WHAT IS THE BEST TREATMENT FOR MY SMALL KIDNEY TUMOUR?
A decision aid to discuss treatment options with your doctor

This decision aid is designed to educate patients with a small kidney tumour. We encourage you and your caregivers to think about different parts of your treatment that are important to you. Small kidney tumours are often defined as tumours less than 4 cm. However, this varies based on your situation and should be discussed with your doctor. All patients are unique. There are no wrong decisions. This decision aid can help you discuss treatment options with your doctor when determining how to best manage your kidney tumour.

This decision aid is for you if:
• You have a small tumour in one of your kidneys (usually less than 4 cm in size).
• You want to consider options for treatment of the tumour.

This decision aid may not be for you if:
• You have multiple tumours in one kidney or tumours in both kidneys.
• You have a kidney tumour larger than 4 cm in size.
• You have an inherited condition that makes kidney tumours more likely to develop.

If you are not sure if this decision aid applies to you, please ask your doctor.
What is a small kidney tumour?:

- A small kidney tumour is an abnormal growth of kidney tissue that is usually less than 4 cm in size.
- Some small kidney tumours (about 1 in 5) are not cancer.
- Most small kidney tumours (about 4 in 5) are cancer, but this can only be known if a sample is taken of the tumour.
- A needle biopsy to sample the tumour, or surgery to remove the tumour, can be done to know if the tumour is cancer.
- Many small kidney tumours that are cancerous, grow slowly and are unlikely to spread to other parts of the body.
Should I have a biopsy of my small kidney tumour?:

- A biopsy is a sample of tissue taken from the abnormal area of tissue with a needle through the skin. This is done to find out if the tumour is cancer or not.

- A biopsy is generally only done if the results are going to change your treatment options or provide more information.

- If the biopsy shows the tumour is not cancer (benign) you may avoid surgery that you do not need.

- A biopsy can sometimes tell the type of cancer and how aggressive the cancer is. This may also change your treatment options.

- Some tumours are easier to biopsy than others due to their size and/or location in the kidney. Sometimes a biopsy is not able to tell if the tumour is cancer or not.

- A biopsy is most commonly done by a radiologist (doctor who reads x-rays, ultrasounds and CT scan) with freezing (numbing) with the patient awake, and is not a surgery.

- Some hospitals have more experience with biopsies of kidney tumours than others.

- Side effects are uncommon. Sometimes patients have bleeding or pain after a biopsy. Spreading of the tumour is not a concern with biopsy.
Several treatment options for small kidney tumours exist, but not all may be appropriate for you. Your doctor can help you determine what options are appropriate for you based on the tumour and your medical history.

My doctor recommends the following options are available for me:

- **Active Surveillance (Monitoring)**
- **Tissue Ablation**
- **Minimally invasive (MIS) Partial (Sub-Total) Nephrectomy**
- **Open Partial (Sub-Total) Nephrectomy**
- **Minimally invasive (MIS) Radical (Total) Nephrectomy**

My doctor feels these are the options available for me because:

On the following pages, you can review information about each of these options. Clinical trials are research studies that evaluate medical tests and treatments. Please ask your doctor if there are any clinical trials that are available for you.
What are the treatment options for patients with a small kidney tumour?

The following treatment options for patients with small kidney tumours will be explained in the next pages. These treatment options are presented in no specific order. Each of these options has benefits and risks that are important to consider when you are thinking about the best treatment option for you.

**Active Surveillance (Monitoring)**

**Radical (Total) Nephrectomy**

**Partial (Sub-Total) Nephrectomy**

**Tissue Ablation**
What are the treatment options for a small kidney tumour?:

**Active surveillance (monitoring):**

- Active surveillance may be a safe option for some patients. Typically, small kidney tumours grow slowly or not at all and some tumours are not cancer.

- You do not need to undergo surgery or ablation treatment immediately.

- You have regular follow-up visits to monitor growth of the tumour or spread outside of kidney.

- Your doctor monitors the tumour using ultrasound, CT (CAT) scans or MRI depending on what your doctor feels is best.

- Sometimes a kidney biopsy is recommended (see page 3).

- If your tumour grows quickly or becomes a large tumour (often >4 cm), treatment with surgery or ablation may be recommended.

- If the tumour spreads to other parts of the body, surgery and/or anti-cancer medicines may be suggested. This may mean the tumour cannot be completely controlled with surgery. A referral to a medical oncologist and/or radiation oncologist is appropriate.
What are the treatment options for a small kidney tumour?:

**Tissue (tumour) ablation:**

- Energy is applied to the tumour with needles through the skin or with minimally invasive surgery (laparoscopic or robotic) to destroy the tumour tissue.

- This can be done with heat to destroy the abnormal tissue (radiofrequency ablation) or with extremely cold needles that destroy the abnormal tissue (cryotherapy).

- This is a procedure that can be done with skin freezing (numbing) with the patient awake (often sedated), or with minimally invasive (laparoscopic or robotic) surgery while the patient is asleep.

- A biopsy is usually done before the treatment or at the time of the treatment.

- Sometimes, more than 1 treatment is needed to destroy the tumour.

- Not all tumours can be treated in this way because of their size or location in the kidney.
What are the treatment options for a small kidney tumour?:

Partial (sub-total) nephrectomy:

- Surgery to remove part of one kidney (the part that includes the tumour).

- This can be done with open surgery or sometimes with minimally invasive surgery (sometimes known as keyhole surgery).

- **Open surgery** means one large incision (15-40 cm) in the side or middle of the abdomen is made for the doctor to remove part of one kidney, including the tumour.

- **Minimally invasive surgery (MIS)*** means either laparoscopic or robotic surgery. Both use 3-5 small incisions, a camera and small surgical tools. One bigger incision (4-10 cm) is needed to take the tumour out.

- A general anesthetic (asleep with breathing tube) is used for this surgery.

- This surgery usually takes 3-4 hours.
What are the treatment options for a small kidney tumour?:

**Radical (total) nephrectomy:**

- Surgery to remove all of one kidney including the tumour.
- This is often done with minimally invasive surgery but may require open surgery.
- Open surgery means one large incision (15-40 cm) in the side or middle of the abdomen is made for the doctor to remove the kidney with the tumour.
- Minimally invasive surgery (MIS) means either laparoscopic or robotic surgery. Both use 3-5 small incisions, a camera and small surgical tools. One bigger incision (4-10 cm) is needed to take the kidney out.
- A general anesthetic (asleep with breathing tube) is used for this surgery.
- This surgery usually takes around 3-4 hours.
What factors may affect your treatment options?:

Circle yes or no and discuss your other health factors with your doctor.

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes or No</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you take blood thinners?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Do you have high blood pressure?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Do you have diabetes?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Do you have a genetic disorder affecting the kidneys?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Do you have renal failure / kidney disease?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Do you have family members with kidney problems?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Do you have other medical or personal issues?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Are you over the age of 80 years?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Have you had previous kidney surgery?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>None of these apply to me</td>
<td>Yes</td>
<td>No</td>
</tr>
</tbody>
</table>

Other comments related to your health:
Working through the 4 steps of this decision aid may help you consider the options.

Step 1: What are the benefits and risks of each treatment option?

Every patient is unique. No one can predict the exact outcome of your chosen option. These diagrams have blocks of 100 faces that show a ‘best estimate’ of what happens to 100 people with small kidney tumours who undergo each treatment option over 5 years. Each face (☺) stands for one person. The shaded areas show the average number of people affected based on current research. There is no way of knowing in advance if you will have these benefits or risks, however, individual factors may help your physician predict your risk. These outcomes could happen at any time, but research has not been done to show what the estimates are beyond 5 years.

Benefits: Patients who benefit from the given treatment highlighted in green

<table>
<thead>
<tr>
<th>Benefit – Likelihood of surviving from kidney cancer at 5 years</th>
<th>MIS radical (total) nephrectomy</th>
<th>MIS partial (sub-total) nephrectomy</th>
<th>Open partial (sub-total) nephrectomy</th>
<th>Tissue ablation</th>
<th>Active surveillance (No surgical treatment)</th>
</tr>
</thead>
<tbody>
<tr>
<td>After treatment or while on surveillance, the likelihood of surviving from kidney cancer is¹,²,³:</td>
<td>98 have survived kidney cancer</td>
<td>98 have survived kidney cancer</td>
<td>98 have survived kidney cancer</td>
<td>98 have survived kidney cancer</td>
<td>98 have survived kidney cancer</td>
</tr>
</tbody>
</table>

¹ Survival rates are calculated based on current research.
² These outcomes could happen at any time, but research has not been done to show what the estimates are beyond 5 years.
³ Individual factors may help your physician predict your risk.

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Benefit – No evidence of kidney cancer in 5 years

After treatment or surveillance, the chance of having no evidence of kidney cancer is\(^1,4,5,6,7\):

<table>
<thead>
<tr>
<th>Procedure</th>
<th>98 have no evidence of cancer</th>
</tr>
</thead>
<tbody>
<tr>
<td>MIS radical (total) nephrectomy</td>
<td></td>
</tr>
<tr>
<td>MIS partial (sub-total) nephrectomy</td>
<td></td>
</tr>
<tr>
<td>Open partial (sub-total) nephrectomy</td>
<td></td>
</tr>
<tr>
<td>Tissue ablation</td>
<td></td>
</tr>
<tr>
<td>Active surveillance (No surgical treatment)</td>
<td>0 are free of tumour that may be cancer</td>
</tr>
</tbody>
</table>

Average length of stay in hospital after surgery or treatment:

<table>
<thead>
<tr>
<th>Procedure</th>
<th>Number of days(^4,14,15):</th>
</tr>
</thead>
<tbody>
<tr>
<td>MIS radical (total) nephrectomy</td>
<td>3 days</td>
</tr>
<tr>
<td>MIS partial (sub-total) nephrectomy</td>
<td>3 days</td>
</tr>
<tr>
<td>Open partial (sub-total) nephrectomy</td>
<td>5 days</td>
</tr>
<tr>
<td>Tissue ablation</td>
<td>1 day</td>
</tr>
<tr>
<td>Active surveillance (No surgical treatment)</td>
<td>0 days</td>
</tr>
</tbody>
</table>
Disadvantages: Patients with side effect of the given treatment highlighted in blue.

**Risk – Spread of cancer to other parts of the body:**
Cancer can spread to other parts of the body after treatment or with no treatment. This is called metastases. This usually requires chemotherapy to treat the cancer. The risk of kidney cancer spreading to other parts of the body over 5 years is \(1,3,4,5,7,12\):

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Cancer Spread Outside the Kidney</th>
</tr>
</thead>
<tbody>
<tr>
<td>MIS radical (total) nephrectomy</td>
<td>2</td>
</tr>
<tr>
<td>MIS partial (sub-total) nephrectomy</td>
<td>2</td>
</tr>
<tr>
<td>Open partial (sub-total) nephrectomy</td>
<td>2</td>
</tr>
<tr>
<td>Tissue ablation</td>
<td>2</td>
</tr>
<tr>
<td>Active surveillance (No surgical treatment)</td>
<td>2</td>
</tr>
</tbody>
</table>

**Risk – Major complication of treatment**
A major complication is one that requires intensive care or monitoring. This may include additional surgery. The rate of a major complication with each treatment is \(2,5,6,8,10\):

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Major Complication</th>
</tr>
</thead>
<tbody>
<tr>
<td>MIS radical (total) nephrectomy</td>
<td>3</td>
</tr>
<tr>
<td>MIS partial (sub-total) nephrectomy</td>
<td>5</td>
</tr>
<tr>
<td>Open partial (sub-total) nephrectomy</td>
<td>11</td>
</tr>
<tr>
<td>Tissue ablation</td>
<td>2</td>
</tr>
<tr>
<td>Active surveillance (No surgical treatment)</td>
<td>0</td>
</tr>
</tbody>
</table>

*Clavien Dindo Grade III-V*
Risk – Post-treatment bleeding
After treatment, the chance of having bleeding requiring a blood transfusion is\(^1\)\(^8\)\(^9\)\(^10\).

- MIS radical (total) nephrectomy:have a post-operative bleed
- MIS partial (sub-total) nephrectomy:have a post-operative bleed
- Open partial (sub-total) nephrectomy:have a post-operative bleed
- Tissue ablation:have bleeding after treatment
- Active surveillance (No surgical treatment):have bleeding

Risk – Post-treatment urine leak
After treatment, the chance of having a urine leak requiring a temporary drainage tube through the skin or between the kidney and the bladder is\(^4\)\(^8\)\(^9\)\(^10\)\(^11\):

- MIS radical (total) nephrectomy:have a urine leak
- MIS partial (sub-total) nephrectomy:have a urine leak
- Open partial (sub-total) nephrectomy:have a urine leak
- Tissue ablation:has a urine leak
- Active surveillance (No surgical treatment):have a urine leak
The decrease in kidney function with treatment of your kidney tumour depends on your kidney function before treatment, your other health conditions (see page 10) and the size of the tumour. Please discuss this with your doctor.
*Some doctors use different incisions to treat kidney tumours. Please discuss the incisions your doctor uses.

**Expected scars after treatment**

- **MIS radical (total) nephrectomy**
  - 3-4 small incisions
  - One larger incision in the lower abdomen to remove the kidney

- **MIS partial (sub-total) nephrectomy**
  - 4-5 small incisions
  - One larger incision is made to remove the tumor

- **Open partial (sub-total) nephrectomy**
  - 1 large incision in side

- **Tissue ablation**
  - 1 small needle entry in side
  - No incisions

- **Active surveillance (No surgical treatment)**
  - No incisions

**Risk – Flank bulge:**

After treatment, some patients develop a bulge in their side (flank) at the site of the incision. This is rarely harmful or dangerous but can be uncomfortable or annoying for patients. The risk of flank bulge for each option is:

- **MIS radical (total) nephrectomy**
  - 0 have a flank bulge

- **MIS partial (sub-total) nephrectomy**
  - 0 have a flank bulge

- **Open partial (sub-total) nephrectomy**
  - 15 have a flank bulge

- **Tissue ablation**
  - 0 have a flank bulge

- **Active surveillance (No surgical treatment)**
  - 0 have a flank bulge
Step 2: What matters to you?

Common reasons to choose each treatment option are listed below.

Check ✓ how much each reason matters to you on a scale from 0 to 5.

‘0’ means the reason is not important to you. ‘5’ means it is very important to you.

### Reasons to choose:

#### Radical (total) nephrectomy

<table>
<thead>
<tr>
<th>Reason</th>
<th>Not Important</th>
<th>Very Important</th>
</tr>
</thead>
<tbody>
<tr>
<td>How important is it to you to remove the entire kidney containing the mass?</td>
<td>0 1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>How important is it to you to have surgery with a quick recovery?</td>
<td>0 1 2 3 4 5</td>
<td></td>
</tr>
</tbody>
</table>

#### Partial (sub-total) nephrectomy

<table>
<thead>
<tr>
<th>Reason</th>
<th>Not Important</th>
<th>Very Important</th>
</tr>
</thead>
<tbody>
<tr>
<td>How important is it to you to avoid decreased kidney function after surgery?</td>
<td>0 1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>How important is it to you to remove the tumor only?</td>
<td>0 1 2 3 4 5</td>
<td></td>
</tr>
</tbody>
</table>

#### Tissue (tumour) ablation

<table>
<thead>
<tr>
<th>Reason</th>
<th>Not Important</th>
<th>Very Important</th>
</tr>
</thead>
<tbody>
<tr>
<td>How important is it to you to treat the tumor with few complications?</td>
<td>0 1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>How important is it to you to avoid surgery?</td>
<td>0 1 2 3 4 5</td>
<td></td>
</tr>
</tbody>
</table>

#### Active surveillance

<table>
<thead>
<tr>
<th>Reason</th>
<th>Not Important</th>
<th>Very Important</th>
</tr>
</thead>
<tbody>
<tr>
<td>How important is it to you to avoid hospitalization?</td>
<td>0 1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>How important is it to you to avoid any treatment side effects?</td>
<td>0 1 2 3 4 5</td>
<td></td>
</tr>
</tbody>
</table>
Now think about what option has the reasons that are most important to you…

Which option do you prefer?

Check ☑ one.

☐ Partial (sub-total) nephrectomy
☐ Radical (total) nephrectomy
☐ Tissue (tumour) ablation
☐ Active surveillance (monitoring)
☐ I have not decided yet

Are there other questions you have for your doctor? If yes, please write them down here.

________________________________________________________________________________
________________________________________________________________________________
________________________________________________________________________________
________________________________________________________________________________

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**Step 3: What else do you need to prepare for decision making?**

Find out how well this decision aid helped you learn the key facts.

Check ☑ the best answer.

<table>
<thead>
<tr>
<th></th>
<th>Total nephrectomy</th>
<th>MIS or open partial (sub-total) nephrectomy</th>
<th>Tissue ablation</th>
<th>Active surveillance</th>
<th>All four options</th>
<th>Not sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Which two options have the best chance of no evidence of cancer in 5 years’ time?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>2. Which option has the lowest risk of complications (bleeding, urine leak)?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>3. Which option might require more than one treatment on the tumour?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>4. Which option has more than 90% of patients surviving from kidney cancer after 5 years?</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
Find out how comfortable you feel about deciding

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you know the benefits and risks of each option?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Are you clear about which benefits and risks matter most to you?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you have enough support and advice to make a choice?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you feel sure about the best choice for you?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

If you answered ‘No’ to any of these, discuss with your doctor

(The SURE Test © O’Connor & Légaré, 2008)

Answers for the key facts: 1. Partial and Total nephrectomy, 2. Active surveillance, 3. Ablation, 4. All four options
Step 4: What are the next steps?

Check ☑ what you prefer.

☐ I prefer to receive a partial (sub-total) nephrectomy.

☐ I prefer to receive a radical (total) nephrectomy.

☐ I prefer to receive tissue (tumour) ablation.

☐ I prefer active surveillance (monitoring).

☐ I need to discuss the options with my doctor and family.

☐ I need to read more about my options.

☐ Other, please specify: ________________________________
This information is not intended to replace the advice of a health care provider.

Publication date:

Last updated: October 14, 2019

This patient decision aid has been peer-reviewed. The patient decision aid will be updated in an ongoing fashion by authors based on changes in studies published and feedback provided by users.

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Funding: Kidney Cancer Research Network of Canada, Canadian Urology Oncology Group, Canadian Urology Association Scholarship Foundation, International Kidney Cancer Coalition

Reviewed and endorsed by: Kidney Cancer Canada, International Kidney Cancer Coalition

All authors have declared no conflict of interest and do not gain from any option made by patients.

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SMOG readability rating: 8.1 (eighth grade)
Benefits and risks data from:


