

Renal cancer surgery patient experience February 2014-February 2015

The specialist renal cancer team have set high patient experience as one of the key objectives of the specialist renal cancer centre. In February 2014 we started collecting data from patients regarding inpatient and outpatient experience

Data collected using a validated cancer patient experience tool

http://www.healthcareimprovementscotland.org/our_work/cancer_care_improvement/programme_resources/cancer_qpis.aspx

The out-patient tool (appendix 1) focuses on 3 domains -Communication, Information giving and shared decision making. The second questionnaire concentrated on the in-patient experience (appendix 2) at the Royal Free during the period of their surgical intervention. Instead of a postal route the patients were asked to complete the surveys at their initial specialist MDT clinic visit and their post-operative clinic visit.

Mid-year report

Achievement against the action plan for mid-year report (appendix 3).

12 month end of year report

Estimated 85% response rate.

Out-patient total: **responses 93 patients**

In-patient total: **responses 77 Patients**

Friends and family test

98% of our patients would recommend the services to friends and family who require the same treatment'

Summary key achievements

Maintained a high volume response. Overall high scoring responses for each domain majority score 98-100% maintained since mid-year report.

Communication: 100% of patients reported, concerns were listened to, healthcare professional was open and honest, discussion was done in a sensitive manner

Information giving: 100% of patients reported, given enough information and it was easy to understand. Health care professional explained fully everything "I wanted to know"

Shared decision making: 100% of patients reported their view was taken into account; they had enough time to reach a decision

Summary key concerns

Lowest scoring responses: lack of Information on support services, approved sources of information opportunity to take part in research, communication with GP.

February 2015 action plan:

KEY AREAS	AIMS	ACTION	TARGET DATE	
Service development and improvement	1	Continue to develop patient support group living with and beyond cancer.	<ul style="list-style-type: none"> Aim to improve advertising, promote the success of the group and highlight benefits to patients Explore the options of alternating venue within other London cancer trusts 	March 2015
	2	Improvement in communication with general practitioners	<ul style="list-style-type: none"> a series of evening educational /networking evening events are planned to update on changing pattern of care in renal cancer. 	September 2015
		Improve recruitment to clinical trials	<ul style="list-style-type: none"> Clinical research notice 3rd floor Research governance group established Clinical Trials to be a standing item monthly academic SMDT 	April 2016
		Improve quality of in-patient nursing care	<ul style="list-style-type: none"> Recruitment of new staff to included renal cancer nursing Planned orientation for all new nurses Renal cancer nursing orientation package for all new staff Advanced communication skills training for key members of ward staff All ward nurse offered online renal cancer nursing module Weekly meeting CNS and ward sister to discuss report concerns Clinical nurse specialist to review all ward patients daily basis Continued training and development of ward nursing specific to renal cancer 	Review September 2015
		Improve patient involvement and feedback	<ul style="list-style-type: none"> Continue patient survey Audit achievement against action plan Use patient support group as focus group for patient involvement Develop a focus group for patient information 	September 2015

In-patients renal cancer		percentage of responses strongly agree/agree
Total responses		
1	I felt I was given enough information in advance to prepare me for my admission	98%
2	From the time I arrived at the hospital for admission I felt it was well organised	92%
3	The nurses and doctors helped me understand about my operation	100%
4	The nurses and doctors helped me understand about the anaesthetic	100%
5	They discussed pain control with me and what to expect.	98%
6	After the operation a member of staff explained to me how it went	95%
7	During my hospital stay my family and friends had the opportunity to be informed about my care	98%
8	I saw a consultant surgeon on a daily basis	97%
9	I felt the hospital staff did everything they could to help control my pain	97%
10	I felt well supported by the clinical nurse specialist during my hospital stay.	94%
11	Overall I was happy with the quality of care I received	93%
12	I was given written information on what to expect after my discharge	90%
13	I was treated with respect and dignity by the hospital staff	95%
14	I would recommend the services to friends and family who require the same treatment?	97%

Table 1

Out-patients renal cancer		percentage of responses strongly agree/agree
Measurement tool: COMMUNICATION		
Total responses 93		
1	The health care professional introduced themselves to me	100%
2	I was told all I wanted to know about my condition and treatment	99%
3	The health care professional helped me understand my condition and treatment	99%
4	My worries and fears or concerns were listened to today	100%
5	I was told about any danger signals to watch for when I got home	94%
6	I was given advice on ways to manage my condition at home	97%
7	My questions were answered in a way I could easily understand	99%
8	I had enough time with the health care professional	99%
9	I know who to contact if I have any further questions	97%
10	Health care professionals gave me consistent information about my condition	98%
11	Health care professionals from the hospital and my GP had a common understanding of my condition and treatment plans so that I did not have to repeat myself	91%
12	My family member, carer or friend were involved in discussions with health care professionals as much as I wanted them to be	98%
13	Health care professionals were open and honest	100%
14	Health care professionals considered my feelings in the way that they spoke to me	100%
15	I feel any information discussed was done in a sensitive manner	100%
16	I felt comfortable to talk about things that mattered to me e.g. money or work concerns, my emotions	99%

Table 2

Out-patients renal cancer		percentage of responses strongly agree/agree
Measurement tool: INFORMATION GIVING		
Total responses 63		
1	I received information to help me understand what would happen at today's appointment	96%
2	I was given enough information about my condition and treatment	100%
3	The information I was given today was easy to understand	100%
4	I was offered information in a format that suited me e.g. large print, Braille, etc.	97%
5	The health care professional explained fully everything I wanted to know about my condition, treatment and care	100%
6	I was offered information on how to access other support services, e.g. financial advice or support groups	90% 80% September 2014
7	I felt able to ask about the results of any tests or ongoing treatment	99%
8	I know who to contact out-of-hours if I'm worried about my condition	93%
9	I was given the contact details of the clinical nurse specialist, my 'key worker'	94%
10	I have been given details of other approved sources of information	89%
11	I was offered the opportunity to take part in research/clinical trials	75%

Table 3

Out-patients renal cancer		percentage of responses strongly agree/agree
Measurement tool: SHARED DECISION MAKING		
Total responses 63		
1	I felt included in discussions about my treatment and care	98%
2	The health care professional explained the risks and benefits of treatments in an understandable way	99%
3	I was given enough information to help me make an informed choice	99%
4	My views were taken into account by the health care professional	100%
5	I had enough time to reach my decision	100%
6	I was involved in decisions as much as I wanted to be	99%
7	I was told about possible side effects and how to manage them	96%
8	I felt that the health care professional I saw today knew enough about my case to provide good clinical care	100%
9	I feel my personal circumstances were taken into consideration	99%

	OUT-PATIENTS COMMENTS Was there anything particularly GOOD about your care?
	First class care as both inpatient and outpatient.
	have received a professional consultation with all my questions answered, no rush
	Clear and concise advice and positive encouragement
	I was extremely happy with care and advice given to me today
	The assurance and care from Consultant Mr Mumtaz is excellent and very grateful to him. P.S. Nurse Jonah is very helpful
	I received excellent care and the staff were very friendly
	Felt built up a good relationship with my nurse Jonah
	Prompt
	Generally very good and positive in all aspects
	Positive attitude of staff part Mr Mumtaz
	my treatment and care was provided with care and in a very professional manner
	As I was early and waiting longer for my appointment, a nurse came round if people had been waiting a long time and enquired when I would be seen, which was next.
	Very polite staff
	The urgency and speed of treatment
	Clear and concise
	Every person new their job which made me feel at ease with what was ahead of me. I can not fault the care & understanding I have received at the Royal Free. I can not thank you all enough.
	v. professional department, excellent surgeon (guy Webster)

	OUT-PATIENTS COMMENTS Was there anything that could have been IMPROVED?
	Phone system in order to request a new appointment
	Waiting time 1 hr 30mins delay. Sometimes feel time with consultant is rushed
	hospital food needs improving a lot
	On the computer registering arrival it stated I had refused ethnicity origin which I have filled in in forms and any telephone numbers were missing. I registered my ethnicity but left the phone numbers blank. It went through successfully though
	had a long wait because my notes were missing
	OK. One comment here; I was distressed about a patient that was brought into the ward while I was recovering. He was disruptive in that he shouted out often and loudly and kept me awake for two nights. I was not able to rest and would have greatly appreciated a solution. If this is something that could be fixed for the future I think that it would aid recovery. Thank you.
	No, it was overall a good organised schedule. Very Helpful and Professional

	IN-PATIENTS COMMENTS Was there anything that could have been IMPROVED?
	Nursing care could be improved
	Whilst not in your control, once I was discharged I had no nursing care. District Nurse wouldn't come out as I could walk, so my wife had to change dressings. Think the communication between hospital and GP should be better
	Not sure it can but staff under massive pressure and workload that even with best will unable to give all patients attention they would like
	During the doctors rounds if the staff were coming round with breakfast & teas they did not return to your bed if they missed you out. Also tablets were given to you at 07.00 am but no food or drink until 8.30am earliest
	no
	hospital food needs to be better
	admission date was changed without letting me know
	The toilet on ward 10 South bed 1-4 didn't always flush on demand. Slow to refill cistern. I completed an online survey in the ward before my discharge. My aunt had trouble getting through to hospital on phone and was cut off after the nurse said "I had gone down" (for operation). I did not say "goodbye" properly as I was sent to Day room to wait for my son to pick me up as new patient was coming in. Overall, I would recommend this hospital.
	The ward nurses seemed to have no time to relate to the patients. I hallucinated that I was behind a clear membrane and that every few hours a nurse came and punched it, making a dent but never quite hitting me.
	Nursing care is not adequate. More nursing staff are needed and that, too, dedicated and taking care of patients
	Yes. Don't think being questioned directly after op to fill out questionnaire good idea. Also, being put in a ward with screaming patient in next bed. Felt discharged too early. One more day would have been better. The bin in room wasn't emptied for 4 days (it was full).
	I was in recovery for a long time before a bed was found.
	Everything OK
	The hospital bed was most uncomfortable. The call button was never easily accessible.
	Yes. The discharge process was too long, without much explanation. It could be better organised as the medication took forever to be sorted out.
	Not enough staff on the ward I went to after ICU.
	Epidural removed prior to pain killers being issued. Staff shortage on ward.
	nothing, everything was great
	post operationally there was huge issues with ward nurses1.nurses were putting needle for administration of painkillers they were leaving air bubbles in the system. I was afraid they would enter my circulation and asked repeatedly to be removed. The nurse (white coat) said there was no problem but then came back and said I was right and needs to be removed(the bubble). 2. I was left in pain for 4 hours shortly after my operation. They did not know about prescription from the surgery team. 3. Three nights after operation (11july on the night shift when I asked help from the nurses due to blisters on my back she was very aggressive putting in my face the bed

	control module(buttons) saying to use that if I have such an issue. afterwards when exiting the room she was laughing with other nurses.(ward nurses completely ignored me on several occasions leaving me without painkillers for 4 hours post operation. my clinical nurse specialist had to intervene for me to have my painkillers. for surgery team and specialist they are amazing disagree with ward
	On the wards there appears to be more agency staff than hospital staff which seems a shame as they were always very busy + staff changed too often to get to know the patient
	Everything was very good
	Very pleased with doctors and with outpatient care, disappointed with nurse care(overall I was happy with the quality of care I received?) Not by the nurses after care on ward 10
	Answering the phone. After a period of 12 minutes hanging on for information disconnected call. Waited nearly 1 hr. for a partner to transfer me to the lobby on being discharged. In patient agency nursing poor.
	Found the meals rather tasteless and therefore difficult to eat, especially savoury. Presentation and choices good though.
	The ladies serving the breakfast were quiet unfriendly. They made me feel uncomfortable asking for boiled water instead of tea. No clip removal details documented on discharge otherwise completely satisfied
	no
	food
	no
	no
	I have been aware the communication with my immediate family was non existent. They were not made aware of my well being or whereabouts after operation.

Out-patient patient experience survey 2014

What is the survey about?

This survey is about your experience of the treatment and care you received for your kidney cancer at the specialist centre at the Royal Free. Your views are very important in helping us to find out how well the services work and how they can be improved.

Your answers will be treated in confidence

Your participation in this survey is voluntary. If you choose not to take part in this survey it will not affect the care you receive from the NHS in any way. If you do not wish to take part, or you do not want to answer some of the questions, you do not have to give us a reason.

Completing the questionnaire

For each question please tick inside one box. Don't worry if you make a mistake; simply cross out the mistake and put a tick in the correct box. There is space at the end of the questionnaire for you to write other comments and suggestions.

If you have any queries about the survey or the questionnaire, please call the

Kidney cancer clinical nurse specialist
Royal Free London NHS Foundation Trust
Direct line – 020 7317 7779
Email: rf.renalcancernursing@nhs.net

Please post the questionnaire into the 'patient feedback' box in the clinic

Thank you for taking the time to complete this survey.

Part 1 – measurement tool

COMMUNICATION

Please read the statements below and select the answer which you feel best describes how you feel about the care you received today		Strongly agree	Agree	Disagree	Strongly disagree	Please note any additional comments below...
1	The health care professional introduced themselves to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
2	I was told all I wanted to know about my condition and treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
3	The health care professional helped me understand my condition and treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
4	My worries and fears or concerns were listened to today	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
5	I was told about any danger signals to watch for when I got home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
6	I was given advice on ways to manage my condition at home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
7	My questions were answered in a way I could easily understand	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
8	I had enough time with the health care professional	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
9	I know who to contact if I have any further questions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
10	Health care professionals gave me consistent information about my condition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
11	Health care professionals from the hospital and my GP had a common understanding of my condition and treatment plans so that I did not have to repeat myself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
12	My family member, carer or friend were involved in discussions with health care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

	professionals as much as I wanted them to be					
13	Health care professionals were open and honest	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
14	Health care professionals considered my feelings in the way that they spoke to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
15	I feel any information discussed was done in a sensitive manner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
16	I felt comfortable to talk about things that mattered to me e.g. money or work concerns, my emotions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

Part 2 – measurement tool

INFORMATION

Please read the statements below and select the answer which you feel best describes how you feel about the care you received today		Strongly agree	Agree	Disagree	Strongly disagree	Please note any additional comments below...
1	I received information to help me understand what would happen at today's appointment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
2	I was given enough information about my condition and treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
3	The information I was given today was easy to understand	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
4	I was offered information in a format that suited me e.g. large print, Braille, etc.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
5	The health care professional explained fully everything I wanted to know about my condition, treatment and care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
6	I was offered information on how to access other support services, e.g. financial advice or support groups	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
7	I felt able to ask about the results of any tests or ongoing treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

8	I know who to contact out-of-hours if I'm worried about my condition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
9	I was given the contact details of the Clinical Nurse Specialist, my 'key worker'	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
10	I have been given details of other approved sources of information	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
11	I was offered the opportunity to take part in research/clinical trials	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

Part 3 – measurement tool

SHARED DECISION MAKING

Please read the statements below and select the answer which you feel best describes how you feel about the care you received today		Strongly agree	Agree	Disagree	Strongly disagree	Please note any additional comments below...
1	I felt included in discussions about my treatment and care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
2	The health care professional explained the risks and benefits of treatments in an understandable way	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
3	I was given enough information to help me make an informed choice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
4	My views were taken into account by the health care professional	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
5	I had enough time to reach my decision	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
6	I was involved in decisions as much as I wanted to be	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
7	I was told about possible side effects and how to manage them	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
8	I felt that the health care professional I saw today knew enough about my case to provide good clinical care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
9	I feel my personal circumstances were taken into consideration	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

Please turn over the page if there are any comments you wish to make.

OTHER COMMENTS

Was there anything particularly good about your care?

Was there anything that could have been improved?

In-patient patient experience survey 2014

What is the survey about?

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Completing the questionnaire

For each question please tick inside one box. Don't worry if you make a mistake; simply cross out the mistake and put a tick in the correct box. There is space at the end of the questionnaire for you to write other comments and suggestions.

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Please post the questionnaire into the 'patient feedback' box in the clinic

Thank you for taking the time to complete this survey.

Please read the statements below and select the answer which you feel best describes how you feel about the care you received today		Strongly agree	Agree	Disagree	Strongly disagree	Please note any additional comments below...
1	I felt I was given enough information in advance to prepare me for my admission	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
2	From the time I arrived at the hospital for admission I felt it was well organised	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
3	The nurses and doctors helped me understand about my operation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
4	The nurses and doctors helped me understand about the anaesthetic	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
5	They discussed pain control with me and what to expect.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
6	After the operation a member of staff explained to me how it went	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
7	During my hospital stay my family and friends had the opportunity to be informed about my care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
8	I saw a consultant surgeon on a daily basis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
9	I felt the hospital staff did everything they could to help control my pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
10	I felt well supported by the clinical nurse specialist during my hospital stay.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
11	Overall I was happy with the quality of care I received	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
12	I was given written information on what to expect after my discharge	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

13	I was treated with respect and dignity by the hospital staff	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
14	I would recommend the services to friends and family who require the same treatment?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

OTHER COMMENTS

Was there anything particularly good about your care?

Was there anything that could have been improved?

Appendix 3

Achievement against action plan: mid-year report September 2014

KEY AREAS	AIMS	ACTION	TARGET DATE	Achievement	
Service development and improvement	1	Establish a patient support group living with and beyond cancer.	<ul style="list-style-type: none"> • Patient expression of interest flyer and poster on ward and in clinic Mail • out invitation to patient treated over past two years • establish meeting at Barnet Hospital and the Royal Free Hospital 	1 st meeting November 2014	Group is now established, Meetings held November February and April at RFL
	2	Improvement in communication with general practitioners	<ul style="list-style-type: none"> • a series of evening educational/networking evening events are planned to update on changing pattern of care in renal cancer. 	September 2015	Ongoing
	3	Improve recruitment to clinical trials	<ul style="list-style-type: none"> • Clinical research notice 3rd floor • Patient information on Biobanking sent with all new clinic appointments • Clinical trials to be a standing item monthly academic SMDT 	April 2015	Established research governance group at RFL. New studies open for recruitment.
	4	Improve quality of in-patient nursing care	<ul style="list-style-type: none"> • Recruitment of new staff to included renal cancer nursing • Planned orientation for all new nurses • All ward nurse offered online renal cancer nursing module • Weekly meeting CNS and ward sister to discuss report concerns • Clinical nurse specialist to review all ward patients daily basis • Renal cancer nursing ward education 	September 2015	Recruitment is ongoing Established 100% compliance CNS daily ward round incorporates ward education.
	5	Improve patient involvement and feedback	Continue patient survey Audit achievement against action plan Use patient support group as focus group for patient involvement Develop a focus group for patient information	September 2015	Annual survey reported. Established support group. Requested patient interest in joining focus group.