 0116 258 4637

<<PtGivenName>> <<PtFamilyName>>
<<PtAddress>>

Dear <<PtTitle>> <<PtFamilyName>>

Kidney Cancer Remote Monitoring Follow-Up Service

Following your recent treatment for kidney cancer, we have put you onto our computerised follow-up system. Periodically, you may require an up to date check of your kidney function by a blood test – we will send you a request form for the blood test if this is required. You can have the blood test through your GP surgery or hospital blood room. The results of these tests are sent back to us, and we will write to you within 1 month of the test to let you know the result.

- If the result is OK, we will send you a letter with the previous results and indicate when your next blood test and next CT scan is due;
- If any of the results are abnormal we will book a telephone or a face-to-face appointment in clinic to discuss them.

Your next blood test is due in ……. and your next CT scan is due in …….

The advantage of this system for you is that you will not have to come up to the hospital so often. However, if you do have any problems, we will be able to see you urgently.
If you have any questions or problems, then you should either contact your GP or telephone the Urology Department using the number 0116 258 4637. When contacting the Urology department you may sometimes get an answerphone. If you do, please leave a short message with your name, NHS number and a contact phone number. We will aim to call you back within 48 hours.

We would also like to hear from you if you have any of the following symptoms;

- Blood in the urine
- Acute back or flank pain
- Unexpected weight loss (persistent and unintentional weight loss more than 10% over last 6 to 12 months).

With best wishes
Yours Sincerely

<<CNSName>>
Kidney Cancer Clinical Nurse Specialist

APPENDIX 2:

Training and assessment required for the Clinical Nurse Specialist for Low, Intermediate and High Risk Kidney Cancer – Provision of Diagnosis and Requesting of Follow up.

The CNS wishing to see patients as part of the agreed nurse led Clinic must complete the appropriate training and assessments:

- The nurse must have an in-depth understanding of all two week wait cancer pathways as per NICE guidance
- The nurse must have completed advanced communication skills training.
- The nurse must understand tumour anatomy, and their significance in triaging. This can be achieved by self-directed learning, instruction from a clinician, MDT discussions, collaborating on research and publications
- The nurse must understand the Histology and Radiology Tests that have been performed. The nurse must be familiar with the normal results for these tests and investigations for patients on this pathway, the significance of deviations and appropriately consequent actions
- The nurse must be able to access all radiology reports and to do this requires that they have completed all their training and e-learning and have been granted access to all the necessary radiological systems
- If appropriate, the nurse must arrange and co-ordinate any further tests which are indicated following discussion with the relevant senior clinician at the MDT
- The nurse must be familiar with all relevant National Guidelines and keep up to date with any changes and recommendations

Training and Assessment Proforma for the CNS:

Record of Diagnosis Support Clinical Nurse Specialist Competence

Demonstrate in depth knowledge in assessing / triaging referrals through discussion and reflective learning for a minimum of individual cases (depending on individual level of competence) which includes:

No.	Competence	CNS Sign / Date	Lead CNS/Consultant Sign / Date
1	Triaging patient that are referred via the Pathway discussed at the MDT		
2	Advanced communication skills training completed		
3	Interpreting outcomes, (Histological, radiological and blood tests as per the referral criteria) and explaining the MDT recommendation for follow up		
4	Knowledge about most common urology medication given		
5	Escalating where appropriate with a clear rationale		
6	Communicating with a patient in an appropriate and sensitive manner when explaining results over the telephone		
7	Documenting clearly the patients plan on Somerset under CNS activities		
8	Adhering to the NMC Code (2015) and recognising their level of competence and any limitations and working appropriately.		

Number of reflective clinical discussion held ……..

This is to confirm, that ……..…… is competent to triage referrals as the Clinical Nurse Specialist as defined within the boundaries of these guidelines.

Signature …… (Clinical Lead)

Print …….

Date ……

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