OVARIAN CANCER WORKSHOP PROGRAM AT THE UNIVERSITY OF PITTSBURGH: SURVIVORS AND CLINICIANS WORKING TOGETHER TO EDUCATE FUTURE PRACTITIONERS

by

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Abstract: Existing programs within ovarian cancer nonprofit organizations where survivors of the disease teach health practitioner students exist, but their evidence base needs to be strengthened in order to better understand their effect and generalizability within current health practitioner education. Amid concerns that health practitioner education does not involve patients in empowering roles or encourage empathy for patients among the soon-to-be medical professionals, giving patients/survivors leadership roles and a forum to have their voices heard is likely to be beneficial to all parties involved. The National Ovarian Cancer Coalition (NOCC) Pittsburgh Chapter has an existing speaker's bureau program that utilizes both clinician and survivor teaching to reach future health practitioners, with a one-hour presentation given on a volunteer basis. The objective of this thesis is to propose an enhanced implementation plan, as well as offer an evaluation plan that will be sustainable for the NOCC Pittsburgh Chapter. Current non-student participants will be polled to build a larger network, with an internal communications strategy laid out to continue to grow and strengthen the program. Students will complete empathy questionnaires before presentations, and again with a two-month follow up survey. Survivor participants will complete empowerment surveys via email. Data will be analyzed and presented to network members regularly via email, with a final in-person presentation at the end of the one-year program. The public health impact of an innovative, evidence-based health education program can be measured in greater survivor involvement and practitioner empathy, with an endpoint of better health outcomes among future patients.

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PREFACE

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1.0 INTRODUCTION

Ovarian cancer is a disease that is difficult to prevent, screen, and treat. Signs and symptoms are nonspecific and vague, which leads to failures - among both sufferers and clinicians - reporting and diagnosing the disease in a timely manner. Because of this, ovarian cancer is rarely caught before it reaches late stages, when the likelihood of survival has dramatically dropped and highly invasive procedures are the only course of action. Future research must advance practitioner knowledge of ovarian cancer etiology, better screening methods, and earlier detection of the disease. Additional education and awareness campaigns are necessary to teach and impassion future practitioners, researchers, and other professionals. Existing programs within ovarian cancer nonprofit organizations use promising and innovative approaches to facilitate survivors of the disease with teaching health practitioner students. However, the evidence base for these programs needs to be strengthened in order to better understand the effect and generalizability within existing health practitioner education. Amid concerns that health practitioner education does not involve patients in empowering roles or prioritize empathy for patients among the soon-to-be medical professionals, giving patients/survivors leadership roles and a forum to have their voices heard is likely to be beneficial to all parties involved. Survivors are experts on many aspects of their disease, through experience and by necessity as they navigate the health care system. They have insight that no one else can offer. This applies to experiences other than

ovarian cancer as well, although ovarian cancer is well suited for patient/survivor input as many factors relating to etiology, risk, and treatment are not well understood and currently require individualized care.

The National Ovarian Cancer Coalition (NOCC) Pittsburgh Chapter has an existing speaker's bureau program that utilizes paired clinician and survivor teaching to reach future health practitioners, with a one-hour presentation given on a volunteer basis. Ovarian cancer characteristics, epidemiological data, risk/protective factors, screening options, treatment options, patient advocacy, and survivorship are all touched upon in this presentation. Presenters hand out post-lecture evaluations, but data collection and analysis is currently minimal. The presentations are reliant on volunteer presentation hosts who donate their class time, with only a few presentations per semester on average.

In order to build a more involved and sustainable program, the NOCC Pittsburgh Chapter requires an enhanced implementation plan that can help resolve recruitment, scheduling, and evaluation limitations. This thesis will begin with an exploration into the epidemiological profile of ovarian cancer, a review of oncology education interventions, and the first steps towards creating a theoretical framework to explain the unique context of survivors as teachers. An implementation plan will then delve into the specifics of enhancing the current program, as well as a budget. The evaluation plan will outline the metrics and tools to help NOCC Pittsburgh understand the processes and outcomes of the enhanced program. The conclusion will discuss limitations and steps forward after the one-year program is complete.

2.0 BACKGROUND

A variety of factors influence the rationale and likely effectiveness of including survivor teaching in existing health practitioner education. This section will seek to explore the specific case for ovarian cancer survivor involvement, although many of these points can be made for other health issues and other actors as well. An epidemiological profile of ovarian cancer itself will be followed by specific information on the teaching of oncology to future health practitioners, with the two synthesized into a theoretical background that might help to focus efforts.

2.1 EPIDEMIOLOGICAL PROFILE

Ovarian cancer kills. A comparison of diagnosis and mortality rates reveals that nearly as many women die as those who discover they have the disease each year. Despite accounting for only 4% of cancer cases among women, ovarian cancer causes more deaths than any other female reproductive cancer worldwide (Permuth & Sellers, 2009). The five-year survival rate of ovarian cancer has remained largely stable over the past 50 years (Kurman & Shih, 2010). One in seventy women will be diagnosed with ovarian cancer in her lifetime, and only about 44% of those women will survive the first five years after diagnosis, as opposed to nearly 70% of those

diagnosed with female genital reproductive cancers as a whole (SEER; Permuth & Sellers, 2009).

An estimated 204,000 new cases of ovarian cancer are diagnosed each year, and 125,000 deaths are attributed to this disease, with 22,430 new cases and 15,280 deaths attributed to the disease in 2007 in the United States alone (Permuth & Sellers, 2009; Sankaranarayanan & Ferlay, 2006). In the United States, the age-adjusted ovarian cancer incidence rate was 11.8 per 100,000 women in 2009 (U.S. Cancer Statistics Working Group, 2013). Pennsylvania had a 2009 incidence rate of 13.1 per 100,000 women (U.S. Cancer Statistics Working Group, 2013).The same database puts U.S. and Pennsylvania mortality rates at 7.8 and 8.8 per 100,000 women respectively in 2009 (U.S. Cancer Statistics Working Group, 2013). Pennsylvania had the second highest incidence rate of all US states and ranked 8th in mortality (Centers for Disease Control and Prevention).

The American Cancer Society uses a system that stages ovarian cancer by the extent to which it is: localized, regional, or distant (American Cancer Society, 2013). Stage I is purely localized to the ovaries, stage II has spread to other organs in the pelvis, but not yet to the lymph nodes or abdomen lining, stage III includes either the lymph nodes or abdomen lining, and stage IV means that the ovarian cancer has spread beyond the abdomen into other parts of the body such as the liver or lungs. Ninety-two percent of women diagnosed at a stage when cancer is localized to the ovaries survive their first five years after diagnosis (American Cancer Society, 2013). Unfortunately, only 15% of cases are detected in this stage; 61% of cases are detected at the distant stage, when the cancer has spread well beyond its original site and the five-year survival rate is only 27% (American Cancer Society, 2013). The overall five-year survival rate

for ovarian cancer is 44%, which means that less than half of women who learn they have ovarian cancer will be alive five years later (American Cancer Society, 2013).

Epithelial ovarian cancer accounts for 90% of cases, but there are a variety of types and origins of ovarian neoplasms, many of which have poorly understood causes and risk factors (Jelovac & Armstrong, 2011; Permuth & Sellers, 2009). Most patients respond to platinum treatment but then experience recurrence (Jelovac & Armstrong, 2011). Less than 10% of cases are tied to three specific genetic traits (BRCA1, BRCA2 and Lynch Syndrome), and non-genetic risk factors are widespread, with the most strongly supported ones relating to hormones and reproduction (Sankaranarayanan & Ferlay, 2006; Permuth & Sellers, 2009; Jelovac & Armstrong, 2011). Pregnancy is a protective factor, with the risk of ovarian cancer falling about 15% per full-term pregnancy, as is the use of oral contraceptives (Permuth & Sellers, 2009). Not surprising, but also not particularly helpful, is the fact that oophorectomy (removal of the ovaries) is protective; one cannot develop cancer in an organ that one does not have (Permuth & Sellers, 2009). One can list a plethora of possible and suspected risk and protective factors, but nearly all of them have inconclusive or conflicting evidence across the literature. Clear etiology has not been demonstrated for the disease (Sankaranarayanan & Ferlay, 2006; Jelovac & Armstrong, 2011).

Screening procedures are also under debate. Screening options include pelvic exam, transvaginal ultrasound, a blood test for a specific cancer marker (CA125), and surgery (Jelovac & Armstrong, 2011). Unfortunately, a statistically significant reduction in mortality among individuals screened by some or all of these measures has not yet been shown (Menon et al., 2009; Buys et al., 2011; Jelovac & Armstrong, 2011). Jelovac and Armstrong (2011) highlight the unique role of surgery in ovarian cancer screening and treatment, including diagnosis,

staging, and treatment. Once identified, most women suffering from ovarian cancer respond well to chemotherapy (especially platinum), however most also suffer recurrences (Jelovac & Armstrong, 2011). In order for a screening protocol to be adopted, it must be adequately sensitive, specific, affordable, non-invasive, and easy to administer; otherwise harms are likely to outpace the benefits of going through the screening process. No current course of action is able to satisfy all of these requirements to meaningfully change health outcomes among asymptomatic women.

One common metaphor for ovarian cancer is as a "silent" or "whispering" killer, as the signs and symptoms are easy to miss for sufferers and diagnosticians alike (Jasen, 2009). Early signs and symptoms are nonspecific to ovarian cancer, although persistence of symptoms for over 12 days a month over the course of a year has been found to be a useful predictor of the disease (Goff et al., 2007; Jordan et al., 2010; Lim et al., 2012). These symptoms, first codified into a symptom index by Goff et al. (2007), are: pelvic or abdominal pain, urinary urgency or frequency, increased abdominal size or bloating, difficulty eating or feeling full. They were shown to be statistically associated with ovarian cancer. Unfortunately, a formalized index made up of these symptoms has not yet been shown to be effective at reducing mortality, even in conjunction with other screening methods (Andersen et al., 2010).

Symptoms associated with ovarian cancer
Pelvic/abdominal pain
Urinary urgency/frequency
Increased abdominal size/bloating
Difficulty eating/feeling full

Figure 1. Ovarian cancer symptom index

Currently, if there are no reported signs or symptoms, and in absence of a family or genetic predisposition towards ovarian or breast cancer, screening is not recommended for women. At the same time, the signs and symptoms listed above are often not considered to be serious nor connected to one another, and therefore not reported or diagnosed with ovarian cancer in mind. This all adds up to a difficult situation where early diagnosis and screening methods are both inadequate. At this time, many of the factors associated with ovarian cancer incidence and survivorship are not easily modifiable. A relative stagnation in medical advances to significantly affect mortality rates among affected individuals point towards an increased need for additional research and new ways to approach this disease.

While risk factors are difficult to isolate and often not modifiable, awareness of them, as well as signs and symptoms, disease progression, and screening and treatment options are modifiable. The need for increased awareness has been documented, among both at-risk groups and health professionals. Multiple studies have shown a low awareness of the signs, symptoms, risk factors, and other facts about ovarian cancer, as well as misconceptions among women and practitioners (Lockwood-Rayermann et al., 2009; Fallowfield et al., 2010; Low et al., 2013). Gajjar et al. (2012) surveyed general practitioners and found a lack of consensus on the risk factors and symptoms of ovarian cancer. One literature review points towards a two-delay model in ovarian cancer care in which person-based delays and primary health care delays both cause women to get treatment later in the progression of the disease (Boughton & Jayde, 2012). Person-based delays arise from women feeling uncomfortable rather than ill, due to the characteristics of ovarian cancer signs and symptoms (Boughton & Jayde, 2012). Health care provider delays arise mainly from misdiagnoses in which symptoms are treated individually instead of recognized as part of a larger pattern (Boughton & Jayde, 2012).

Despite the bleak picture painted in this epidemiological profile, or perhaps especially because of it, steps must be taken to improve health outcomes for those affected by ovarian cancer. The importance of continued research and technological advancement in understanding the disease cannot be understated. However, there is another aspect of this picture that we can begin to shift, and that involves the dissemination of information to key individuals. Individuals who will treat these patients in the future, or who will decide to devote their career to answering the many questions that ovarian cancer still leaves unanswered. In order to create change, awareness is the first step.

2.2 INTERVENTION LITERATURE REVIEW

Both of the delays mentioned above can be ameliorated through education. Lockwood-Rayermann et al. (2009) and Boughton & Jayde (2012) specifically cite the potential role of nurses in increasing awareness of symptoms and risk factors among women. Loerzel (2013) echoes this recommendation, but points out the fact that less common cancers often get short shrift in existing curricula. Awareness and education efforts are key to improving health outcomes for those affected by ovarian cancer. It is unreasonable to expect women at risk to understand the facts of the disease when their own health care providers do not have a firm grasp themselves. In the face of this, however, there is not strong literature on the teaching of oncology to future health practitioners.

A 2006 literature review found only 48 articles about teaching oncology to medical students, and found that many innovations were neither studied systematically nor well-documented (Gaffan, Dacre & Jones, 2006). Few had control groups or assignment of

randomized participants, and the results were often focused on student attitudes and were largely descriptive (Gaffan, Dacre & Jones, 2006). One intervention specific to ovarian cancer consisted of a theatrical performance by an ovarian cancer survivor to faculty and students, followed by a panel discussion (Shapiro & Hunt, 2003). Shapiro and Hunt (2003) did not record results beyond immediate understanding and empathy. There are worries that current medical training has a tendency to reduce rather than emphasize empathy among students (Neumann et al., 2011) and that there is tension between professional and compassionate practice (Curtis, Horton, & Smith, 2012). Health practitioners are expected to keep a certain amount of distance between themselves and their patients to maintain their professional role. On the other hand, health professionals need to develop a close enough relationship to foster trust and communication with patients. Managing these two impulses can be difficult, especially without guidance during education and training. Therefore, despite the absence of strong follow-up data, the empathy results alone may point towards better care for these students' future patients (Neumann et al., 2012).

The Ovarian Cancer National Alliance (OCNA) has a program that utilizes survivor expertise to educate future health practitioners about ovarian cancer in a program called Survivors teaching Students® (STS). Three panelists and a facilitator talk to students, covering specific aspects of disease symptoms, risk factors, and progression in addition to telling the personal stories of all three survivors in a one hour period. A short question and answer session follows in which students can interact directly with the survivors. A pre and post test of knowledge measures is given to students and then added to an online database for internal use only. This program has grown across the United States and Canada, and is implemented in over 150 different programs, reaching almost 10,000 students in 2012 (OCNA). Fitch et al. (2011) published findings that included both qualitative and quantitative student and survivor data on

the STS program in Canada directed at undergraduate medical and nursing students. Students and survivors reported positive attitudes towards this style of teaching. Pre and post workshop tests showed a significant increase in knowledge about ovarian cancer, especially in the realms of disease progression, symptoms, risk factors, and perspectives of women upon diagnosis (Fitch et al., 2011). An adapted version of the Ovarian Cancer National Alliance STS® program for baccalaureate nursing students was studied at a large university in Florida showed similar immediate results, but had less encouraging long-term data (Loerzel, 2013).

Student interaction with patients is common in existing curricula, although usually later in their school career and with the patients acting as passive exemplars rather than active teaching roles (Rees, Knight & Wilkinson, 2007). Patients have been shown to play an important role in teaching communication in addition to clinical experience (Jha et al., 2009). There is a growing impetus to expand the role of patients and include them as experts in student teaching, especially in the realm of chronic disease, where students have demonstrated an increased understanding of the experience after in-depth reflection with patients (McKinlay, McBain & Gray, 2009). Rees, Knight & Wilkinson (2007) stress the concept of learning with rather than merely about patients. Campbell et al. (2010) looked into the experience of sickle cell disease patients and found that many of them considered health professionals to exhibit ignorance of the disease, which points to a very clear gap that patients can fill as teachers, if health professionals and students are willing to listen. One problem with current examples is that they are one-time interventions that do not have appropriate follow-up in terms of understanding their impact, and also to reinforce the teaching style. Since they are one-time sessions and the patient-teacher is limited to their own personal experience, students may not get a full understanding of the range of experiences that an illness can elicit. One answer to this problem would be the inclusion of

more patient voices throughout student training. Another problem is that, even when patient voices are included, they are not necessarily a part of education development, and therefore have limited ability to shape students in the existing framework. A one-hour conversation or performance is not likely to have the impact of continued interaction. This may limit the extent to which results can be identified. It is important to keep in mind that patient-centered approaches do not seek to undermine and replace current training, although future study could show that their inclusion in developing training could have large effects on the shape of future health education and health professional understanding of illness. One positive peripheral effect of survivors with teaching roles is that they report satisfaction and empowerment in the process (Fitch et al., 2011). This is a concept worth following up on; empowerment among survivors of a disease due to leadership roles needs further exploration.

2.3 THEORETICAL BACKGROUND

Existing literature on the matter explores many possible theoretical pathways and concepts, some of which will be revisited in the implementation plan. Others are included here to give a more complete picture of the theoretical background surrounding issues of patient/survivor and practitioner interactions and oncology education. Regardless of whether they can be readily evaluated in a workshop program, they are important to consider.

A patient-as-teacher framework can be situated in a larger patient-centered framework, although both suffer from a lack of consensus in the literature (Mead & Bower, 2002; Jha et al., 2009; McKinlay, McBain & Gray, 2009; Holmstrom & Roing, 2010). There is a movement towards patient-centered practices in medicine, but a supporting model still needs to be fully

realized in order to show proof of its effects and value. Mead & Bower (2002) define patient-centered care as having five dimensions: 1. the inclusion of social and psychological outcomes in addition to biomedical factors (biosocial perspective), 2. a patient-as-person understanding, 3. the sharing of power and responsibility between patients and professionals, 4. the development of a therapeutic alliance to create common goals and bond, and 5. a doctor-as-person understanding. These dimensions can be applied to a patient-as-teacher model as well, with perhaps the expansion of the "as-person" dimension to apply to all actors involved, whether they be students, health educators, or patients/survivors.

The Rees, Knight & Wilkinson (2007) article uses what they term the socio-cultural learning theory, which puts learning activities into social context where newcomers develop skills that allow them to move from peripheral participants to full members of a community. They do this through access to activities and artifacts, working within existing power relations to develop an identity. Rees, Knight & Wilkinson (2007) show that patients are often relegated to peripheral roles and struggle to reach fuller participation. Central to this problem is the empowering or disempowering role of relations. Medical students gain power as they progress in medical school, but this mechanism is not often in place to empower patients, who enter and leave the realm of medical training rather than remaining integrated to the process.

Davenport (2000) cites the idea of social reflexivity, or the ability of certain experiences to allow for a reframing of social beliefs and practices. The example in this article is of medical student visits to a free homeless clinic, which offers new perspectives that heighten the learning opportunities of the students. Novel settings and teaching approaches may be valuable in their very newness, as they allow learners new ways in which to view information they have already been exposed to. A survivor volunteer can bring information to students in a new way, such as

interacting with homeless patients made for unforgettable experiences among medical students. Another useful concept is that patients provide an alternative to the professional lens by providing professionals (and future professionals) their own patient lens, which will help practitioners interact with patients in the future and better understand patient experience to affect patient outcomes (Jha et al., 2009; Neumann et al., 2012).

Patient empowerment in and of itself is worth considering as a theoretical concept (Aujoulat et al., 2008). A person affected by illness must redefine themselves in the face of this new addition to their own identities, and this must be taken into account when including patients/survivors in health professional education. Traditional medical training has a tendency to reduce people to their disease, their symptoms, their health outcomes. This is a concept that patients struggle to overcome. Patient empowerment and patient centeredness do not necessarily have a shared foundation, but have been shown to be complementary to one another (Holstrom & Roing, 2010). Holstrom and Roing (2010) point out the basis of empowerment in critical social theory, which links power and shared experience. They further state that power and health are tied in two ways; those with more power experience better health outcomes, but there is also a mechanism for patient empowerment through interactions with the health care system.

Van Den Berg et al. (2013) have created a Cancer Empowerment Questionnaire specifically for cancer survivors, based on four overarching empowerment factors: personal strength, social support, community, and healthcare. The questionnaire has 40 questions, split among the factors above. This questionnaire offers not only an operationalized measure of empowerment that has an evidence base, it is also specifically tailored to breast cancer survivors. This could easily be changed to ovarian cancer with minimal work, and can be a useful metric by

which to gauge empowerment of survivors for the framework of survivor-as-teacher in terms of their perceptions on the four factors listed above.

A more abstract theory that Bleakly and Bligh (2006) propose arises from literary theory, in which patients are compared to literary text that has been assumed to be transparent and single-dimensional, when in fact it is not. Patients are neither transparent to doctors, students, nor even themselves, and their narrative must be given weight alongside more scientific, evidence-based medical knowledge. This is interesting, but difficult to consider in a program of this scope.

Power dynamics are key to the theories proposed for patient-centered care and education. A recurring concept is that patients are rarely considered to be experts in their illnesses, and that they have valuable insight that is ignored. Furthermore, students are socialized into this disempowering power structure early in their school careers, when patients and students alike have much to gain from early access to patients not as passive problem cases, but as valuable partners in providing health.

The patient-as-teacher model needs to be further clarified, but it is clear that there is a strong case for its use. Patients offer a unique view into illness, and that view is seeing increased validation as a useful tool for health professionals. Power relations and the role of the patient needs to be reframed in order to make the most of this tool. Empathy among practitioners and patients has been shown to improve patient outcomes (Neumann et al., 2012), and yet there are not strong mechanisms to encourage empathy among medical and nursing students. Interactions with patients centered on their experience rather than the technical expertise to be gained from using them as clinical examples needs to be further studied, and a grounded theory needs to be created that takes all of these disparate pieces into a unified approach. Input from non-traditional experts should be examined not only in information dissemination and hands-on training, but

also curriculum development. Only then can the true value of these survivors in expanded and more empowering roles be measured and understood.

Different studies have approached and defined these concepts in many different ways, and there is value in creating a practice-grounded theory to further provide evidence for how they interact both in education and in patient outcomes among practitioners. Empowerment, patient expertise and unique experience, social reflexivity as a teaching tool, as well as the collaborative dimensions that are central to the patient-centered model are all useful concepts that can be organized and made into a cohesive whole.

3.0 IMPLEMENTATION

The National Ovarian Cancer Coalition Pittsburgh Chapter currently supports a speaker's bureau in Pittsburgh, which offers survivor-and-clinician-taught lectures to students at the University of Pittsburgh. These outreach efforts are limited by the fact that the program relies entirely on voluntary involvement of a few key individuals, and the organization's need for a concerted monitoring and evaluation effort. This intervention will seek to solve both of these problems by gathering current participants in a cohesive network with a clear communications strategy; collecting and analyzing pre-workshop, post-workshop, and follow up data; and setting up a sustainable maintenance plan for the NOCC.

3.1 PITTSBURGH AS SETTING

As the second largest city in Pennsylvania, Pittsburgh is the seat of Allegheny County, with an estimated 2012 population of 306,211 (US Census, 2014). Allegheny County had a 2012 population estimate of 1,229,338, 81.5% of whom were White, 13.4% Black, 3.1% Asian, and 1.8% Latino (US Census, 2014). Pittsburgh's demographics are more diverse than Allegheny County at large, with 2010 percentages running at 66.0% White, 26.1% Black, 4.4% Asian, and 2.3% Latino (US Census, 2014). Roughly 35% of the Pittsburgh adult population held bachelor's degrees in the 2008-2012 timeframe, which is slightly above average across the state of

Pennsylvania (US Census, 2014). 13.7% of the population was 65-years-old or over in 2010 (slightly less than the state average), and 51.6% of the population was female (slightly more than the state average) in the same year (US Census, 2014).

According to the Pittsburgh Regional Alliance (2013), three of the top ten private employers are in health care or health insurance (UPMC Health System, Allegheny Health System, Highmark, Inc.), and three others are in higher education (University of Pittsburgh, Carnegie Mellon University, Education Management Corporation). Financial services (PNC Financial Services Group, BNY Mellon Corp.) and telecommunications (Verizon Communications Inc., Comcast) round out the list of largest private employers (Pittsburgh Regional Alliance, 2013). UPMC, as the single largest private employer, employed 42,900 people as of 2013, with the University of Pittsburgh coming in second at 12,450 employees (Pittsburgh Regional Alliance, 2013). Between these two private employers lie two governmental employers, the US Government with 19,416 employees and the Commonwealth of Pennsylvania, employing 13,610 people in the Pittsburgh region (Pittsburgh Regional Alliance, 2013). The University of Pittsburgh is important to the region not only because of the people it employs, but also the population that it teaches; there were 28,769 students enrolled at the Pittsburgh campus - 18,429 undergraduate and 10,340 graduate students - in Fall 2012 (University of Pittsburgh, 2013).

The Pittsburgh Regional Alliance reported that 30 hospitals, with a total of 5,428 beds, existed in Allegheny County as of 2011 (Pittsburgh Regional Alliance, 2013). UPMC alone has nine hospitals in Pittsburgh (UPMC, 2014) and many others in the area. Thirty-five UPMC Cancer Center locations with 180 affiliated oncologists also reside in the area (UPMC, 2014). The strong UPMC and University of Pittsburgh presences in the area make it an excellent

location to expand and study the merits of survivor involvement with health practitioner education. Allegheny ovarian cancer rates are above the national and state rates. Allegheny County had an estimated incidence rate of 13.5 per 100,000 women (2006-2010) and a mortality rate of 9.4 per 100,000 women (National Cancer Institute). That translates to 90 deaths and 119 diagnoses each year in Allegheny County alone (National Cancer Institute). These rates are reported to be largely stable (National Cancer Institute).The epidemiological profile detailed above also supports the existence of a regrettably strong foundation and urgent need for a program focusing specifically on ovarian cancer based out of Pittsburgh.

3.2 KEY STAKEHOLDERS

There are a variety of stakeholders involved in this program, which are summarized in figure 2 on page 20. Organizations and identities of stakeholders are both listed in order to clarify the different roles that organizations represent as potential stakeholders. Stakeholders include all people and organizations involved with implementing the program, as well as those who receive the implementation. Additionally, there are a variety of stakeholders that represent more passive roles that can range from referring participants to the program to emotional support of those affected by ovarian cancer.

The National Ovarian Cancer Coalition (NOCC) is a network of local Chapters with a shared mission to raise awareness and educate people across the United States about ovarian cancer. Based in Dallas, Texas, the NOCC began in 1995 (National Ovarian Cancer Coalition). The local Pittsburgh Chapter has existed since 2000, and has one full-time staff member, Mary Urban, and an office in Squirrel Hill. Volunteers and student interns also contribute to the

Pittsburgh Chapter and its day-to-day activities and needs. One of the main pillars of the NOCC is an education and awareness of ovarian cancer campaign that consists of attendance at health fairs, maintenance of a speaker's bureau, and other outreach events (National Ovarian Cancer Coalition). Other pillars include a support network of survivors, kits for newly diagnosed women, and an annual run/walk event.

The University of Pittsburgh is also a central stakeholder, with the Schools of Nursing and Medicine targeted for this program. Faculty gatekeepers currently decide if they want to bring the existing speaker's bureau into their course schedule on an individual basis. It is important to take into account both the factors that lead faculty to include the NOCC presentation and also the barriers they face in doing so. Some amount of staff involvement will also be necessary to reach a greater number of students, and to reach them in a systematic way. As of Fall 2012, the School of Medicine had 2,363 faculty employed and 1,701 staff members, and the School of Nursing employed 93 faculty members and 99 staff members (University of Pittsburgh, 2013). The students themselves are also stakeholders, and the program must be tailored to their needs and interests in order to create any impact. The School of Medicine has a student headcount of 1023 students enrolled in post-baccalaureate studies in Fall 2012; the School of Nursing had 627 undergraduate and 475 graduate students (University of Pittsburgh, 2013). The reach of the program can be evaluated with these numbers (updated as the new Factbooks are published) in mind.

Of the healthcare facilities located in the Pittsburgh area, UPMC has several that would make especially important partners in efforts to expand the current NOCC program. Hillman Cancer Center at UPMC Shadyside and the UPMC CancerCenter at Magee-Womens Hospital of UPMC are both located near campus and focused on women's cancer care and research. UPMC

Presbyterian and UPMC Shadyside are both education sites for University of Pittsburgh students. These are places whose involvement are necessary in the recruitment of passionate clinicians and act as important channels through which to reach survivors in the area, and also committed to the education of future practitioners. Oncologists in Pittsburgh, whether they are affiliated with UPMC or not, are also stakeholders who must be taken into consideration.

Ovarian cancer survivors in the area, as well as their support networks, are vital to the mission of survivors-as-teachers. Their involvement will largely be through UPMC and NOCC mediated pathways, but other opportunities to reach and involve this population must be made throughout the program.

Organization	**Stakeholder Identities**
University of Pittsburgh (medical and nursing)	Faculty, staff, students
UPMC/other Hospitals	Clinicians, patients
NOCC	Staff, volunteers
Other Ovarian Cancer Support	Survivors, family, friends

Figure 2. Key stakeholders

3.3 STAFF AND VOLUNTEERS

The National Ovarian Cancer Coalition Pittsburgh Chapter head, Mary Urban, will be instrumental in supporting efforts to expand the already existing speaker's bureau. Her office, volunteer staff, survivor network, and support network play a central role in achieving a successful and sustainable program. One additional staff member will join existing staff and volunteers. The team leader/evaluator will take the lead on growing NOCC's existing speaker's bureau network, establishing monitoring and evaluation documentation and activities, and scaling up the number of events in which survivors speak directly to future health practitioners.

This staff member will work half-time over the course of the first year of the intervention, leaving behind an infrastructure that can be supported by a volunteer or graduate intern to continue data analysis and maintain the workshops and the network from which participants will be gathered. In order to smooth the transition, the team leader will craft a handbook for future volunteers/NOCC staff.

This program relies on a cadre of outside volunteers to give the workshops. Each workshop requires a trained clinician and a survivor, both of whom are essential to the form and content of the workshop itself (although it is possible that they can both be the same person, if a volunteer is both a clinician and a survivor). Since the program relies so heavily on a purely voluntary workforce, maintaining this volunteer pool is vital to its success. Scheduling workshops relies on the voluntary support of faculty members within the university and the availability of volunteer teachers. This is why one large aspect of this program is focused on the growth and maintenance of this network, in addition to the overarching goal of building a stronger evidence base for the program itself.

3.4 LOGIC MODEL

Specific Objective: In an effort to increase earlier diagnosis and treatment of ovarian cancer and increase the proportion of 5-year survivorship, a survivor-taught awareness and education program will be implemented at the University of Pittsburgh (medical and nursing schools) with workshops starting spring semester 2015.

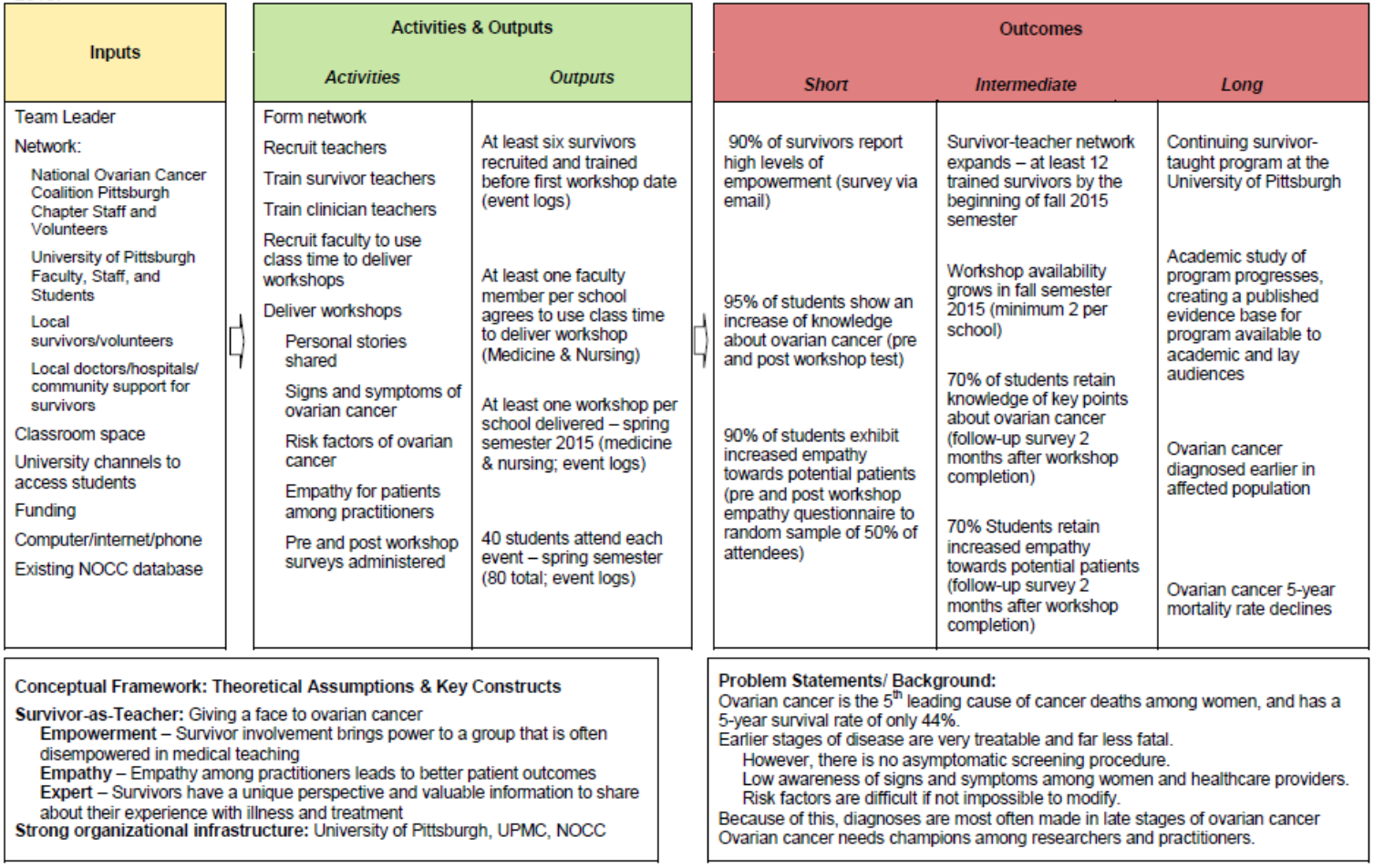

Figure 3. Logic Model of Implementation Plan

3.5 PROGRAM OVERVIEW

3.5.1 Planning Phase

A nine month planning phase will allow the team leader to create a solid network, audit existing workshops, train an extended pool of volunteers, and create the monitoring and evaluation tools to be used in the pilot implementation phase starting spring semester 2015. In order to better visualize the components described below, please see figure 4. The Gantt chart breaks down the activities and their timeline for this phase.

| Preparation Phase | | 2014 | | |

3.5.1.1 Network Formation

In order to convert a preexisting, loosely organized speakers' bureau into an evaluable survivor-taught workshop series, a strong network must be in place with people filling a variety of roles. In order to build this network, NOCC Pittsburgh Chapter staff and volunteers are instrumental. Staff and volunteers agree to participate in the network, and to give contact info and current channels of communications used by NOCC. The team leader will utilize these leads in order to expand the network, via email messages and phone calls to individual contacts who have participated in the program previously. The team leader will follow up with previously-used communications channels as well. NOCC staff will write and approve a script for these invitations that expresses the purpose of the program, the rationale behind its growth and monitoring, the commitment a participant should expect, and the different roles network members will play. Because the network should not be coercive or unduly invasive, participation will be on a purely opt-in basis, with network participants able to remove themselves from the network and any communications lists at any time.

The roles that network members play can be organized in two different ways, by identity and role. Network members will identify themselves as a clinician, survivor of ovarian cancer, university contact, NOCC contact, and/or other. Since these categories are not mutually exclusive, network members may opt in to any identity that they feel represent themselves. Additionally, they will define what roles they are interested in playing within the network: teacher (survivor/clinician), workshop host (university contact), reviewing monitoring and evaluation materials (all), administrative volunteer (all), and referring other contacts into the network (all). Some of the roles can only be played by people subscribing to certain identities.

Role	Identities
Teacher	Survivors, Clinicians
Workshop Host	University Faculty/Staff
M&E Reviewer	Clinician, Survivor, University Contact, NOCC Contact, and/or Other
General Support	Clinician, Survivor, University Contact, NOCC Contact, and/or Other
Referrals	Clinician, Survivor, University Contact, NOCC Contact, and/or Other

Figure 5. Network Roles/Identities

For instance, the workshops are led by clinicians and survivors, so only clinicians and survivors are able to take on the role of teacher. A workshop host must have the authority to schedule class time with health professional students, so faculty member or other university contacts are the only ones who can fill this role. The planning phase will include the creation of monitoring and evaluation tools, and it will be very helpful to have stakeholder input on these materials while they are under development. Any stakeholder can take on this role. Any stakeholder can agree to donate their time to assist in the NOCC office, at workshop sites, or as-needed with other aspects of the program – this role has been labelled “administrative volunteer.” One of the most important roles included in the network consists of referring other individuals, channels of communication, and outreach methods for the continuation and growth of the program.

Working closely with NOCC staff, the team leader will use Google tools (the current preferred set of tools for NOCC Pittsburgh) to organize the network so that all roles are well-represented. This will also offer a clear directive for which roles might create bottlenecks in growing the workshop series program. Without even growth among the different identities and

roles, the program will not be sustainable. Clinician-teachers, survivor-teachers, and workshop hosts are all necessary in relatively equal parts in order to maximize the program. Due to the voluntary nature of all of these roles, new participants will be necessary to sustain even the current amount of reach that the program currently experiences, especially when it comes to survivors, who unfortunately are likely to have a higher turnover rate due to the reality of ovarian cancer survivorship.

The last step to network formation is to set communication guidelines within the network. In order to avoid fatigue, messages should not be sent beyond what is necessary, and should be targeted only to the correct recipients. Teachers will receive a monthly call for workshop scheduling. Hosts will receive messaging about hosting workshops during class time prior to the start of every semester. Each month, a referral survey will be sent to interested participants with generic info about volunteer opportunities supporting the program, as well as an update on the program's general progress. The monitoring and evaluation feedback will be part of the planning phase, and administered only to those who express an interest in contributing, as needed. Follow-up messaging to individuals who respond to mass emails will be done as needed on an individual basis for all message types. These messages will be scheduled regularly and coordinated so that someone signing up for multiple roles will not receive multiple emails in the same week (individual communications notwithstanding).

3.5.1.2 Training and Workshop Auditing

Training for prospective teachers of this program involves two components. Prospective teachers receive the PowerPoint presentation used for all events, which they peruse at their own leisure. In addition, prospective teachers also sit in on existing events, so that they can see the entire presentation before they step in front of a class for the first time. By setting aside an entire

semester before starting the scale-up initiative, new prospective teachers can be trained without modifying this system, so long as the schedules of all parties involved can be aligned. This semester is also an excellent time for the team leader to attend and observe events, in order to craft evaluation tools that accurately reflect the goals and process measures of the event.

3.5.2 Implementation

Once a network has been formed, additional survivor and clinician lecturers have been recruited, and monitoring and evaluation tools have been created, this program can begin to collect data and grow its reach in earnest. Figure 6, on the next page, illustrates what the first semester of implementation (currently scheduled as Spring 2015) would look like, which should also serve as the blueprint for future semesters as well.

Survivor-Taught Workshops, Spring 2015 Semester			2014				2015																													
Gantt Chart		**D**	Nov				Dec				Jan				Feb				Mar				April				May									
Workshops		**16**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**13**	**14**	**15**	**16**																		
	Schedule workshops	8	n	n	n	n	n	n	C	c																										
	Conduct workshops	8									n	n	n	n	n	n	n	n																		
Monitoring and Evaluation		**17**									**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**13**	**14**	**15**	**16**	**17**									
	Administer pre and post test	8									n	n	n	n	n	n	n	n																		
	2 month follow up survey	8																	n	n	n	n	n	n	n	n										
	Network surveys	--									As needed																									
	Analysis	17									n	n	n	n	n	n	n	n	n	n	n	n	n	n	n	n	n									
	Report to NOCC/network	2																								n	n									
Maintenance Phase		**--**	**Continuous**																																	
	Maintain/grow network		Continuous																																	
	Recruit/train new teachers		As needed																																	
Annotations																																				
D	Duration (Months broken into quarters)																																			
n	normal																																			
c	critical																																			

Figure 6. Gantt Chart of Spring Semester 2015

3.5.2.1 Scheduling and Conducting Workshops

Scheduling workshops for the implementation phase will happen well in advance of the spring semester. Individual workshop sessions will ideally be scheduled with prospective host contacts after the semester class schedule has been published, and before syllabi are finalized. Students will be targeted early in their studies, as upper level students spend more time outside of the classroom and in the health care environment. The team leader will target mid-sized classes (30-40 students) in order to reach as many students as possible during each event, while maintaining a setting where students feel they are able to connect and interact with the speakers. Without the interaction, empathy will not likely be fostered to the same extent. First or second year students are a good target for these reasons. Hosts will be a good resource to determine how good a fit a specific class setting poses for the workshop.

Hosts are encouraged to open up their classrooms earlier in the semester, for the sole purpose of having a "captive audience" for a two-month follow-up survey that can be administered by a volunteer during class time (this activity will take 10 minutes). Follow-up data on this type of program has been difficult for researchers to come by, so the convenience of having class sessions where a large proportion of students can be expected to attend regularly is a great boon for evaluation efforts (Fitch et al., 2011). Very high response rates can be expected in a class where attendance is mandatory for each session. This does not mean that workshops can only be scheduled early in the semester, simply that achieving more generalizable follow-up results that reflect the student population at the schools of nursing and medicine is much more feasible and straightforward a process if the same student body can be reached within the same course where the original workshop took place. Other measures can and will be collected for workshops that do not fall into this "sweet spot," but it is unlikely that useful two-month follow

up data will be obtained without a significant additional investment to track down the original participants. Once the class is over, in-person data collection will be difficult and we can only expect results similar to other online surveys. One recent analysis of student surveys found that the average email survey had only a 24% response rate (Millar & Dillman, 2011).

The focus for the first semester of implementing the expanded workshop plan will be to pilot monitoring and evaluation tools, rather than to drastically expand the reach of the program at the University. While the preparatory semester is used to craft the tools, the implementation semester will give the stakeholders valuable process and short-term outcome measures by which to gauge the program's value and justify its continued growth. The reach of the program will expand slowly over the course of multiple semesters, according to the size and participation of the network itself. It is important to note that expansion of the program will eventually lead to a situation in which students will be exposed to repeat presentations. This issue, and potential solutions, will be addressed in the conclusion when future actions are discussed.

3.5.2.2 Monitoring and Evaluation

Monitoring and evaluation components are included in the Gantt chart in order to illustrate their time table alongside implementation. This topic will be revisited in detail in section 4.

3.5.2.3 Network Maintenance

Continual maintenance and recruitment within the supporting network is the only way to make it sustainable. The communications strategy within the network formation activity of the planning phase will be key to maintaining the network. Emails will be sent to network members according to their roles and identities. The specifics of this strategy are not included in the Gantt chart because they will be finalized during the planning phase. At this point it will be useful for the

team leader to create a clear schedule of communications in order to reduce fatigue among network members.

Faculty members and other university contacts who are network members will be asked to schedule workshops before their syllabi are finalized. Individuals will be contacted after workshops in order to provide input regarding the experience, and to remind them of the two-month follow up survey. They will coordinate with the team leader for paper surveys to be delivered to class and collected at the two-month mark in order to gauge any continued effects on knowledge and attitudes of students.

Survivors and clinicians who showed an interest in lecturing will receive periodic calls for scheduling events. Additionally, in order to gauge any possible empowering effects the experience may offer, survivors will also regularly receive empowerment surveys, which can be analyzed with their level of participation in the program.

All network members will receive regular updates, with information on the program and a link to a survey that asks them what recruitment opportunities (be they locations, events, or specific people) they would suggest the program use in order to further grow the program. If any changes are made to the program, the network will also be surveyed, as they represent expertise in different aspects of the program. Attitudes of network members are key, as their enthusiasm and perceived benefits of the program will ultimately decide if the program will flourish.

The Gantt chart specifically includes the training of new teachers, as they are the cornerstone of the program. Survivor teachers are especially important to recruit, as most survivors are also in treatment, and their ability and interest in participating will be highly reliant on their own health. No network participant should feel as if they are coerced or goaded into participating, which is why a larger network is so important. Since the training process is built

into the existing workshops themselves, this process can continue seamlessly so long as workshops are scheduled and participant schedules align. A larger network that is actively growing can create a virtuous cycle where scheduling will be less difficult as more participants volunteer.

3.6 PROGRAM BUDGET

Please refer to Figure 7on the following page for the details of the budget itself. The section that follows provides further notes and justification for the different line items of the budget.

3.6.1 Budget Document

PROGRAM BUDGET					
Personnel	**Hourly Wage per person**	**Expected % Effort per Participant**	**In-Kind Volunteer Contribution**	**Funder Request**	**Annual Total (Includes In-Kind Donations)**
Team Leader	Salaried	0.500		$18,500.00	$18,500.00
Survivor Volunteer Teachers (6)	$21.25	0.050	$12,750.00		$12,750.00
Clinician Volunteer Teachers (3)	Salaried	0.100	$20,400.00		$20,400.00
Administrative Volunteers (2)	$21.25	0.125	$10,625.00		$10,625.00
Personnel Wage Subtotal			$43,775.00	$18,500.00	$62,275.00
Fringe Benefits Calculated at 33% of applicable salary for employee health insurance, FICA, Workers Compensation, Life Insurance, Long-term Disability, and Unemployment Insurance.			N/A	$6,105.00	$6,105.00
TOTAL PERSONNEL			$43,775.00	$24,605.00	**$68,380.00**
Equipment			**In-kind Volunteer Contribution**		**Annual Total (Includes In-Kind Donations)**
Participants will provide their own computers and other equipment, or use resources donated by NOCC Pittsburgh			$5,000		$5,000
TOTAL EQUIPMENT			$5,000.00		**$5,000.00**

Figure 7. Program Budget

Supplies	**Per individual, annually:**	**Weekly estimate of cost:**		**Funder Request**	**Annual Total (Includes In-Kind Donations)**
Mileage for Teachers	$200.00			$ 1,800.00	$1,800.00
Room Reservation		--			--
Advertising		$10.00		$520.00	$520.00
Participation Rewards	$10.00			$500.00	$500 .00
Jefferson Empathy Questionnaire (200)				$700.00	$700.00
Additional Misc.				$100.00	$100.00
TOTAL SUPPLIES				$3,620.00	**$3,620.00**
Contractual	**Hourly Wage per person**	**Expected % Effort per Participant**	**Estimated In-kind Volunteer Contribution**	**Funder Request**	**Annual Total (Includes In-Kind Donations)**
University of Pittsburgh Workshop Hosts (6)	Salaried	0.050	$24,000.00		$24,000.00
NOCC Pittsburgh Chapter Manager	Salaried	0.100	$5,100.00		$5,100.00
Other Network Members	N/A	N/A	N/A	N/A	
TOTAL CONTRACTED			$29,100.00		**$29,100.00**
TOTAL COSTS			$77,875.00	$28,225.00	**$106,100.00**

Figure 7. Program Budget Continued

3.6.2 Budget Notes and Justification

The program runs for one year, and the costs listed should cover all anticipated expenses. Additional explanation for details and cost justifications are below. Overall, $28,225 in funds can be leveraged to cover a program that is valued at $106,100 in equivalent effort and resources. Only one semester of this year will include full implementation of the program. If two workshops are given in Spring 2015, with a goal of at least 40 students per workshop, then 80 students will be reached in the first scaled up semester. Once year one is complete, one can expect to at least double this number, since the next school year will be able to take advantage of the expanded program and its strong framework. The largest single cost by far of this program is to employ the single staff member, which means that the program will be very nearly without costs to the NOCC Pittsburgh Chapter, although it will likely require the creation of an additional intern position and increased use of the NOCC Pittsburgh Chapter Manager's time, which should be expected of a program that is growing. It is worth reiterating that this program does not exist in a vacuum, and many of these tasks are being completed already, albeit in a less formalized manner, under the guidance of NOCC Pittsburgh.

3.6.2.1 Personnel

Team Leader/Evaluator - The team leader works with NOCC to expand a local survivor taught workshop program using local ovarian cancer survivors and their networks, as well as University of Pittsburgh resources to reach health-related disciplines on campus. Key duties during the planning phase include: creating a formalized network, planning a communications strategy, creating monitoring and evaluation tools, and making certain that volunteer teachers are recruited

and trained. Once the implementation phase begins, the Team Leader will focus on the collection and analysis of monitoring and evaluation data, as well as maintaining the network and workshop schedule. During implementation, the Team Leader will also help transition this program into one that can sustainably be supported by existing NOCC staff and volunteers. The Team Leader will work at half-time equivalency, with a projected salary of $18,500[1] (half of the full-time Indeed.com estimate for a Program Coordinator salary in Pittsburgh as of March 12, 2014) with additional fringe support of $6,105 for benefits. This brings the total salary of the Team Leader to $24,605 for the duration of the program.

Survivor Volunteer Teachers (6) - Volunteers will receive a PowerPoint presentation and sit in on existing workshops to prepare to lead their own sessions. Once trained, they agree to conduct hour-long workshops in front of health-focused students. Hours include training, preparation, travel, communications, and the workshops themselves. Schedule will depend on availability and need. Survivor volunteer teachers are expected to work an average of two hours each week. The survivor teachers are estimated to have an hourly wage of $21.25, which is the estimated volunteer wage equivalency for the state of Pennsylvania.[2] A goal of six volunteer teachers will be recruited (including the preexisting volunteers) who are able to devote at least this amount of time to the program. Their donated time is valued at $12,750 throughout the year.

Clinician Volunteer Teachers (3) - Volunteers will receive a powerpoint presentation and sit in on existing workshops to prepare to lead their own sessions. Once trained, they agree to conduct hour-long workshops in front of health-focused students. Hours include training, preparation, travel, communications, and the workshops themselves. The schedule will depend

[1] http://www.indeed.com/salary?q1=Program+Coordinator&l1=Pittsburgh

[2] http://www.independentsector.org/volunteer_time

on availability and need. Clinician volunteer teachers will spend up to four hours per week, as only three of them will be recruited, and they will be attending as many workshops as the six survivor volunteer teachers. Their rate of pay equivalence for their donated time is higher, as a clinician teacher's average salary in Pittsburgh is estimated to be $68,000.[3] This runs to a total combined $20,400 value in donated time among the three.

Administrative Volunteers (2) - Volunteers will work on their own time to help input data, schedule communications, schedule workshops, and do other administrative work for the team leader as needed. Schedule will depend on availability and need. The administrative volunteers should be able to work a combined 10 hour work week, managing communications, collecting and inputting data, and otherwise assisting the Team Leader. The budget accounts for two volunteers working five hours each week, although the work can be split up in other ways as volunteer availability allows. The estimated value of their donated time is a total of $10,625 throughout the year.

Of course, since the program is so reliant on volunteers, and they do not have contracts, this arrangement is likely to differ from the budgeted plans. The number of people accomplishing the work of the program may be different, but the equivalence of their work and effort should reflect these prescriptions. The budget for personnel illustrates that funders will get the equivalent of about two full-time workers for the price of one half-time worker.

[3] http://www.simplyhired.com/salaries-k-clinician-educator-l-pittsburgh-pa-jobs.html

3.6.2.2 Equipment

The Team Leader will use a personal computer. Any additional equipment needs will be met by the NOCC Pittsburgh Chapter, who will donate their facilities, printers, and other equipment as needed. This is estimated to run to about $5,000 in in-kind equivalency.

3.6.2.3 Supplies

Mileage for Teachers - A travel stipend has been included in the budget, with $200 allotted to each volunteer teacher. This is in recognition of the fact that driving time, gas money, and parking can put a strain on volunteers, and that their participation should be encouraged. With nine estimated volunteer teachers, this will total $1,800 annually. In order to minimized costs, the stipend will only be allotted to those who apply for it.

Room reservations - Room reservations are included in the budget, despite the fact that the rooms are all expected to be free of charge, donated by workshop hosts when they offer their class time. Additional office space will be provided for administrative duties by the NOCC Pittsburgh Chapter as needed for the team leader and administrative volunteers.

Advertising - Advertising is included with a maximum of $10 per week, which can be used for online advertising, placing flyers in network-supported locations, and other venues that might have costs that exceed the ability of NOCC to support. This totals $520 for the year. An extra $100 has been budgeted as petty cash of unanticipated needs.

Participation Rewards – In order to foster a sense of community and reward network participants for their time and effort, a small gift for up to 50 participants (teachers, hosts, and others involved in programming) is included in the budget. Teachers, hosts, and other network members who contribute meaningfully to the program's success will all receive recognition and a small reward. Rewards will consist of a certificate of appreciation and a branded commuter hot

beverage mug, estimated to cost approximately $10 per person. These can be handed out at a final meeting of participants at the close of the program, at the same time that results are shared and ownership of the program is passed to NOCC staff.

Jefferson Empathy Questionnaire (100) – This is the only line item of the budget that is purely for evaluation usage, in order to test empathy levels of students who received the intervention. The Jefferson empathy questionnaire consists of twenty questions that have a strong evidence base with physicians, medical students, and health professional students (Fields et al., 2011). Unfortunately, these measures are proprietary, and it costs $600 to order 100 forms. However, this saves the team leader a significant amount of survey formulation and testing time, with 100 forms an adequate number to administer to half of student participants with a pre and post test, and also to administer to student participants at the 2-month follow up point.

Misc. – This budget item is here to account for unanticipated costs, essentially a "petty cash" account for the program. For example, volunteers should not have to worry about spending out of their own pockets if any last-minute supplies are needed at host sites.

3.6.2.4 Contractual

While the administrative volunteers and volunteer teachers were included as staff, the contractual volunteer personnel are ones whose tasks are subsumed into their preexisting duties elsewhere.

University of Pittsburgh Workshop Hosts (6) - Hosts have been placed into contractual labor, as they are performing their duties as part of their roles as faculty and staff members at the University of Pittsburgh. They are expected to use the same amount of effort as the survivor

teachers (up to two hours), which makes their donated time equivalent to about $24,000 annually as a whole[4]. A goal of six hosts is listed in the budget.

NOCC Pittsburgh Chapter Manager – The NOCC Pittsburgh Chapter Manager, Mary Urban, will support the team with her connections, expertise and resources. Since the program is designed specifically for her organization and to facilitate an expansion of her program, she is central to its activities without being an actual staff member of the program itself. Her donated time is estimated to be up to four hours a week, equivalent to $5,100 annually.[5]

Other Network Members - Network member participation is contractual in nature, although there are so many different potential players with potential roles that this is a difficult number to quantify. The network consists of all of the staff and contractual personnel, but others will also play roles, be they oncologists, non-host faculty members, interested community members, or others. No numbers have been given to this line item due to the unpredictable make-up and participation of this group as a whole.

[4] http://www.indeed.com/salary?q1=university+professor&l1=pittsburgh%2C+pa&tm=1

[5] http://www.simplyhired.com/salaries-k-regional-coordinator-nonprofit-jobs.html

4.0 MONITORING AND EVALUATION

One of the two main process goals of this program involves creating and maintaining evaluation metrics to gauge the effects of the workshops as and after they are conducted. Because of this, many aspects of the evaluation plan have been hinted at in preceding sections. This section serves to create a more in-depth picture of evaluation metrics, tools, and processes.

4.1 EVALUATION TEAM

The evaluation team consists of the Team Leader and two Administrative Volunteers, who report directly to the NOCC Pittsburgh Chapter Manager. Not only will the evaluation team report to NOCC, they will also disseminate their findings to the supporting program network on a regular basis.

4.2 EVALUATION PLAN

The evaluation plan has two main sections. A process evaluation matrix outlines the conditions by which successful outputs can be measured. This has been split into the following sections: network formation, training and workshop auditing, monitoring and evaluation tool

development, workshop implementation, and maintenance/network growth. The outcome evaluation matrix focuses on the intended outcomes of the workshops among students, survivors, and network members. Students will be measured for their attitudes and knowledge, as well as their empathy levels. Survivors will be measured for empowerment. The end goal, although it is well beyond the scope of direct impact for this program, is to increase early detection and treatment of ovarian cancer in order to raise the five-year survival rate for the disease in the US population overall.

4.2.1 Process Evaluation Matrices

Network Formation			
Activity	**Outputs**	**Associated Questions**	**Forms/Source of data**
Identify Existing NOCC Contacts	30 contacts gathered	How many people are currently involved in the program? Do we have permission to contact them? How can we best contact them?	-NOCC Pittsburgh Regional Manager
Existing contacts invited to opt in to network	30 contacts invited	How many contacts were successfully reached?	-Email records -Phone records
Contacts opt in and fill out initial survey	33% of current contacts agree to join network Opt ins offer an average of one new potential contact each	How should initial communications email be worded? How should the survey be disseminated? What identities and roles do opt ins self-identify as?	-Email records -Phone records -Initial survey -Google tools
Opt ins are recorded and organized	At least 2 network members identify as potential: clinician volunteer teachers, survivor volunteer teachers, workshop hosts, reviewers of monitoring and evaluation materials		-Email records -Google tools
Communication strategy for future communications established	A schedule of planned email communications divided by roles and identities	How often should participants be contacted? What should communications look like? (script, wording, survey content, etc.)	-Google tools -Gantt chart of communications

Figure 8. Process Evaluation Matrix, Network Formation

Training and Workshop Auditing			
Activity	**Outputs**	**Associated Questions**	**Forms/Source of data**
Identify Survivor Teachers	6 survivor teachers identified	Do volunteers have any limitations or concerns?	-Email records -Initial survey
Identify clinician Teachers	3 clinician teachers identified	Do volunteers have any limitations or concerns?	-Email records -Initial survey
Teachers receive presentation materials	All 9 teachers receive presentation materials		-Email records
Teachers attend an existing workshop	All 9 teachers attend a workshop		-Email records
Team Leader attends existing workshops	At least 2 workshops attended by Team Leader	What aspects of the workshops appear most important? What aspects of the workshops can be used to gauge knowledge measures?	

Figure 9. Process Evaluation Matrix, Training and Workshop Auditing

Monitoring and Evaluation Tool Development			
Activity	**Outputs**	**Associated Questions**	**Forms/Source of data**
Develop network recruitment and attitude survey	Network recruitment and attitude survey framework developed	What attitude measures do we want to collect? (perceived usefulness of program, weaknesses of program, expected number of communications, happiness with network membership)	-NOCC staff
Develop survivor empowerment survey	Survivor empowerment survey developed		-Cancer Empowerment Questionnaire
Develop pre/post test survey for students	Student pre/post test developed	Which measures do we want to collect? How should the measures be formulated?	-Existing post workshop test from NOCC -Audit of existing workshop events -Presentation materials -Jefferson Empathy Scale
Develop 2-month follow up survey for students	Student follow up survey developed		-Existing post workshop test from NOCC -Audit of existing workshop events -Jefferson Empathy Scale -Presentation materials
Test surveys with willing network members	Feedback gathered from at least 3 distinct network members	How can materials be improved?	-Email records
Report to network	Progress reported to network	How do network members want this information communicated to them? How often?	-Email records

Figure 10. Process Evaluation Matrix, Monitoring and Evaluation Tool Development

Workshop Implementation			
Activity	**Outputs**	**Associated Questions**	**Forms/Source of data**
Schedule Workshops for Spring 2015	Six workshops scheduled for Spring 2015	Who is willing to host workshops? Who is willing to teach workshops? How were they scheduled?	-Email records
Conduct workshops for spring	Six workshops conducted in Spring 2015	Who hosted the workshop? How many attendees were present? What course/discipline/level of student was represented?	Attendance logs Pre and post test data
Administer Pre and Post test to students	30-40 matched pre and post tests administered at each workshop conducted		
Administer 2-month follow up survey to students	30-40 follow up surveys administered in class	Who can schedule returning to the course? Should this be matched with pre and post tests?	

Figure 11. Process Evaluation Matrix, Workshop Implementation

Maintenance/Network Growth			
Activity	**Outputs**	**Associated Questions**	**Forms/Source of data**
Integrate new network members	12 new members integrated over the course of the planning period, 12 new members integrated over first implementation period		-Email records -Recruitment and attitude survey
Recruit new volunteer teachers	6 new volunteer teachers sign onto program during first implementation period		-Email records -Recruitment and attitude survey

Figure 12. Process Evaluation Matrix, Maintenance/Network Growth

4.2.2 Outcome Evaluation Matrices

Short Term Outcomes		
Outcome	**Associated Questions**	**Forms/Source of data**
90% of students demonstrate increased knowledge about ovarian cancer	Self-reported and knowledge test questions (See Appendices A and B)	-pre and post test, administered in person
90% of students express satisfaction with the workshop	5-point Likert satisfaction scale (See Appendices A and B)	-post test, administered in person (Appendix B)
90% of students report that the patient perspective influenced their thoughts on ovarian cancer	5-point Likert patient influence scale (See Appendices A and B)	-post test, administered in person (Appendix B)
Baseline empathy of students collected.	7-point Likert scale (20 questions) – see page 52	--Jefferson Empathy Scale (administered to students before the presentation)
80% of survivors report increased empowerment after involvement in the program	5-point Likert scale (40 questions) – see page 52	-Cancer Empowerment Questionnaire, administered by email
90% of network participants report positive attitudes of the program		-recruitment and attitude survey, administered by email

Figure 13. Outcome Evaluation Matrix, Short Term

Mid Term Outcomes		
Outcome	**Associated Questions**	**Forms/Source of data**
70% of students retain knowledge from the workshop in a follow-up survey	Self-reported and knowledge test questions	-follow up survey administered in class (Appendix C)
Students report statistically significant higher empathy levels compared to baseline at 2-month follow up		--Jefferson Empathy Scale
The support network continues to exist and grow		-Google tools -Email records -Attitude and recruitment survey
The capacity of the network to provide more workshops and reach more students grows		-Event logs -Google tools -Email records

Figure 14. Outcome Evaluation Matrix, Mid Term

Long Term Impact **(outside the scope of this evaluation)**		
Outcome	**Associated Questions**	**Forms/Source of data**
Workshop program becomes an integral part of future health practitioner education at the University of Pittsburgh		
Health practitioners demonstrate increased knowledge and understanding of ovarian cancer		
Evidence base grows for patient/survivor as teacher education		Peer-reviewed literature
Higher proportions of ovarian cancer diagnoses are made in earlier stages		
5 year survivorship of ovarian cancer patients grows		-Disease registry incidence and mortality data

Figure 15. Outcome Evaluation Matrix, Long Term

4.2.3 Contribution to Impact

A one-year program will be unable to measure any direct effects upon health practitioners or patients. It is important to keep the long term impact in mind, however, and not get bogged down entirely in the mechanics of the program. The program seeks to raise awareness of a disease that is far too often not thought about or screened for until it is too late. It is not meant to replace current training and education, but to supplement facts with narrative stories and told by people with both clinical and patient experience. Giving a face to a disease that the student may not see for years in practice, this tool raises awareness and also the likelihood that ovarian cancer will be recognized earlier in future patients. Any patient/survivor interaction in which the potential patient acts as expert rather than as a subject can reframe medical care and raise empathy between parties, and hopefully patient outcomes as well. It also offers a productive outlet for survivors of ovarian cancer, who are given the tools to share their stories more effectively and placed in a supportive environment where they know they have the power to help future generations. Strengthening the evidence base for this promising program will give impetus for its expanded use, and may be instrumental in the formation of similar strategies for other diseases and teaching strategies as well. Therefore, while the long term impact might not be possible to measure or determine in the timeframe of this program, it remains a very important part of the puzzle.

4.3 SURVEY DETAILS

Data will be collected on students, survivors, and network members during the course of this program. Students will be tested for their knowledge, attitudes, empathy, and demographics. Survivors will be tested for empowerment. Network members (these are hosts, teachers, NOCC staff, and other interested parties) will be surveyed to determine their roles and identities, recruit potential new members, and gauge their actual and ideal level of involvement with the program.

4.3.1 Student Pre, Post, and Follow-up Test

The evaluation team will use an existing NOCC post-presentation questionnaire (not included in this document) as a basis for the pre and post tests. Demographic data is collected, as well as self-reported knowledge and attitude questions about the content of the presentation. The current NOCC questionnaire asks participants to judge the extent to which the presentation met the following objectives: “review anatomy and types of ovarian cancer; name risk/protective factors for ovarian cancer; identify those at high risk for ovarian cancer; recall screening guidelines for the general population; recognize the symptoms of ovarian cancer; describe the diagnosis and treatment of ovarian cancer; and review ovarian cancer treatment symptom management (NOCC unpublished questionnaire). This information, while valuable, does not collect actual knowledge measures on the different objectives. A multiple-choice or true/false question for each of the seven objectives will be formulated by the team leader/evaluator with the help of existing network members’ expertise and the presentation document (see Appendices A and B for a draft of the pre and post test respectively).

The pre-test will contain demographic data, as well as general self-measured expertise about ovarian cancer, which can be compared with actual knowledge from the measures created around the objectives mentioned above. The post test will resemble the current NOCC post-presentation questionnaire, with an extra knowledge module. Staff will match the pre and post tests using the student names, so demographics will not be necessary. Once complete, the surveys should take up no more than six pages and take no more than five minutes to complete. The follow-up test (Appendix C) will be administered in class two months after the presentation and has the same knowledge measures as included in the pre and post test.

In order to judge any changes in empathy that the presentation may create, the Jefferson Empathy Scale will be utilized, when the additional burden of a 20-question survey is acceptable to students. The questions in this Jefferson Empathy Scale are proprietary, and therefore cannot be fully divulged here. Different versions of the Jefferson Scale are aimed at medical students, physicians, and healthcare provider students. The health provider student scale is a Likert-based one with seven points ranging from strongly disagree to strongly agree (Fields et al., 2011). One example of a question is, "Healthcare providers' understanding of the emotional status of their patients, as well as that of their families is one important component of the healthcare provider–patient relationship" (Fields et al., 2011). Some measures are positively worded, while others are negatively worded. This component will be utilized in the pre test and the follow up test, but not in the post test. Medium term measures of empathy are considered more important than immediate changes after the presentation, and the forms are proprietary. Therefore the empathy post test has been eliminated to reduce the burden on students and also to save money.

Pre, post, and follow-up tests will be matched for analysis. Pre and post test knowledge measures (self reported and test questions) will be compared, with the Likert scales being

subjected to a Wilcoxon signed rank test, and the knowledge measures being given a grade (0-100% correct). Empathy scores follow the same Likert-style In order to demonstrate this, the knowledge questions from the pre test survey have been formalized into a measurement matrix, which is included on the next page.

Question Number	Concept Measured	Level of Measure	Statistical Test
SRK1.	Self-reported knowledge: anatomy and types of ovarian cancer (Likert)	Ordinal	Wilcoxon signed rank with post test measure, Wilcoxon signed rank with follow-up measure
SRK2.	Self-reported knowledge: risk/protective factors of ovarian cancer (Likert)	Ordinal	Wilcoxon signed rank with post test measure, Wilcoxon signed rank with follow-up measure
SRK3.	Self-reported knowledge: high risk population for ovarian cancer (Likert)	Ordinal	Wilcoxon signed rank with post test measure, Wilcoxon signed rank with follow-up measure
SRK4.	Self-reported knowledge: screening guidelines for ovarian cancer (Likert)	Ordinal	Wilcoxon signed rank with post test measure, Wilcoxon signed rank with follow-up measure
SRK5.	Self-reported knowledge: symptoms of ovarian cancer (Likert)	Ordinal	Wilcoxon signed rank with post test measure, Wilcoxon signed rank with follow-up measure
SRK6.	Self-reported knowledge: diagnosis and treatment of ovarian cancer (Likert)	Ordinal	Wilcoxon signed rank with post test measure, Wilcoxon signed rank with follow-up measure
SRK7.	Self-reported knowledge: treatment management for ovarian cancer (Likert)	Ordinal	Wilcoxon signed rank with post test measure, Wilcoxon signed rank with follow-up measure
KT1.	Knowledge test: anatomy and types of ovarian cancer	Nominal	Paired t-test of overall knowledge score (0-100% correct), post and follow-up tests measured separately
KT2.	Knowledge test: risk/protective factors of ovarian cancer	Nominal	Paired t-test of overall knowledge score (0-100% correct), post and follow-up tests measured separately
KT3.	Knowledge test: high risk population for ovarian cancer	Nominal	Paired t-test of overall knowledge score (0-100% correct), post and follow-up tests measured separately
KT4.	Knowledge test: screening guidelines for ovarian cancer	Nominal	Paired t-test of overall knowledge score (0-100% correct), post and follow-up tests measured separately
KT5.	Knowledge test: symptoms of ovarian cancer	Nominal	Paired t-test of overall knowledge score (0-100% correct), post and follow-up tests measured separately
KT6.	Knowledge test: diagnosis and treatment of ovarian cancer	Nominal	Paired t-test of overall knowledge score (0-100% correct), post and follow-up tests measured separately
KT7.	Knowledge test: treatment management for ovarian cancer	Nominal	Paired t-test of overall knowledge score (0-100% correct), post and follow-up tests measured separately

Figure 16. Pre-Test Measurement Matrix

4.3.2 Survivor Empowerment Survey

In order to minimize the burden on survivor-teachers, who are already volunteering their time and likely dealing with a serious medical condition, the empowerment survey must be short and easily accessible. Survivors will be sent an empowerment survey via email when they join the network, which can be compared against empowerment surveys that will be emailed to them the day after their initial presentation, and then routinely every six months (if they maintain an active role in the program). There is an existing survey called the "Cancer Empowerment Questionnaire" that contains 40 items with a five-point Likert scale, and has been used successfully with breast cancer survivors (Van Den Berg et al., 2013). A small change in wording to make the questionnaire pertain to ovarian cancer instead of breast cancer would take minimal effort, and will measure empowerment in terms of personal strength, social support, community, and health care. One example of a personal strength question is, "I decide how to become in charge of my life" (Van Den Berg et al., 2013). Social support is measured by questions like, "I can share my own experiences with others with similar experiences" (Van Den Berg et al., 2013). One community measure altered to apply specifically to ovarian cancer would be, "In our society, people with ovarian cancer are not discriminated against" (Van Den Berg et al., 2013). A health care question is, "My health care professionals and I are in a good cooperative relationship."(Van Den Berg et al., 2013). For a full listing of all the items in this questionnaire, please refer to Van Den Berg et al., (2013).

4.3.3 Network Entrance and Satisfaction Survey

Network members will fill out a survey upon joining the network. This will collect their contact information, their perceived roles and identities, their preferred level of interaction, and information to recruit new members. After the initial opt in, a basic satisfaction survey will be emailed to network members on a monthly or quarterly basis. This is in support of maintaining and improving communications. Network members need to feel involved without feeling burdened by too-much interaction. A short series of five point Likert scaled questions will delve into the quantity and quality of network interactions, as well as open-ended questions about improving the program and about referring new members into the network. This will be used to better reach network members and adjust communication as-needed, and will not be subject to statistical tests. Administrative volunteers will track these surveys each month and report back any abnormalities and data trends to the team leader.

4.4 EVALUATION BUDGET

The evaluation budget is included in program budget. The Team Leader is expected to contribute 75% of his or her time to evaluation activities, with the remaining 25% devoted to the growth and maintenance of implementation processes. The administrative volunteers will split their time evenly between evaluation and implementation. One item, the Jefferson Empathy Scale, is on the implementation budget but is a purely evaluation-related line item.

4.5 DELIVERABLES/DISSEMINATION PLAN

In addition to monthly/quarterly in-network email updates, the Team Leader will meet monthly with NOCC Pittsburgh Chapter Manager to share results and progress. Final results will be shared in person among network members and other interested parties at the University of Pittsburgh in an event where volunteers will also be recognized for their hard work. This will both allow an opportunity to share results and to foster further team spirit among network participants and other stakeholders. Once data has been collected and analyzed, efforts must be made to share results with larger academic and lay audiences, by inclusion on the NOCC website, speaking at conferences and other events, and publishing data to peer reviewed journals. These larger dissemination plans are outside of the scope of a one-year funding plan, however.

5.0 CONCLUSION

The NOCC model for a clinician and survivor taught workshop is one that has not been extensively studied. It currently exists as a voluntary speakers' bureau with few evaluation metrics and very little evidence base. In order to better study the program and gauge its effectiveness, it must be both large enough to reach a significant number of students and collect strong and standardized evaluation metrics. The epidemiological, education, and theoretical background provide a convincing argument to further study such programs. The plan outlined above can scale up an existing program instead of starting from scratch, and has been designed to be sustainable using minimal effort and resources from an already busy organization. With funding, a strong speakers' bureau can become much more, and can set the stage for future patient/survivor-led education and better outcomes for practitioners and patients alike. The following section is split into limitations and prescriptions for moving forward.

5.1 LIMITATIONS

The program relies almost entirely on volunteer workers, which makes it difficult to enforce standards of participation and quality of interactions within the network and at the workshops themselves. The inclusion of a paid staff member can mitigate some of these effects, but as the staff member is not able to take on all roles of the program, vigilance is needed to

maintain and build the program's presence. Since this program will operate outside of an experimental setting, there are real limits on the generalizability of data collected for this program. Since hosting a workshop, teaching a workshop, and following up with workshops are all voluntary acts, there is a strong chance that the settings will not be representative of the university itself, especially at beginning stages..For now, however, the limited time and resources of all participants must be taken into account. Efforts must be made to implement and evaluate this program in a way that is useful for the stakeholders involved, and does not overburden a largely volunteer workforce. For example, this is why there is no strict control group in the plan (a pre-test will simulate this by providing baseline data).

A single workshop does not create the same level of empathy or information-sharing as prolonged contact. We cannot expect one workshop alone to transform medical training or to foster an interest and expertise in ovarian cancer among all students. However, we also cannot argue for any changes without an evidence base, and even one workshop may be able to tip the scales and show the value of reframed student-patient interactions.

One complication to this particular program is that a different organization, the Ovarian Cancer National Alliance, has a similar program that is proprietary in nature, with tools and results not generally shared beyond participants and funders. It is possible in the future that the two programs can be reconciled. It is worth noting that the inclusion of a clinician as well as survivor in NOCC lectures might have different outcomes than a survivor-only panel, so there is reason to support and examine this small program even with the existence of a large, international program already in existence. The lack of OCNA presence in Pittsburgh would make it very difficult to implement the STS program without stepping on the toes of existing NOCC infrastructure in the region. Despite the limitations, this program represents one clear way

in which to better understand the dynamics of survivor-taught events and their place in health practitioner education.

5.2 MOVING FORWARD

The end of this one-year scale up program will require a conscientious passing of the torch from team leader to NOCC Pittsburgh Chapter staff and volunteers. In order to maintain order and address the issue of sustainability, the team leader will help the NOCC Pittsburgh Chapter Manager craft a practicum experience for a University of Pittsburgh Graduate School of Public Health intern, who can utilize the framework created by the program to continue evaluation data collection and analysis. Administrative volunteers will continue their network maintenance and growth work, and the Chapter Manager will continue to devote time to evaluation metrics and network maintenance as well.

As the program grows, the University of Pittsburgh Schools of Medicine and Nursing should be contacted in order to create a more systematic exposure for students. Providing outcome measures to leaders within the schools can prove the merit of the program, and creating a system where students are exposed to the presentation early in their student careers but not exposed multiple times (and creating fatigue among students). This must be managed carefully, as empathy may be undermined in a large lecture setting. A certain amount of interaction and a relatively intimate setting are both needed in order to maintain the connection that makes this program so unique. Until real data can be presented, it is difficult to argue for real integration into school curricula. This is one reason why creating an evaluable program is so important for

the growth of the program. Additional volunteer teachers will continue to be recruited, as attrition rates are likely to remain high.

The next steps for this program would best be served by the creation of a local advisory committee. Stakeholders with the university, NOCC, and the greater Pittsburgh community would act as champions for the program and improve it. Navigating the university requires a strong faculty and administrative presence. Survivors and other volunteers need consistent support. Every actor must feel that their work is valuable, and that the program serves their needs. By bringing representatives to the table on a quarterly basis, we can guarantee that the program will flourish and the community will find real value in its growth.

As evidence for this program grows (and assuming the evidence continues to show the utility of this model), other topics may be integrated into a similar model, which can have broad-reaching effects on student learning and patient outcomes for those treated by practitioners with higher empathy and knowledge.

APPENDIX A: PRE-TEST DRAFT

Presentation Pre-Test

Name: _____

Thank you for your time! This is not a graded assignment, and your answers will not be tied to your class grade in any way. Your name will be used to pair your pre-test, post-test, and follow-up test, and will be discarded afterwards. Participation is voluntary, and will help NOCC gauge the current strengths and weaknesses of the presentation you are about to see. If you do not wish to complete this survey, you may stop at any time.

Directions are in italics.

Section I: Self-Reported Ovarian Cancer Knowledge

On a scale of 1-5, with 1 meaning "strongly disagree" and 5 meaning "strongly agree," please ***circle a number to rate your current level of ovarian cancer expertise*** *on the following measures.*

SRK1. I know the anatomy and types of ovarian cancer

1----------	**2**----------	**3**----------	**4**----------	**5**
Strongly Disagree		Neither Agree Nor Disagree		Strongly Agree

SRK2. I am able to name the risk/protective factors for ovarian cancer

1----------2----------3----------4----------5

Strongly Disagree	Neither Agree Nor Disagree	Strongly Agree

SRK3. I am able to identify those at high risk for ovarian cancer

1----------2----------3----------4----------5

Strongly Disagree	Neither Agree Nor Disagree	Strongly Agree

SRK4. I am able to recall screening guidelines for the general population

1----------2----------3----------4----------5

Strongly Disagree	Neither Agree Nor Disagree	Strongly Agree

SRK5. I am able to recognize the symptoms of ovarian cancer

1----------2----------3----------4----------5

Strongly Disagree	Neither Agree Nor Disagree	Strongly Agree

SRK6. I am able to describe the diagnosis and treatment of ovarian cancer

1----------2----------3----------4----------5

Strongly Disagree	Neither Agree Nor Disagree	Strongly Agree

SRK7. I am familiar with ovarian cancer treatment symptom management

1----------2----------3----------4----------5

Strongly Disagree	Neither Agree Nor Disagree	Strongly Agree

Section II. Demographics

D1. Gender: *(please mark one answer)*

__ Male
__ Female

D2. Age

What is your birthday?

(Please you the following format: Month/Year)

____/_____

D3. Race/Ethnicity

D3a. Are you Hispanic/Latino? *(please mark **one answer**)*

__ Yes
__ No
__ Prefer not to specify

D3b. What is your race? *(please mark **all that apply**)*

__ White
__ African American
__ Asian
__ Other/Prefer not to specify

D4. What best describes the level of education that you have currently **completed**? *(Please select **one** answer. **Do not** include degrees that you are currently working on but have not completed)*

__ High school or equivalent
__ Two-year junior/community college
__ Four-year college/university
__ Graduate/professional school
__ None of the above options describe my education

D5. What is your current occupation? *(Please select **all that apply**)*

__ Student
__ Healthcare Professional
__ Other Professional
__ Volunteer
__ Other (please specify: _____)

D6. Have you attended an NOCC event in the past?

__ Yes
__ No

Section III: Knowledge Test:

This is not a graded assignment, and will be used to get an idea for a baseline level of your knowledge about ovarian cancer before the presentation. Please select the answer you think is best for the following seven questions. Questions are all multiple choice or true/false. ***Please mark only one answer per question.***

KT1. Approximately what percentage of ovarian cancer cases are estimated to come from BRCA1/BRCA2 mutations?

a.) About one percent (1%)
b.) Ten to twenty percent (10-20%)
c.) Forty to fifty percent (40-50%)
d.) Above ninety percent (>90%)
__ I don't know

KT2. Which of the following is NOT a risk factor for ovarian cancer?

a.) Being over 55 years old
b.) Obesity
c.) Using oral contraceptives
d.) Never having children
__ I don't know

KT3. Germline mutations can cause a woman's ovarian cancer lifetime risk to be as high as 40%.

__ True
__ False
__ I don't know

KT4. There is a routine screening protocol to test all adult women for ovarian cancer.

__ True
__ False
__ I don't know

KT5. Which of the following is **NOT** a typical sign or symptom of ovarian cancer?

a.) Fatigue
b.) Difficulty eating
c.) Urinary urgency/frequency
d.) Abdominal pain
__ I don't know

KT6. Which of the following tools is **NOT** used to diagnose ovarian cancer?

a.) Test for the CA125 marker
b.) Pap test
c.) Transvaginal ultrasound
d.) Surgery
__ I don't know

KT7. Symptoms of treatment should **NOT** be addressed unless a patient asks for help managing them.

__ True
__ False
__ I don't know

Section IV: Jefferson Empathy Scale
(proprietary)

Thank you for your participation!

Please hand this survey back to the survey administrator

If you have any questions or concerns about the content of this survey, the presentation itself, or about the NOCC, please contact Mary Urban at murban@ovarian.org or call 412-661-1095.

APPENDIX B: POST-TEST DRAFT

Presentation Post-Test

Name: _____

Thank you for your time! This is not a graded assignment, and your answers will not be tied to your class grade in any way. Your name will be used to pair your pre-test, post-test, and follow-up test, and will be discarded afterwards. Participation is voluntary, and will help NOCC gauge the current strengths and weaknesses of the presentation you just saw. If you do not wish to complete this survey, you may stop at any time.

Directions are in italics.

Section I: Self-Reported Ovarian Cancer Knowledge

On a scale of 1-5, with 1 meaning "strongly disagree" and 5 meaning "strongly agree," please ***circle a number to rate your current level of ovarian cancer expertise*** *on the following measures.*

SRK1. I know the anatomy and types of ovarian cancer

1----------	**2**----------	**3**----------	**4**----------	**5**
Strongly Disagree		Neither Agree Nor Disagree		Strongly Agree

SRK2. I am able to name the risk/protective factors for ovarian cancer

1----------2----------3----------4----------5

Strongly Disagree	Neither Agree Nor Disagree	Strongly Agree

SRK3. I am able to identify those at high risk for ovarian cancer

1----------2----------3----------4----------5

Strongly Disagree	Neither Agree Nor Disagree	Strongly Agree

SRK4. I am able to recall screening guidelines for the general population

1----------2----------3----------4----------5

Strongly Disagree	Neither Agree Nor Disagree	Strongly Agree

SRK5. I am able to recognize the symptoms of ovarian cancer

1----------2----------3----------4----------5

Strongly Disagree	Neither Agree Nor Disagree	Strongly Agree

SRK6. I am able to describe the diagnosis and treatment of ovarian cancer

1----------2----------3----------4----------5

Strongly Disagree	Neither Agree Nor Disagree	Strongly Agree

SRK7. I am familiar with ovarian cancer treatment symptom management

1----------2----------3----------4----------5

Strongly Disagree	Neither Agree Nor Disagree	Strongly Agree

Section II: Knowledge Test

This is not a graded assignment, and will be used to get an idea for your knowledge about ovarian cancer immediately after the presentation. Please select the answer you think is best for the following seven questions. Questions are all multiple choice or true/false. ***Please mark only one answer per question.***

KT1. Approximately what percentage of ovarian cancer cases are estimated to be genetic in nature?

a.) About one percent (1%)
b.) Ten to twenty percent (10-20%)
c.) Forty to fifty percent (40-50%)
d.) Above ninety percent (>90%)
__ I don't know

KT2. Which of the following is NOT a risk factor for ovarian cancer?

a.) Being over 55 years old
b.) Obesity
c.) Using oral contraceptives
d.) Never having children
__ I don't know

KT3. Germline mutations can cause a woman's ovarian cancer lifetime risk to be as high as 40%.

__ True
__ False
__ I don't know

KT4. There is a routine screening protocol to test all adult women for ovarian cancer.

__ True
__ False
__ I don't know

KT5. Which of the following is NOT a sign or symptom of ovarian cancer?

a.) Fatigue
b.) Difficulty eating
c.) Urinary urgency/frequency
d.) Abdominal pain
__ I don't know

KT6. Which of the following tools is NOT used to diagnose ovarian cancer?

a.) Test for the CA125 marker
b.) Pap test
c.) Transvaginal ultrasound
d.) Surgery
__ I don't know

KT7. Symptoms of treatment should not be addressed unless a patient asks for help managing them.

__ True
__ False
__ I don't know

Section III: Post-Event Evaluation

The following questions are about your experience with the presentation itself. On a scale of 1-5, with 1 meaning "strongly disagree" and 5 meaning "strongly agree," please ***circle a number to rate the extent to which you agree or disagree*** *with the following statements.*

PE1. As a result of this lecture I will make a change in my practice/professional responsibilities.

1----------2----------3----------4----------5

Strongly Disagree	Neither Agree Nor Disagree	Strongly Agree

PE2. In an overall sense, I was satisfied with this program.

1----------2----------3----------4----------5

Strongly Disagree	Neither Agree Nor Disagree	Strongly Agree

PE3. I would like to see this program topic repeated in the future.

1----------2----------3----------4----------5

Strongly Disagree	Neither Agree Nor Disagree	Strongly Agree

PE4. Hearing a patient's perspective influenced my thoughts about ovarian cancer.

1----------2----------3----------4----------5

Strongly Disagree	Neither Agree Nor Disagree	Strongly Agree

Additional evaluation questions:

PE5. In the presence of ovarian cancer symptoms, do you know what to do next?

__ Yes
__ No

PE6.The information presented today:

__ Reinforced my knowledge on the topic
__ Increased my knowledge on the topic
__ This information was completely new to me

PE7. Do you have any additional comments or suggestions?

_____

_____

_____

_____

Thank you for your participation!

Please hand this survey back to the survey administrator.

If you have any questions or concerns about the content of this survey, the presentation itself, or about the NOCC, please contact Mary Urban at murban@ovarian.org or call 412-661-1095.

APPENDIX C: FOLLOW-UP SURVEY DRAFT

Presentation Follow-Up Test

Name: _____

Thank you for your time! This is not a graded assignment, and your answers will not be tied to your class grade in any way. Your name will be used to pair your pre-test, post-test, and follow-up test, and will be discarded afterwards. Participation is voluntary, and will help NOCC gauge the current strengths and weaknesses of the presentation you just saw. If you do not wish to complete this survey, you may stop at any time.

Directions are in italics.

Section I: Self-Reported Ovarian Cancer Knowledge

On a scale of 1-5, with 1 meaning "strongly disagree" and 5 meaning "strongly agree," please ***circle a number to rate your current level of ovarian cancer expertise*** *on the following measures.*

SRK1. I know the anatomy and types of ovarian cancer

1----------	**2**----------	**3**----------	**4**----------	**5**
Strongly Disagree		Neither Agree Nor Disagree		Strongly Agree

SRK2. I am able to name the risk/protective factors for ovarian cancer

1----------2----------3----------4----------5

Strongly Disagree	Neither Agree Nor Disagree	Strongly Agree

SRK3. I am able to identify those at high risk for ovarian cancer

1----------2----------3----------4----------5

Strongly Disagree	Neither Agree Nor Disagree	Strongly Agree

SRK4. I am able to recall screening guidelines for the general population

1----------2----------3----------4----------5

Strongly Disagree	Neither Agree Nor Disagree	Strongly Agree

SRK5. I am able to recognize the symptoms of ovarian cancer

1----------2----------3----------4----------5

Strongly Disagree	Neither Agree Nor Disagree	Strongly Agree

SRK6. I am able to describe the diagnosis and treatment of ovarian cancer

1----------2----------3----------4----------5

Strongly Disagree	Neither Agree Nor Disagree	Strongly Agree

SRK7. I am familiar with ovarian cancer treatment symptom management

1----------2----------3----------4----------5

Strongly Disagree	Neither Agree Nor Disagree	Strongly Agree

Section II: Knowledge Test

This is not a graded assignment, and will be used to get an idea for your knowledge about ovarian cancer at the current time. Please select the answer you think is best for the following seven questions. Questions are all multiple choice or true/false. ***Please mark only one answer per question.***

KT1. Approximately what percentage of ovarian cancer cases are estimated to be genetic in nature?

a.) About one percent (1%)
b.) Ten to twenty percent (10-20%)
c.) Forty to fifty percent (40-50%)
d.) Above ninety percent (>90%)
__ I don't know

KT2. Which of the following is NOT a risk factor for ovarian cancer?

a.) Being over 55 years old
b.) Obesity
c.) Using oral contraceptives
d.) Never having children
__ I don't know

KT3. Germline mutations can cause a woman's ovarian cancer lifetime risk to be as high as 40%.

__ True
__ False
__ I don't know

KT4. There is a routine screening protocol to test all adult women for ovarian cancer.

__ True
__ False
__ I don't know

KT5. Which of the following is NOT a sign or symptom of ovarian cancer?

a.) Fatigue
b.) Difficulty eating
c.) Urinary urgency/frequency
d.) Abdominal pain
__ I don't know

KT6. Which of the following tools is NOT used to diagnose ovarian cancer?

a.) Test for the CA125 marker
b.) Pap test
c.) Transvaginal ultrasound
d.) Surgery
__ I don't know

KT7. Symptoms of treatment should not be addressed unless a patient asks for help managing them.

__ True
__ False
__ I don't know

Section III: Jefferson Empathy Scale
(proprietary)

Thank you for your participation!

Please hand this survey back to the survey administrator.

If you have any questions or concerns about the content of this survey, the presentation itself, or about the NOCC, please contact Mary Urban at murban@ovarian.org or call 412-661-1095.

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