



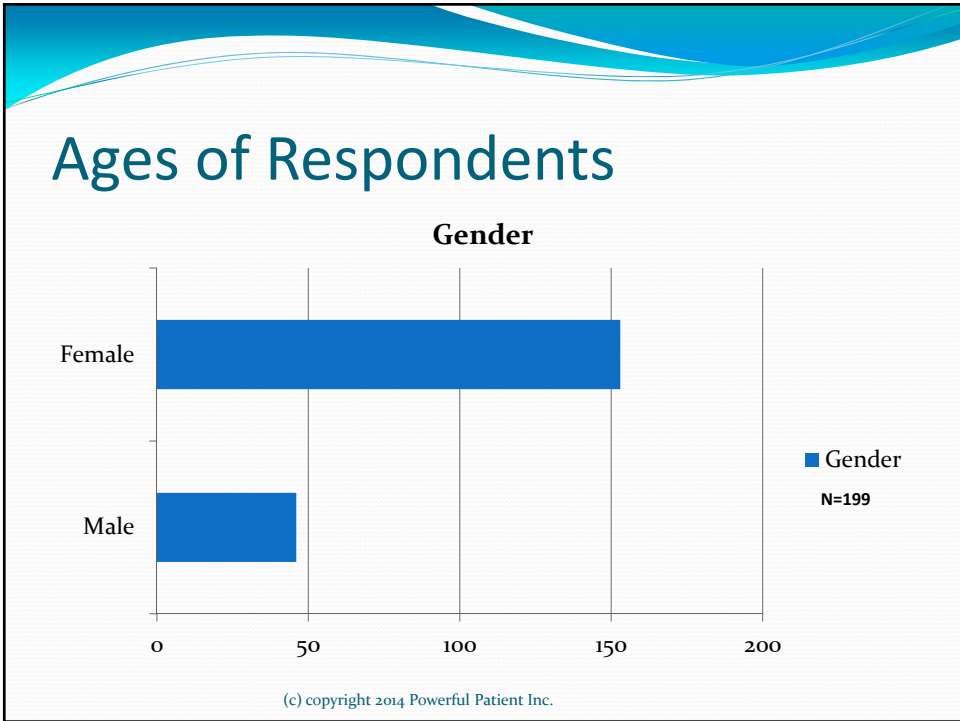
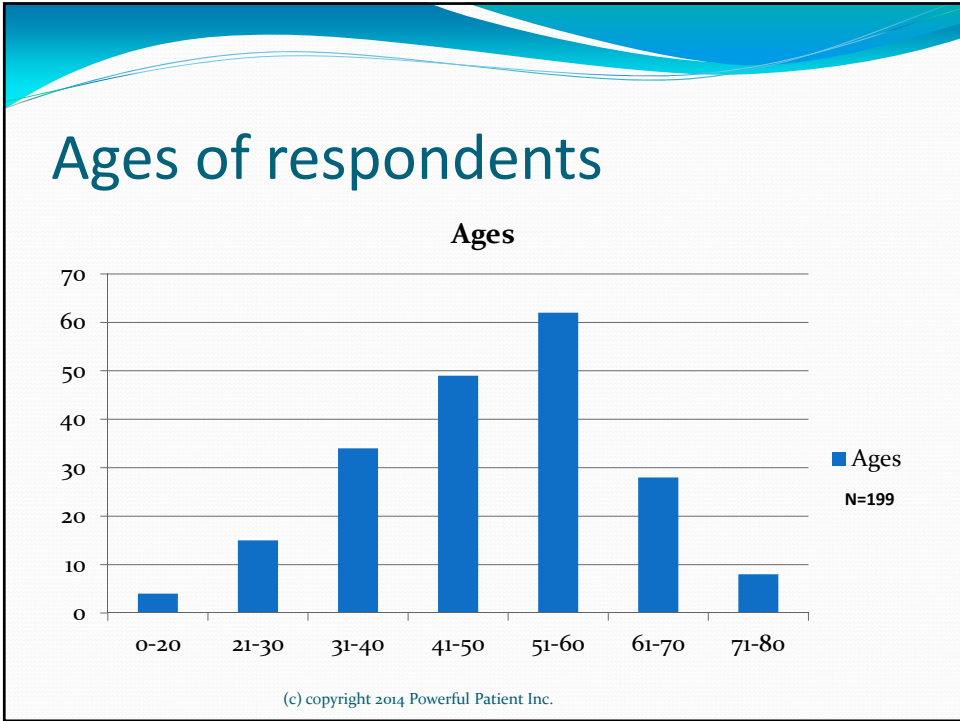
Patient Perspectives on Radiation Dose

Joyce Wilcox Graff, Powerful Patient Inc.
Presentation June 2014 in Varna, Bulgaria, to the
International Conference on
Radiation Protection in Medicine, RPM2014,
sponsored by the International Atomic Energy Agency

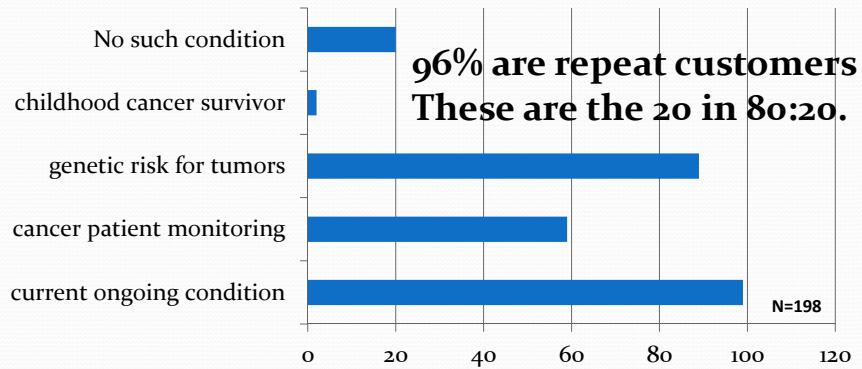
What is YOUR opinion about radiation safety in medicine?

- Recruited respondents from rare disease and cancer support group, March-May 2014
- 199 people replied,
 - 95% for themselves,
 - 5% for their children

(c) copyright 2014 Powerful Patient Inc.

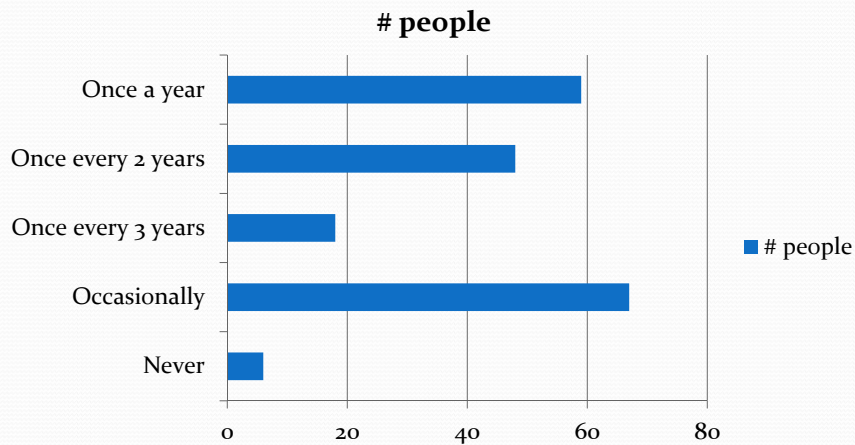


Do you have a condition that requires periodic scans for preventive screening?

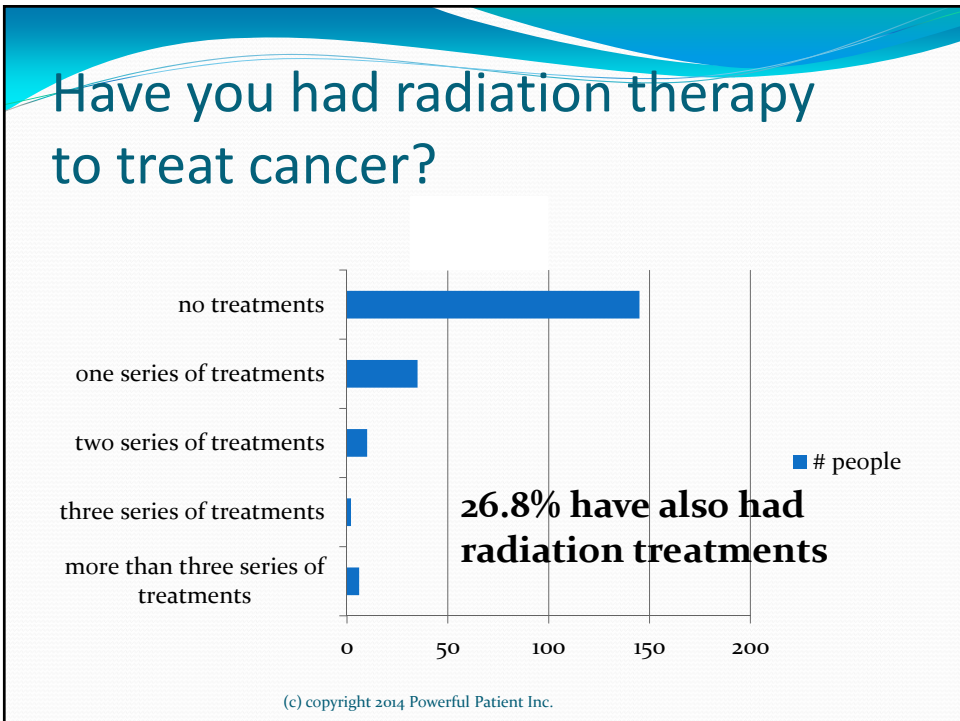
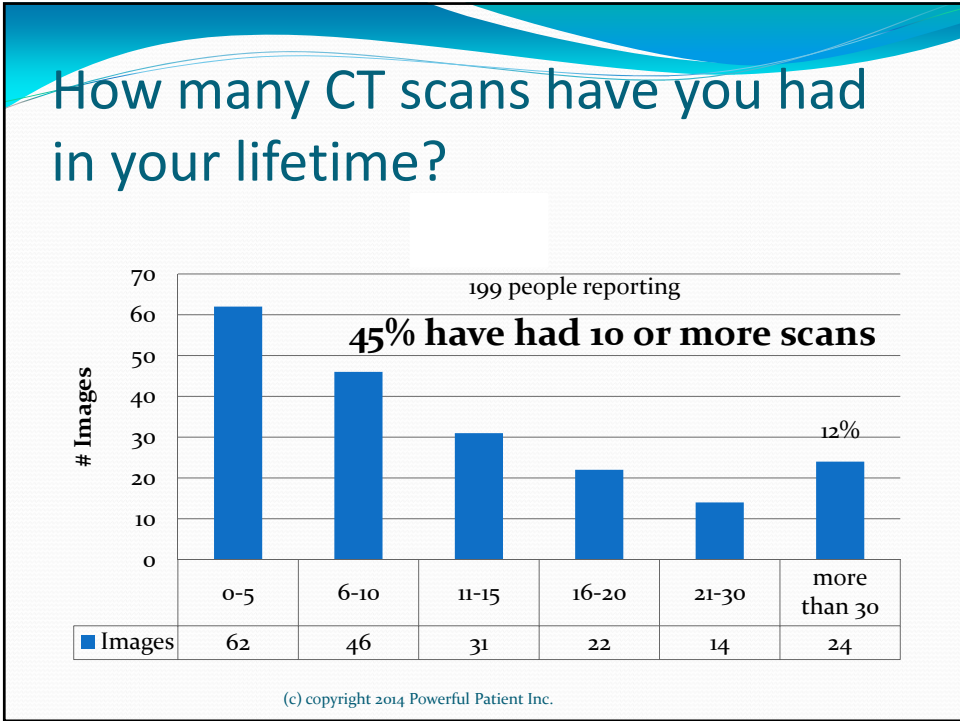


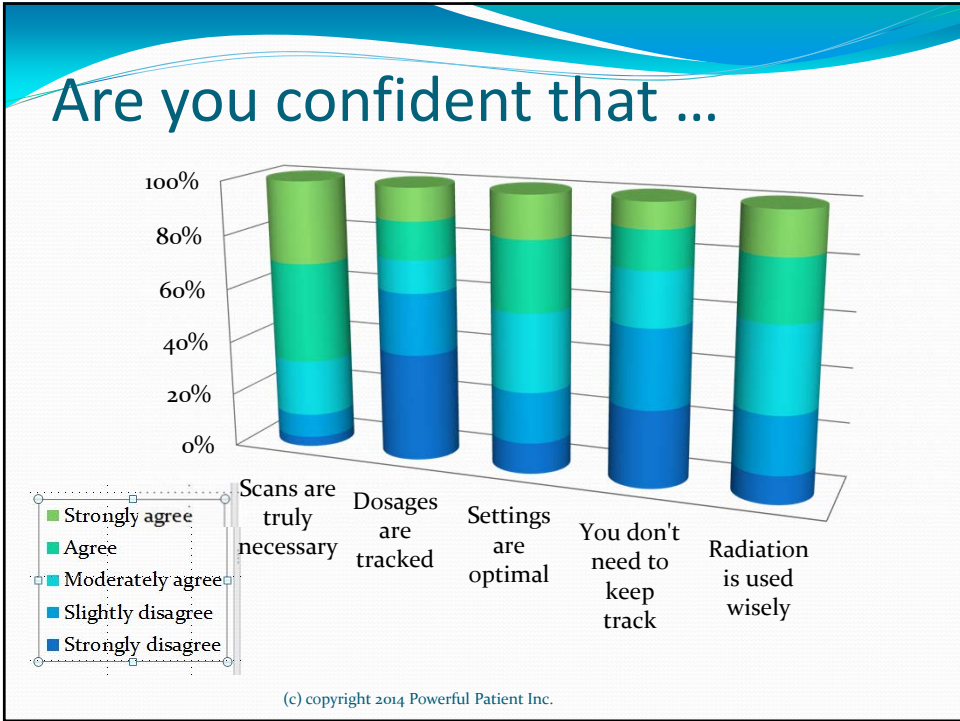
(c) copyright 2014 Powerful Patient Inc.

How often do you get dental x-rays?



(c) copyright 2014 Powerful Patient Inc.





- ## People are worried
- How much radiation is too much?
 - 25% of these respondents have spoken with their doctors about using MRI instead of CT for at least some of their scans.
 - Staff wear badges to cumulate exposure – do patients need badges too?
 - Many of these patients now have total exposures greater than that allowed by law for staff.
- (c) copyright 2014 Powerful Patient Inc.

How much radiation is too much?

- What is a lifetime safety dose?
- At what point does radiation cause cancer?
- What is the limit of the radiation per year, and what is the effect in long term
- My niece who is 17 years old is going thru thyroid cancer since age 13. When she was a baby in Central America they did x-rays to see if she had a sinus infection. Could that radiation had caused her thyroid cancer?

(c) copyright 2014 Powerful Patient Inc.

Recognizing all sources

- Why doesn't the radiology department ask about my prior radiation exposure?
- I would like to ask how much attention the delegates give to environmental radiation exposure of the patient. For example I am an airline pilot and as such already receive a higher than normal exposure to radiation than the average person. My protocol would like to scan me right up to the maximum recommended exposure level per year. I have trouble convincing them that they need to be cogniscent of the radiation exposure I have already had outside of medicine.

(c) copyright 2014 Powerful Patient Inc.

Tracking the cumulation

- How much radiation do we receive from each CT?
- How many CTs in a year would be considered a lot?
- Please devise a way to keep track on a chip or badge.
- Is there a test to check for accumulated radiation?
- Should I keep track myself? How?
- There is little available to tell a layman in comprehensible terms what amount of radiation is involved in each type of scan or procedure. When care is obtained at different locations over time, only the patient can keep track. Any possibility of a simple guide/log to be given to patients?

(c) copyright 2014 Powerful Patient Inc.

Worries . . .

- I really think that patients who have 200 or more of RAI should stay in the hospital and not be allowed to go home and contaminate their homes. I left the hospital after my dose of 208 RAI and had to avoid a pregnant mom in the parking lot . . .
- I nearly had an accident going home from my radiation therapy. If people had had to rescue me I could not have even told them about the radiation I was emitting.
- Should we shield the thyroid during mammograms?

(c) copyright 2014 Powerful Patient Inc.

Don't hinder the benefits!


- Please ensure that you consider the **benefits** of radiation tests and avoid enacting rules that hinder the radiologist's ability to detect disease. If a 3 phase CT is the best exam to define a problem, we want it! Radiologists are starting to be "gun shy" about prescribing good imaging.

(c) copyright 2014 Powerful Patient Inc.

Results from the conference

- This was a group of more than 200 radiation physicists as well as radiologists and radiographers.
- They listened quite seriously to the problems we outlined. There are no clear answers at this time.
- They are in agreement that patients need to compile their own records of radiation exposure.
- There are badges and blood tests, but nothing terribly practical at this time.
- On the Powerful Patient, we will be presenting several approaches to doing this data collection for yourself.

(c) copyright 2014 Powerful Patient Inc.



Joyce Wilcox Graff
joyce@powerfulpatient.org
Powerful Patient, Inc.
46 Williams Street, Suite 1
Brookline, MA 02446 USA

(c) copyright 2014 Powerful Patient Inc.