

# Screenshots of the Colorectal Cancer Survivor's Personal Health Record (CRCS-PHR) User interface of specific features and functions

Figure 1: Relationships screenshot

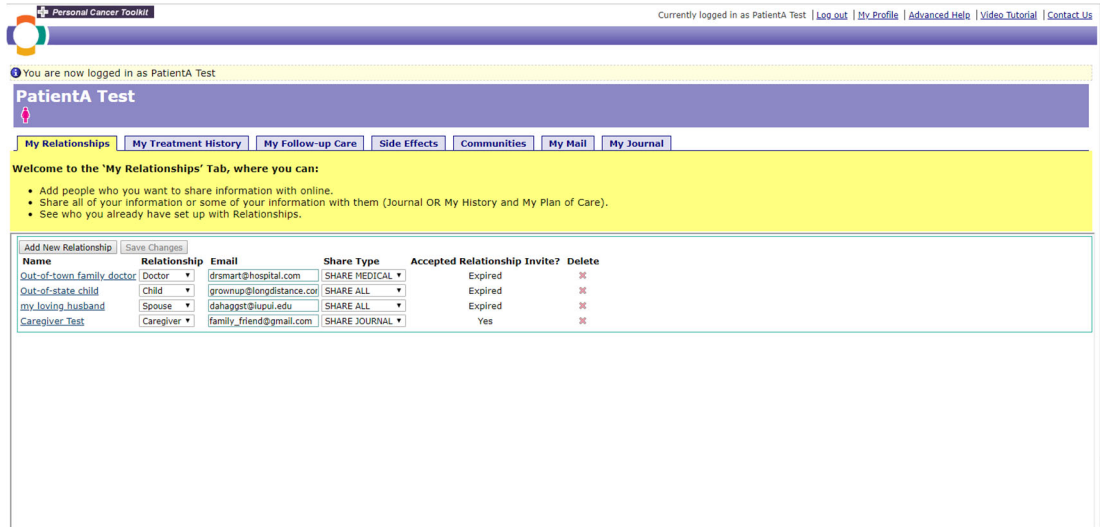


Figure 2: Treatment Summary screenshot

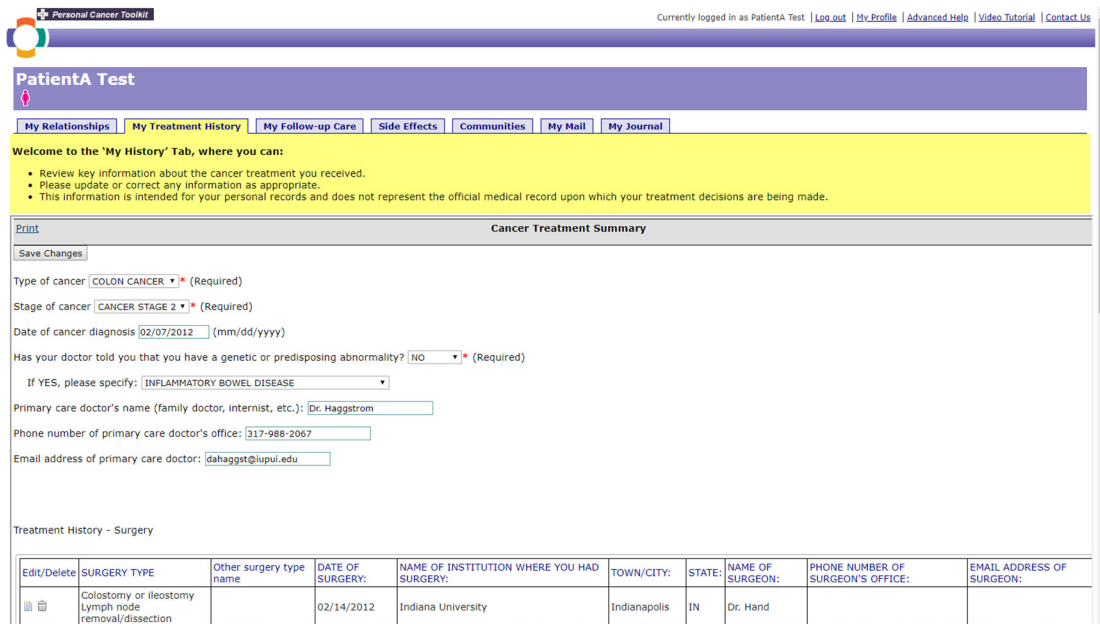


Figure 3: Surveillance Care screenshot

Welcome to the 'My Plan of Care' Tab, where you can:

- Review follow-up care (or surveillance tests) that you and your doctor may consider given your type of cancer
- The Calendar on the left reflects a potential follow-up schedule given the date of your cancer diagnosis.
- The Follow-up Care Received on the right provides a place for you to enter and track surveillance tests.

**Potential Follow-up Care Calendar**

Target Dates	Recommended Care
01/07/2013	Colonoscopy (COMPLETED 12/14/2012)
07/20/2018	Colonoscopy (COMPLETED 09/03/2018)
07/20/2019	History and Physical
07/20/2020	Colonoscopy
07/20/2020	History and Physical

**Follow-up Care Received (as recorded by you, the patient)**

Date Completed	Care Received	Doctor Name	Comments	Action
12/14/2012	Colonoscopy	Dr. Fobbit	no polyps - OK	Save Delete
09/03/2018	Colonoscopy	Dr. Tarver	normal	Save Delete

Add Followup Care Perform

- History and Physical
- CEA Tests
- CT Scan Chest/Abdomen
- CT Scan Pelvis
- Flex Sigmoidoscopy

(NOTE: This calendar is based on clinical guidelines for testing for cancer recurrence. As each year goes by, your risk for recurrence goes down. At the end of this period of time, no further tests for recurrence are typically recommended.)

Figure 4: Side Effects screenshot

Welcome to the Side Effects Tab, where you can:

- Review potential side effects you may experience and simple steps you can take to address them.
- Side effects may be caused by either your cancer, or the treatment you received.
- Some side effects may occur shortly after diagnosis or treatment, and others may occur years later.
- Discuss any new medical issues that arise with your doctor.

**General Health**

Colorectal (CRC) cancer survivors are encouraged to adopt a healthy lifestyle. Maintaining a healthy weight typically includes regular exercise and eating a healthy diet, including lots of fruits and vegetables. Other important steps include avoiding any tobacco use and using alcohol only in moderation. In discussion with their physicians, CRC survivors should also follow recommended guidelines for cancer screening.

Many people find both help and friendship in a support group, whether it is in-person or on-line.

The following sections will address risks related to the treatments you received.

**Risk of fatigue**

Fatigue is the one of the most common side effects of cancer treatment. Patients who have received chemotherapy or radiation treatment may be most likely to experience fatigue. Pain, emotional distress, sleep problems, and other medical problems may also contribute to the experience of fatigue.

This feeling of complete exhaustion can last for several months to years after treatment ends. Soon after treatment is complete, friends, family and co-workers often expect the survivor to be back to doing the things they did before treatment, with the same level of energy, although this may not be immediately possible. Research has suggested that moderate exercise may reduce fatigue, along with emotional distress and sleep disturbance.

**Lymphedema (leg swelling)**

The removal of lymph nodes from the abdomen or groin area can lead to decreased drainage in the legs, causing lymphedema, or swelling of the limb. Signs of lymphedema near the area of surgery (leg, abdomen, genitals) may include skin changes (reddened, warm, hard, stiff) or pain. You may also experience difficulty fitting into clothes or pants. Lymphedema can occur months, or even years after treatment. If swelling develops, early recognition may allow for better outcomes.

Colorectal cancer survivors should notify their healthcare providers with any signs of swelling to determine if this may be caused by lymphedema, versus another medical problem (heart failure, blood clots). A certified lymphedema therapist may be consulted.

**Colostomy or Ileostomy**

During surgery, some patients undergo a diversion of the bowel in the form of a temporary or permanent ostomy. An ostomy has many possible effects on daily life, including wearing an ostomy bag underneath one's clothing, possible skin irritation, challenges with diet selection and bowel control. Social, emotional, or sexual issues may also arise. Colorectal cancer survivors with an ostomy are advised to empty and seal their pouch before engaging in sexual activity. At some point, survivors with an ostomy should see an ostomy nurse, who can provide help and education in caring for the ostomy and its associated appliances.

**Sexuality Issues for Women**

Women of any age may have sexuality concerns after cancer treatment. Issues may include vaginal dryness, painful intercourse, and reduced sexual desire. Many of these issues can be caused by the start of menopause, which can occur with cancer treatment. With the start of menopause, women may also experience hot flashes, mood swings, fatigue and irritability. Women should not hesitate to raise these issues with their healthcare provider. Evaluation by an endocrinologist may be considered for early menopause.

Concerns about changes in your body appearance and the emotional distress of cancer can also cause changes in your relationship with your partner and

Figure 5: Community Resources screenshot

Personal Cancer Toolkit Currently logged in as PatientA Test | [Log out](#) | [My Profile](#) | [Advanced Help](#) | [Video Tutorial](#) | [Contact Us](#)

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You are now logged in as PatientA Test

**PatientA Test**

[My Relationships](#) | 
 [My Treatment History](#) | 
 [My Follow-up Care](#) | 
 [Side Effects](#) | 
 **[Communities](#)** | 
 [My Mail](#) | 
 [My Journal](#)

**Welcome to the Communities Tab, where you can:**

- Connect to Websites of local and national organizations that provide knowledge or support for cancer survivors.
- Clicking on the links will direct you to a website outside your Cancer Toolkit.

**Useful Contacts**

ORGANIZATION	TELEPHONE	WEB SITE
C3 Colorectal Cancer Coalition 1225 King St Alexandria, VA 22314	703-548-1225	<a href="http://www.fightcolorectalcaner.org">www.fightcolorectalcaner.org</a>
Frankly Speaking about Colorectal Cancer, 2nd ed, 2008	703-548-1225, Ext 10	<a href="http://advocacy.fightcrc.org/FranklySpeaking">advocacy.fightcrc.org/FranklySpeaking</a>
Yearly calendar of colon cancer survivors		<a href="http://www.colondar.com">www.colondar.com</a>

**Cancer Survivor Resources for Patients and their Caregivers**

1. Support Groups – check at your treating hospital, in your community and online (American Cancer Society’s Cancer survivors Network (<http://csn.cancer.org>), and the University of Pennsylvania’s Oncolink (<http://oncolink.org>). Both of these sites are reliable & reputable.
2. American Cancer Society <http://www.cancer.org/docroot/home/index.asp> 1-800-ACS2345
3. CancerCare <http://www.cancercares.org> 1-800-813-HOPE (4673)
4. National Coalition for Cancer Survivorship – see also the Cancer Survivor Toolbox [www.canceradvocacy.org/](http://www.canceradvocacy.org/)
5. Lance Armstrong Foundation LiveStrong <http://www.livestrong.org>
6. NCI – Office of Cancer Survivorship <http://dcccps.nci.nih.gov/ocs/>
7. NPR – "My Cancer" blog <http://www.npr.org/blogs/mycancer/>
8. The Wellness Community, [www.thewellnesscommunity.org](http://www.thewellnesscommunity.org), 888-793-WELL
9. For Patients who work: [www.cancerandcareers.org](http://www.cancerandcareers.org)
10. Internet blog for patients to stay connected: [www.caringbridge.org](http://www.caringbridge.org)
11. FertileHope: <http://www.fertilehope.org>
12. Facing Forward: Life After Cancer Treatment, NCI, NIH Publication No. 06-2424
13. CURE magazine [www.curetoday.com/subscribe](http://www.curetoday.com/subscribe), 800-210-CURE

English (United Kingdom) | English (United States) | Last Build: Apr 18 2012 08:50 AM | Version: 1.7.3 dev Build 25497 | Powered by OpenMRS | Made possible by Personal Cancer Toolkit

Figure 6: Secure Messaging screenshot

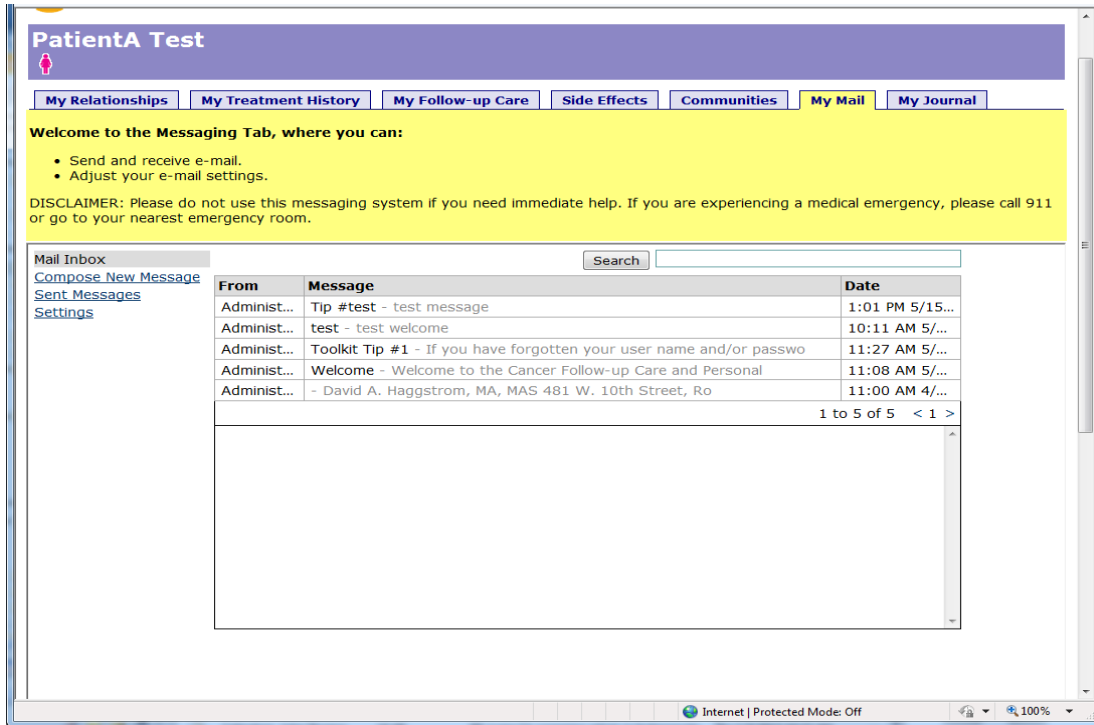


Figure 7: Journal screenshot

