

Decision Aid – Should I have surgery or radiation and chemotherapy to treat my bladder cancer?

This decision aid is for you if:

- You have bladder cancer that is invading into the muscle layer of the bladder.
- Your doctor said you would be a good candidate to receive either surgery to remove the bladder, or radiation with chemotherapy, to treat your bladder cancer.

This decision aid may not be for you if:

- You have a large cancer, many cancer growths, or your kidney is blocked by cancer. For patients with these features, surgery to remove the bladder is usually preferred over radiation.
- Your bladder cancer has spread to other parts of your body or you have a rare type (histology) of bladder cancer.
- Other aspects of your cancer or your health are not suited to surgery or radiation with chemotherapy (see p18)

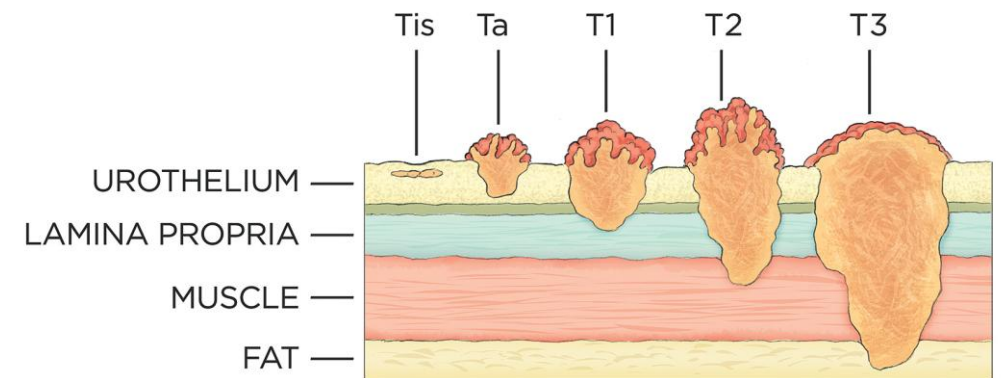
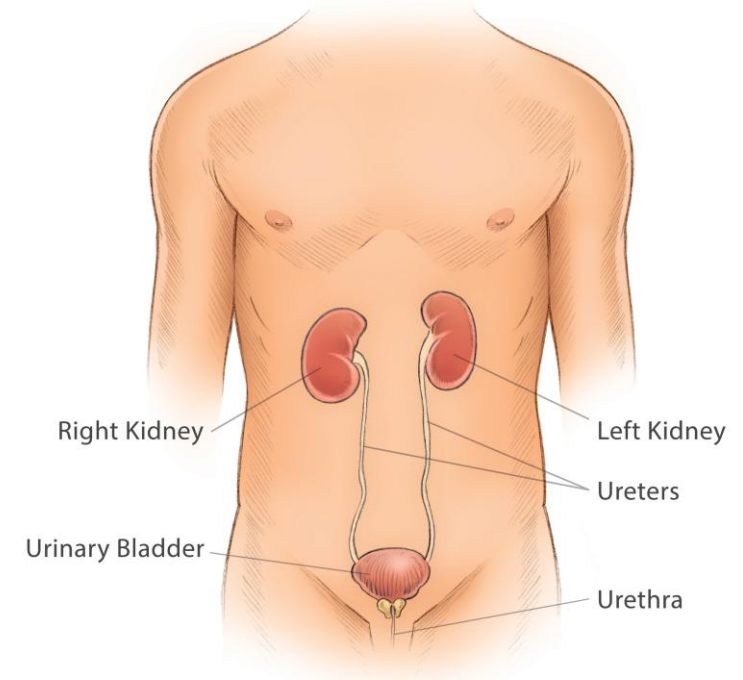
We encourage you to think about your treatment, your values, and priorities.

All people are unique, there are no wrong decisions.

If you are not sure if this decision aid applies to you, please ask your doctor.

WHAT IS MUSCLE-INVASIVE BLADDER CANCER?

- Cancer can involve different layers of the bladder:
 - thin inner lining (Ta or T1)
 - thick muscle layer (T2)
 - outer fat layer (T3)
- When cancer grows into the muscle layer or beyond, it is called “muscle-invasive bladder cancer.” (T2/T3)
- Muscle-invasive bladder cancer has a higher risk of spreading to other parts of the body and is usually not curable without surgery to remove the bladder or radiation with chemotherapy.
- Bladder scraping alone (TURBT) to remove the cancer is unlikely to cure muscle-invasive bladder cancer.
 - TURBT = transurethral resection of bladder tumor



WHAT ARE THE TREATMENT CHOICES?

Surgery to remove the bladder

- This surgery is called a “radical cystectomy.”
- Note: your doctors may recommend **full** dose chemotherapy/immunotherapy before or after surgery.

Radiation with chemotherapy

- High energy X-rays are directed at your bladder which kills cancer cells.
- **Low dose** chemotherapy is given at the same time as radiation to help the radiation kill cancer cells.
- Note: your doctors may recommend **full** dose chemotherapy/immunotherapy before or after your radiation as well.

No further treatment

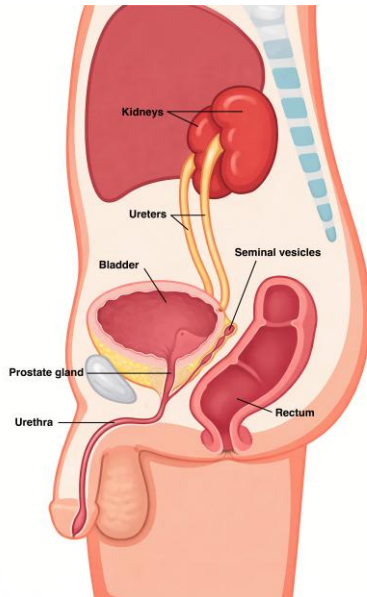
- You have the option of declining treatment.
- Without treatment, muscle invasive bladder cancer usually grows and spreads through the body, cannot be cured, and may cause suffering.
- You could still have minor surgery (TURBT – see page 3).
- This is **not recommended** for patients who want to cure the cancer.
- Please see page 8 for details

WHAT IS SURGERY?

- Surgery (radical cystectomy) removes your bladder completely.
 - This is a major surgery and usually takes 4-8 hours.
 - A general anaesthetic (asleep with breathing tube) is used.
 - Most patients stay in hospital for 5-10 days.
- During surgery for bladder removal, other organs around the bladder may be removed:

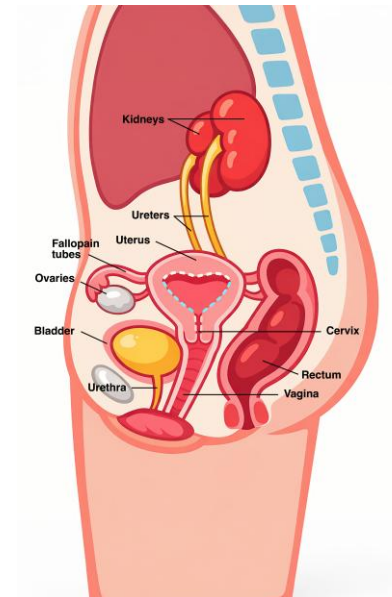
Organs removed in males:

Bladder, prostate, seminal vesicles, lymph nodes



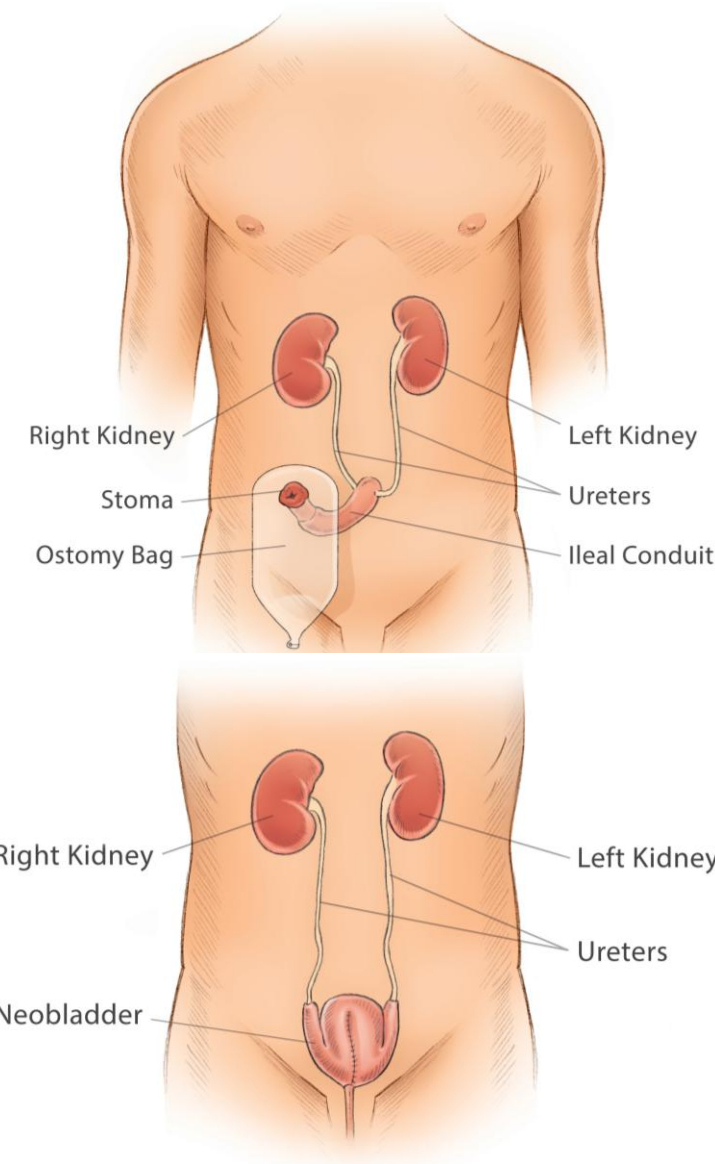
Organs removed in females:

Bladder, lymph nodes, +/- uterus, ovaries, vagina



WHAT IS SURGERY?

- After bladder removal, you require a new way to empty urine from your body (urinary diversion). Several emptying methods exist and each uses your bowel (intestine):
 - **Ileal conduit stoma** = draining urine continuously through your abdomen into a bag that sticks to your skin
 - **Neobladder internal reservoir** = pass urine through urethra
 - **Continent catheterizable channel** = a channel on the abdomen that can be drained with a tube several times per day
- *There is another decision aid available online to help you with your choice of urinary diversion, please ask your doctor for details.*
https://decisionaid.ohri.ca/docs/das/Surgery_for_Bladder_Cancer.pdf



WHAT IS RADIATION WITH CHEMOTHERAPY?

- Radiation with chemotherapy is also referred to by some doctors as “radiotherapy with chemotherapy” or “chemoradiation” or “tri-modal therapy (TMT)” or “bladder preservation therapy”.
- **Radiation** includes 20-32 separate treatments at the hospital. Each treatment lasts about 30 minutes.
- Treatments occur with daily visits in the hospital, from Monday to Friday, for 4-6 weeks.
- The treatment is not invasive and is delivered by a machine that emits x-rays.
- **Low dose chemotherapy** with an intravenous (IV) is given every few weeks while you are receiving radiation. On the days you receive chemotherapy, you will be at the hospital longer.
- After radiation with chemotherapy, you will continue to urinate through the urethra.
- After radiation with chemotherapy, you will require regular cystoscopy (camera test) for the rest of your life to monitor for cancer coming back. You may also require repeat surgeries if cancers return in the bladder.

WHAT HAPPENS IF I DON'T WANT ANY TREATMENT?

“No treatment” is not recommended because:

- The risk of the cancer growing and spreading to the rest of the body is high.
- The cancer may cause pain, bleeding, or other problems requiring urgent hospitalization and treatments like smaller surgeries or radiotherapy.
- If bladder cancer spreads to other parts of the body, it is not curable and may shorten your lifespan.
- Chemotherapy/immunotherapy may be an option to help control the cancer if it spreads.

Ask your doctor what options for treatment are recommended for you.

Should I have neoadjuvant therapy before either surgery or radiation?

- **“Neoadjuvant therapy”** refers to chemotherapy/immunotherapy that may be given before surgery or radiation. It is delivered for about 3 months. **This is full dose.**
- This may be recommended to **shrink** your cancer and **treat cancer cells that may have** spread but that cannot be seen on scans. It may improve your chance of being cured and living longer.
- **The most common side effects are:**
 - Infection (severe)
 - Feeling sick to your stomach and vomiting
 - Tiredness, muscle aches, hair loss, low blood counts
 - Tingling and pain in hands and feet
 - More severe side effects could include kidney, nerve, or hearing damage
- *The choice to proceed with neoadjuvant therapy may be related to your decision to receive surgery or radiation. **It is often recommended before treatment.** Note: Chemotherapy received at the same time as radiation is **different and at a lower dose.***

Working through the following 4 steps of this decision aid may help you consider the options.

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

Every patient is unique. No one can predict the exact outcome of your decision.

The following diagrams have blocks of 100 faces that show a ‘best estimate’ of what happens to **100 people** with “muscle-invasive bladder cancer” who undergo each treatment option, over a period of **5 years**.

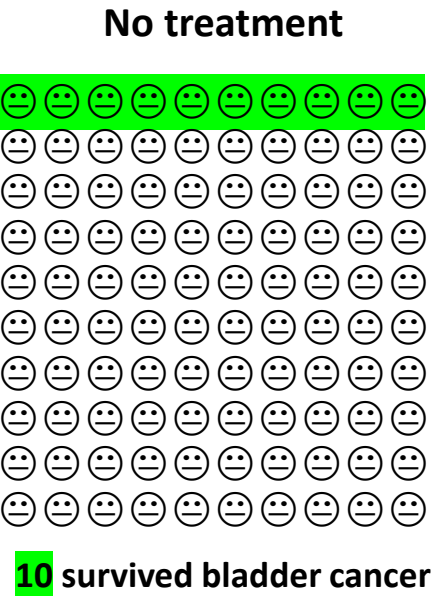
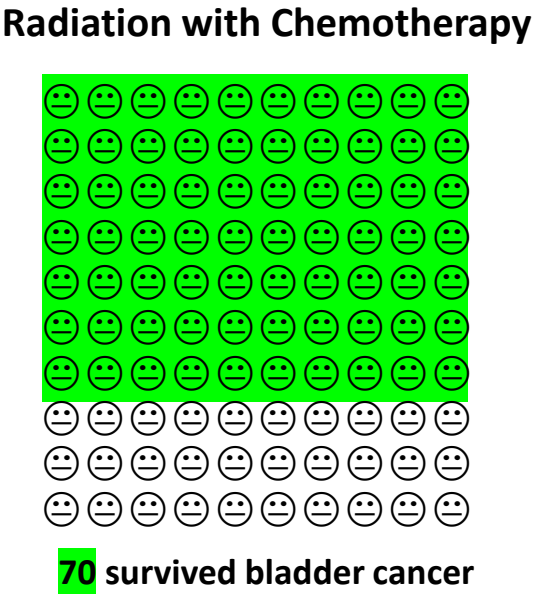
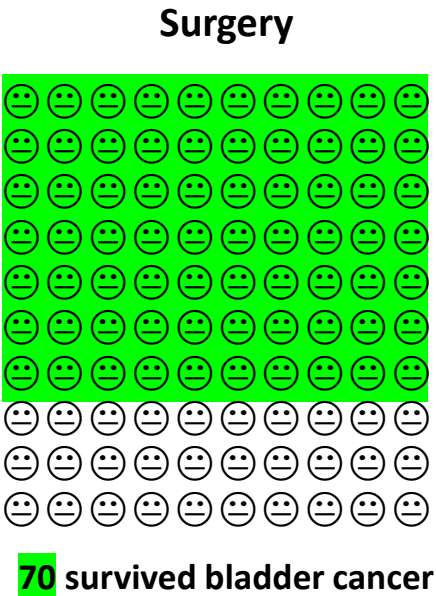
Each face (😊) stands for one person. The shaded areas (🟡) show the average number of people affected based on current research. ***Note: these treatments have never been compared to each other, results may vary based on individual factors. Results listed are a summary of many studies.**

There is no way of knowing if you will experience these benefits or side effects, however, unique factors about you and your cancer (see pages 18 and 19) may help your doctor predict your risk.

Benefits: Patients who benefit from the treatment are in green (out of 100).

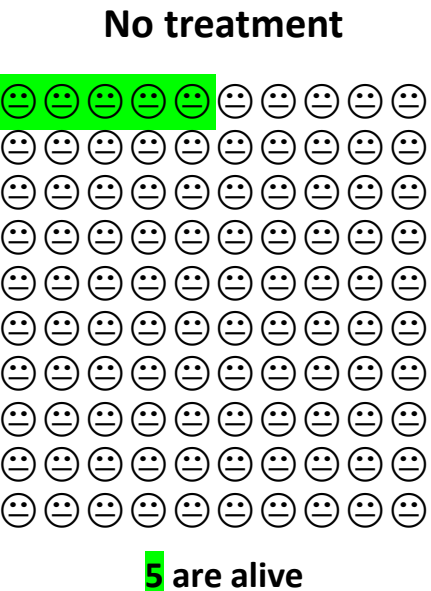
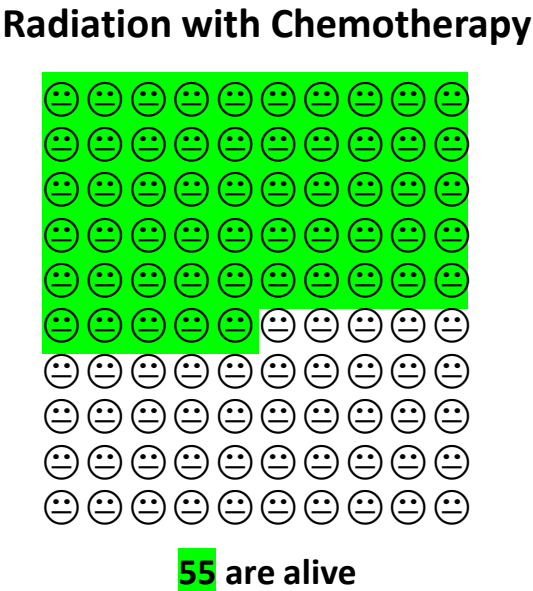
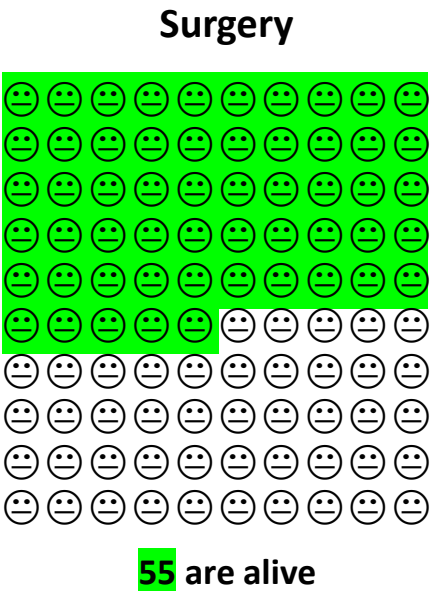
Benefit – being alive from cancer in 5 years

The chance of not dying due to muscle-invasive bladder cancer is:¹⁻⁸



Benefit – being alive in 5 years

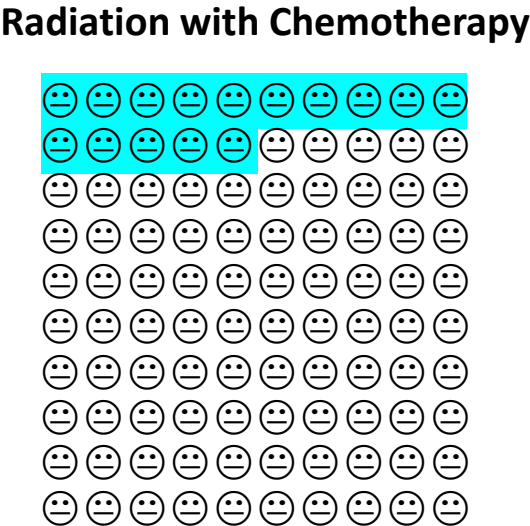
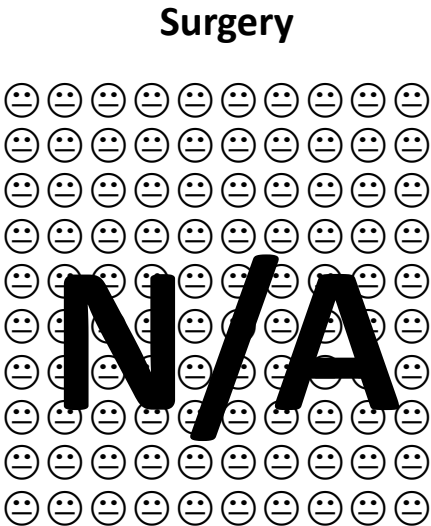
The chance of not dying due to any cause, for example heart attack, car accident, or muscle-invasive bladder cancer is:¹⁻⁸



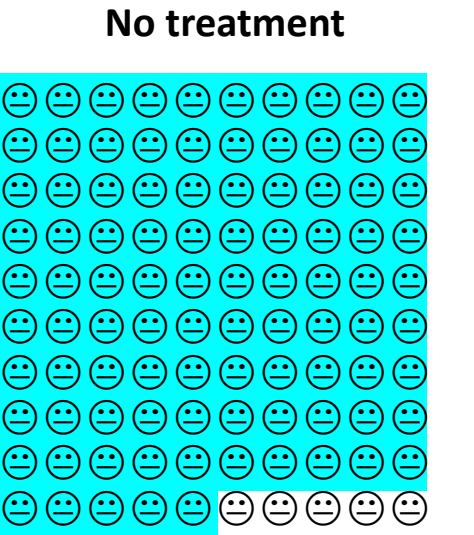
Risks: Cancer coming back in bladder requiring bladder removal are in blue (out of 100).

Risk – Needing surgery to remove bladder within 5 years

After treatment, the risk of the cancer coming back in the bladder that requires bladder removal because the cancer is not cured is:^{2,4-5,7,9,11}



15 have bladder removed



95 have cancer continue to grow

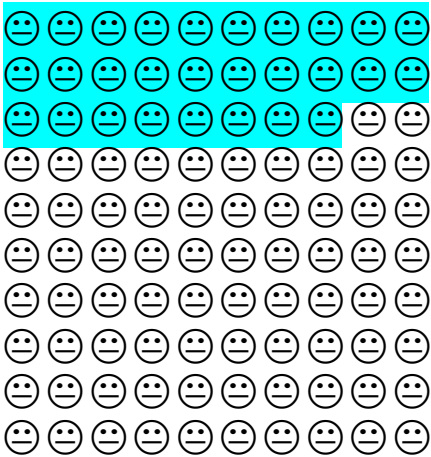
NOTE: If bladder removal is required after radiation, either due to side effects or untreated cancer, the surgery will have a higher risk of complications than reported in this decision aid due to scarring caused by radiation. Also, a neobladder urinary diversion is not usually possible after radiation.

Risks: Patients with side effects from the chosen treatment are in blue (out of 100).

Risk – Major short-term complications from treatment

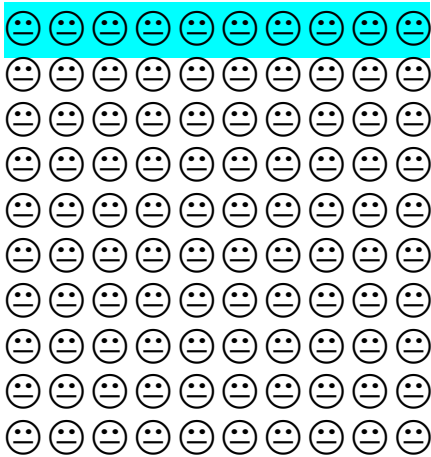
The risk of major complications with each treatment within 90 days is:^{2-3,9,12-13}

Surgery



28 have a major short-term complication

Radiation with Chemotherapy



10 have a major short-term complication

No treatment

Patients who have ‘no treatment’ usually experience worsening symptoms from their cancer (see page 8). There is no available data for risk of major short-term complications from no treatment.

A **major complication** after surgery requires monitoring, hospitalization or intensive care.

For example: severe infection, wound healing issues, and heart attacks.

*Clavien-Dindo grades III-IV

A **major complication** during or after radiation results in severe change in urination such as increased frequency, urgency, leakage, and bleeding, or severe change in bowel habits leading to diarrhea and bleeding. These could require surgery or other procedures to fix.

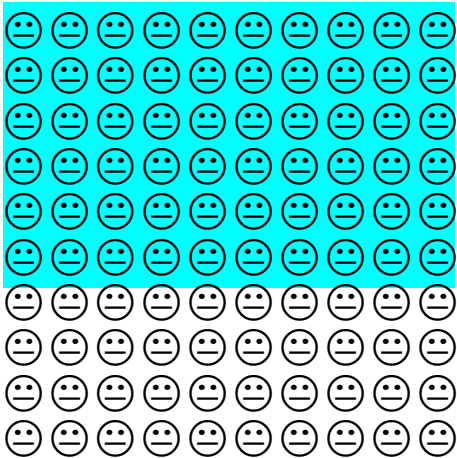
*RTOG grades 3-4

Risks: Patients with side effects from the chosen treatment are in blue (out of 100).

Risk – Minor complication

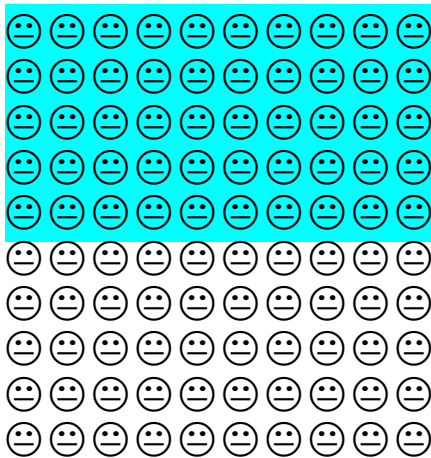
The risk of minor complications with each treatment is:²-3,5,9,13-14

Surgery



60 have a minor complication

Radiation with Chemotherapy



50 have a minor complication

No treatment

Patients who have ‘no treatment’ usually experience worsening symptoms from their cancer (see page 8). There is no available data for risk of minor complications from no treatment.

A minor complication after surgery requires a longer stay in hospital or medication. For example: urinary or surgical site infection, blood clots, and difficulty having a bowel movement.

*Clavien-Dindo grades I-II

A minor complication during or after radiation includes increase in frequency and urgency of urination, and diarrhea with stomach cramping.

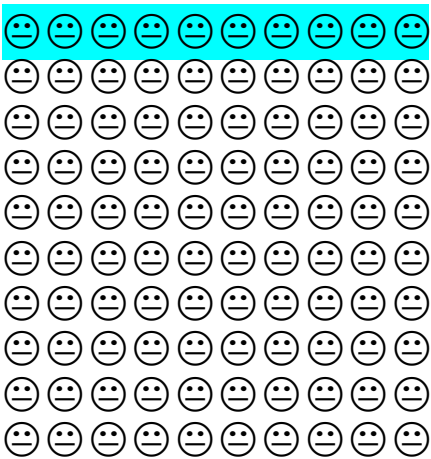
*RTOG grades 1-2

Risks: Patients with side effects from the chosen treatment are in blue (out of 100).

Risk – Major long-term complications:

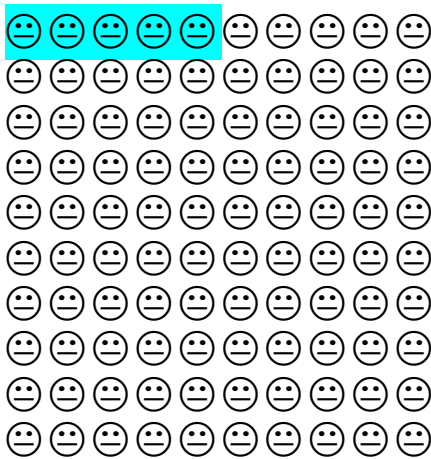
The risk of major long-term complications from treatment with each treatment is:^{3,5,15}

Surgery



10 have a long-term complication

Radiation with Chemotherapy



5 have a long-term complication

No treatment

Patients who have ‘no treatment’ usually experience worsening symptoms from their cancer (see page 8). There is no available data for risk of major long-term complications from no treatment.

A major **long-term complication** after surgery may require another surgery. Examples are hernia, narrowing of the ureter (tube connecting between kidney and bladder), kidney stones, and kidney disease.

*Clavien-Dindo grades III-IV

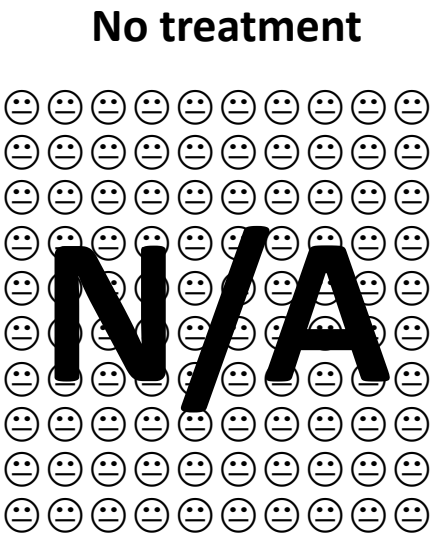
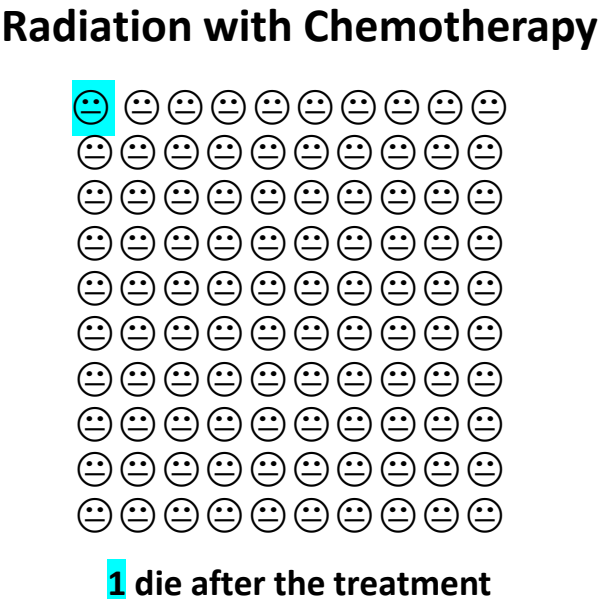
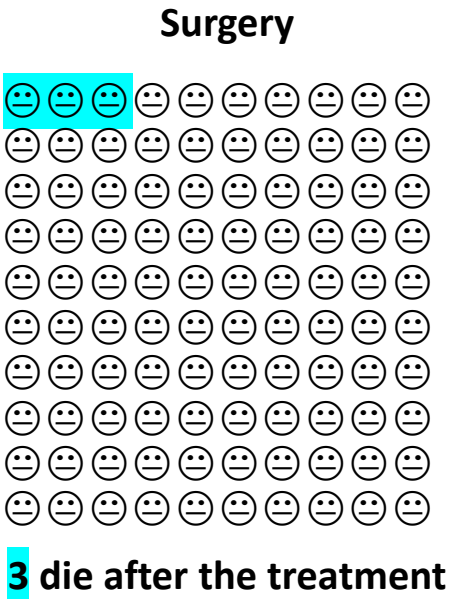
A major **long-term complication** after radiation may require surgery. For example, severe and frequent urination, bleeding, and leakage of urine, or diarrhea and poor control of bowel movements. A very rare risk is a second cancer caused by the radiation.

*RTOG grades 3-4

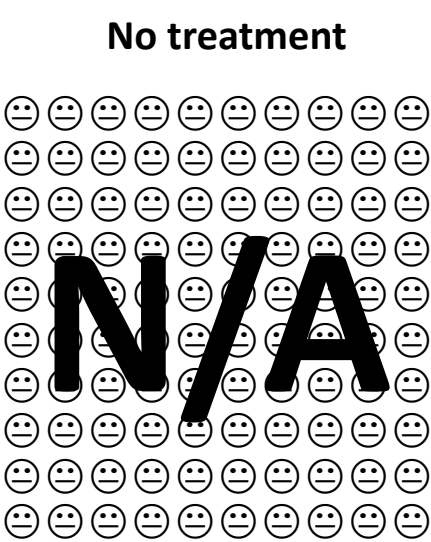
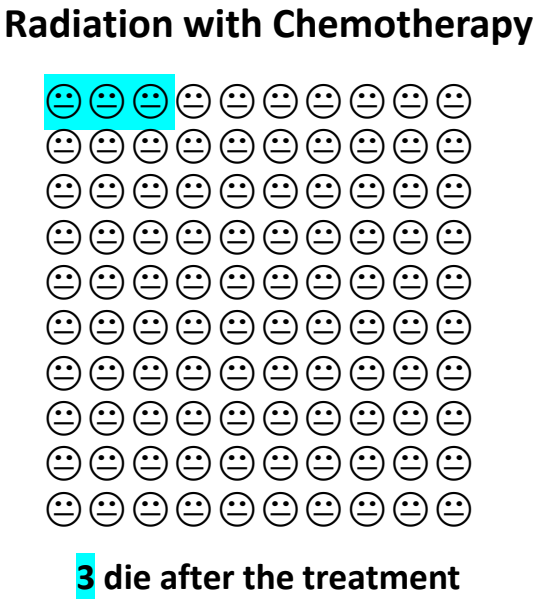
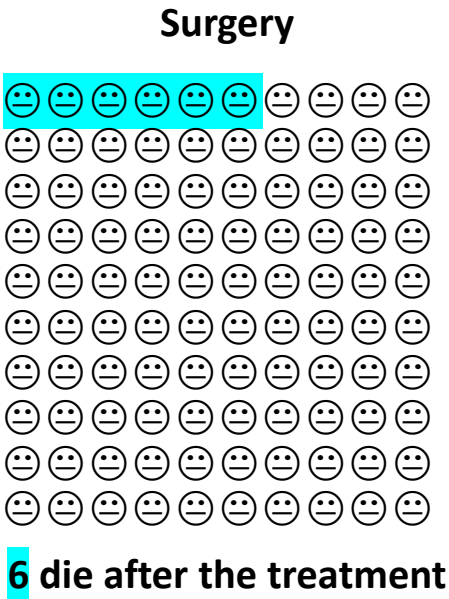
Risks: Patients with side effects from the chosen treatment are in blue (out of 100).

Risk – Dying

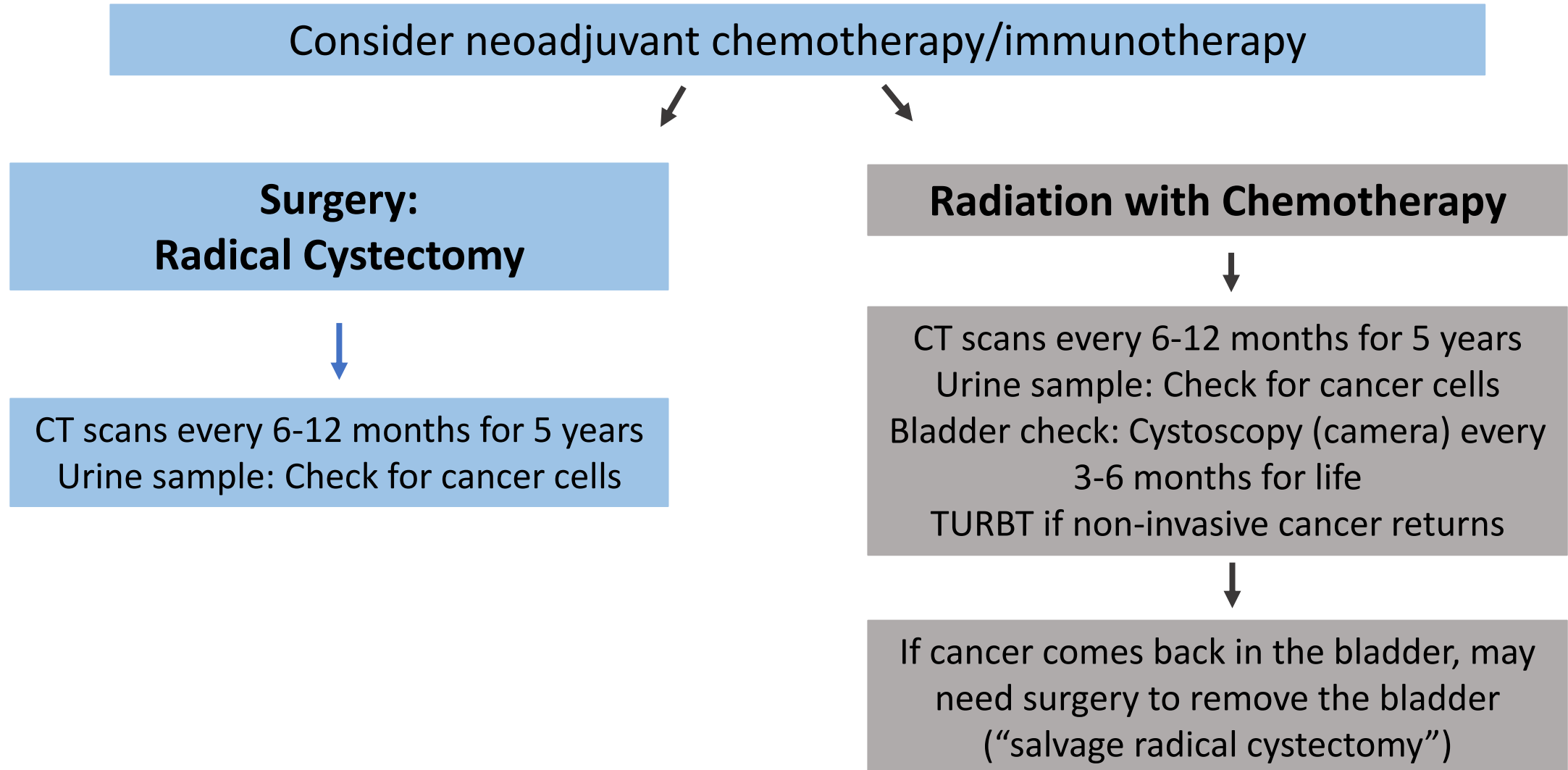
The risk of dying within 3 months for patients under 80 years of age due to the treatment or from muscle-invasive bladder cancer is:^{6,10,13,16-17}



The risk of dying within 3 months for patients 80 years of age or older due to the treatment or from muscle-invasive bladder cancer is:^{6,10,13,14-15}



WHAT IS THE EXPERIENCE FOR PATIENTS AFTER SURGERY OR RADIATION?



WHAT FACTORS ABOUT MY CANCER MAY INFLUENCE MY TREATMENT CHOICE AND MY DOCTORS RECOMMENDATIONS?

Surgery may be a better choice if you have:

- A larger bladder cancer
- Cancer that has grown into the tissues outside the bladder
- More than 1 cancer growth in your bladder
- Kidneys blocked by the cancer
- Pre-cancerous areas (carcinoma in situ) in your bladder
- You want more detailed information about your cancer to guide further treatment

Radiation with Chemotherapy may be a good choice if you have:

- No sign of cancer in your bladder after TURBT
- A cancer in the bladder that is small
- A single cancer growth in your bladder
- Kidneys that are not blocked by the cancer

WHAT FACTORS ABOUT MY HEALTH MAY INFLUENCE MY TREATMENT CHOICE AND YOUR DOCTORS RECOMMENDATIONS?

Surgery may be a better choice for you if:

- Your bladder function is poor (urinate very often, no control of urination).
- You are young, because you may be more likely to develop long term risks of radiation such as tissue scarring, organ damage, blood in the urine, a second cancer caused by radiation.
- You want a neobladder urine diversion.

Radiation with Chemotherapy may be a better choice for you if:

- You are older or frail, because the risk of major complications is higher after surgery and recovery may be more difficult.
- You have major medical issues such as heart, kidney, or liver disease.

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: Surgery	Not Important			Very Important		
How important is it to you to remove all the cancer including the bladder?	①	②	③	④	⑤	
How important is it to you to avoid daily trips to the hospital for 4-6 weeks?	①	②	③	④	⑤	
How important is it to you to avoid cystoscopy/surgeries in your bladder for life?	①	②	③	④	⑤	

Reasons to choose: Radiation with chemotherapy	Not Important			Very Important		
How important is it to you to avoid major surgery?	①	②	③	④	⑤	
How important is it to you to keep your bladder in your body?	①	②	③	④	⑤	

Now think about what option has the reasons that are most important to you...

Which option do you prefer?

Check ☒ one.

☐ Surgery

☐ Radiation with Chemotherapy

☐ No treatment

☐ I have not decided yet

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

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.

	Surgery	Radiation with Chemotherapy	No treatment	Not sure
1. Which option requires you to stay overnight in hospital for 5-10 days?	☐	☐	☐	☐
2. Which option has the lowest chance of you being alive in 5 years?	☐	☐	☐	☐
3. Which option can result in you having increased problems urinating during and after treatment?	☐	☐	☐	☐
4. Which option requires lifelong bladder monitoring with camera in the bladder (cystoscopy) to see if cancer comes back?	☐	☐	☐	☐

Step 4: What are the next steps?

Check ☒ what you prefer.

- ☐ I prefer to receive surgery.
- ☐ I prefer to receive radiation with chemotherapy.
- ☐ I prefer to receive no treatment.
- ☐ I need to discuss the options with my doctor and family.
- ☐ I need to read more about my options.
- ☐ Other, please specify: _____

Find out how comfortable you feel about deciding



Do you know the benefits and risks of each option?

Yes

☐

No

☐

Are you clear about which benefits and risks matter most to you?

☐☐

Do you have enough support and advice to make a choice?

☐☐

Do you feel sure about the best choice for you?

☐☐

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. surgery, 2. no treatment, 3. radiation with chemotherapy, 4. surgery

This information is not intended to replace the advice of a health care provider.

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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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SMOG readability rating: 8th grade

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