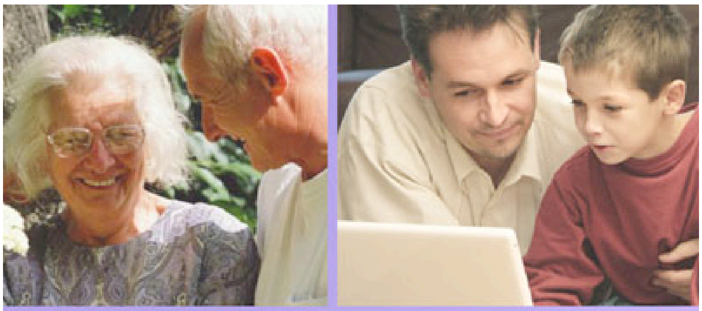
APPENDIX A



CONTRIBUTE TO THE CREATION OF AN ONLINE NETWORK FOR INDIVIDUALS AND GROUPS IN THE LOCAL CANCER SURVIVORSHIP COMMUNITY

Learn about participating in this Vanderbilt study at

WWW.SURVIVORSHIPNETWORK.ORG

or contact Jacob Weiss at 615-936-1773

THE MIDDLE TENNESSEE
SURVIVORSHIP COMMUNITY NETWORK

APPENDIX B

ID #: ____________

Cancer Survivorship Sense of Community Survey

Today's Date: ____________

Instructions: Before completing this survey form, please write a short description of how you personally would define "the middle Tennessee cancer survivorship community," including the **types of organizations and individuals** that are members of this community:

The middle Tennessee cancer survivorship community…

	Please circle a response for each question				
1. I can get what I need in the middle Tennessee cancer survivorship community.	Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly Agree
2. The middle Tennessee cancer survivorship community helps me fulfill my needs.	Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly Agree
3. I feel like a member of the middle Tennessee cancer survivorship community.	Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly Agree
4. I belong in the middle Tennessee cancer survivorship community.	Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly Agree
5. I have a say about what goes on in the middle Tennessee cancer survivorship community.	Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly Agree
6. People in the middle Tennessee cancer survivorship community are good at influencing each another.	Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly Agree
7. I feel connected to the middle Tennessee cancer survivorship community.	Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly Agree
8. I have a good bond with others in the middle Tennessee cancer survivorship community.	Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly Agree

APPENDIX C

Appendix - Survivor and Family Demographics Data

Age

mean	57
st dev	6.1

Gender

3 Male
7 Female

Race

8 Caucasian
1 African-American
1 African-American, Other

Marital Status

1 Single
1 Single, living with partner
5 Married
2 Divorced
1 Widowed

Education

2 two year degree
5 four year degree
2 some college
1 graduate degree

Work

6 Employed full time
3 Retired
1 Unemployed

Income

1 $20,001 to $30,000
1 $30,001 to $40,000
1 $50,001 to $60,000
5 Over $60,000
1 Do not care to respond

Connection

6 Cancer survivor
2 Relative of a cancer survivor
1 Friend of a cancer survivor
1 Other (widow-cancer survivor advocate)

Diagnosis

2 Prostate

1 Cervical Cancer
4 Colon
1 Ovarian cancer
2 Breast cancer
1 Melanoma

Time since last treatment

Mean	4.7 years
St Dev	5.15 years

Internet access

9 Broadband
1 None

Relations that have Internet

10 Most

Sociodemographic Data

ID # ____________ **Today's Date _________________**

1. **What is your date of birth? ______-______-______**

2. **What is your gender? Male Female**

3. **What is your race?**
   - ☐ Caucasian
   - ☐ African-American
   - ☐ Asian
   - ☐ Native American
   - ☐ Other [Please list, _______________________]

4. **What is your marital status?**
   - ☐ Single
   - ☐ Single, living with partner
   - ☐ Married
   - ☐ Separated
   - ☐ Divorced
   - ☐ Widowed
   - ☐ Other

5. **Please circle the highest grade of education completed:**

   1 2 3 4 5 6 7 8 9 10 11 12

   [some college] [2 year degree] [4 year degree] [graduate degree]

6. **Which of the following best describes your current work status?**
   - ☐ Employed full time
   - ☐ Employed part time
   - ☐ Homemaker
   - ☐ Retired
   - ☐ Unemployed
   - ☐ Other [Please list, _______________________]

7. **What is your yearly household income?**
   - ☐ $10,000 or less
   - ☐ $10,001 to $20,000
   - ☐ $20,001 to $30,000
   - ☐ $30,001 to $40,000
   - ☐ $40,001 to $50,000
   - ☐ $50,001 to $60,000
   - ☐ Over $60,000
   - ☐ Do not care to respond

8. **Which of the following best describes your connection to cancer survivorship?**
   - ☐ Cancer survivor
   - ☐ Relative of a cancer survivor
   - ☐ Friend of a cancer survivor
   - ☐ Other [Please list, _______________________]

9. **Cancer Diagnosis Type(s):**

   Please list: _______________________

10. **Cancer Treatment(s) Received:**

    Please list: _______________________

11. **Date of Completion of Last Treatment:**

    Month/Year: _______________________

12. **Do you have Internet access at home?**
    - ☐ No
    - ☐ Yes, Dial-up
    - ☐ Yes, Broadband (cable/dsl)
    - ☐ Yes, Other [Please list, _______________________]

13. **How many of your friends and relatives use the Internet or email?**
    - ☐ None
    - ☐ A few
    - ☐ Most
    - ☐ Don't know

APPENDIX D

Free response answers from Sense of Community Survey

Instructions: *Before completing this survey form, please write a short description of how you personally would define "the middle Tennessee cancer survivorship community," including the types of organizations and individuals that are members of this community:*

The middle Tennessee cancer survivorship community…

consists of a strong network of people & organizations who are eager to help cancer pts & families. However, often times, services are duplicated & there is not strong communication between groups.

patients, their families and their friends. Medical staff who participate in the care of survivors. Members & leaders of organizations that help survivors.

is a large, multi-level comprehensive group of individual cancer survivors, community organizations, health care providers, & others who work together to educate, inform, collaborate, & support each other.

1. Community support organizations - e.g. Gilda's, Sister's, etc. 2. Actual Health care providers - vumc, Sarah Cannon, etc. 3. Pt. Advocates 4. Oncology Social Workers 5. Tennessee Comprehensive Cancer Control Coalition 6. Outreach workers @ VICC, Meharry, Metro Health Dept, etc.

is the loose network of org's & individuals involved in cancer survivorship. Obvious examples would be Gilda's & anyone who has had cancer, but also hospitals, online resources, etc.

doesn't exist outside of support groups (Gildas, Sisters, etc…). There is a great deal of misinformation, and lack of coordination between community organizations, academia, & community medicine.

includes men, women, teens & children with all types of cancer and their family members & friends and all the agencies, organizations, & medical facilities that serve them.

Gilda's Club, VICC, Children's Hospital, All local hospitals, mental health professionals, doctors (oncologists), nurses, St. Thomas/Seton Support/Camp Bluebird, ACS, Minnie Pearl Cancer Foundation. Encouraging, but still somewhat territorial.

is a growing, developing network of various organizations. That being said, it is a community that needs more "connection" and "conversations" to fully develop and serve our constituents.

The middle Tennessee community encompasses individuals with cancer, their families, those affected indirectly and supportive organizations (those specifically dealing with cancer and those related to broader _____ - housing, insurance, transportation.

is a comprehensive network of resources that strive to meet the needs of cancer survivors. Becoming and opening up more and more to collaboration among groups, this network is an active source of support and is gaining national support.

is comprised of many different organizations & agencies, each trying to meet the varying needs of cancer survivors. Within these organizations are a variety of committed individuals who have the best interests of these survivors at heart and work hard to give great support.

has good intentions but seems to segregate. Each program offers something special & unique but doesn't seem to want to connect to each other.

Nashville & Surrounding counties

composed of local and statewide cancer centers, Tccc, all support groups & agencies, all support & educational programs, oncologist, nurses, patients, families, and everyone who works to provide care & support.

The MTCSC provides education, support and community resources for cancer pts/survivors, health care professionals and the general community-"One stop shopping" - Orgs & individuals would include hospitals, ______ facilities, Drs, Rns, Physical Therapists Nutritionist, Psychologists, Counselors, Sexual Health Experts for Ca Pts, ACS, TBCC, Komen, MD Anderson, Duke Cancer Center, Sloan Kettering in

NYC. *This community is in need of a local & regional Intimacy & Sexual Health Expert. This is currently a need that is not being addressed fully by health care professionals with their patients. Sexual issues often occur years ____ diagnosis & treatment and patients do not have a forum where they can get information & support for improved intimacy & sex life. I would like to see some webcast or online forum w/an expert in this field (local or national) on the MTCSC.
includes cancer survivors and their friends and family, along with those organizations & individuals who provide resources, services & support for cancer survivors & their friends and family.
to me is made up of both survivors, their families & friends, & those who treat them (nurses, physicians, even religious leaders).
a group of medical and support service providers with no formal or established relationship other than networking of services. A group that needs increased collaboration and true sharing of resources.
provides support to cancer survivors, their families and other caregivers. Its members include recently and not-so-recently diagnosed individuals, caregivers, social workers, clergy, and other interested groups.
includes organizations focused on including targeted efforts to support individuals who have survived cancer-both those in treatment and in remission-as well as their families who have been a source of strength and support to the individual.
cancer prevention organizations, survivor/support groups at hospitals, organizations that promote screening, nonprofit organizations, survivors, hospitals, senior centers, women/men groups, medical students interested in cancers, clinical trial coordinators, nurses, etc.
is a loose network of groups and individuals who offer counseling, support and opportunities for cancer survivors and families to work toward a goal of education and outreach
what is available and I am aware of.
is comprised of people from all walks of life who have been touched by cancer
resources _____ to cancer patients & professional caregivers to get what they need. Resources need to be know about & easily accessible to those who need them.
people involved w/Gilda's & ACS & Komen, as well as patients & families in local hospitals are the people I feel are actively participating in the community. However, I feel many survivors don't know about these programs & live ______ in Nashville w/o getting in touch w/other survivors.
is a still-too-fragmented collection of organizations and their stakeholders with the common thread of being touch/involved in cancer research, treatment, education, advocacy, & philanthropy. Includes medical centers, hospitals, research groups, advocacy groups, support organizations, charities, survivors, caregivers, friends.
pediatric survivorship clinic. Adult survivorship clinic
many support groups located outside Davidson Co. In Davidson Co-mainly Gildas. ACS tries to touch patient by one or more of their programs.
is a group comprised of cancer survivors, their friends and family, working to educate each other in life after cancer, providing support and encouragement, sharing moments of happiness and under__ing each other when things go bad. Encouraged by local organizations such as ACS, Gilda's Club, US Too, PCCTN, TCCCP, Advocacy groups & individuals, health care providers, with the goal of improving LIFE AFTER CANCER and educating about long term effects of treatment
is created to serve communities in need. This is accomplished by forming partnerships with cervical cancer coalition of TN, Breast & cervical early detection program, sister to sister African-American Breast support groups, and other groups that are educating the people.
source of support, information and resources for people whose lives are touched by cancer.
provides an opportunity to educate the patient, family and friends of what to expect while dealing with the treatment of cancer. Once a survivor, the change in relationships and attitudes toward life

have to be dealt with.
has a relatively small, strongly bonded support group. I am not familiar with the types of organizations & individuals that are a part of the middle Tennessee cancer survivorship community. Hopefully I will have an opportunity to become familiar with these organizations.
The professional employees of the medical community who provide support to doctors who treat cancer patients. The medical community may be a group of physicians, a hospital or charitable organizations.
All cancer survivors in middle TN area. I would include Vanderbilt, Gilda's Club and internet connections-NCI, Cancer Care, and Lance Armstrong. Also local community groups ie: churches.
head neck cancer support group
needs computer access support-local as well as worldwide.

APPENDIX E

Appendix - Synthesized Definition Categories

adjectives/Described as

- Group Properties
  - accessible
  - available
  - committed
  - unique
- Network Properties
  - bonded
  - comprehensive
  - large
  - loose
  - multi-level
  - small
  - strong
- Overall Community Properties
  - growing
  - active
  - developing
  - Encouraging
  - improving

challenges/Challenges and Competition

- doesn't exist
- duplication
- fragmented
- lack of coordination
- misinformation
- poor communication
- segragate
- territorial
- needs conversations

connection/Relationships

- collection
- common thread
- formal relationship
- network
- partnerships

motivations/Motivations and Purpose

- best interests
- eager to help
- good intentions

offerings/What it offers

- Cognitive Resources
  - opportunities
  - source
  - source of strength
- Resources and Services
  - community resources
  - resources
  - services

perceptions/Perceived Existence

- aware of

Appendix - Synthesized Definition Categories

verbs/Actions		
	Done to or for a person	
		care
		educate
		inform
		meet needs
		serve
		support
		support doctors
		understanding
	Done together	
		collaborate
		sharing moments
		true sharing
		work together
	Quality of Efforts	
		gaining
		strive
		targeted efforts
		work hard
		work toward a goal

individuals		
	General	
		general community
		men
		others
		people from all walks of life
		religious leaders
		students
		women
	Patients and Survivors	
		adult
		advocates
		African-American
		anyone touched
		cancer type
		caregivers
		children
		families
		friends
		in treatment
		long-term survivors
		patients
		recently diagnosed
		remission
		survivors
		teens
	Professionals	
		clinical trial coordinators
		Counselers
		doctors
		everyone who works
		leaders
	Physical Therapists	Medical staff
	professional caregivers	Members
	professional employees	mental health professionals
	Psychologists	nurses
	Sexual Health Experts	Nutritionist

Appendix - Synthesized Definition Categories

	Social Workers	oncologist
	those who treat them	Oncology Social Workers
		Outreach workers

Appendix - Synthesized Definition Categories

topics	
Cancer Topics	
	advocacy
	life after cancer
	long-term effects
	pediatric
	prevention
	research
	screening
	sexual issues
Psychosocial Topics	
	happiness
	housing
	information
	insurance
	outreach
	philanthropy
	things go bad
	transportation
	what to expect

where/Where Located	
Type of practice	
	academia
	community medicine
Geographical	
	Davidson County
	local
	Nashville
	national support
	statewide
	Surrounding counties
	worldwide
Media	
	online resources

organizations		
	Cancer Support	
		advocacy groups
		cancer specific
		Gilda's Club
		nonprofit
		programs
		State Coalition
		support groups
		support service providers
	Clinical Care	
		Adult survivorship clinic
		cancer centers
		health care providers
		hospitals
		medical centers
		medical facilities
		medical service providers
		Nationwide Cancer Centers
		pediatric survivorship clinic
	Community Health	
		agencies
		Metro Health Dept
	General Community Groups	
		charities
		churches
		general supportive services
		others
		senior centers
		women~men groups
	Research	
		research groups

APPENDIX F

Appendix

Part 1: For the Community Assessment/Map

1. The contact person/info for cancer survivors or family/friends is …

2. The contact person/info for community partners is …

3. Is your group part of a larger network or organization?

4. Describe your group's role in the local community for cancer survivorship?
   a. Specifically for survivors following the end of treatment?

5. Describe resources or services do you offer that you would like survivors/co-survivors to be aware of?
   a. Describe resources or services do you offer that you would like *community partners* to be aware of?

6. Describe groups/individuals your group has partnered with?
   a. What groups/individuals would your group like to partner with more?
   b. What information or resources from others would help your group?

Part 2: Sense of Community and Interest in Online Community

1. Sense of community questions:
   a. *Needs Fulfillment*
      i. How have other members of the middle Tennessee cancer survivorship community helped you fulfill your needs?
   b. *Group Membership*
      i. Describe how you feel like a member of the community?
   c. *Influence*

            - **i.** Describe how you have a say about what goes on in the community?

    - ***d.*** *Emotional Connection*
        - **i.** How are you connected with other members of the community?

2. How can you envision participating in an online survivorship community for Middle Tennessee?
    a. What content or functions should be included and how might it help you?
    b. Describe the types of roles that should be included in the online community.
    c. What roles might you or your group play?
    d. Is there a role for online communication internal to your group?
    e. How might the online community address needs following the end of treatment?
    f. What challenges can you envision in starting this project?

APPENDIX G

2008

Middle Tennessee Survivorship Community Network

February Design Meetings Report

www.survivorshipnetwork.org

Contents:

Additional Documents Online:

1. Storyboards from February meetings
2. Timeline
3. Screenshot of proposed web site

Vanderbilt University, Department of Biomedical Informatics

3/6/2008

TABLE OF CONTENTS

ADDITIONAL MATERIALS AVAILABLE ONLINE

Cancer Survivor and Health Care Professional Storyboards

Screenshot of Proposed Design Sections

Proposed Timeline through June

You may offer your input and discussion of this report on the project web site or by contacting Jacob Weiss

jacob.weiss@vanderbilt.edu

615-936-1773

survivorshipnetwork.org

Meeting Overviews

TUESDAY, FEBRUARY 5TH

Participants included **three cancer survivors and one co-survivor (spouse)**, Jacob Weiss (Principal Investigator), Franklin DeFelice (Vanderbilt student), and Ben Hefner (Vanderbilt student).

WEDNESDAY, FEBRUARY 6TH

18 representatives from organizations involved in cancer survivorship participated, including groups from Vanderbilt, St. Thomas, TSU's Center for Health Research, Meharry Medical College, the Tennessee Breast Cancer Coalition, the Leukemia and Lymphoma Society, and the Tennessee Comprehensive Cancer Control Coalition.

We have had great discussions and input from everyone at both the December and February meetings! There are a total of 10 cancer survivors and co-survivor family/friends and 27 health care professionals from various organizations participating in this design project.

MEETING ACTIVITIES

The primary purpose of the February meetings was to determine the **design priorities** for the online cancer survivorship community **to be developed by June, 2008.**

We first discussed a **"storyboard" scenario** of a few possible design ideas (available on the project web site). We then discussed a **priorities worksheet** in which each participant put a check by their top choices for different possible design features.

The design choices on the storyboard and worksheets were based on the ideas suggested at the December meetings.

ABOUT THIS DOCUMENT

This document is for the consented participants in the Survivorship Network research project only. Please do not share.

Thank you - Jacob

Survivorship Network First Priorities

Shared Stories, Experiences, and Knowledge

A central theme and foundation for the online community.

Items to Develop

Four Main Sections

Our Shared Experiences

Resource Guide and Map

Events and Programs

Make Connections and Get Involved

Theme of the Month

Articles and Information

Survivor Profiles

Interviews with local professionals

Sharing stories, experiences, and knowledge:
A central theme and foundation for the online community

The **majority of survivors and health care professionals** prioritized the sharing of stories, experiences, and knowledge among the community members. This choice also appeared to be **feasible to develop**.

This focus will **highlight middle Tennessee's many assets** and improve awareness of local resources, individuals, and common challenges faced by cancer survivors, family and friends, and health care professionals.

I will outline in this report how the focus on sharing stories, experiences, and knowledge can incorporate and **tie together many of the other priority ideas**.

Four Main Sections of the Proposed Design

Our Shared Experiences

The main space for **sharing stories and collaboration among individuals and groups**. There will be a place for cancer survivors to share their experiences, as well as a place for health care professional to share lessons learned working in the community.

Resource Guide and Map

Both a **text-based guide and an integrated "Google map"** will be included. Community members can suggest updates to resource listings as well as write reviews on their experiences with a certain resource or organization.

Events and Programs

Members can **create or register for events** in the local community.

Make Connections and Get Involved!

This section provides **opportunities to volunteer and get involved in the real-world community**, such as signing up to be a patient-to-patient mentor, a mentor for other professionals, interest in a speakers bureau, and other relatively basic connections.

Theme of the Month

Additionally, we will have a theme of the month that combines **Articles and Information**, **Profiles of Cancer Survivors/Co-Survivors/Volunteers**, as well as **Interviews/Profiles of local professionals**. The monthly theme will create awareness and highlight the local experiences and knowledge on specific cancer-related topics.

Our Shared Experiences

SURVIVORSHIP NETWORK FIRST PRIORITIES

OUR SHARED EXPERIENCES

For cancer survivors, family, friends, and health care professionals.

ITEMS TO DEVELOP

Topics/categories for sharing experiences

Initial "seed" collection of experiences

Ability to submit and browse experiences

Ability to choose intended audience (survivors and/or professionals)

Allow some structured content (e.g. web links)

FOR CANCER SURVIVORS, FAMILY, AND FRIENDS

Survivors and anyone touched by cancer can share their stories and key things they've learned from their experiences. We can highlight certain topics around which people can share experiences, such as

- Myths about cancer that need awareness and clarification
- Co-workers' tips for supporting a cancer survivor at work
- Importance of early detection and testing
- Financial challenges and strategies
- Participation in studies and clinical trials
- Positive aspects of experiencing cancer

… and other suggested topics.

FOR HEALTH CARE PROFESSIONALS

This is where we can achieve collaborative synergy between organizations and their representatives. We can **compile a shared collection of the informal knowledge** and lessons learned by local professionals on topics such as

- Event and Program planning: What didn't work
- Web sites that I use on weekly basis.
- Local contacts to email press releases
- New professionals or groups: Where to start.

… and other suggested topics.

CRITICAL DEVELOPMENT STRATEGIES

- Specific categories for sharing experiences, rather than an open discussion for general questions and advice, to help focus and ease into the initial growing phase of the community.
- Jacob will work closely with individual design phase participants to determine the topics and the type of experiences that can be shared.
- By June, we will have a focused set of initial topics with initial content contributed by design phase participants.

Resource Guide and Map

SURVIVORSHIP NETWORK FIRST PRIORITIES

RESOURCE GUIDE AND MAP

Searchable text-based guide and Google map.

ITEMS TO DEVELOP

Resource Guide

Tagging and categories assignment on resource submission

Mini-articles synthesizing resources

Display of resource listings by category

Display of an individual resource

Ability to write/read testimonials for a resource

Ability to attach street address to resources for mapping

Google Map

Display of resources on map by category and individually

Search

Ability to search for resources by key words

RESOURCE GUIDE AND COMMUNITY MAP COMBINATION

Both a **"Google map" of locations + a text-based guide** to the community resources were given **equal priority**, and so both will be developed together (to some extent), along with the **ability to search** using keywords.

COLLECTIVE KNOWLEDGE AND EXPERIENCES WITH LOCAL RESOURCES

Online community members can notify the resource guide monitor(s) about updates to the resource guide and map (capturing **their collective knowledge** of local resources and organizations).

Individual survivors or professionals may also write testimonials to **share their own experiences** in appreciate for a local resource or organization. This feature can link to the "our shared experiences" section.

Community organizations will be listed as resources, and other resources can be associated with an organization as well.

CRITICAL DEVELOPMENT STRATEGIES

- Determine the types of resources, services, and organizations that will be included.
- Feedback on phrasing for tags and categories
- Feedback on classification of resources into appropriate categories
- Feedback on usability on display of resources and ease of finding resources
- Volunteers to monitor/confirm member-submitted updates

All participants are encouraged to explore the categories and resources as they are added to the project web site, and to write a comment or contact Jacob with feedback.

Jacob will also contact participants individually to discuss more in depth feedback in person or on the phone.

SURVIVORSHIP NETWORK FIRST PRIORITIES

EVENTS AND PROGRAM CALENDAR

A centralized community-wide listing for events and programs.

ITEMS TO DEVELOP

Events and Programs

Ability to create an event or program for a specific date

Ability to associate an event with an organization

A way to recognize volunteers for the event

Ability to browse upcoming events

Ability to sign up/RSVP for an event

Ability to read/write testimonials of an event

Mark events as "in planning stages"

EVENTS AND PROGRAM CALENDAR

Community members will be able to submit items to be listed on a **centralized community-wide listing** for events and programs.

Events will be treated similarly to resource listings, but with additional properties (such as dates and times, ability to RSVP, and ability to recognize event volunteers).

As with resource listings, community members can share their experiences and testimonials of an event or program.

PROMOTING COLLABORATIVE EVENTS

If time and feasibility permits (by June), **programs and events may be marked as "in planning stages" and visible to other local professionals** before being shared with the entire community. This is intended to facilitate awareness of events in progress to promote collaboration, avoid scheduling conflicts, and achieve greater synergy between organizations.

CRITICAL DEVELOPMENT STRATEGIES

- Gather information on events being planned by organizations represented in our design team; "seed" the calendar with these events.
- Work with the participating organizations that currently maintain listings of community programs and events; determine feasibility of sharing/feeding event information between calendars.
- Explore partnerships to push event information to other calendars, email lists, and local publications to provide a one-stop, central event submission for listing on multiple sites.
- Have local Cancer Survivors Day events be the first live promotion of the events calendar and sharing of experiences

SURVIVORSHIP NETWORK FIRST PRIORITIES

MAKE CONNECTIONS AND GET INVOLVED

Linking the online and real-world communities.

ITEMS TO DEVELOP

Speakers Bureau & Professional Mentorship

Sign-up/interest forms

Display of individuals to contact directly with a request

Speaker or mentor request form

Patient-to-Patient

Sign-up/interest form

Secure connection to existing programs or program managers

Volunteering

Ability to submit volunteer opportunity (tied to events calendar)

Sign-up forms to volunteer

Listing of volunteer opportunities

Synthesis of ongoing volunteer opportunities

Mailing Lists

Sign-up forms

Browse archives

Make Connections and Get Involved!

CONNECTING TO THE REAL-WORLD COMMUNITY

This section will facilitate ways to get involved in the local community and mentor or meet other individuals in person or on the phone.

To prepare for June: We will build features that support the *future* development of a formal local speakers bureau, professional-to-professional mentorship program, and patient-to-patient connection programs. **Starting more informally**, these three initiatives can be coordinated online in similar ways.

This section also will **compile and promote opportunities to volunteer and mailing lists that individuals can join** to stay connected with various programs or groups.

SPEAKERS BUREAU

- Sign-up form to be part of a speaker's bureau
- Request a speaker on a topic for your program or organization.
- Listing of speakers on certain topics.

PROFESSIONALS MENTORSHIP PROGRAM

- Sign-up form to be a mentor
- Sign-up form to request a mentor.
- Listing of professionals who want to be contacted for advice.

PATIENT-TO-PATIENT PROGRAMS

- Sign-up form for cancer survivors to be a mentor/ buddy/advocate.
- …which feeds into the existing local p-t-p programs.

VOLUNTEERING/MAILING LISTS

- Submit or browse volunteer opportunities/sign-up.
- List existing local mailing lists
- Archives of participating lists

CRITICAL DEVELOPMENT STRATEGIES

- For the speakers bureau and professional mentorship plans, seek out initial individuals who already do speaking engagements/informal mentoring of new professionals for initial listings of people and topics.
- Outline initial guidelines for a speakers bureau or professional mentorship program
- Partner with existing patient-to-patient programs to explore how to add survivor sign-ups into their databases.
- Compile and synthesize current volunteer opportunities for all groups
- Compile existing lists and talk to owners of all local mailing lists.

OTHER PARTS TO DEVELOP

Essential items to be written, formalized, and developed.

ITEMS TO DEVELOP

Online Features

Video guide/tutorials

People to welcome new members

Promotion of the Site

Partnering organizations

Marketing and Press Release

Outreach to other networks

Interactive booths for cancer survivors day.

Rules and Guidelines

Terms of use

Privacy statement

Mission statement

Posting guidelines

Other Parts to Develop

In addition to the specific sections, there are several essential parts of the online community that need to be written, formalized, and developed.

ONLINE FEATURES APPEARING THROUGHOUT THE SITE

- Video guide and welcome greeters
- Profiles for member individuals and groups (controlled by the individual or group representative)

PROMOTION OF THE ONLINE COMMUNITY WEB SITE

- Official partnering organizations (they are listed in online community + they promote the online community in their materials)
- Marketing outreach to local media and networks (libraries, church, etc.) to publicize the launch in June
- Plan interactive booths for local cancer survivors day events

RULES AND GUIDELINES

- Terms of use and privacy statement
- Official mission/purpose statement
- Rules for the posting of events, resources, and testimonials

CRITICAL DEVELOPMENT STRATEGIES

- Steering committee to guide the writing of rules and guidelines.
- Find one or two professionals and survivors to greet new members
- Find professionals and survivors who want to be "video guides"
- Create promotional material for partnering groups to display or share in their publications
- Create press release and other general promotional material
- Reach local media and other networks through existing relationships of participating groups.

APPENDIX H

Survivorship Network Vision

Let's imagine communication and collaboration in the future…

1) Among local cancer survivors

- Encouragement and support-resources
- Share information about treatments, studies, resources
- Knowledge of facts about disease.

2) For general community awareness

- Help the community to recognize needs of survivors

3) Between cancer organizations and their members/survivors

- Collaboration – greater use of pooling funds
- Advertising of events
- Utilizing strengths

4) Between cancer survivors and family/friends/co-workers

- Education for family and friends, how to support the survivor

Survivorship Network Vision

Let's imagine communication and collaboration in the future…

1) Among local cancer survivors

- Media (T.V., Radio, papers)
- Meeting groups (spt)
- M.D.
- Community leaders (rotary, etc.)
- *Easy to find and define internet info*

2) For general community awareness

- Media Attn:
    - Medical Req
    - Family Focus
    - Financial Impact
- Networking thru: Jobs, Friends, Family

3) Between cancer organizations and their members/survivors

- On line info:
    - Medical
    - Financial
    - Mental health
        - Family

4) Between cancer survivors and family/friends/co-workers

- Support groups
    - There is no centralized information system
    - M.D.s do not support
    - Gather info for awareness of different social/economic impact on survivors and family

Survivorship Network Vision (Research Team)

Let's imagine communication and collaboration in the future…

1) Among local cancer survivors

- Message boards
- Profiles, messaging system, social networking

2) For general community awareness

- Calendar of events scheduled by local groups (conglomerate)
- List groups, contact info, locations
- Links to sites w/pertinent information (NCI, ACS, etc)

3) Between cancer organizations and their members/survivors

- Message boards, emails, messages
- Specific pages within the site for each group
- People can sign-up to get messages from organizations on the site.

4) Between cancer survivors and family/friends/co-workers

- Profiles with "status", pictures,
- Friends et al can get set-up to be notified of changes to profile, receive messages

Survivorship Network Vision (Research Team)

Let's imagine communication and collaboration in the future…

1) Among local cancer survivors

- Connections to like people
- Move toward wellness
- [?]

2) For general community awareness

- Events-not only about cancer, but about life or living
- Message boards/blogs: Screened so that negative people and comments are cut off

3) Between cancer organizations and their members/survivors

- Combine where appropriate for the best [?] for survivor.

4) Between cancer survivors and family/friends/co-workers

- Not much- I am probably too private to readily share.

Survivorship Network Vision (Research Team)

Let's imagine communication and collaboration in the future…

1) Among local cancer survivors

- Every patient that is diagnosed with cancer connects to a group and mentor for advice and support.

2) For general community awareness

- Survivors can connect w/local news stations through the network to tell their story.

3) Between cancer organizations and their members/survivors

- Each group in the community has a private online space where their real-world members can connect between meetings.

4) Between cancer survivors and family/friends/co-workers

- Survivors can connect family/friends/etc. to information on what to expect during treatment and after treatment is complete.

APPENDIX I

Survivorship Network Vision

Let's imagine communication and collaboration in the future…

1) Among local cancer organizations

- Newsfeeds
- Meetings
- Group Calendar
- Wiki?

2) For general community awareness

- Work with churches-org's like TNT
- Newsfeeds
- Talk to Sheila
- Work w/Mayor's office

3) Between cancer organizations and their members/survivors

- Blast emails like my Emma
- Targeted emails (e.g. breast news for breast survivors)

4) Among local cancer survivors

- Forums
- Blorgs/Blog aggregation

Survivorship Network Vision

Let's imagine communication and collaboration in the future…

1) Among local cancer organizations

- Communicating programs that we're doing so that we can leverage funds
- Cross-pollinate
- Submit grants together
- Advocacy opportunities

2) For general community awareness

- A centralized location to post services, programs, etc.
- Make the community more aware of survivorship issues
- Make them aware of ways they can help, such as advocacy

3) Between cancer organizations and their members/survivors

- Let survivors know about programs, services, opportunities to volunteer.
- More importantly would be opportunity for survivors to let orgs know what they need- quickly, confidentiality if they'd like. Way to do survey monkey would be a good way to save funds spend on postage so that we have more $$$ to put towards programs/initiatives.

4) Among local cancer survivors

- Another way to connect people in their geographical area who aren't "group" people or whose schedules and resources aren't conducive to attending groups.
- Survivors can share their experiences/wisdom with one another.

Survivorship Network Vision

Let's imagine communication and collaboration in the future…

1) Among local cancer organizations

- Having each of these organizations have regular group meetings, discussing progress and projects.
    - This would prevent overlap in programming and allow more collaboration

2) For general community awareness

- Local events that show the collaboration between different cancer survivorship orgs to the community
- New developments in research
- Advertising at local public libraries

3) Between cancer organizations and their members/survivors

- Our org doesn't usually deal with survivors, more on prevention.
- Online forums? Chat rooms discussing a topic?
- A "search engine" on the website that would allow survivors to find which local support/advocacy events fit their needs.

4) Among local cancer survivors

- Have people who do not currently associate themselves with a cancer survivorship organization feel comfortable [?] in the collaborative online community to share their thoughts and how they are dealing with survivorship.
- Have survivors [associ-?] with [?] org/community as well as [online?]

Survivorship Network Vision

Let's imagine communication and collaboration in the future…

1) Among local cancer organizations

- Quarterly meetings
- Online communications
- Public policy (coordination, support)
- Partnerships for projects and programs

2) For general community awareness

- Special events
- Media
- Education
- Programs

3) Between cancer organizations and their members/survivors

- Events, such as Ride, Race, Pink Tie
- Newsletters (online)
- Workshops/Seminars/Community Outreach
- Increased funding for grantees

4) Among local cancer survivors

- Support groups
- Online support
- A voice in shaping public policy

Survivorship Network Vision

Let's imagine communication and collaboration in the future…

1) Among local cancer organizations

- Mobilization of the community for policy-i.e. letters, emails to congress on [key?] NIH Funding. Proposal or hearing on a cancer-related issue.
- "Orientation" for new folks to the community.

2) For general community awareness

- Find survivors in response to national or local media inquiries-to help raise awareness of key cancer issues. (PAN)
- Coordinate PR efforts on issues of common concern
- Media partner

3) Between cancer organizations and their members/survivors

- Education/information about cancer research, new developments
- Chats/Q&A to doctors, nurses, other experts re: issues of concern
- Clinical trials

4) Among local cancer survivors

- Forum for exchange of ideas, support, resources
- Mobilize support when survivor/community member is in trouble

Survivorship Network Vision

Let's imagine communication and collaboration in the future…

1) Among local cancer organizations

- Sharing of events (comm), services, fundraising needs, volunteer opportunities (Nashville)
- [have?] a central portal/network/directory/calendar
- List serve
- Develop cancer consortium/network (similar to NCCN?)

2) For general community awareness

- Same as above-links for community opportunities
- Email blasts through individual org to members
- Community advisory boards/focus groups

3) Between cancer organizations and their members/survivors

- News letters (electronic) or written [spec pt? pts]
- Blog

4) Among local cancer survivors

- Something like a blog/list serve
- Networking meetings based on community needs/not disease specific
- Something written for *all* patients newly diagnosed, brochure/etc.

Survivorship Network Vision

Let's imagine communication and collaboration in the future…

1) Among local cancer organizations

- One [like?] one website that lists all cancer events, support group meetings, ways and opportunities to volunteer.
- Each organization would have a link to this.

2) For general community awareness

- For each month of a national cancer awareness have that be the home page for this web-based program with updated info with community contacts for testing, treatment, and support.

3) Between cancer organizations and their members/survivors

- Have links on each organization's web site-info at all cancer centers (brochures)

4) Among local cancer survivors

- Some still like meeting in groups
- Some by phone, and
- Some by email
- Survivors advisory council

Survivorship Network Vision

Let's imagine communication and collaboration in the future…

1) Among local cancer organizations

- An understanding of the give-get relationship in [inter?]-actions between organizations.
    - What we can bring to the table-what you can, too.

2) For general community awareness

- A resource tool-who's doing what when across the cancer care continuum; prevention, detection, treatment, survivorship, palliation.

3) Between cancer organizations and their members/survivors

- Additional resources to share
- Greater understanding of roles and synergistic effect on efforts
- Recognition for volunteers
- Ways to reach the unreachable

4) Among local cancer survivors

- A place to contribute and receive support and information
- Anonymous participation

Survivorship Network Vision

Let's imagine communication and collaboration in the future…

1) Among local cancer organizations

- Sharing services (descriptions and schedules) by subject on a website.
- Referring people to each others' services.
- Developing and sharing new services-and supporting one another in it-without being threatened.
- Recognizing the need and value of each program.

2) For general community awareness

- A general public knowledge that "Nashville has one of the strongest support networks for survivors in the nation."
- Public libraries
- TNT-Tying Nashville Together

3) Between cancer organizations and their members/survivors

- Communication via every means available (mail, web, email, papers), but grounded in personal relationships based on care and trust and confidentiality
- (Search engine)
- Churches, worship, "Y's" community center.

4) Among local cancer survivors

- A common bond and mutual support-a sense of mutual value of experiences, an awareness of all of the various org's as well as the SN.

Survivorship Network Vision

Let's imagine communication and collaboration in the future…

1) Among local cancer organizations

- Sharing services
- Web sites that help with services
- Advertising services of (i.e. Gilda's club)
- [Book?] swapping on cancer related topics

2) For general community awareness

- Websites
- Newspaper articles about cancer survivors

3) Between cancer organizations and their members/survivors

- Websites that help patients navigate their conditions
- Clinics that help patients learn about survivorship issues
- Seminars, etc to help patients understand disease process

4) Among local cancer survivors

- Through online chats
- Websites: myspace pages, etc.
- Local chapters

Survivorship Network Vision

Let's imagine communication and collaboration in the future…

1) Among local cancer organizations

- Not duplicating services
- Be educated about what's available, what each organization does

2) For general community awareness

- Media awareness
- Communication between medical community and (doctors/nurses to) support services

3) Between cancer organizations and their members/survivors

- Staff be aware of what's out there

4) Among local cancer survivors

- Always have a place to come back to no matter how far out of treatment they are.
- Somewhere that provides a comprehensive list of community resources for all stages of "survivorship"

APPENDIX J

2007

Middle Tennessee Survivorship Community Network

December Design Meeting Report

www.survivorshipnetwork.org

Jacob Weiss
Vanderbilt University, Department of Biomedical Informatics
12/18/2007

TABLE OF CONTENTS

ADDITIONAL MATERIALS AVAILABLE ONLINE

"A Collaborative Community" Diagram (1 page)

You may offer your input and discussion of this report on the project web site or by contacting Jacob Weiss.

Meeting Overviews

TUESDAY, DECEMBER 11TH

A meeting with **two cancer survivors**, Jacob Weiss (Principal Investigator), Nancy Lorenzi (Faculty Advisor/facilitator), and Ben Hefner (Vanderbilt Student).

WEDNESDAY, DECEMBER 12TH

A meeting with **11 cancer organization representatives**, including Vanderbilt (VICC, VU, VCH), St. Thomas, Baptist, Komen-Nashville, the Tennessee Comprehensive Cancer Control Coalition, and Gilda's Club.

Many of the organization representatives and survivors participating in this project could not attend the first meeting, but will participate online and/or at the future meetings.

MEETING ACTIVITIES

The primary activity at the meetings focused on a vision for communication and collaboration in a future where there is a local cancer survivorship network. The participants presented and discussed vision ideas in the following categories (based on an "ecological" model of the community):

1) Among local cancer organizations (Wednesday only)
2) For general community awareness
3) Between cancer organizations and their members/survivors
4) Among local cancer survivors
5) Between cancer survivors and family/friends/co-workers (Tuesday only)

The Wednesday participants also completed a short design exercise to suggest a title for the online community/network and begin to envision how the proposed ideas could come together on a web-based layout.

Among Local Cancer Organizations

SURVIVORSHIP NETWORK VISION

COMMUNICATION AND COLLABORATION AMONG LOCAL CANCER ORGANIZATIONS

Getting knowledge/ experience to those that need it

Collaboration, networking, and partnerships – Real world and online

Centralizing resources + connecting beyond

Advocacy and public policy

SNAPSHOT OF IDEAS

Cancer-related book swapping

Query local professionals

A "Myspace" model

Share and "digg" links

A "give-get" model

Value each program in town

Help new orgs grow

A philosophical commitment to each other

GETTING KNOWLEDGE/EXPERIENCE TO THOSE THAT NEED IT

New organizations or new staff members can **learn from other experienced professionals** in the community. When a new staff member joins a cancer-related organization, they can be introduced to the community and learn about the other local organizations and resources.

Staff can **share their knowledge** with each other, such as useful web links, or by coordinating cancer-related book swapping. An organization may be able to query a network of professionals to gather feedback and advice (e.g. on best practices).

CENTRALIZING RESOURCES + CONNECTING BEYOND

Have **centralized community-wide listings** for events, services, support groups, news, and viewable by subject.

Include national events on the calendar as well, so local programs can be planned with those in mind.

Include ways for people who are not online to access the resources of the online community, such as through **printed materials and papers.**

COLLABORATION, NETWORKING, AND PARTNERSHIPS: REAL WORLD AND ONLINE

There is a need for an **umbrella organization with sub-groups** for different topics and interests (this fits with many aspects of the Tennessee Comprehensive Cancer Control Coalition). Additionally, there is a desire for a **"myspace model"**- a less structured social networking approach to connect individuals and groups.

We need to recognize that "as wonderful as the web is, this kind of **philosophical commitment to each other** has to take place at least initially **in person**.

In thinking about a centralized events calendar, we need to "move beyond a calendar to a **'give-get model'**-I don't think we need just another listing of what's happening, I think we need to figure out a way that we can **partner and synergize** it between the organizations."

ADVOCACY AND PUBLIC POLICY

A tool to **mobilize the community members** for influencing voting on legislation (e.g. smoke free workplace, funding for research, etc.)

Survivorship Network Vision

COMMUNICATION AND COLLABORATION FOR GENERAL COMMUNITY AWARENESS

Community Partnerships and Networking

Range of topics needing awareness

Community recognition on a national level

Ways to get the word out

SNAPSHOT OF IDEAS

- Partner with existing networks and communities
- Awareness through social networking
- Connect medical and support services
- Work with the media
- Awareness of ways to help
- Focus on financial impact
- Mental health issues
- New research developments
- Prevention through continuum of care
- Edu-tainment
- Theme of the month
- Blogs, podcasts, and videos
- Coordinate PR efforts
- Public knowledge of Nashville's strengths

General Community Awareness

COMMUNITY PARTNERSHIPS AND NETWORKING

Knowledge of, and partnering with, **relevant organizations, communities, and events** (faith-based, libraries, government, music industry, veterans, rotary, etc.).

Connect between the **medical community** and support services (including doctors and nurses). Also include a community advisory board.

Coordinate a **"speakers bureau"** of survivors, as well as professionals, available for community organizations and events.

Networking through employees to spread the word.

Work with the media to connect them to local survivors to interview. Small towns "thirst" for stories to print. Also, educate the media about survivorship issues that need to be addressed.

COMMUNITY RECOGNITION ON A NATIONAL LEVEL

A general public knowledge that "Nashville has one of the **strongest support networks** for survivors **in the nation**"

RANGE OF TOPICS NEEDING AWARENESS

Community awareness of survivorship issues that the public is not familiar. (e.g. financial impact on families).

An inclusive focus on **prevention through the continuum of care**.

Mental health of patients and families.

Sharing new developments in **research**.

Make the community aware of **ways they can help**, such as advocacy.

Medical care/topics **specific to geographical communities**.

WAYS TO GET THE WORD OUT

Develop **"Edu-tainment"**: Fun and creative ways to educate the public.

Create a **theme of the month** for each cancer awareness month by changing the front page online and linking to monthly programs.

Use **new media** such as blogs, podcasts, and streaming videos.

Coordinate PR efforts on issues of common concern to all organizations.

Between Organizations and Survivors

SURVIVORSHIP NETWORK VISION

COMMUNICATION AND COLLABORATION BETWEEN CANCER ORGANIZATIONS AND THEIR MEMBERS/ SURVIVORS

Reaching out to survivors

Receiving from survivors

Providing education, information, and advice

Celebrating survivors and community events

SNAPSHOT OF IDEAS

- Use multiple types of media
- Staff needs to be aware of what's out there
- Each org has a profile and private space online
- "Reach the unreached"
- Get input from survivors on what they want and need
- Donations/raising money
- Volunteering
- Home for blogs
- Search function for finding specific resources
- Workshops, seminars, etc.
- Recognize volunteers
- Rides, races, and balls
- Survivors appreciate collaborative events

REACHING OUT TO SURVIVORS

Organizations can connect to survivors by **multiple types of media** (blast emails, e-newsletters, phone, letters, etc.).

Staff need to be aware of what's out there to inform their members and patients. **Brochures for the online community** can be placed in cancer centers and community organizations.

Each organization can have a **profile and private space** in the online community for their members and groups.

We need to find a way to **"reach the unreached."**

RECEIVING FROM SURVIVORS

Organizations and staff need a way to **get input from survivors** to learn what they want and need (this can help determine services and programs to offer).

Non-profit organizations also receive **donations and fundraising** efforts from their members.

Provide people with ways to get involved and "**volunteer now**!""

PROVIDING EDUCATION, INFORMATION, AND ADVICE

Create a **home for blogs** and live chats with experts.

People should be able to **search to access specific topics** quickly.

There is a need for **workshops, seminars**, education about cancer research, and clinics that educate on survivorship issues. These resources may exist in the real-world and/or in the online community.

CELEBRATING SURVIVORS AND COMMUNITY EVENTS

A place to **recognize and show appreciation** for volunteers.

Celebrating survivorship with events such as **rides, races, and balls**.

Survivors appreciate events where multiple organizations **collaborate** (e.g. for Cancer Survivors Day).

SURVIVORSHIP NETWORK VISION

COMMUNICATION AND COLLABORATION AMONG LOCAL CANCER SURVIVORS

A common bond and a place to gather

Sharing information and finding resources

Give a voice to survivors

Opportunities to help other survivors

Characteristics of support

SNAPSHOT OF IDEAS

A Common bond and (virtual) place to go

Myspace model profiles/SN

Blogs and forums

Separate "room" for young adults

Ability to cite references for facts

Voice for affecting public policy

Opportunities to give back

"Cancer Craig's List"

A way to mobilize support for a survivor in trouble

Anonymity and moderation

Need to feel safe

Different types of support in different groups

Real world and phone support are still important

Among Local Cancer Survivors

A COMMON BOND AND A PLACE TO GATHER

Geographically local survivors sharing a **common bond** and sense of mutual value of experiences, with a common **place to go** (especially when sick, if not a "group" person, or when schedules/resources aren't conducive to attend meetings in person).

The **"Myspace" model** of personal profiles and social networking to find other survivors with similar experiences and interests. Also have **blogs and forums** for survivors, and the ability to aggregate existing blogs from outside the community.

Networking based on community needs, but some sections focused on specific groups (e.g. a **separate "room" for young adults**)

SHARING INFORMATION AND FINDING RESOURCES

Share information on **treatment, clinical trials, looking outside the box, news from other parts of the country**-with an emphasis on being **able to cite references** for claimed facts (e.g. pubmed).

GIVE A VOICE TO SURVIVORS

Encourage survivors' **voice for affecting public policy**, and engage a Survivor Advisory Council

OPPORTUNITIES TO HELP OTHER SURVIVORS

A place that offers survivors **opportunities to give back** and help others

A **"Cancer Craig's List"** to share unneeded resources with other survivors

A way to **mobilize support** for a fellow survivor in trouble.

CHARACTERISTICS OF SUPPORT

The ability to remain **anonymous** online

The ability to **moderate** user-generated content and **control** inflammatory messages/people

Need to **feel comfortable and safe** before opening up and sharing

Be able to **move towards "wholeness,"** not always focused on the illness.

Some groups **emphasize information** while others **emphasize emotions** and socializing (but there is still some emotional support when the information shared).

Real-world **groups and local chapters are still important**; utilize all communication channels (online, email, phone, in person).

SURVIVORSHIP NETWORK VISION

COMMUNICATION AND COLLABORATION BETWEEN CANCER SURVIVORS AND FAMILY/FRIENDS/CO-WORKERS

Communication barriers and assumptions

Psycho-social-economic concerns

SNAPSHOT OF IDEAS

Myths, fears, and assumptions about cancer

Breaking down myths/fears is a hard challenge

Caregivers supporting each other

Educating medical professionals on how to treat families.

Mental health needs

Anger, self-esteem, and identity changes

Issues of "life" with family

Economic impact of cancer on family

With family, friends, and co-workers

COMMUNICATION BARRIERS AND ASSUMPTIONS

A need to **clarify myths, fears, and assumptions** held by family, friends, and others about cancer and survivorship (e.g. you can't "catch" cancer).

Breaking down the assumptions of family, friends, and others would be **a very hard challenge**.

Caregivers (e.g. wife of prostate cancer survivor) **need to talk with other caregivers**; friends can't relate.

Medical professionals need to be educated on how to interact with patients and families.

PSYCHO-SOCIAL-ECONOMIC CONCERNS

Mental health needs to be addressed with cancer survivors, and the family should be included.

Cancer survivors may have **challenges with anger, self-esteem and identity** (e.g. the loss of a job and not wearing a uniform anymore)

Need to **gather information on issues of "life"** with family.

The **economic impact of cancer** on the survivor and family (and community).

APPENDIX K

February 5-6, 2008

Middle Tennessee Survivorship Community Network

February Directions and Priorities Worksheet

1) Updates over Time

Regularly Updated Features

_____ Theme of the month
_____ Survivor/Volunteer recognition
_____ Interviews with different local experts

Maintaining Up-to-Date Resource Directory

_____ A few knowledgeable contributors who update the site
_____ Allow members to indicate active groups/resources
_____ Link to existing online resource listings

---

2) Online Environment and Interaction

Organization of the Resource Directory/Map

_____ Google map of orgs/resources
_____ Highlighted topic areas/articles

Style of Interactions between Community Members

_____ Query the community with questions to get advice (Yahoo Answers)
_____ Moderated discussion forums
_____ Chat rooms
_____ Photo sharing
_____ Sharing of stories, experiences, and helpful knowledge
_____ Sharing and recommending links to key web sites
_____ Intranets to share key documents and tools within a team
_____ "cancer craig's list" – donating un-needed items

3) Topics and Populations

Specific Topics to Include

_____ Post-treatment survivorship ("facing forward")
_____ Prevention through continuum of care
_____ Emotional support for health care professionals
_____ Highlight lesser known survivorship issues
_____ Fertility and fertility services
_____ Focus on financial impact
_____ Clarify myths, fears, and assumptions for family and friends
_____ Supportive care and community-based research

Specific Populations to Include

_____ Childhood cancer survivors (children and parents)
_____ Young Adults
_____ Family and friend caregivers
_____ Minorities and Health Disparities

---

4) Collaboration between Organizations

Facilitating Real Synergy between Groups

_____ Event and program development idea sharing
_____ Public events calendar
_____ Compile/archive local email lists

A Real-world Collaborative Initiative to Facilitate

_____ A speakers bureau (survivors + professionals)
_____ Sign up for local patient-to-patient database
_____ A specific grass roots public policy campaign
_____ A referral network among professionals who treat cancer survivors
_____ A collaborative event for cancer survivors day
_____ Job opening listings in local groups
_____ A local mentoring program for professionals and group leaders

5) Giving a “Personality” to the Online Community

Creative and Friendly Atmosphere

_____ “Edu-tainment”
_____ Photo/video daily experiences by members
_____ A place to just hang out and be around other people
_____ Welcome greeters and guides for new members
_____ Live help/instant messaging to navigate information

---

6) Connecting to Health Care Professionals and Community Partners

Connecting Survivors with Health Care Professionals

_____ Connecting researchers and community participants
_____ Connecting program developers with survivors for input
_____ Ask the (local) Expert
_____ Live presentations with interactive questions and streaming video
_____ Sending email blasts to an organization's members

Connecting to the General Public

_____ Connecting with college-age students
_____ Coordinating volunteers and finding volunteer opportunities

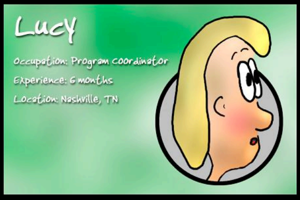
Real-world Partners

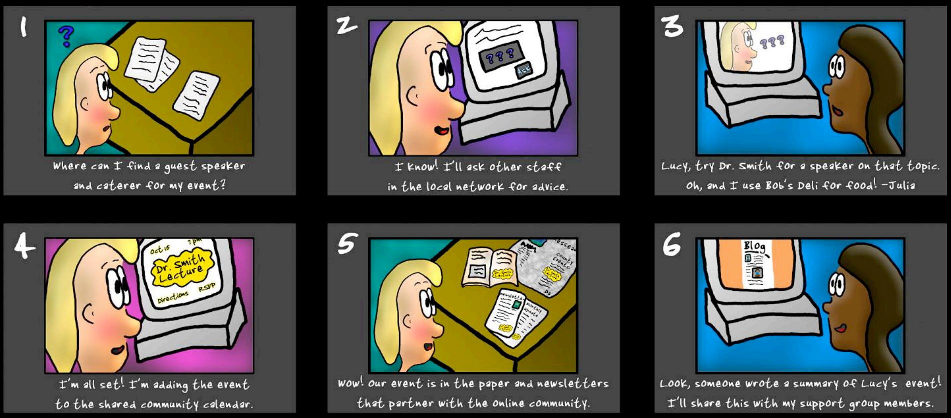
_____ Printed publications (from cancer organizations)
_____ Local papers and magazines events listings
_____ Connect the media to survivors
_____ Storycorps
_____ Other types of networks (libraries, faith-based, clinician networks, etc.)
_____ East/West Tennessee (beyond middle)

APPENDIX L

The Middle Tennessee Survivorship Community Network©

Health Care Professionals



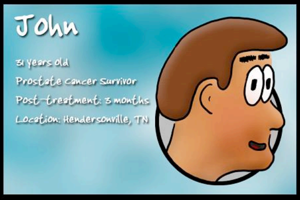


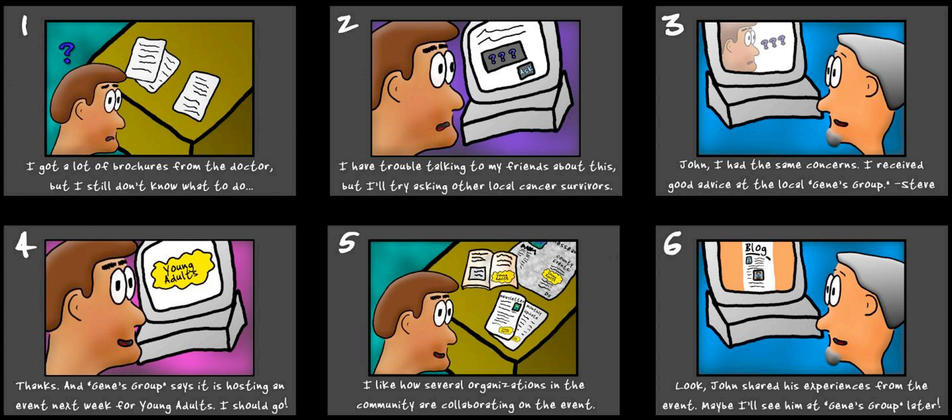
www.survivorshipnetwork.org

Jacob Weiss - Feb 2008

The Middle Tennessee Survivorship Community Network©

Cancer Survivors





www.survivorshipnetwork.org

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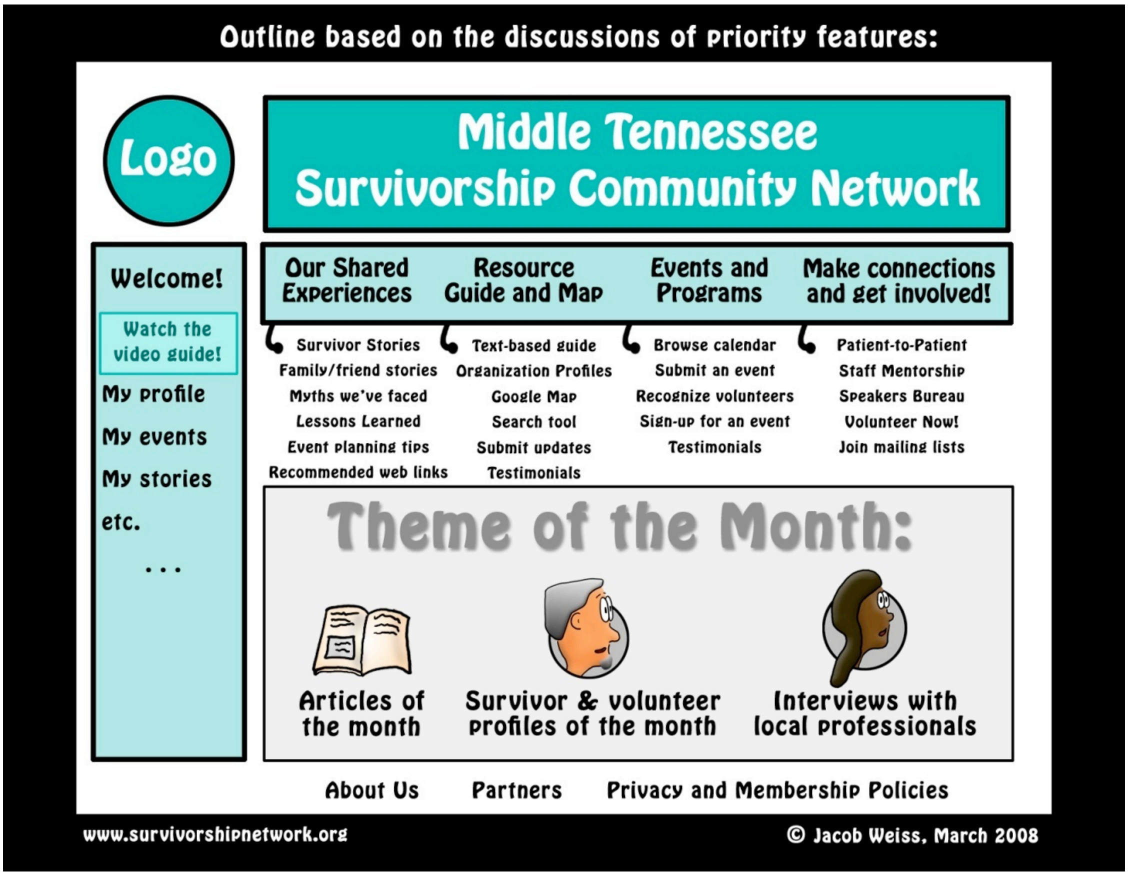
APPENDIX M



Outline based on the discussions of priority features:

Logo

Middle Tennessee Survivorship Community Network

Welcome!

Watch the video guide!

- My profile
- My events
- My stories
- etc.
- . . .

Our Shared Experiences
- Survivor Stories
- Family/friend stories
- Myths we've faced
- Lessons Learned
- Event planning tips
- Recommended web links

Resource Guide and Map
- Text-based guide
- Organization Profiles
- Google Map
- Search tool
- Submit updates
- Testimonials

Events and Programs
- Browse calendar
- Submit an event
- Recognize volunteers
- Sign-up for an event
- Testimonials

Make connections and get involved!
- Patient-to-Patient
- Staff Mentorship
- Speakers Bureau
- Volunteer Now!
- Join mailing lists

Theme of the Month:

- Articles of the month
- Survivor & volunteer profiles of the month
- Interviews with local professionals

About Us Partners Privacy and Membership Policies

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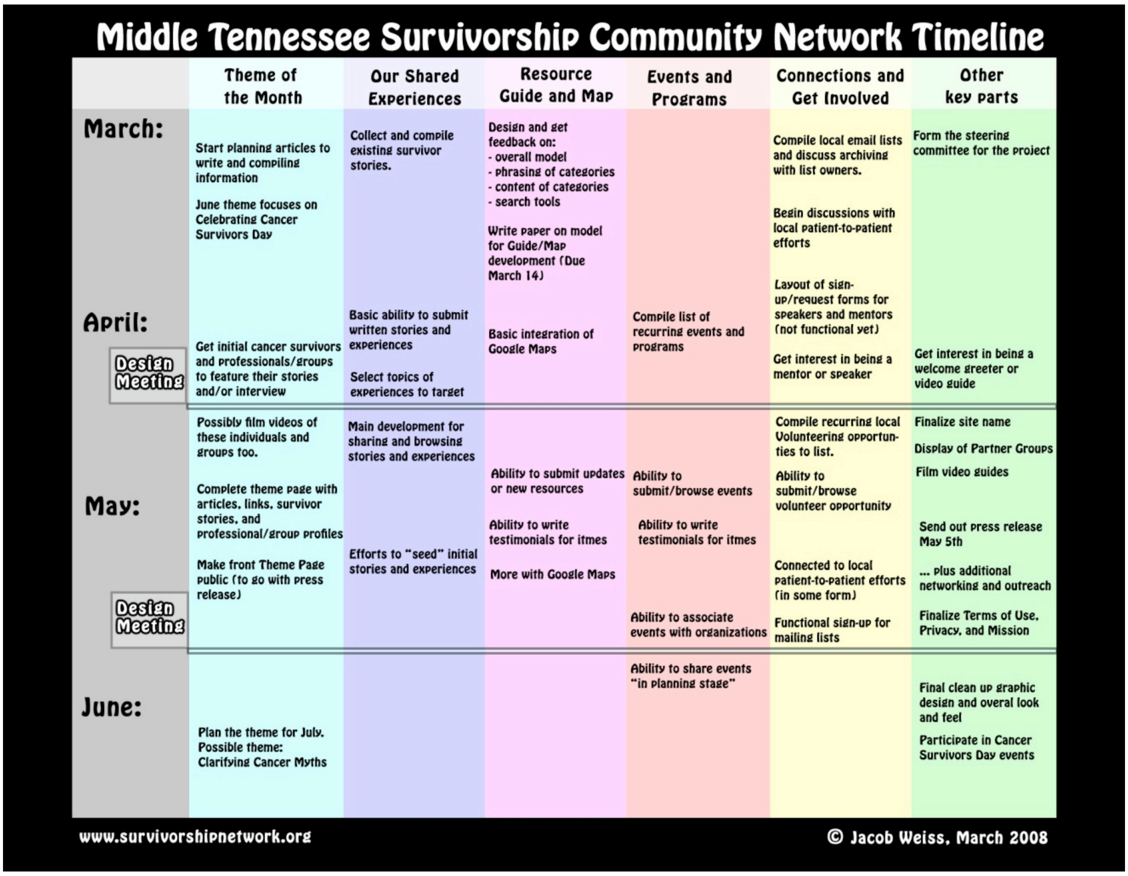
APPENDIX N



Middle Tennessee Survivorship Community Network Timeline

	Theme of the Month	Our Shared Experiences	Resource Guide and Map	Events and Programs	Connections and Get Involved	Other key parts
March:	Start planning articles to write and compiling information June theme focuses on Celebrating Cancer Survivors Day	Collect and compile existing survivor stories.	Design and get feedback on: - overall model - phrasing of categories - content of categories - search tools Write paper on model for Guide/Map development (Due March 14)		Compile local email lists and discuss archiving with list owners. Begin discussions with local patient-to-patient efforts	Form the steering committee for the project
April: Design Meeting	Get initial cancer survivors and professionals/groups to feature their stories and/or interview	Basic ability to submit written stories and experiences Select topics of experiences to target	Basic integration of Google Maps	Compile list of recurring events and programs	Layout of sign-up/request forms for speakers and mentors (not functional yet) Get interest in being a mentor or speaker	Get interest in being a welcome greeter or video guide
May: Design Meeting	Possibly film videos of these individuals and groups too. Complete theme page with articles, links, survivor stories, and professional/group profiles Make front Theme Page public (to go with press release)	Main development for sharing and browsing stories and experiences Efforts to "seed" initial stories and experiences	Ability to submit updates or new resources Ability to write testimonials for itmes More with Google Maps	Ability to submit/browse events Ability to write testimonials for itmes Ability to associate events with organizations	Compile recurring local Volunteering opportunties to list. Ability to submit/browse volunteer opportunity Connected to local patient-to-patient efforts (in some form) Functional sign-up for mailing lists	Finalize site name Display of Partner Groups Film video guides Send out press release May 5th ... plus additional networking and outreach Finalize Terms of Use, Privacy, and Mission
June:	Plan the theme for July. Possible theme: Clarifying Cancer Myths			Ability to share events "in planning stage"		Final clean up graphic design and overal look and feel Participate in Cancer Survivors Day events

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APPENDIX O

Middle Tennessee Survivorship Community Network

May Steering Committee Groups

4/29/2008

In addition to the main May design meeting, we will have sub-groups with more focused discussions.

Contact Jacob Weiss at jacob.weiss@vanderbilt.edu or 615-936-1773 to express interest in a group or multiple groups.

The first groups will require less time and energy, while groups 5 and 6 will involve more in-depth planning and meeting in person.

1) Text Group

Individual phone/email feedback

1. Input on wording of menus and form labels
2. Input on wording of instructions and help text
3. Input on items for professional/survivor personal profiles

2) Content Group

Individual phone/email feedback

1. Contribute initial content for experiences, events, or resources
2. Make sure key community resources or events are not missing
3. Advise or assist with the initial theme of the month stories/articles

3) Testing Group

Individual phone/email feedback

1. Periodically try out the site and offer feedback (when notified by email or phone that new components are added).

4) Marketing Group

Individual phone/email feedback

1. Work with Jacob to guide strategies for marketing and promoting the new site to the community
2. Brainstorm headlines, marketing phrases, etc.

5) Categories Group

Face-to-face group discussion

Individual phone/email feedback

1. Determine the categories for "tagging" resources, events, etc. (e.g. Cancer Type)
2. Add appropriate category "tags" to the existing resources (as a group and individually)

6) Rules Group

Face-to-face group discussion

Individual phone/email feedback

1. Determine what types of content are allowed for…
    a. Shared experiences (e.g. not about treatment)
    b. Types of events
    c. Types of organizations/resources
2. Who can be considered a "partner" group?
3. Overall terms of agreement sections
4. Who can register as a certain role, and how are they verified (professional, survivor, family/friend)

APPENDIX P

Internal Collaborative Functioning Scales

Instructions: Indicate how you feel the collaborative is functioning by circling the number on each scale that you feel is most descriptive of our collaborative.

Shared Vision	**We do not have a shared vision**	1	2	3	4	5	6	7	**We have a shared and clearly understood vision**
Goals and Objectives	**Members do not understand goals and objectives**	1	2	3	4	5	6	7	**Members understand and agree on goals and objectives**
Responsibilities and Roles	**Roles and responsibilities of members are not clear**	1	2	3	4	5	6	7	**Members are clear about their roles**
Decision Making Procedures	**We do not have effective decision making procedures**	1	2	3	4	5	6	7	**We have effective decision making procedures**
Changing Membership	**We do not have procedures for changing members**	1	2	3	4	5	6	7	**We have procedures for changing members**
Conflict Management	**Conflict keeps us from doing anything**	1	2	3	4	5	6	7	**We are able to successfully manage conflict**
Leadership	**Leadership is not shared and inadequate**	1	2	3	4	5	6	7	**Leadership is effective and shared when appropriate**
Plans	**We do not follow work plans**	1	2	3	4	5	6	7	**Plans are well developed and followed**
Relationships/Trust	**People don't trust each other**	1	2	3	4	5	6	7	**Members trust each other**
Internal Communication	**Members do not communicate well**	1	2	3	4	5	6	7	**Members communicate well with each other**
External Communication	**We do not communicate well externally**	1	2	3	4	5	6	7	**Our external communication is open and timely**
Evaluation	**We never evaluate our performance**	1	2	3	4	5	6	7	**We have built evaluation into all our activities**