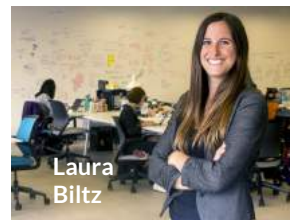
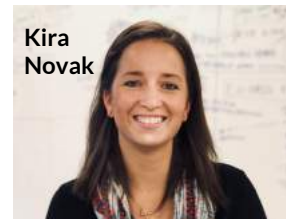

Communicating the External Beam Radiation Experience

meet the team



project brief

We want to decrease the overall level of anxiety patients may have *before, during, and after* radiation treatment through an improved explanation of the process.

The original timeline



Research

What can we know?

Plan
Literature review
Audit
Primary research
Analysis

Synthesis

What does this mean?

Integrate our findings
Insights
Principles
Interpretation

Prototype

What can it be?

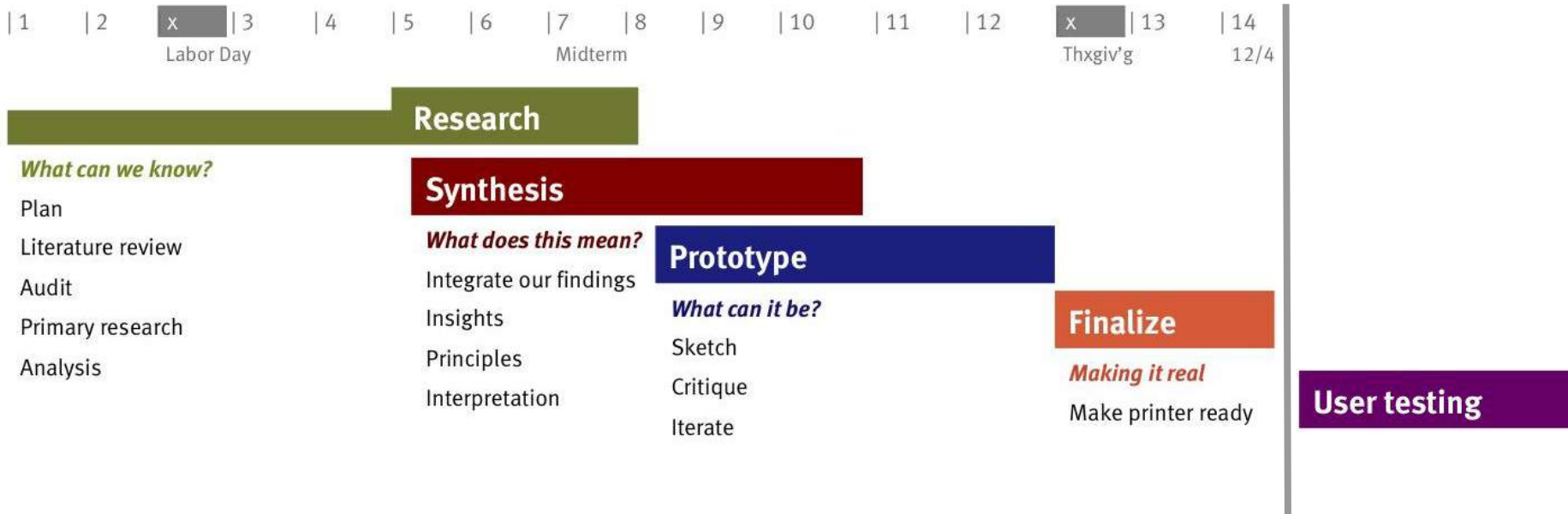
Sketch
Critique
Iterate

Finalize

Making it real

Make printer ready

Adjusting for IRB approval



agenda

current state

external beam radiation treatment (EBRT) experience

discussion guide

next steps

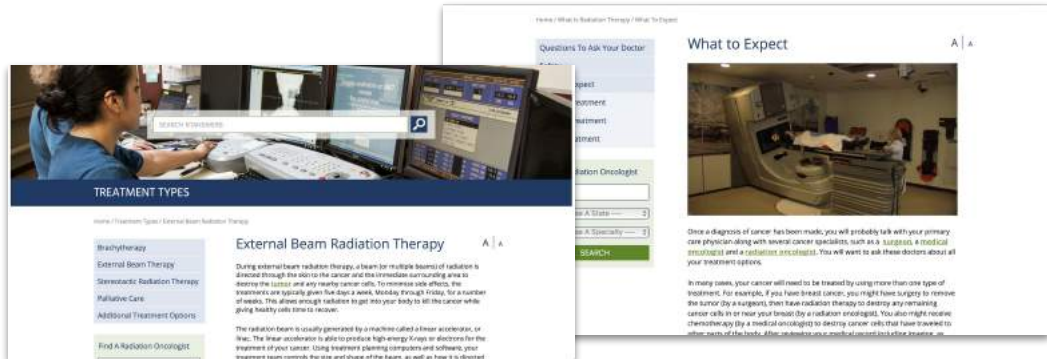
current state

how it's done today

Patients are given resources at initial consultation and/or can look online.
Resource materials are:

- Mostly text
- 11th-12th grade reading level

Physician and nurse supplement resources with verbal review of treatment strategy.



RTanswers.org



Radiation Therapy and You, National Cancer Institute

Tomoko Ichikawa | Faculty Research | Fall 2017

visual narrative

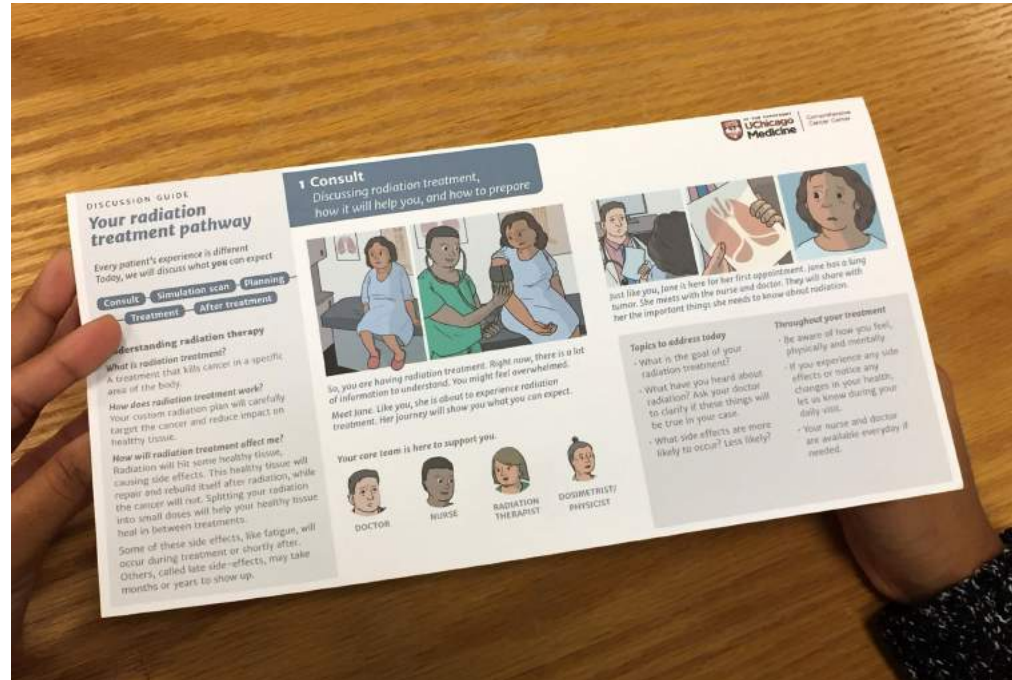
Fast changing medium, tackling very serious topics:

- Abortion
- Mental health
- Death
- Cancer survivorship
- Urban planning education



<https://thenib.com/your-work-is-killing-you?t=default>

A new discussion guide



Intro

- Consult
- Simulation Scan
- Planning
- Treatment
- Post-Treatment


2 Simulation scan

Determining the best position for your treatment


After today, the next step will be your CT scan for treatment simulation. During this visit, your care team will take steps to make sure the radiation hits the cancer and avoids your healthy tissue.


Things your care team may do to make sure the radiation is going to the right place:


- Create a face mask or body mold to keep you still.
- Give you oral contrast dye.
- Place a urinary or rectal catheter.
- Limit food beforehand.
- Place skin markings on your skin for alignment.




BODY MOLD POSITION










RADIATION THERAPIST




You'll get great X's for these scans to plan your treatment.

3 Planning

Creating your custom radiation plan

Your custom plan includes a specific arrangement of radiation beams. These target the cancer while limiting the effect on the healthy tissue. In order to create this plan, your doctor will typically take about 5 treatments.



It's time to discuss your treatment plan with your doctor to prepare her custom radiation plan.

4 Treatment

Visiting your clinic for radiation

You will likely receive radiation every weekday. You will meet with your nurse and doctor once a week. Even though you will not see them every day, your doctor is in close communication with your radiation therapists and reviews any x-rays or CT scans obtained during your treatment.

During treatment, you may be asked to:

- Stop or start medications.
- Drink water or eat food before visits.
- Stop or start chemotherapy with radiation, with your doctor's permission.

The radiation therapists position you based on her CT scan/diagram. She may take an x-ray or CT scan on each visit to make sure a correct position.

During treatment, your therapist keeps the treatment room. From the control room, they can see and hear your side and listen.

5 What you can do while you wait

What will you get for the clinic? Will anyone need to come with you?




If you will need to stay, will anyone you need to help?

Organize

If you have questions about insurance or billing?

Ask support

Will you go to for emotional support?

www.rpa-uk.co.uk - uk - uk - uk - uk - uk - uk

just don't feel the radiation while it is happening, given it is safe to be around anyone as soon as she finishes each treatment. She's not radioactive.

There aren't any other different types of radiation therapy. The pain can subside but the effects on the surrounding tissues, like the intestines, would. She can't be around her family or friends.

After treatment goes on, most girls start to feel the radiation but they're more tired. The ones to listen to her body and stop her from doing anything she could do at the beginning.

[illegible][illegible]

DISCUSSION GUIDE

Your radiation treatment

Every patient's experience is different. So we will discuss what you can expect.

General • Simulation exam • Planning • Treatment • After treatment

3. Consult

Discussing radiation treatment, how it will help you, and how to prepare



What is radiation treatment?

A treatment that kills cancer in a specific area of the body.


How does radiation treatment work?

Your custom radiation plan will carefully target the cancer and spare as much of your normal tissue as possible.


How will you be treated and what?

Radiation will be your healthy tissue, and you will be treated with a linear accelerator and external beam radiation. You will be treated with a linear accelerator into small beams that help your healthy tissue heal in between treatments.

Some of these effects include, but are not limited to, hair loss, fatigue, and skin changes or sore throat or difficulty eating. Others, called side effects, may take months or years to show up.



University of Michigan
Cancer Medicine



What is radiation treatment?

Radiation is a form of cancer treatment. It uses high-energy rays to kill cancer cells. It is used to treat many types of cancer. It can be used to shrink tumors, to kill cancer cells, or to relieve symptoms. It can be used to treat the whole body or a specific part of the body. It can be used to treat the cancer or to prevent it from coming back. It can be used to treat the cancer or to prevent it from coming back. It can be used to treat the cancer or to prevent it from coming back.

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Intro

- Consult
- Simulation Scan
- Planning
- Treatment
- Post-Treatment

My Information

Intro

- Consult
- Simulation Scan
- Planning
- Treatment
- Post-Treatment

Tomoko Ichikawa | Faculty Research | Fall 2017

Intro

Journey

- Consult
- Simulation Scan
- Planning
- Treatment
- Post-Treatment

My Information


2 Simulation scan

Determining the best position for your treatment


After taking the time to discuss the best CT scan for treatment simulation, during which your team will take steps to make sure the radiation hits the cancer and spares your healthy tissue.

Things your team may do to make sure the radiation is going to the right place:


- Create a mask so you'll need to keep you still.
- Give IV or oral contrast dye.
- Place a urinary or rectal catheter.
- Use food beforehand.
- Place skin markers or tattoos for alignment.




TREATMENT ROOM




Some things you may do to make sure the radiation is going to the right place: We'll give you a mask so you'll need to keep you still.




We'll give you a mask so you'll need to keep you still.



RADIATION THERAPY



We'll give you a mask so you'll need to keep you still.



We'll give you a mask so you'll need to keep you still.

[illegible]

coordinate your schedule.

she is aligned correctly.

press - click - click - click - click - click - click - click

you don't feel that radiation while it is happening, you're safe so the original concern is not one we have to address. She is not radioactive.

the first treatment is usually the longest. You're good!

Jane doesn't feel any different now she did before treatment. The way she walks her hips are the normally would. She has been around friends and family daily.

As treatment goes on, some pain is normal but it's not meant to be there all the time. Your body will adjust and you may not be able to do everything the usual day at the beginning.

driving principles

content

- Patient-centered
- Help anticipate possible needs to reduce surprises
- Visualize what's coming next in journey to help decrease anxiety
- Empower patient to be an active participant in conversation
- Allow patients to reference information throughout their journey
- Promote positive relationship between physician and patient to improve care delivery
- Relatable across multiple organizations and geographies (for use outside of U of C)

driving principles

form

- Printing and assembly requires standard equipment and minimal time
- Illustrations are relatable to patients
- Text at a fifth grade reading level

EBRT experience

secondary research

Principles of healthcare communication

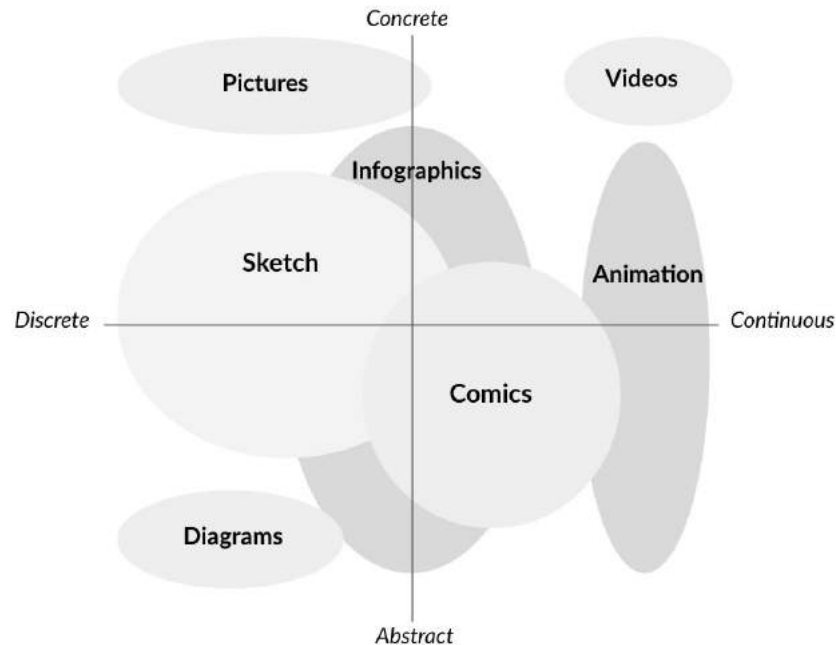
Comics 101

principles of healthcare communication

- Reduce noise
- Describe what *should be done*, not what should be avoided
- Tell stories to engage audiences
- Use visuals and texts to support each other
- Choose the right abstraction level
- Consider who may also access and use the tool
- Take into account where it will be used

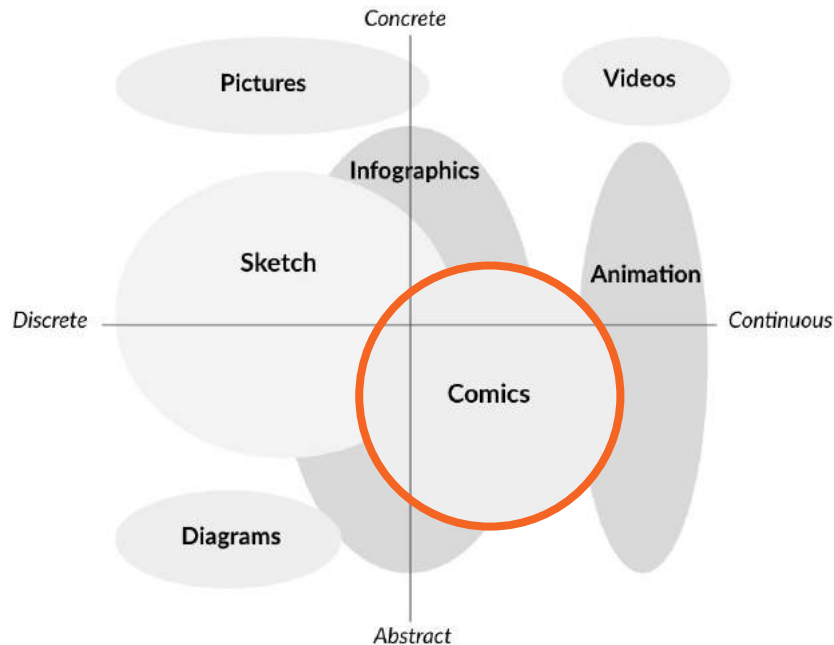
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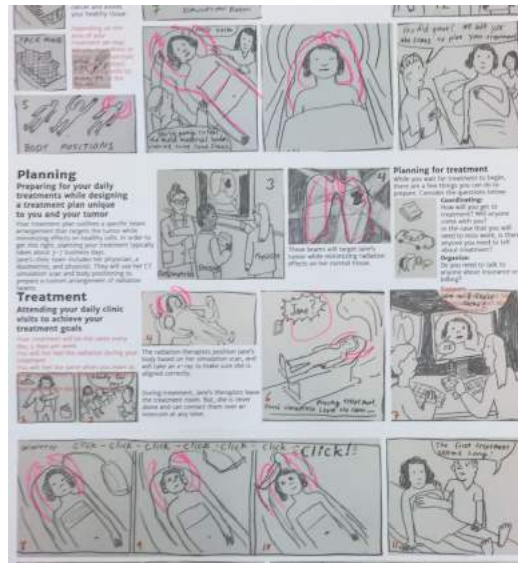


Comics are different

Attributes of comic narratives:

- Clarity
- Intensity





primary research

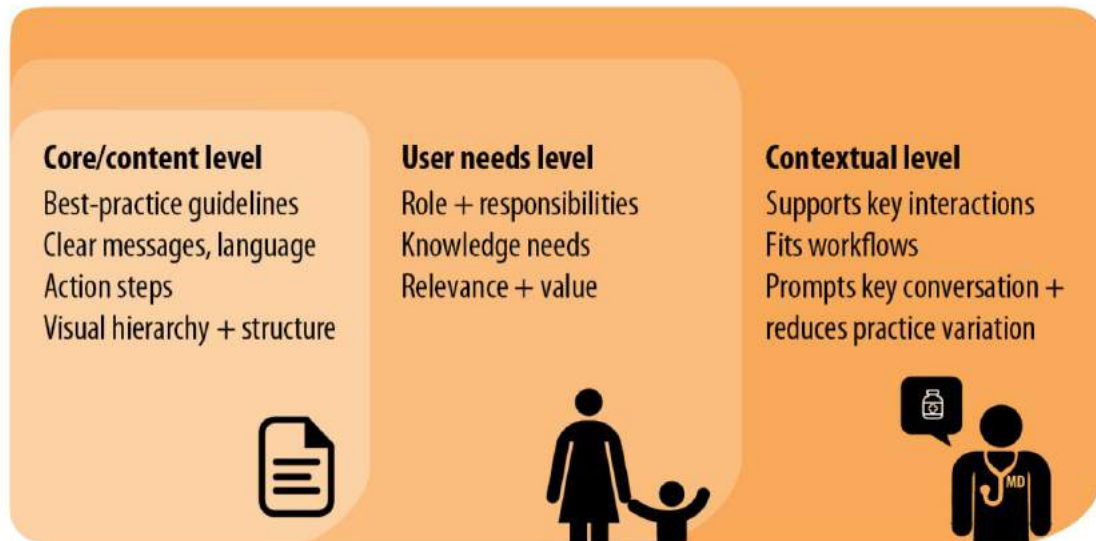
multi-level requirements framework

clinic visit

interviews

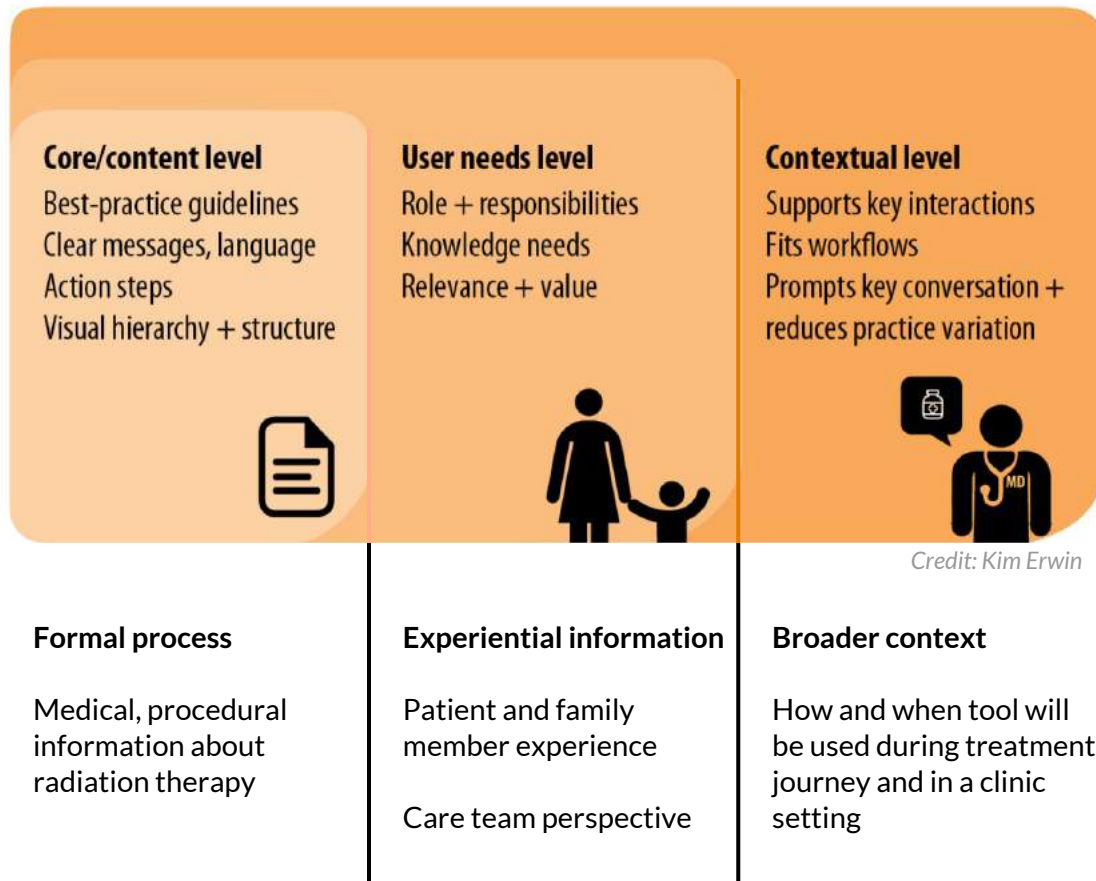
insight structuring

— multi-level requirements framework

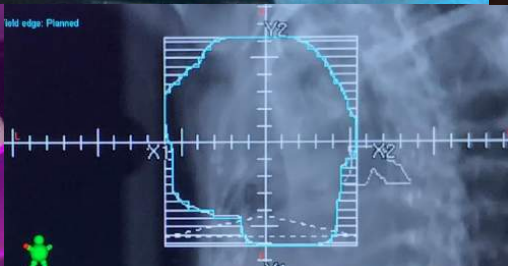
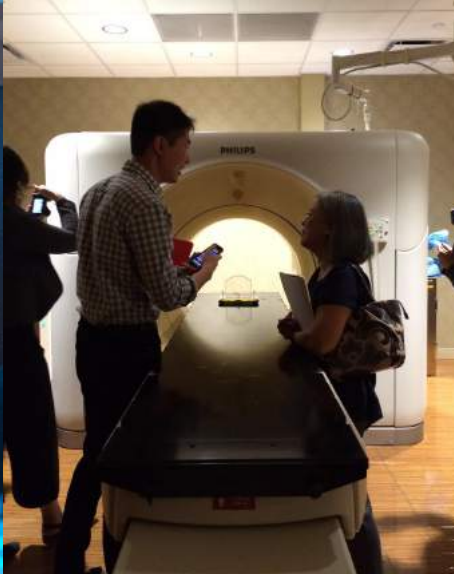
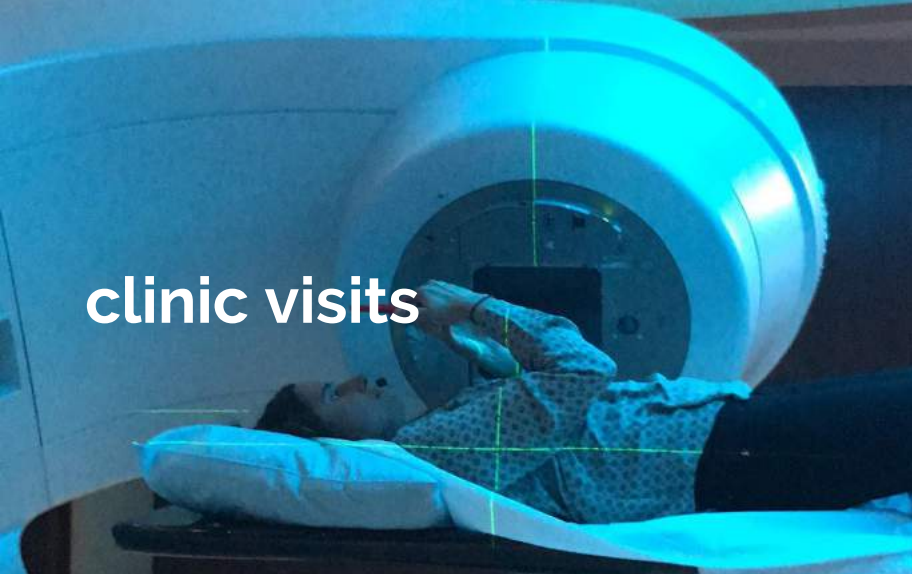


Credit: Kim Erwin

— multi-level requirements framework



Credit: Kim Erwin



—

who we talked to

8

patients

currently undergoing
radiation treatment

4

family members

supporting a patient

10

medical staff
patient facing

radiation oncologists,
radiation therapists,
nurses

2

medical staff
non-patient facing

physicists, dosimetrists

3

non-medical staff
patient support

social workers,
patient service reps,
practice admins

—

protocols

—

protocols

patients

family members

- Patient journey from diagnosis to treatment
- Communication and support
- Needs

medical staff *patient facing*

- Perspective on patient journey
- Resources and information
- Clinic context

medical staff *non-patient facing*

- Perspective on patient journey
- Clinic context, contribution to journey

non-medical staff *patient support*

- Perspective on patient journey
- Resources and information
- Clinic context

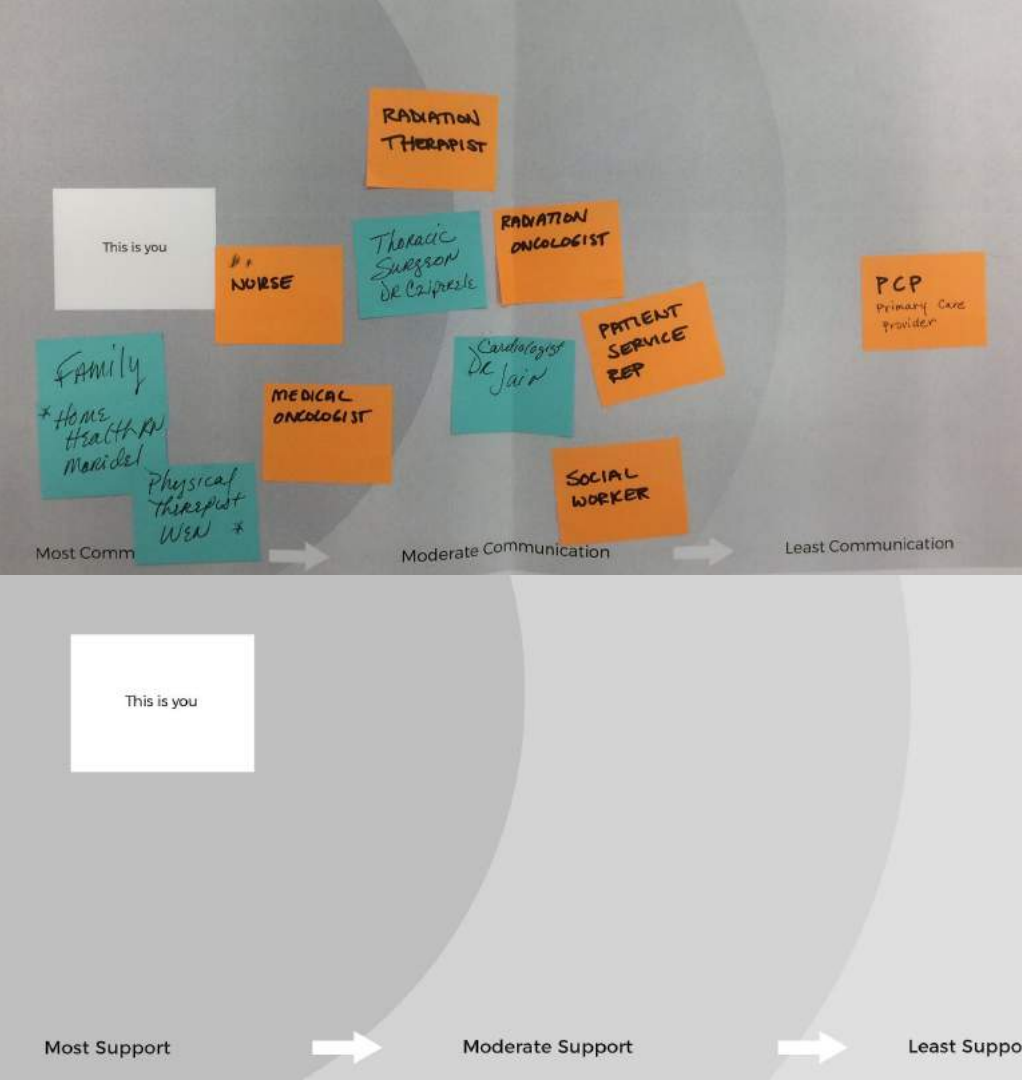
protocols

Understanding patient journey and resources along the way

point to one choice from each scale

negative	☹️	😞	😐	😊	😄	positive
calm	🧘	🧘	🧘	🧘	🧘	excited
controlled by something else	👤	👤	👤	👤	👤	in control

Event, stage, or timeframe	Event, stage, or timeframe	Event, stage, or timeframe	Event, stage, or timeframe
What I was	What I was	What I was doing	
How I was	How I was	How I was feeling	
What others were doing	What others were doing	What others were doing	



protocols

Early tests for visual style



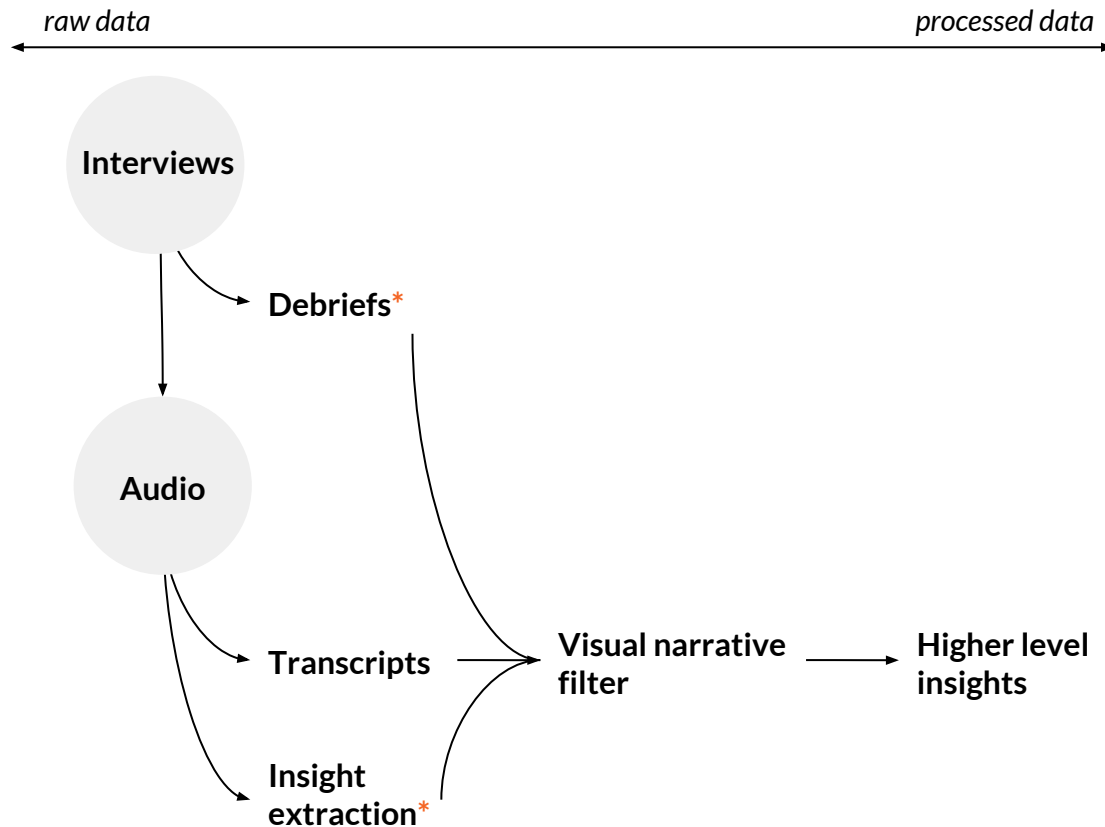
— distilling data to make it useful

Interviews are open ended for wider contextual understanding; need to distill what we heard to meet our design objectives

Challenges:

Compressed timeframe

Need for outcome specific approach and methods



* Methods from design research practice

Insights that inform content

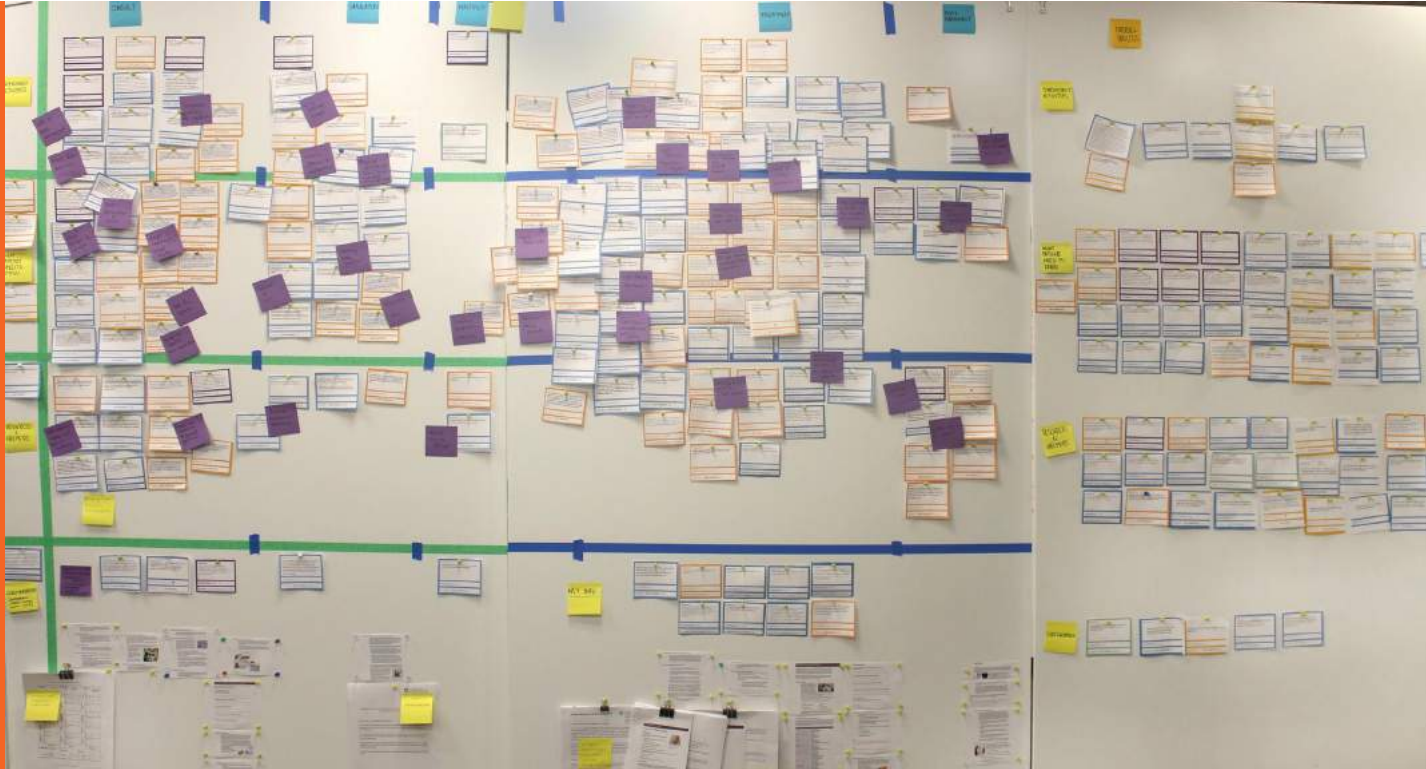
Interview content includes much more than we need.

How to distill into meaningful categories?

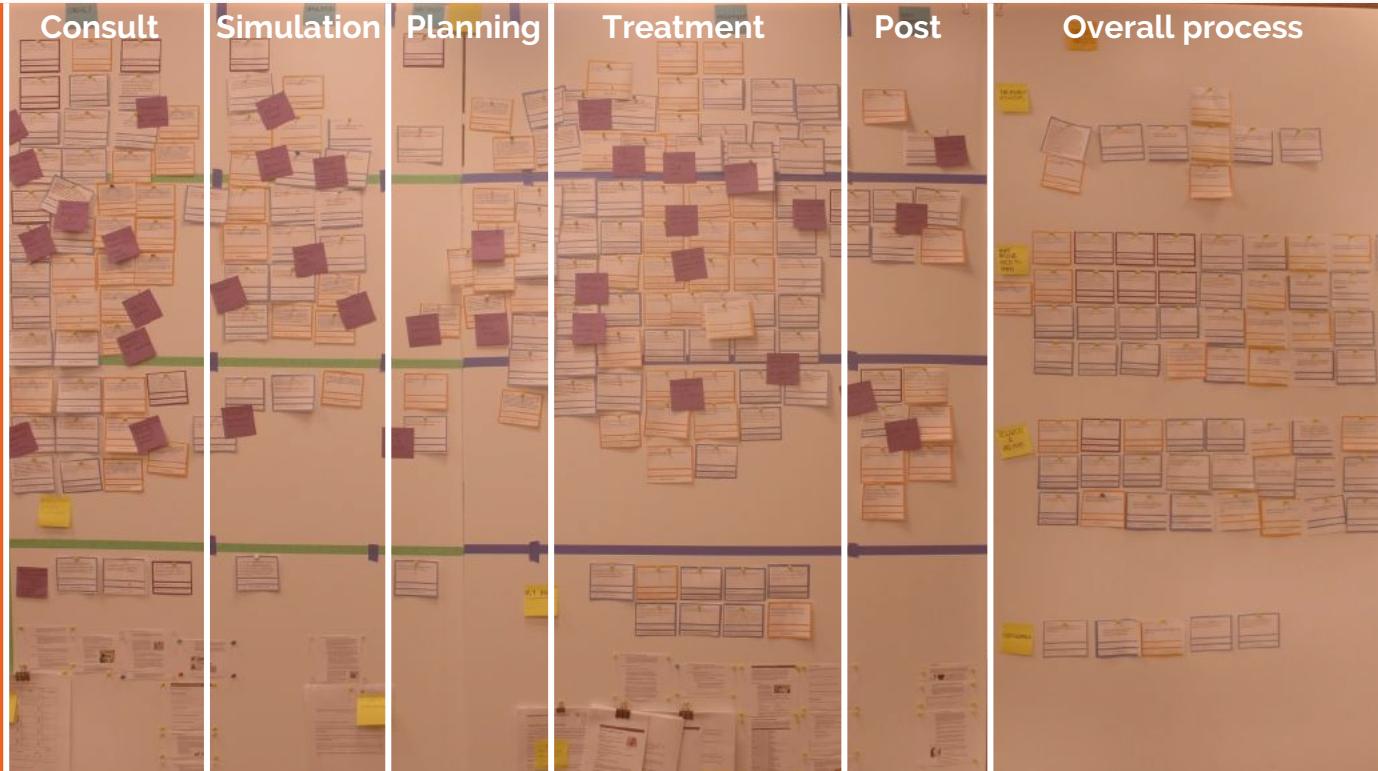
	Group	#	Insight	Quote	Engagement Code	Group	#	Insight	Quote
O	Group 3	1	Every new patient at the clinic completes a "distress thermometer" worksheet that is shared with the social worker. Patients might not be expecting their radiation therapy clinic to be interested or asking these types of questions. Note: Would be interesting to find out if other clinics use a similar tool.	When the patients are new, they have a packet of papers they need to fill out. One of them is called the Distress Thermometer, and it's 0-10 and you can write whatever it is...it's checkboxes actually. Financial, insurance, they have basically one column of psychosocial, like emotional, spiritual, psychosocial. And then the other column is purely physical.	09251702MSPKM	Group 2a	2	overall nurse role throughout treatment (high level)	doing a little bit of education in that initial time with them, that first 30-40 minutes golden comes in, then following up with any processing or ordering before we start radiation, and then once they're on radiation, symptom management with Dr. golden for followup, ordering imaging, again symptom management
O	Group 3	2	There are multiple barriers that make it hard for the social worker to connect with patients: time (patients already spend a lot of time at the clinic), stigma (some patients aren't open to getting help from a social worker), and maybe lack of knowledge (not clear what a social worker can do for them). The visual narrative could introduce a social worker and provide some examples for things they can do to support a patient.	If it's 4 or above, I try to make an appointment with the patient. And when I try to make the appointment with the patient, I try to connect it to either a radiation appointment or chemo appointment or something like that. I've been a social worker a long time and there is a stigma, going to a social worker. Just as there is a counselor or a therapist. So I try to make it as easy as I can for the patients so they don't have to make a special trip.	09251702MSPKM	Group 2a	3	Every patient's treatment is different, so we can't represent all of what will happen to them in a narrative but we can say that nurse is main point of contact for questions around those differences	I like to tell patients that I keep the puzzle pieces together. So I gather them up by history, putting together a story line, and then as we're going through we're continuing to that story. So making sure there is coordination, that if they have questions a lot of times there's a lot of specialists involved, I'm always in the loop in terms of other physicians are ordering in combination with what we do. And then trying to make that it's all in line.
O	Group 3	3	Meetings with the social worker can be very quick informal check-ins.	Sometimes it'll be as informal as going into the dressing room when they're dressed and waiting for the, just to kind of meet them where they're at. They don't have to go into an office or that type of thing.	09251702MSPKM	Group 2a	4	Nurse and doctor see patient weekly throughout treatment.	When going through treatment we see them once a week or as needed. We see them one month after treatment is done, and besides that it depends how often (post-treatment)
O	Group 3	4	A third party's perspective on the role of nurses compared to doctors in radiation therapy. How can the tool support both of them, and communicate their roles to the patient?	The nurses ask all the more clarifying questions during their assessment. The doctors have a more global view of things. And the nurses get into the more nitty gritty.	09251702MSPKM	Group 2a	5	All patients have followup one month after treatment ends, then it varies what post treatment is like	We see all of our patients after they're done with treatment one month after then it then it depends on you know we are going to see them in three months, six months
O	Group 3	5	"On treatment visits" - that's when the patient will typically meet with the doctor during the course of their treatment, one day per week.	Typically, they see a nurse once a week. There's a thing called an "on treatment visit." Dr. Golden has them on Thursdays and Dr. McCall has them on Mondays. And so before the doctor goes into see the patient on treatment, the nurse will go in.	09251702MSPKM	Group 2a	6	Besides weekly OTVs, patients can see doctors or nurses as needed throughout treatment. This "as needed" could be for symptom management, confusion with meds, etc.	head and neck patients have difficulty swallowing so they'll be going through treatment have seen them on a Thursday how's your swallow it's fine, no problems at the weekend all of a sudden there are issues so they'll stop at the nurses station to see Kathleen about having some additional pain
O	Group 3	6	The idea that it's more than just "treatment" - it's a process and a journey for patients. The radiation therapy isn't the only thing going on in their lives, it can impact everything in their life, and it might be taking place after other intense treatments and tough decisions.	I like to call it a journey. I ask "how is your journey going" and "what is the hardest thing for you, what is the easiest, what is your support system like?" I don't use those clinical terms like "support system." I'll say "well, who helps you?" That type of thing. Just to try to gauge of where they are at emotionally.	09251702MSPKM	Group 2a	8	You can always speak up to the nurse or doctor, even if you're not sure if they're the right person to talk to	In the exam rooms we have a sign that says speak up and it is a way for patients if they see anything...we always say have a question about the care you're getting them - the best way that I can help them is if they feel comfortable, come to me for any questions or concerns
					09251702MSPKM	Group 2a	9	Patients should feel comforted by the fact that they'll be in the clinic	n/a

10041722MSPNF	Group 2a	8	to keep the appointment on time, everything is briefly introduced to patients	unclear can be helpful
10041722MSPNF	Group 2a	9	nurses usually can cover everything they need to cover	
10041722MSPNF	Group 2a	10	side effects may be introduced when they encounter them	
10041722MSPNF	Group 2a	11	patients usually get used to cancer treatment when they come to radiation therapy	
Engagement Code	Group	#	Insight	Quote
09261704PFCWS	Group 1	14	Patients can feel guilty for not reading the information.	But there could be a little more context in that information packet because when I let like I could have filled up a whole, or to be honest, a small version of an Encyclopedia Britannica. And I'm telling my wife, "hey did they say something about radiation and there was?" "I don't know." "I don't know if you need to bring your whole family with you know what the answer is. I don't do what you ladies do, but I can only tell you how I that's on me because I didn't read the information, but you can bet that I did after I felt well, hey, dummy.
09261704PFCWS	Group 1	15	Life has an expiration date when one has cancer.	[What he remembered from consult] how many radiation treatments I was going to have, actually, but then, you know, a few days go by and you're still in a fog. Someone says you've got cancer and God forbid they tell you you've got a life expectancy. Or to extend your life five years. No matter how you slice it they still put an expiration date on it.
09261704PFCWS	Group 1	16	Casual conversations between patients in changing room can impact how the patient perceives the situation.	A conversation has to happen about mental health, you know what I mean? Because dark place to be. Maybe they'd be looking me up in a rubber room if I was having this conversation with a psychiatrist. I don't know, but I'm just telling you where I'm coming and people I've talked to in the changing room, which might sound bizarre. You know your day going? I thought I felt bad when I got here. A guy told me, I don't know how want to be intrusive. Said, "Ah, almost a month I've been doing this crap." Said, "I know you feel." He says, "I don't know how much longer I can take this." I'm like, "You can long as you keep putting one foot in front of the other." It's hard to come here.
09261704PFCWS	Group 1	17	guilt, guilt, guilt	And then I think about man, am I entitled to feel this way because look at the little kid thought about those little kids at St. Jude, you know. I'm like, I'm 56 years old, I've got problems. These kids are two years old, for Christ's sake, they got more losses in an than than a plumber's job.
09261704PFCWS	Group 1	18	Emotional support from staff he's in contact at the clinic, not from family.	[Care circle people who helps with emotional stress] Dr. Golden and his staff. Dr. Go. Kathleen, the girl in the radiology that give you your schedule or updated schedule.
09261704PFCWS	Group 1	19	Believes that mental mindset affects physical outcome.	The bottom line on that is you can do all the radiation but if your mind isn't in the right you're not going to have a good outcome. It isn't going to happen. Then if you're in the you're thinking well, what am I doing this for because I'm still in this mindset halfway my treatment.
09261704PFCWS	Group 1	20	Would appreciate having psychiatrist to help in the clinic, everyone's feeling down about their situation. Having a credible, authoritative professional would help.	And then I'm like, well, it's not on them to say hmmm, B... told young ladies he psychiatrist so better get one. It's up to me to say something. It really is. But if they're hey, if you're having any problems with depression and anxiety, somebody to talk to. Personally, I don't want to go to the Cancer Center in Mokena and talk to somebody or respectfully, 30 years old. Sit there and nod your head.












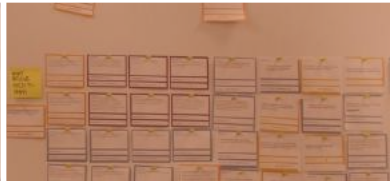
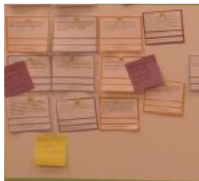






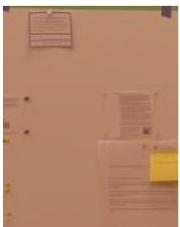


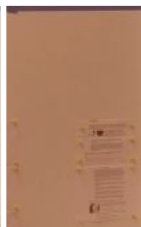
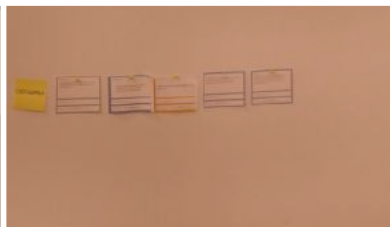
Insights that inform content



Insights that inform content



Insights that inform content

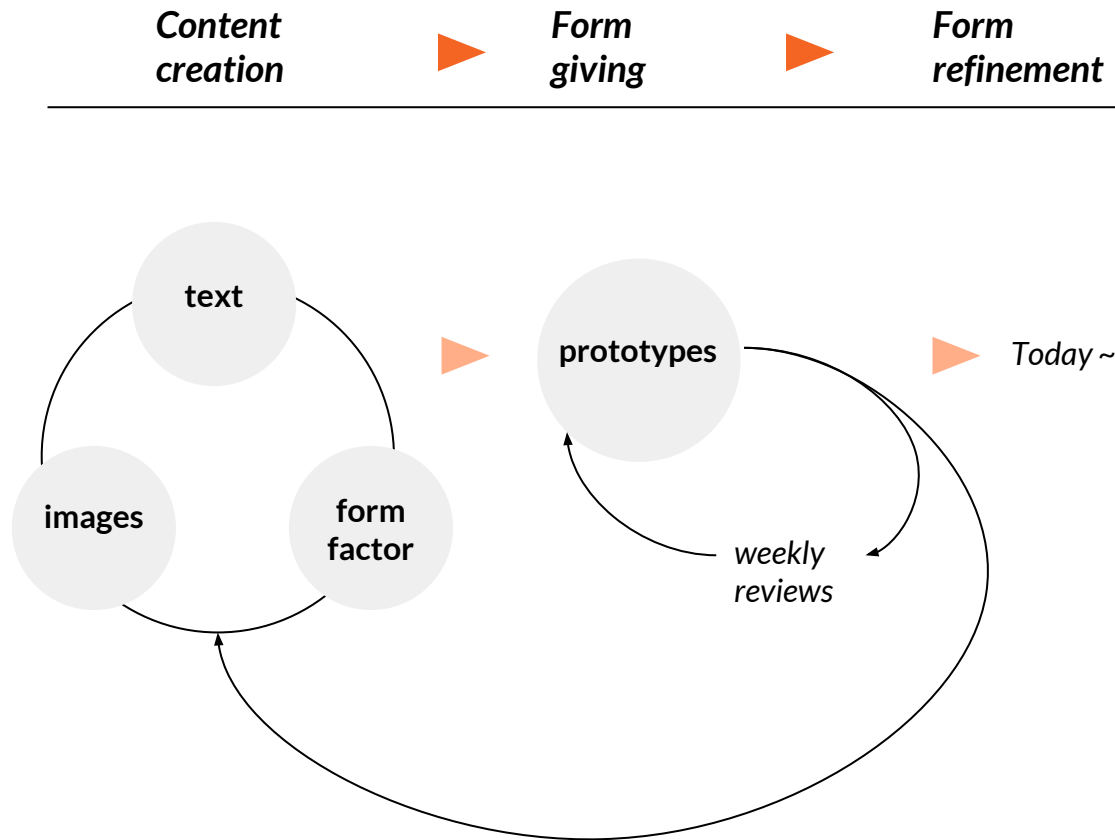
	Consult	Simulation	Planning	Treatment	Post	Overall process
Treatment activities <i>What can we show visually?</i>						
What patients need to know <i>What information needs to accompany visuals?</i>						
Resources <i>What suggestions and tools can we offer to patients?</i>						
Customization <i>What clinic and physician differences do we need to consider?</i>						

discussion guide

from insights to real

Simultaneous exploration in

- **Text:** language simplicity
- **Images:** level of abstraction, style
- **Form factors:** easy to use and produce



prototyping

form

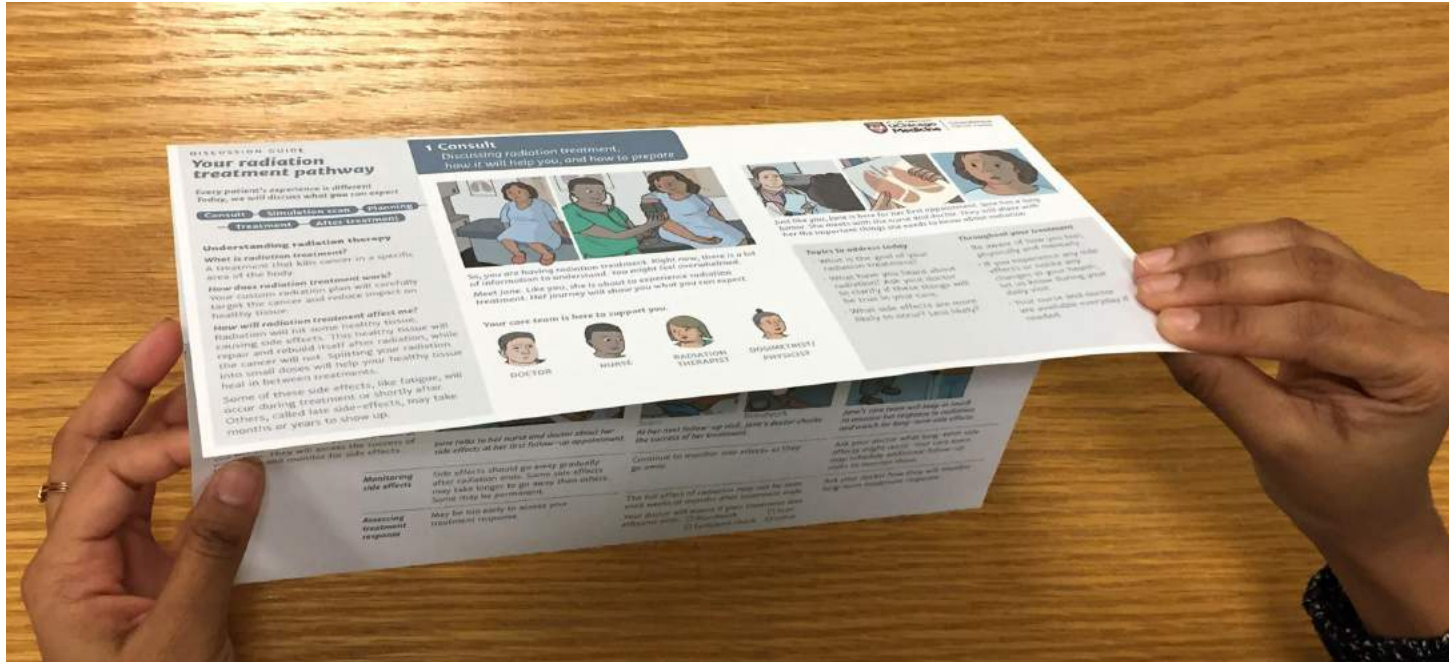
content

Patient education materials get stacked and 'never looked at again'

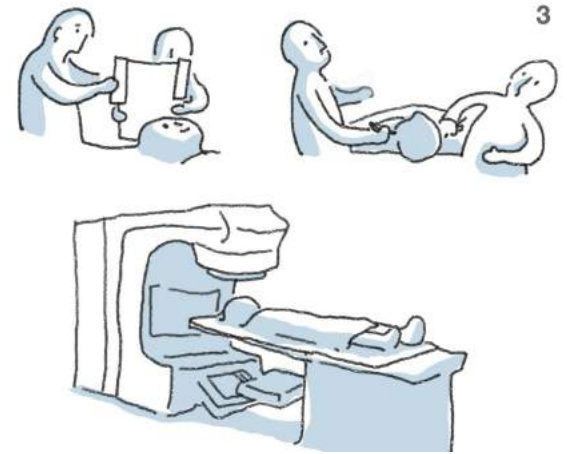
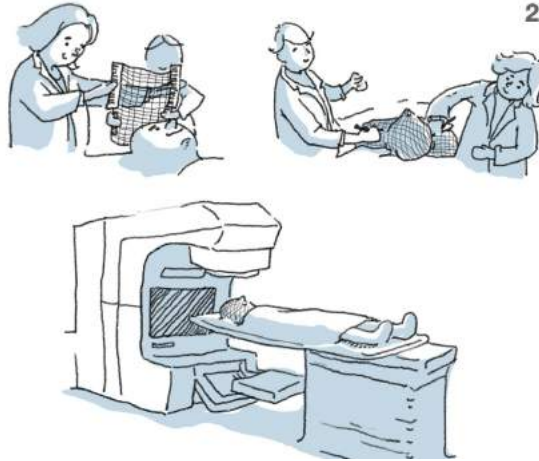
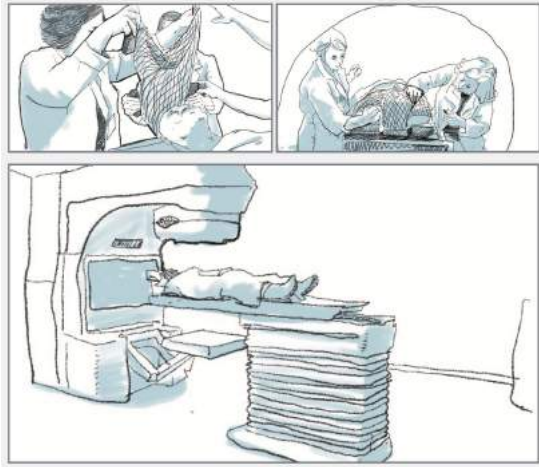


Education materials get stacked and 'never looked at again'

Guide needs to look and feel unique



***Detailed images are hard to relate to,
while abstract images seem childish and unrefined***

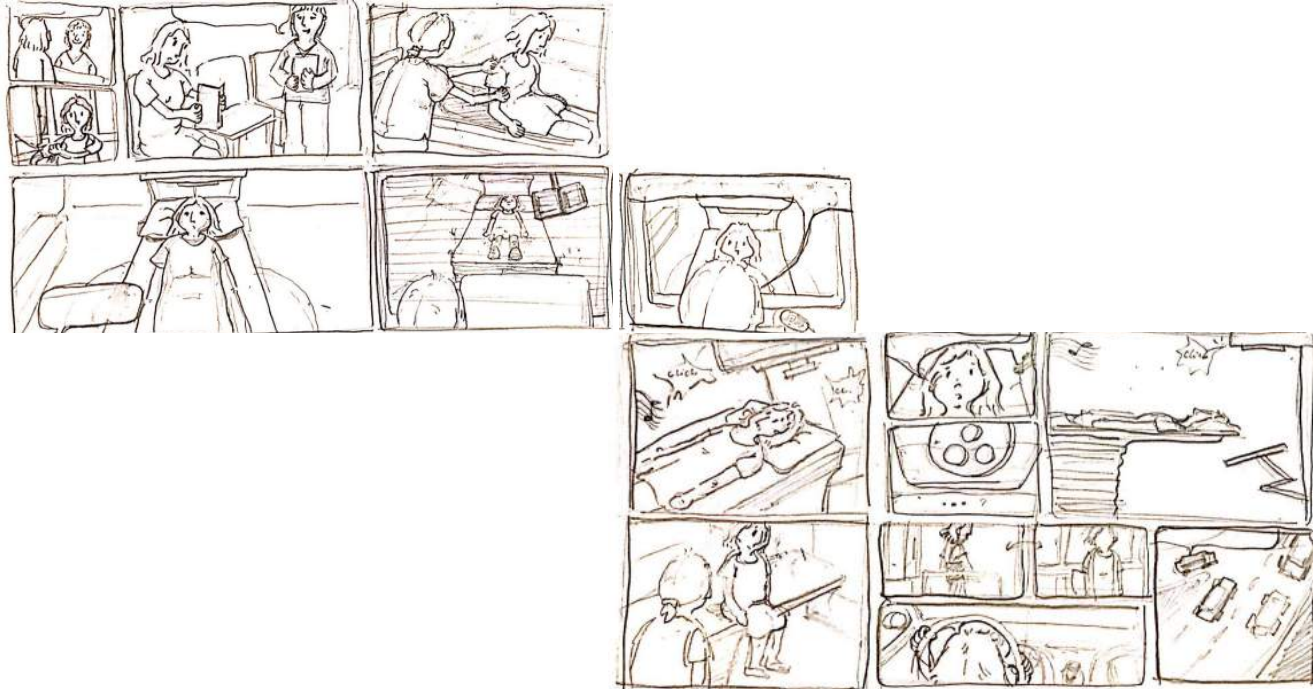


Detailed images are hard to relate to, while abstract images seem childish and unrefined

Images must meet the 'Goldilocks principle'



Visual narratives have their own pacing and language, making them a strong medium for helping patients envision what's to come



Visual narratives have their own pacing and language

Reduce surprises by providing substantial visual narrative



Jane does not feel the radiation while it is happening. Jane is safe to be around anyone as soon as she finishes each treatment. She is not radioactive.

Current material is written at a 12th grade reading level

What are my treatment options?

- [Treatment options overview](#)
- Is radiation therapy necessary if the margins of the removed tissue are clear?
- How can I make a decision between mastectomy and breast conservation therapy?
- What are the cosmetic results of breast conservation therapy?
- What is the prognosis after recurrence?

Treatment options overview

Treatment options include mastectomy or breast conservation therapy (BCT). Mastectomy is an operation to remove the entire breast, and usually the entire nipple. Often an axillary sampling is also done which removes the glands under the arm called axillary nodes. The surgeon may evaluate just one or two nodes (sentinel node/s) or may perform a more extensive axillary dissection to check for disease spread. Mastectomy sometimes requires a hospital stay. A drainage tube is sometimes temporarily left in the surgical cavity after a mastectomy to help prevent fluid accumulation. Women who undergo a mastectomy have the option of breast reconstruction.

Breast conservation surgery removes the breast tumor and a margin of surrounding normal tissues. It is also known by other names: [lumpectomy](#), partial mastectomy, segmental mastectomy or quadrantectomy. [Radiation therapy](#) usually follows lumpectomy to eliminate any microscopic cancer cells in the remaining breast tissue. The purpose of breast conservation therapy is to give women the same cure rate they would have if they were treated with a mastectomy but to leave the breast intact, with an appearance and texture as close as possible to what they had before treatment. The surgeon may remove some lymph nodes by performing a sentinel lymph node procedure or axillary dissection at the same time as the lumpectomy procedure or later. It is estimated that 75 percent to 80 percent of patients can be treated with breast conservation therapy rather than mastectomy with excellent results. Years of clinical study have proven that breast conservation therapy offers the same cure rate as mastectomy.

Your radiation therapy procedure might include:

- **External Beam Therapy** - see the [External Beam Therapy page](#)
- **Intensity-Modulated Radiation Therapy** - see the [Intensity-Modulated Radiation Therapy page](#)
- **Brachytherapy** (interstitial, single catheter or balloon-based) - the temporary placement of radioactive materials within the breast to treat partial breast only or employed to give an extra dose of radiation to the area of the excision site (called a "boost") - see the [Brachytherapy page](#).

Patients may also have [chemotherapy](#) or hormonal therapy if there is a risk that the cancer may have spread outside of the breast to other body organs.

Do you have a personal story about radiology?



Related Articles and Media

- [External Beam Therapy \(EBT\)](#)
- [Mammography](#)
- [X-ray \(Radiography\) - Chest](#)
- [General Ultrasound](#)
- [Computed Tomography \(CT\) - Chest](#)
- [Intensity-Modulated Radiation Therapy \(IMRT\)](#)
- [Brachytherapy](#)
- [Introduction to Cancer Therapy \(Radiation Oncology\)](#)
- [Breast Cancer Screening](#)
- [Breast Cancer](#)
- [Skeletal Scintigraphy \(Bone Scan\)](#)
- [Clinical Trials and Screening: What You Need to Know](#)
- [Images related to Breast Cancer Treatment](#)

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Current material is written at a 12th grade reading level

Text should score near fifth grade reading comprehension

Averages

Sentences per Paragraph	1.5
Words per Sentence	9.1
Characters per Word	4.6

Readability

Flesch Reading Ease	72.1
Flesch-Kincaid Grade Level	5.4
Passive Sentences	0%

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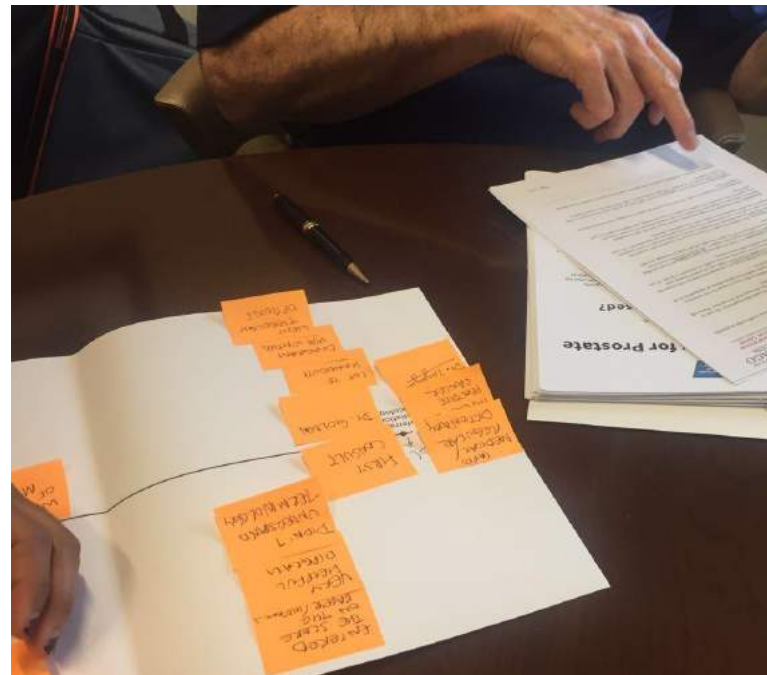
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Everyone's cancer journey is different

Event stage, or timeframe	Event stage, or timeframe	Event stage, or timeframe	Event stage, or timeframe
REFERRAL TO NEWLANDS	CONSULT	SIMULATION	EXAM ROOM
What I was doing SURGERY	What I was doing	What I was doing Middle	What I was doing VISIT W/ NURSE - SIBERT VISIT W/ DR. DAN ABC QUESTIONS
How I was feeling (circle one choice from each scale)	How I was feeling (circle one choice from each scale)	How I was feeling (circle one choice from each scale)	How I was feeling (circle one choice from each scale)
negative (sad face) neutral (neutral face) positive (happy face)	negative (sad face) neutral (neutral face) positive (happy face)	negative (sad face) neutral (neutral face) positive (happy face)	negative (sad face) neutral (neutral face) positive (happy face)
controlled by symptoms (sad face) controlled by anxiety (neutral face) controlled by other (happy face)	controlled by symptoms (sad face) controlled by anxiety (neutral face) controlled by other (happy face)	controlled by symptoms (sad face) controlled by anxiety (neutral face) controlled by other (happy face)	controlled by symptoms (sad face) controlled by anxiety (neutral face) controlled by other (happy face)
What others were doing DR. LIA IN PORTAL THEN REFERRED TO GOLDEN	What others were doing Dr. Golden	What others were doing Explaining all the diff. positions, looking at power they were good at it.	What others were doing
Event stage, or timeframe Postoperative Treatment (1st)	Event stage, or timeframe SUBSEQUENT TREATMENTS		
What I was doing Lay down, adjust position Wait for CT scan, 30 min Met Eric	What I was doing Wait 20 min		
How I was feeling (circle one choice from each scale)	How I was feeling (circle one choice from each scale)		
negative (sad face) neutral (neutral face) positive (happy face)	negative (sad face) neutral (neutral face) positive (happy face)		
controlled by symptoms (sad face) controlled by anxiety (neutral face) controlled by other (happy face)	controlled by symptoms (sad face) controlled by anxiety (neutral face) controlled by other (happy face)		
What others were doing Adjust position + relax CT scan wait for doctor to check positioning Nurses	What others were doing Eric looking in room - controls positioning machine Nurses there to write position instructions		



Everyone's cancer journey is different

Provide areas to customize patient information, textually and graphically

Doctor's sketchpad

My Information

Your treatment is unique. Record important information and progress here.

Preparing for your simulation scan

My simulation scan 12/12 at 3:00 pm

The time between my CT simulation scan and the start of radiation will be about 3-4 days/weeks

Before my CT simulation scan, I will need...

☒ bloodwork ☐ urine test
☒ to cut my hair ☐ to stop eating at _____ am/pm
☐ to drink _____ of water
☐ to stop these medications: _____

During the CT scan, I will need...

☐ a catheter ☒ to get an IV

Anything else I need to do/know? _____

My treatment information

Throughout treatment, I will see my doctor every M T W Th F

I need to...

☐ drink water
☐ limit food and water for _____ hrs
☐ start these medications: _____
☐ Other _____

My after treatment information

My first follow-up appointment _____ at _____

Missing appointments

Sticking to your treatment is important. If you miss an appointment, contact your doctor. Each missed day will affect the end of your treatment. Long breaks between treatments could make your treatment less effective.

Numbers to call

For medical questions and concerns
(999) 999-9999 DAYTIME
(999) 999-9999 NIGHTS/WEEEKENDS

For billing and insurance questions
(999) 999-9999

For scheduling questions or missed appointments
(999) 999-9999

Treatment tracker

My treatment will be 35 visits.

1	2	3	4	5	6	7	8	9
26	27	28	29	30	31	32	33	34

This work was supported in part by the University of Chicago Bucklebaum Institute for Clinical Excellence. For more information: Dr. Dan Golden golden@radonc.uchicago.edu
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There are differences across RT clinics



There are differences across RT clinics

Guide should accommodate differences in environment and care team

Your care team is here to support you.



DOCTOR



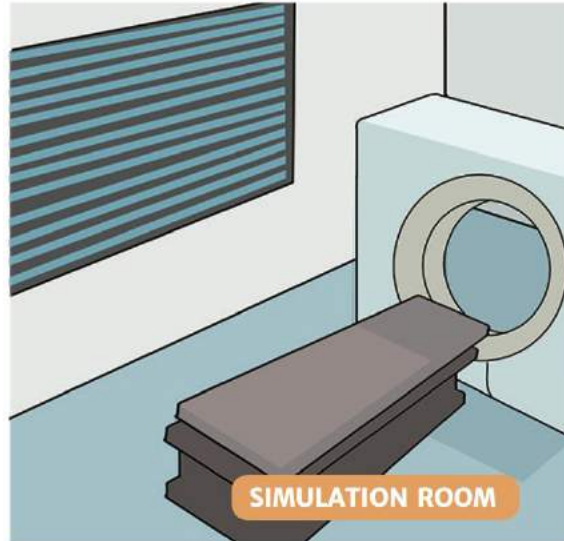
NURSE



RADIATION
THERAPIST



DOSIMETRIST/
PHYSICIST

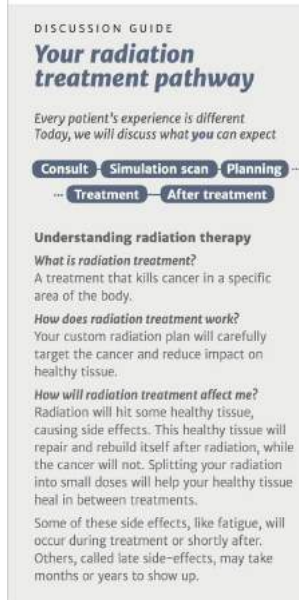


Jane arrives at the clinic, checks in, and changes into a gown. Her team of radiation therapists call her into the room for her CT scan.

[illegible]

Patients do not retain information given during consult

Divide experience and information into phases for timely references



1. Consult

Discussing radiation treatment

2. Simulation Scan

Determining the best position

3. Planning

Creating your custom plan

4. Treatment

Visiting your clinic for radiation

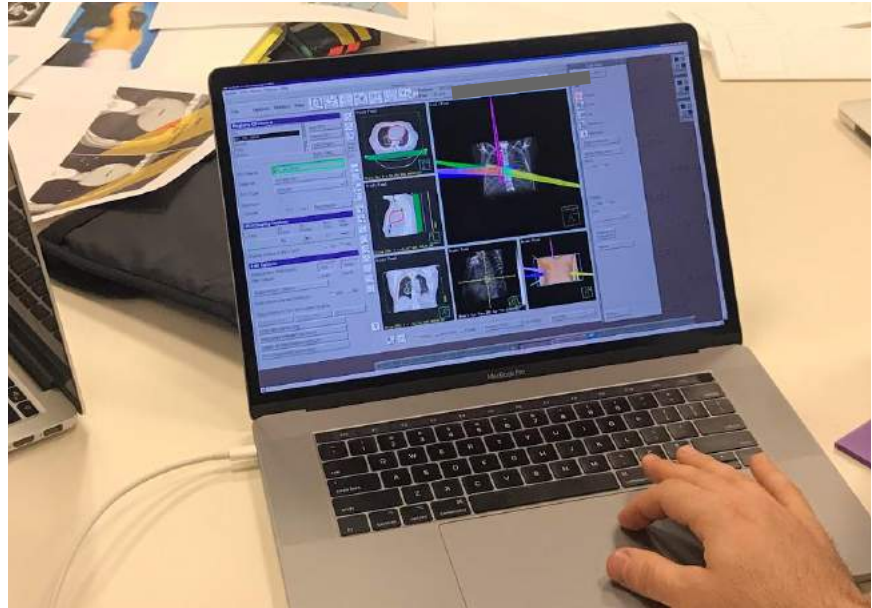
5. After Treatment

Assessing the effects of treatment

Patients want to start treatment immediately, and do not understand why they have to wait

Do you talk to the patients about the physicists and their role?

“ I don't. Um, sometimes, if they're in the room, then I introduce them and let them know why they're there. Sometimes when we're talking about the treatment plan I say “there's a whole team working on your plan”. But I generally don't talk about them... maybe I should. ”



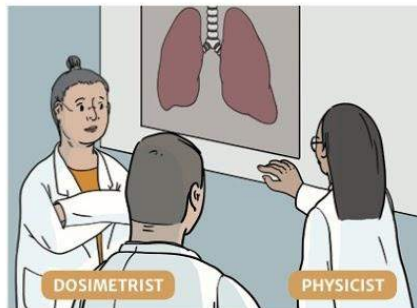
Patients want to start treatment immediately, and do not understand why they have to wait

Be transparent regarding treatment planning

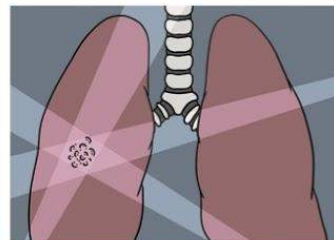
3 Planning

Creating your custom radiation plan

Your custom plan includes a specific arrangement of radiation beams. These target the cancer while limiting the effect on healthy tissue. In order to get this right, planning your treatment typically takes about 3-7 weekdays.



Jane's care team will use your CT simulation scan to prepare her custom radiation plan.



These radiation beams will target Jane's tumor while limiting effects on her normal tissue.

What you can do while you wait

Coordinate

How will you get to the clinic? Will anyone need to come with you?

If you will need to miss work, is there anyone you need to tell?

Organize

Do you have questions about insurance or billing?

Seek support

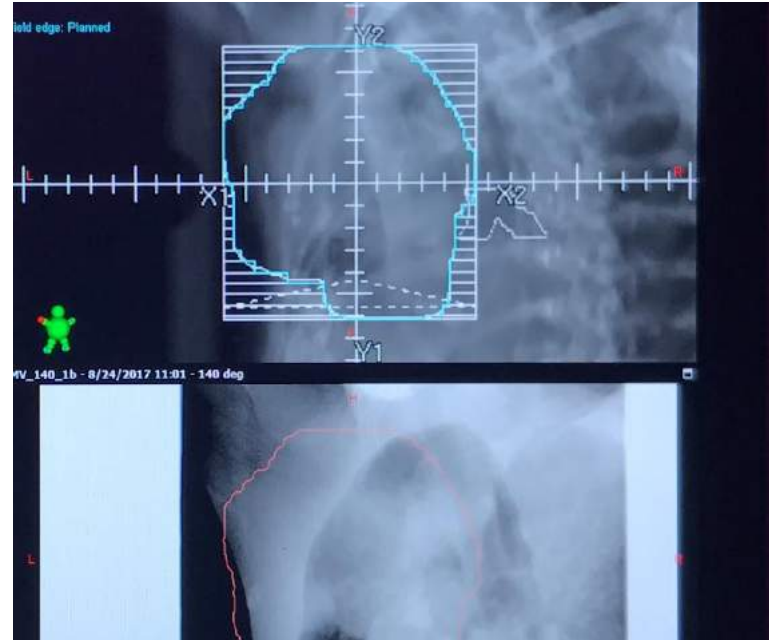
Who can you go to for emotional support?



Patients do not understand the long-term implications of radiation on healthy tissue

“ There was a swallowing specialist, we went and had swallowing tests, and my husband thought that was a complete and utter joke.

I didn't think it was a joke, and really it's come back to haunt us because he still can't swallow and she wanted him to do swallowing exercises and he thought it was a complete joke and he would never do any of them. But in retrospect he should have, because he has all these problems now. ”



Patients do not understand the long-term implications of radiation on healthy tissue

Highlight after-treatment care as an important part of the journey

5 After treatment

Assessing the effects of treatment on the cancer and your body



Jane is done with her treatment.

After radiation treatment ends, the effects of radiation continue to treat the cancer. You will continue to see your care team at your clinic. They will assess the success of treatment and monitor for side effects.

Monitoring side effects

Side effects should go away gradually after radiation ends. Some side effects may take longer to go away than others. Some may be permanent.

Assessing treatment response

May be too early to assess your treatment response.

1 month



Jane talks to her nurse and doctor about her side effects at her first follow-up appointment.

A few months



Scans
At her next follow-up visit, Jane's doctor checks the success of her treatment.

Bloodwork

Continue to monitor side effects as they go away.

The full effect of radiation may not be seen until weeks or months after treatment ends. Your doctor will assess if your treatment was effective with:

- ☐ Bloodwork
- ☐ Scan
- ☐ Symptom check
- ☐ Other

Long term



Jane's care team will keep in touch to monitor her response to radiation and watch for long-term side effects.

Ask your doctor what long-term side effects might occur. Your care team may schedule additional follow-up visits to monitor these.

Ask your doctor how they will monitor long-term treatment response.

next steps

next steps

1/2

Pilot of clinical implementation

Evaluation of **patient perceptions** of communication tool

- Does tool improve knowledge of the radiation treatment course?
- Does tool alleviate anxiety associated with radiation treatment?

Evaluation of **physician/care team perceptions** of communication tool

- Does tool facilitate communication between care team and patient?
- What works? What doesn't?

Dissemination of the tool

Presentation at international meetings (ASTRO, American Association of Cancer Education, Graphic Medicine, etc)

Publication in peer review journals

Dissemination via Radiation Oncology Education Collaborative Study Group

next steps

2/2

Refining tool based on feedback

Form factor changes

Specific variations for **common disease sites** (breast cancer, lung cancer, prostate cancer, etc.)

Specific variations for **other radiation therapy types**: stereotactic body radiation therapy (SBRT), stereotactic radiosurgery (SRS), and brachytherapy

Extending the visual narrative concept

Consider developing graphic narrative into animation/video

discussion