Handbook for International Undergraduate Research

A student-created model

Lauren Taylor, 2010
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Introduction

To The Reader:

This manual/model for international undergraduate research has been created for current and future students based on my personal research experiences in Costa Rica and South Africa.

Purpose of this model is to help you (the student) work through the research process so that your international project will be successful. This model includes guidelines for you to follow, exercises to do prior to departure, and tips on how you can make the most out of your time on the ground.

There are several road blocks that come up when doing research in a foreign country and some insight on how to overcome these challenges might help you to avoid certain pitfalls such as language barriers. There were many things that I never even thought about before I left the country. For example, I never would have thought that I would have had to gain national ethical approval for my research in South Africa prior to seeing patients.

I hope that having this document and preparing for this process will help to encourage you to conduct research abroad. In order to try and relate this material to as many students as possible, I have included the experiences of other students, hopefully someone’s project will be similar to the one you plan to pursue.

Regards and Best Wishes,

Lauren C. Taylor
Elon University, 2010
Framing the Discussion

Related literature on undergraduate research

A recent study by Russell et al. (2007), found that students who participated in research opportunities increase their understanding, confidence and awareness of the topic they are investigating. They also were more likely to think about graduate school and obtaining a PhD.

Beyond a few studies (such as the above) that focus on just undergraduate research as a whole, little has been done to investigate the effectiveness, development, or implementation of international undergraduate research. However, this will likely change in the next few years as more universities are offering programs and grants for international research to their bachelor students.

International Organizations for Research

- International Research and Exchanges Board
  http://www.icrw.org/

- International Center for Research on Women
  http://www.irex.org/

- International Ethical Guidelines for Epidemiological Studies
  http://www.cioms.ch

- United Nations Research Institute for Social Development (UNRISD)
  http://www.unrisd.org/

Further Resources:

- Texas A & M University
  http://ugr.tamu.edu/opportunities-1/funding/externalinternational

- International Research and Studies Program
Resources for Ethical Consideration

- International Association for Research on Service-Learning and Community Engagement
  http://www.researchslce.org/

- International Compilation of Human Research Protections (Country Specific Regulations)
  http://www.hhs.gov/ohrp/international/HSPCompilation.pdf

- The Belmont Report
  Please see Appendix III

- The Fogarty/CFAR Research Ethics Website
  http://bms.brown.edu/fogarty/index.htm
Resources at Elon University

The Isabella Cannon International Center (for Study Abroad): ICIC
- [http://www.elon.edu/international](http://www.elon.edu/international)
- Call: 336.278.6700
- Located on the first floor of the Carlton Building
- Set up an appointment to speak with a program advisor if your research will be conducted abroad so you can understand the process of doing an IEPA (Independent Elon Program Abroad)

The Office of Undergraduate Research: URP
- [http://www.elon.edu/undergraduate_research](http://www.elon.edu/undergraduate_research)
- Call:
  - Current Director of Undergraduate Research: Dr. Paul Miller  336.278.5882
  - Administrative Assistant for Undergraduate Research: Mrs. Edie Alexander, 336.278.5652
- E-mail Dr. Miller ([millerp@elon.edu](mailto:millerp@elon.edu)) to set up a time to meet or ask any questions

The Career Center
- [http://www.elon.edu/career_services](http://www.elon.edu/career_services)
- Call: 336.278.6538
- Located in Duke 101
- Set an appointment to speak with a career/ internship advisor

The Lumen Prize
- [http://www.elon.edu/e-web/administration/president/lumenprize](http://www.elon.edu/e-web/administration/president/lumenprize)
- For more information e-mail to: lumenprize@elon.edu
- Current Director: Dr. Paul Fromson  336.278.6451or [fromson@elon.edu](mailto:fromson@elon.edu)

Elon University Fellows and Honors Programs
- [http://www.elon.edu/Fellows](http://www.elon.edu/Fellows)
- Several Fellows Program encourage their students to conduct research abroad and provide some funding for these projects
Periclean Scholars

- [http://www.elon.edu/pericleanscholars](http://www.elon.edu/pericleanscholars)
- For more information contact Dr. Tom Arcaro (*Current* Director of Project Pericles) at 336.278.6442 or [arcaro@elon.edu](mailto:arcaro@elon.edu)
- Apply for the Periclean Scholars Program in March of your first year

The Kernodle Center for Service Learning

- [http://www.elon.edu/servicelearning](http://www.elon.edu/servicelearning)
- Location: Moseley 230
- Call: 336.287.7250
- Set up an appointment to meet with a staff member to discuss your project proposal

National and International Fellowships

- [http://www.elon.edu/e-web/academics/fellowships/](http://www.elon.edu/e-web/academics/fellowships/)
- Coordinator: Dr. Janet Myers [jmyers@elon.edu](mailto:jmyers@elon.edu)
- For more information, please contact Dr. Myers
San Jose, Costa Rica (International Center for Development Studies) Spring 2008

-Research Project:

My research project in Costa Rica was based on a small study I conducted with peers as part of our HSS Research Methods course. Using the same questionnaire, I surveyed university students at ULatina in San Jose, Costa Rica regarding and their knowledge and perceptions of HIV.

-Progression of Research:

This smaller project stemmed out of my Human Service Studies Research Methods Course where I surveyed approximately 50 Elon students regarding their knowledge and attitudes of HIV. Since this initial study was so successful, I decided to replicate it while I studied in Costa Rica.

-Challenges:

Although I spoke Spanish relatively fluently, the language barrier was still a struggle due to the medical terminology in my questionnaire. In order to address this problem, before I left Elon, I asked two staff members who were native Spanish speakers to translate my survey. While studying in Costa Rica, I did not have large amounts of free time in which I could conduct my research. In order to collect my target number of 50 participants, I would have had to spend hours going around to students in the dining area. Instead, I worked with my Spanish professor to have distributing and explaining my survey to function as a class activity. With my ten peers, distributing and collecting the completed surveys took less than an hour for all 50 Costa Rican students.

-What Worked:

Having done a similar project at Elon, I was well-prepared for any questions my perspective participants raised regarding the questionnaire. Before I left, I had native Spanish speakers look over my survey for grammatical errors and cultural sensitivity. As soon as I had collected all of my data, I entered it all into a computer so that I would have all of the coding fresh in my mind.
Cape Town, South Africa (Stellenbosch University) Summer 2009

-Research Project:

This was my main research project that focused on the knowledge and attitudes of midwives in Cape Town, South Africa.

-Progression of Research:

When I first started to work on HIV, I was a first year student. I knew that I was interested in women’s health and the feminization of HIV around the globe. This broad topic was then narrowed down over the course of 2 years.

First, my mentor (Dr. Fair) had me write three separate annotated bibliographies. Each annotated bibliography was on an area within women and HIV and the region of Sub-Saharan Africa (since this is where the highest concentration of individuals infected with HIV reside). The three annotated bibliographies were on: HIV and traditional birth attendants, women and HIV and HIV-related stigma. This process was immensely helpful as it forced me to find gaps in the existing literature and see where areas of further research might be. For example, the myth of traditional birth attendants was quite alluring at first. However, after reading several articles, it became clear that there were simply not enough traditional birth attendants concentrated in one area that I would be able to interview or survey. Additionally, I had originally hoped to do my research in Ghana since it was the country that my 2010 class of Periclean Scholars was focusing on. Yet, the prevalence of HIV in Ghana was much lower than other African countries such as South Africa, where the need for more research and focus was more urgent.

Secondly, based on the literature that I had been reading, I came up with a detailed proposal for my research project. I will go into more detail in the guideline regarding “Project Proposals”.

Third, I contacted professionals on the ground where I wanted to work to coordinate my prospective study.

Finally, I went to South Africa and collected my data.
Challenges:

This research project was much more extensive than my first, smaller-scale study in Costa Rica. One of the biggest challenges was finding someone to work with while I was in South Africa who would be able to allow me to interview/survey participants but also fill my extraneous time with meaningful work.

Elon did not have a program abroad to South Africa for a semester that fit what I was looking to do. Thus, I had to make all of my own arrangements which literally took months. It is important to understand that sometimes communication between countries can be slow and that multiple e-mails or even phone calls may be necessary in order to secure all of your details.

Accessing technology was much harder in South Africa than either the US or Costa Rica which made making additional copies of my surveys cumbersome.

My expectations of South Africa were not fixed; however, it is a more dangerous country which forced me to stay indoors quite a bit at night. This allowed me to get all of my data entered before I left but also gave me a bit of cabin fever.

What Worked:

In order to focus solely on this project, I chose to go over the summer so that I would not be trying to manage my classes with my research.

By working a lot for the department that I partnered with up front, I gained their respect which opened many doors for contacting and surveying more participants.

Entering all of my data into excel before I even came home lightened the amount of analysis that I had to do back at Elon.
Guidelines

These seven guidelines are meant to be a starting point for you to begin and work through the process of doing research on an international level. Depending on your research focus and country of interest, some of these ideas may or may not apply to you.

1. **Find a faculty mentor who has expertise in your area of interest and review the process for doing an Independent Elon Program Abroad (IEPA) through the Isabella Cannon International Centre**

2. **Plan Ahead: The proposal, IRB and related literature**

3. **Establish Contacts in Your Host Country**

4. **Develop an Alternative Plan**

5. **Have Patience and Be Flexible**

6. **Communication on the Ground**

7. **Remain Positive**
1- Faculty Mentor

“Somewhere, something incredible is waiting to be known.”
~ Dr. Carl Sagan

The Big Ideas:
◆ Find a faculty mentor at Elon (or two) who will be able to guide you during your research project
◆ Be able to call in reinforcements
◆ Turn to the literature and your mentor’s expertise as a starting point

At this point, you may have a wonderful idea (or two). You may have an area of interest or are looking to expand upon a previous project. Now you need someone to help guide you from your foundation of interest and excitement into a feasible plan. This is exactly what a research mentor is for. As an undergraduate, it is not expected that you know all of the “ropes” about research or even international research. Ask around and try to find a faculty mentor at Elon who has similar interests, who would be willing to help you along your research journey. It is possible that there is no “one” mentor who will fulfill all of your needs. For example: although my mentor has her expertise in HIV and maternal health, she has never been to or studied Africa. In this case, I met with Dr. Layne and Dr. Frontani who have strong backgrounds in Africa and more specifically, South Africa.

When looking for a mentor, ask a lot of questions:

- What would you expect of me as your research student?
- How many research students have you had in the past and what have they worked on?
- What can I expect of you as my mentor?
- What would the final product of our research look like?

One of the best ways that your mentor can help you in your research is to point you to appropriate articles and literature related to your topic. This is an essential piece of all research and your mentor can help you answer the question: What is the current discussion surrounding my topic and what can I contribute? The answers to this are often excitingly complex and intriguing.
2- Plan Ahead

“Research is formalized curiosity. It is poking and prying with a purpose.”
~ Zora Neale Hurston

The Big Ideas:
◆ How will this affect your studies?
◆ Where will you go?
◆ What will you do?
◆ What will the impact be and on whom?
◆ Will you produce any products?
◆ What do I need to do in order to make my research “official”?

Although research is certainly interesting, going away for a semester and then not graduating on time will probably not make your parents too happy. Thus, it is very important that you and your academic advisor (for Elon, for your research, at the ICIC, and the Research Department) understand how to manage your research while still meeting all of your major and general studies requirements. Many times this will come in the form of receiving 499 research credits through a particular department (often the department of your research mentor).

Now that you have your research mentor, you both need to decide where you will go and what you will do when you get there (when you are on the ground). The best way to do this is to see what the current academic discussion is surround your area of interest. For example: what information is available on traditional birth attendants in India? Where do they practice? How are they trained? Why are they important? What information is missing/lacking in the literature? Once you have identified “gaps” in the literature, you can work on formulating a plan on how you will fill that gap. This will vary from discipline to discipline. For example: doing medical research on parent relationship representation doesn’t make sense. However, analyzing and interviewing parental dyads regarding power dynamics does.

When you have a more clear idea and focus of what your research will focus on, you’ll need to submit an IRB and research proposal. You will also need to gain approval from the ICIC and Elon’s URP. This can take quite some time and needs to be quite thorough since you will be responsible for affecting human lives in other countries. It is also important to note that the ethical guidelines are different in each country (Please see the resources
section of this handbook). For example: in South Africa, the government has to approve your research before you can start surveying participants. Additionally, securing contacts in your host country is vital for gaining a firm foot-hold in your country of choice. Good contacts can help to point you in the right direction by offering information on ethical approval, research procedures, the feasibility of your proposed project, and assistance in networking with participants and local institutions. This will be covered in more detail in the following section.
3- Establish Contacts in Your Host Country

“In much of society, research means to investigate something you do not know or understand.”
~ Neil Armstrong

The Big Ideas:
- Know who you will be working with
- Your expectations and their expectations of you
- Establish “what’s in it for them”
  - Eg. co-authorship of articles

This can either be a relatively easy task or an incredibly hard and tedious task depending on where you are planning on going and what you are looking to do for your research. I was fortunate enough to establish two wonderful contacts simply by contacting the authors of a research article related to my topic. I highly recommend talking to faculty members to see if they have any contacts in your host country. Also, looking at organizations, NGOs and universities where you hope to conduct your research could be beneficial.

Once you have established a relationship with someone in your country of focus, ask them questions related to your project. One important question is the cultural sensitivity of your project. Will your questions be able to be understood, communicated and answered in such a way that is proper, ethical and beneficial? Other important questions include: How do they see it fitting in with their current research? What will they do to help facilitate your project? What will you contribute? I offered to help my contact review articles for her PhD students which she very much appreciated. In essence, you need to look to form a partnership where there is give and take on both sides. Finally, I would recommend discussing the issue of co-authorship. If you publish your study, will they appear as an author on your paper?
4- **Develop an Alternative Plan**

“Planning is bringing the future into the present so that you can do something about it now”
~ Alan Lakein

The Big Ideas:
- What happens if you get there and obstacles come your way?
- Will you be able to take your time and experiences and turn them into something similar to your original intentions?

When you get to your host country, it goes without saying that not everything you have planned, envisioned or proposed will go smoothly. For example, you may get stuck at the airport, you may need to wait several days in order to get internet access or official identification where you are working. First, take a deep breath. Second, have an alternative plan ready. If you do not have a computer for several days, what else can you do? If you won’t be able to meet with any prospective participants, what can you do that will be a meaningful use for your time? I wasn’t able to gain access to the midwives I wanted to interview for my first two weeks so I spent my time working in the department that was sponsoring me and interning at local clinics to get a better sense of the South African healthcare system. This turned out to be an invaluable experience as I was able to supplement what I observed in the clinics with what my participants were reporting.

My personal philosophy: “Hope for the best, plan for the worst.”
5- **Have Patience and Be Flexible**

“There is nothing like looking, if you want to find something. You certainly usually find something, if you look, but it is not always quite the something you were after.”

~ J.R.R. Tolkien

*The Big Ideas:*

- Different countries are just that, different
- Embrace a new culture
- Keep yourself focused
- As suggested above, have a plan a, b, and c

It goes without saying that each country in the world is different, unique and equipped with its own set of challenges. That being so, going in to your project knowing that, can relieve quite a bit of stress. I found that really embracing the culture that you will be in is enormously important. This can be done both before and after your have left. For example, I have observed that people in other countries are impressed and more willing to talk to foreigners when you show knowledge of and interest in their country. Similarly, if you do not speak the language fluently, even trying a few words shows initiative.

With so many new things to see any do, it is easy to lose track of time and why you are there. To keep focused, I recommend setting daily or weekly goals that you hope to accomplish for your research. This will help you gauge your progress and also let you know when you may need to ask for help. For example, if you are planning to collect 10 questionnaires by the end of the week, but only have 5 on Monday, you’ll need to make more copies. Now, in the USA, this would not be a problem. However, access to computers, printers and translators (when necessary) is not a simple or quick process in all countries. In Costa Rica, it took me one week to have my survey sent to the print shop and come back with 50 copies. This nicely fits with the above section on having a backup plan. What if the print shop loses your copies or file? Finally, giving yourself enough time and patience to be flexible will assist you in keeping your focus.
6- Communication on the Ground

“Make yourself necessary to somebody.”
~ Ralph Waldo Emerson

The Big Ideas:
♦ What do you need and intend to do?
♦ Recognize that the people that you are working with might not know what you need
♦ Be clear and upfront

Continuing from the previous section, articulating what you need from others (both in your host country and from partners in the US) is pivotal. Not only can miscommunication or lack of communication make your project more complicated, it can cause personal frustration and misunderstandings among your peers. Each country has different standards for how to communicate. For example, when I needed a form signed by my co-investigator in South Africa, I only received a response when I made my e-mail sound dire. However, a similar e-mail would have caused an immense amount of concern in Costa Rica. In any case, when you need help, make sure you let others know.

By observing how local people interact or how other foreigners interact with natives, you can better judge how to appropriately convey your expectations and needs. It is also important to understand that it is your responsibility to understand what your co-investigators or contacts need from or could use from you. By making yourself useful and necessary to those you are working with on the group, you will be showing your appreciation for the extra time they are taking out of their schedules to accommodate you. This may even include giving them a culturally and professionally appropriate gift before your leave to thank them for their assistance.
7- **Remain Positive**

“Every day may not be good, but there's something good in every day.”
~Author Unknown

**The Big Ideas:**
- Even if your host country presents you with challenges, keep trying your best to move forward
- Research is hard
- Research is a process
- No matter what you accomplish, your experiences will be priceless

Another quote that I thought of for this section was: “Rome wasn’t built in a day” or “if research was easy, everyone would do it.” Even if you plan ahead, have a great and support mentor at Elon and on the ground, and find funding for your project, you’ll still face challenges. My experience has taught me that moving forward (even if it is only an inch at a time) will help you reach your goals. The process that gets you from your initial idea to your final product is an important and rewarding experience. By remaining positive and trying your best, you’ll come out on top and gain the respect of your peers and your own personal self-empowerment.
Suggested Time Line

- The reality:

  The rough beginnings of my research project in South Africa began more than a year before I left. The final products began to be generated a full four months after my return since the data analysis was tedious. For Costa Rica (a smaller project) I started formulating my proposal 6 months in advance and presented my finding soon after my return. I would suggest having everything done and ready a month before you intend to go and while you are there, do as much as you can because as soon as you come back, life rushes in.

- I only have a few months! Can I still do it?:

  Short answer: Maybe

  If you are planning to interview 10 native Canadians on their views of the past 2010 Olympics in Vancouver, you’ll be just fine.

  If you are planning to conduct research on migrant workers from Nicaragua working in Costa Rica who have contracted malaria, that is probably not going to work.

  Your faculty mentor, an advisor from the ICIC and Elon’s research director will be the best people to talk to in order to determine the feasibility of doing your proposed project well and under a time crunch.
Dos and Don’ts

Student Stories:

Maja Niemierko '07

What was your research project?

I did a comparison study of the US and French healthcare system and included interviews with people both in the US and in France. I spent a semester in Paris so I was able to interview people on the ground both there and in the US.

What did you do to prepare for it?

I mostly prepared by doing an extensive lit review as well as reading some opinion pieces (not scientific literature) to see what kind of mainstream published articles there were on people’s attitudes towards their healthcare system (both in the US and in France). I also did some research on focus groups and interviewing and more technical reading on transcribing and proper interview techniques.

What challenges did you face both here and on the ground?

Random sampling was probably the biggest challenge, both here and in Paris, because as an undergraduate student you don’t have that much credibility to the outside world as a researcher. I didn't feel as though placing advertisements in newspapers or around cities would yield many results so I had to rely on contacts and friends for many of the interviews.

What advice would you give to future students working to complete an undergraduate research project internationally?

I think that as soon as you know where you’re going abroad and what your research project is try and see if you can contact a professor or some researcher at a university where you are going abroad. If you can have a contact there who understands research and has connections I think it would make things a lot easier. This person would also be helpful as a sort of advisor or mentor in the country since they are more familiar with the culture, norms, and how research is typically conducted.

Virginia C. Rodgers ’07

I did my research on HIV prevention programming within the African community in London using ethnographic methods. I was looking for barriers to providing HIV prevention programming within this community. In preparation for collecting my data, I did some background research using online journals as well as popular news articles on cultural differences between British ideas about sex and STDs as well as African (specifically Ugandan) beliefs about sex and illness. I also identified an organization in London called the London Asian African Caribbean Center (LAAC) with which I obtained an internship so that I would
have some "key informants", essentially an "in" into that specific community. It was very challenging for me to attempt to complete an ethnography in such a short amount of time (only about 3 1/2 months!!). Although I was linked with LAAC, I didn't have enough time to identify key players in the community & obtain the information I needed to understand the actual barriers within the community. I had wanted the research to emerge "organically" as ethnography does in its purest form, however if I had identified a few variables I was going to focus on such as funding, cultural beliefs about sex, etc., I might have taken the research to another level. If I could offer advice to someone conducting research internationally, I would definitely suggest identifying one person or organization to use as an "in". It really helped me to gain access to the population I was studying. Also, I would suggest speaking candidly with your advisor about what will be realistic in considering the amount of time you will have to conduct the research, and the resources you will have at your disposal. Planning is key!

Katherine A. Hight '07

What was your research project?

My title was "Historicizing the Supernatural: Creating Place through Stories of Supernatural Encounters in London." My research drew from the disciplines of sociology, anthropology and folklore (Tom Mould was my mentor) to examine the functions of ghost stories in creating a sense of place for Londoners. I found that for many Londoners, the recounting of ghost stories functions to bring the past into the present in order to discuss both a distinct and historical past as well as a dynamic process of change through time. Further, the stories provide a link between the tangible and the intangible in an attempt both to make the past more understandable and meaningful, as well as to heighten the experiential quality of the narrative performance. Consequently, stories of ghosts often serve as historical narrative at least as much as supernatural ones.

What did you do to prepare for it?

Since my research was qualitative (I used ethnographic methodology... open-ended semi-structured interviews and participant-observation, mostly) the preparation was very important. Having a good grasp of the current scholarship helped me to know how to frame my questions and appear knowledgeable when I was interviewing. Also, meeting with Tom often was essential because once I was abroad, I was on my own. The biggest preparation tool I think was knowing enough about my topic and having the tools I needed to be confident. Having to acclimate to a foreign place is anxiety provoking on its own, so having confidence to go and talk to complete strangers was key!

What challenges did you face both here and on the ground?

Time management was challenging. There were so many things I wanted to see and do in London, and I no longer had weekly scheduled meetings with Tom, so I had to be really intentional about sticking to the plan of action for my data collection.
What advice would you give to future students working to complete an undergraduate research project internationally?

You’re probably going to be nervous, and it’s okay! Once you start collecting data and realize that you have the knowledge and skills, you’ll be in your element and you’ll be fine. Prepare beforehand by researching the culture and etiquette of the country you’re visiting so you’ll have a better understanding of how to comfortably gain rapport.

John R. McGreevy ‘10

During WT 2010, John traveled to Haiti to assess the work load of women and the impact of solar cookers on their labor. While there, a devastating earthquake killed thousands of people. Luckily John was not injured and was able to establish firm relationships in his community.

Katie Strickland ‘10

What was your research project?

My research is for my honors thesis/Lumen research, and it focuses on effective development aid in Ghana. Basically, I am looking at what makes development aid projects successful? My thought is that listening to the recipient, and incorporating them into a partnership will result in the most effective aid project. Effective meaning most successful in terms of meeting a need of the recipient, creating positive change in the lives of the recipients, and making most effective use of resources.

What did you do to prepare for it?

To prepare I did some preliminary research. I should have done a literature review, but I did not, which resulted in a lot more work for me later on. I also worked on making the correct contacts and planning travel time, planning interview questions, etc.

What challenges did you face both here and on the ground?

I faced quite a few challenges in the process of my research. When I was actually in Ghana, I thought I would have tons of time to complete my research, since I was there for 4 months. I had to spend a lot more time than expected just generally getting used to the culture and life there as well as making actual plans to visit the village where I did my research. I visited a couple of times, but only conducted official interviews there during my last weekend in the country. Complicating matters more, the day before the interviews, I realized that I had malaria. I had no choice but to continue with the interviews, trying extremely hard not to get sick or pass out. It made it far more complicated than it should have been.
In addition, I had issues with a language barrier and had to use a translator. I also questioned bias that people might feel because of who I was. As a guest to the village, a white woman doing research, would they just tell me what they thought I wanted to hear? Were they honest with me?

Upon coming back to the United States, I had general issues interpreting my data (transcribing Ewe accents is hard!).

What advice would you give to future students working to complete an undergraduate research project internationally?

My advice would be to start far earlier than you think you need to. I found myself doing research my last weekend in the country, and I got sick! If I had done it earlier, I could have had other options of times to return to the village and conduct more extensive interviews when I was feeling better. I would also be sure to make good contacts—you cannot just expect to walk into a random village and be allowed to conduct research. You want to be as culturally sensitive as possible and respect their traditions and norms—that includes getting permission from a leader before doing research and keeping them very informed of your project.

If possible, talk to people who have been to the region where you are going, or even better, people who have conducted research there! Make an effort to talk to these people, because they will give you an insider perspective and help you anticipate problems that perhaps you did not think of. If you do this, you will be better prepared and your life will be much easier!

Faculty Stories:

Dr. Heidi Frontani

“I am a geographer in the nature-society tradition, whose research has examined the relationship between park management approach and conservation effect, particularly the extent to which participatory, ‘bottom-up’ co-management can not only protect biodiversity, but also local people’s livelihoods. Many of my publications are based on studies which employ a political ecology framework and ethnographic field research. I have worked with fishing communities in New England and the Florida Keys in the United States and Swahili-speaking communities living near marine protected areas in Kenya. Africa is my regional area of interest and expertise. Most recently I have used memoirs, newspapers, and radio broadcasts for Africa- focused, non-field based people-environment studies and sought out exceptional students with shared research interests for mentoring.”
Activities For Success

1. Write an annotated bibliography with sources that are relevant to your research idea
2. Write a research proposal
3. Interview someone from the country you would like to conduct research in
4. Establish your research question
References

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Ginny Mann

Maja Niemierko

The Lumen Prize

The Elon College Fellows Program

The Isabella Cannon Leadership Program

Dr. Janet Myers

Dr. Tom Arcaro

Stellenbosch University
Appendix I:

Proposal- Midwives in South Africa: Knowledge and Attitudes of HIV in a Changing State

Abstract

The face of HIV/AIDS is changing. Worldwide, women are the fastest growing population for new infections each year and comprise 58% of those infected (Avert, 2008). Although the consequences of HIV-among women are of concern in every country, the situation is quite grave in the region of Sub-Saharan Africa. Specifically, in South Africa, HIV is responsible for 17% of maternal morbidities and 65% of maternal mortalities (Bodkin, 2006). Midwives provide the majority of care for these women. However, the literature suggests that many of these professionals have little knowledge of HIV, face challenges regarding adequate supplies, and have fear of contracting the virus. Conversely, most midwives have a great amount of empathy for their HIV-infected patients. This presents a paradox and this study seeks to explore midwives regarding their attitudes, perceived challenges, and knowledge of maternal care and HIV in South Africa. Pervious research will be examined on the topics of HIV in South Africa, HIV and women, access to treatment, and midwives.

I. Related Literature (i.e., literature review)

HIV & South Africa

HIV was first seen in South Africa in the 1982, and like many countries, it was first believed to be primarily a gay disease, effecting only men who have sex with men. However, by 1985, people had to admit that HIV was not just infecting men.

Abstract
The face of HIV/AIDS is changing. Worldwide, women are the fastest growing population for new infections each year and comprise 58% of those infected (Avert, 2008). Although the consequences of HIV among women are of concern in every country, the situation is quite grave in the region of Sub-Saharan Africa. Specifically, in South Africa, HIV is responsible for 17% of maternal morbidities and 65% of maternal mortalities (Bodkin, 2006). Midwives provide a majority of the care for these women. However, the literature suggests that many of these professionals have little knowledge of HIV, face challenges regarding adequate supplies, and have fear of contracting the virus. Conversely, most midwives have a great amount of empathy for their HIV-infected patients. This presents a paradox and this study seeks to explore midwives regarding their attitudes, perceived challenges, and knowledge of HIV in South Africa. Previous research will be examined on the topics of HIV in South Africa, HIV and women, access to treatment, and midwives.

I. Related Literature

HIV & South Africa

HIV was first seen in South Africa in 1982, and like many countries, it was first believed to be primarily a gay disease. However, by 1985, people had to admit that HIV was not just infecting men; it was spreading to heterosexual couples, even during marriage (Avert, 2008). With the end of apartheid, health care reform began. Under the Reconstruction and Development Program, the public sector was expanded and more health care became available to everyone. The government also started to regulate laboratory testing, supplied compensation for work-related injuries, and started regulating health care professionals in order to provide more rigorous training (Benatar, 2004).

By the late 1990's it was clear that HIV/AIDS was going to be a formidable problem for South Africa. However, it was not until 1999 that the first report: Management of Occupational Exposure to the Human Immunodeficiency Virus (HIV) came out on South Africa and the AIDS pandemic. The Management of Occupational Exposure to HIV focused mostly on the transmission, danger, and
treatment of AIDS. The infection risk was a scary and real threat for many people in South Africa and health care workers were the first to realize it and developed a great amount of fear of HIV (South Africa Department of Health, 1999). The 17 year delay in the government’s recognition of HIV contributed to the national and international criticism of the South Africa to make the connection between HIV infection and full-blown AIDS. This led many people to seek inappropriate interventions and instill a national sentiment of stigma and denial (Benatar, 2004 & Avert, 2008).

By early 2000, South Africa was forced to address the crisis of HIV and AIDS as it became the number one cause of death for people in the country (Benatar, 2004). The Department of Health started by outlining a five-year plan to combat HIV and AIDS. This was overseen by the newly implemented AIDS Council. The healthcare budget was expanded and several reports were published about mother to child transmission (MTCT) of HIV, HIV and AIDS prevention, and HIV treatment (South Africa Department of Health, 2008 and Benatar, 2004). However, the prevalence rate of HIV and AIDS in South Africa has remained among one of the highest in the world with an average prevalence rate of 30% (UNAIDS, 2008).

There has been a strong presence of confusion, mistrust, and fear that has led to harsh discrimination against HIV-infected people (Avert, 2008). Some of the issues of stigma that people who have HIV or AIDS (PLWA) are dealing which include: losing one’s job or occupation, increasing poverty, decreasing one’s productiveness, losing the option to marry or find a partner, loss of power and decision making capabilities/ disempowerment, tainted reputation, poor service from others (e.g. health care professionals), HIV status and disclosure, and gender-based violence (South Africa Department of Health, 2006; Avert, 2008; UNAIDS, 2008; The President’s Emergency Plan for AIDS Relief: PEPFAR, 2008 & Benatar, 2004)
Although publicly reversed by the newly appointed Health Minister, the detrimental effects of confusion and denial can still be felt throughout much of South Africa. The South African government has also been charged with incorrect information about transmission and infection. One example of this is former Health Minister Dr. Manto Tshabalala-Msimang. Dr. Tshabalala-Msimang was famous for telling citizens that the best way to treat HIV/AIDS was to consume beetroot, garlic and lemon. He even denied the fact that HIV causes AIDS (Knight, 2006).

Furthermore, many citizens were given inadequate access to antiretroviral medications (ARVs). For example, the ARV to prevent MTCT was given to only 2% of women who needed it. However, pregnant women are at an increased risk for spreading the infection, getting the infection, and having adverse health outcomes due to HIV/AIDS (Kalipeni, Craddock, and Ghosh, 2006). Additionally, ARV administration to the general population fell way below initial proposals. This left many citizens with a positive HIV status and no means of treating the virus (Avert, 2008; Knight, 2004 & South Africa Department of Health 2008).

HIV & Women

In addition to the structural problems in the provision of HIV care, there are several cultural aspects that make women in South Africa especially vulnerable to HIV infection. First, they are typically disempowered. They have little access to health care and education, and are often subject to disparities such as not being able to control their sexual encounters (Global Disparity, 2007). Second, HIV-related stigma is deeply rooted and far reaching. In a recent study done in South Africa, more than half of the community expressed the belief that it is unacceptable for an HIV-positive individual to engage in sex, even if it is protected. (Myer et al., 2006). Campbell, Foulis, Maimane, and Sibiya (2005) found that communities in South Africa use HIV-related stigma as a means of social policing. Those who violate social norms for appropriate gender and sexual behavior are punished and shunned. Parents of HIV-
infected teens and young adults often ban their offspring from the home. Specifically related to infected women in South Africa, Leclerc-Madlala (2002) suggests the HIV epidemic has resulted in the disempowerment and demonization of women.

Although the number of HIV-infected women living in South Africa is startling, the treatment and care available for these women is minimal. Antiretroviral treatment (ART) are drugs that help slow the progression of the virus, allowing patients to live longer and healthier lives. However, ART is only available to 1% of the women who need it. Not only is treatment often inaccessible, but the fear of violence, stigma, and abandonment keeps many women from being tested, revealing their HIV status, or seeking treatment (Avert, 2008; Global Disparity, 2007). Thus, many women have to face the “double burden” of being female and HIV-positive (Center For Reproductive Rights, 2005).

Most of the current research concerning HIV-infected women in South Africa focuses exclusively on preventing MTCT of HIV during the pregnancy process. This means that recent research has failed to adequately consider the health care of the mother (Global Disparity, 2007). There are many increased risks associated with pregnancy and HIV infection including a greater likelihood of pre-term delivery, pregnancy-induced hypertension, increased susceptibility to infections such as syphilis and urinary tract infections, and being denied pre/post-natal services (Center For Reproductive Rights, 2005; Bodkin, 2006).

Women who do have access to ARVs have to face tough decisions because of the potential side effects of the medication. If women chose to take the medications that significantly reduce MTCT, they are far more likely to develop resistance to ARVs in the future which would ultimately be compromising their own health. The more resistance a patient has to ARVs, the more likely they are to die of HIV/AIDS related causes in the next year. In one study, 19% of women had developed resistance to ARVs only 6 weeks after giving birth (Loutfly, & Walmsley, 2004). The current literature does not focus on the significantly predicted depression, guilt and discrimination that these mothers-to-be are likely to face.
and how this will affect their health (Simbayi et al., 2007). While reducing the chance of MTCT is very important, the care of women cannot be forgotten (Center for Reproductive Rights, 2005).

**Maternal Care & Midwives**

An area of research that focuses on maternal wellbeing in addition to child outcomes is that of satisfaction with prenatal care. Research suggests that satisfaction with maternal care is associated with lower stress levels, a decreased risk of depression, increased birth weight in neonates, and a decreased likelihood of maternal and child mortalities (Kajuri, et al., 2005).

A key component of maternal health, especially in developing regions like South Africa, are midwives/nurse-midwives (Raisler & Cohn, 2005). According to Dohrn, Miller & Bakken (2006) over 75% of all births in South Africa are attended by a midwife. Midwives are registered, degreed health professionals who are usually licensed after a two-year government-run training program (Davis-Floyd, 2000). Although midwives do not usually have an extensive knowledge of HIV, they tend have a positive attitude towards HIV-infected women (Sayler et al, 2008 & Veeramah, 2008). They are less likely to avoid HIV patients than other health professionals and are more likely to have high empathy (Martin & Bedimo, 2000).

According to a study done in the United States, mothers tend to be more satisfied with midwifery care over a doctor which leads to better maternal health outcomes (Harvey et al, 2002). Midwives are also the primary health care workers and clinicians for most of South Africa and are in the best position to provide ARVs (Raisler & Cohn, 2005).

Recent research conducted in Uganda suggests that midwives need more support than they currently receive. In Uganda, midwives are often assigned to communities that they do not know and are confronted with obstacles that require extensive training such as how to work with a community’s traditional birth attendant (Franngard et al., 2006). Midwives also have a strong fear of being infected by
others, and are not exposed to HIV-infected mothers during their training (Franngard et al., 2006; Sayler et al., 2008; Veeramah et al., 2008). This seems to be contradictory since they have a high fear but also high empathy for their HIV-infected patients.

Ndikom and Oniboku (2007) also found similar results from their study in Nigeria. They study looked at midwives’ knowledge of HIV and MTCT and their behavior towards HIV-infection. Their research found that most midwives in Nigeria were afraid of HIV infection. Among the 155 midwives involved in this study, only 28.4% knew the correct name for HIV: Human Immunodeficiency Virus. The researchers found that midwives had very little access to supplies such as gloves and clean water. However, they also had a lot of empathy for their patients.

In South Africa, Dohrn, Miller, and Bakken (2006) looked at student midwives’ knowledge of HIV. Their objective was to see if student midwives’ knowledge of HIV and MTCT would improve after a short training session. The pretest results showed that one-third of the participants did not know about HIV blood tests. The authors suggested that South African midwives need more training and education of HIV and ARV-related knowledge.

Current Study

The purpose of this study is to gain more knowledge about midwives working in South Africa. Recent research from other African countries suggests that midwives in this region face many challenges, do not have adequate access to resources, fear becoming infected, and do not have enough knowledge about HIV/AIDS. However, many studies have shown midwives to have a high amount of empathy for their patients. Even though midwives are a vital part of South Africa’s health care system, little research has been specifically addressing midwives. This study seeks examine midwives in South Africa in four ways.
1. How has South Africa’s new health administration impacted maternal, midwifery, and HIV/AIDS care?

2. What kind of knowledge do midwives in South Africa have of both MTCT and HIV/AIDS?

3. What challenges do midwives in South Africa face, specifically regarding access to resources?

4. Do midwives have contradictory feelings of avoidance and empathy for their HIV-infected patients and if so, how are they constructed?

II. Methods / Process:

A. Participants. Registered and working midwives in the Cape Town region of South Africa will be contacted based on networking with Professor Cheryl Nikodem who is a professor at the University of Stellenbosch, South Africa and a registered nurse/midwife. She has also written many articles regarding midwives and HIV. Professor Nikodem has published in conjunction with Dr. Brown and I’m hopeful that my work with Dr. Brown during the spring will facilitate my research with Professor Nikodem.

B. Materials. The following measures will be used:

   i. Formal questions for participant survey:

   1. *HIV and MTCT Knowledge*: Questions regarding HIV knowledge will be taken from The Ministry of Health of Ethiopia (2005) which includes true and false questions such as: HIV/AIDS can be transmitted by casual contact. MTCT true and false questions measuring MTCT knowledge will be taken from Walisimbin& Okonsky (2004) and includes questions like: standard diagnosis of infants for HIV infection according to WHO guidelines occurs within 48 hours of birth using HIV-DNA PCR testing (see appendix 6 and 5).

   2. *Association with PLWA*: This will be a simple question asking participants if they know or have someone within their family who has/had HIV/AIDS (Ndikom and Onibokun, 2007) (see appendix 2).
3. **Patient Profile**: Questions regarding patient profiles will be taken from Nidkom and Onibokun (2007) and include questions on the number patients a midwife sees, how many births she attends, and how many of her patients are HIV-infected (see appendix 2).

4. **Fear of HIV and Avoidance**: Questions regarding midwives’ fear of HIV/AIDS-infection will be taken from Li, Wu, Shao, Lin, Detels and Wu (2006) and also Froman and Owen (1997). Examples of these questions include true or false questions such as, if I were assigned to a patient with AIDS, I would worry about putting my family at risk for contacting the disease (Froman and Owen, 1997). A five-point Likert scale will also be used to ask questions like: People with HIV are dangerous to other people (Li et al., 2006) (see appendix 3 and 4).

5. **Empathy**: Questions regarding midwives’ empathy towards their patients will be taken from Li et al. (2006) and includes questions such as their willingness to strike up a conversation with someone who is HIV-infected. These questions will be answered using a five-point likert scale (Li et al., 2006) (see appendix 3).

ii. **Informal Questions For Focus Group**

1. **Challenges faced** (eg. Lack of clean water): During the focus group questions regarding the challenges that midwives face will be addressed by asking them questions derived from Franngard, Hansveden, and Liljestrand’s (2006) study on midwives in Uganda. Open-ended questions such as: what are your working conditions? (see appendix 7)

2. **Effects felt from new Health Minister**: Due to the fact that South Africa now has a new Health Minister, open-ended questions will be asked during the focus group to get a sense of any changes that may have occurred in the health field. These original questions include: Do you feel that HIV/AIDS care has changed in the last year? (see appendix 8).
3. *Hopes for the future*: Original questions have been generated to address what hopes the midwives have for the future of maternal and HIV care. These questions include: what would you like to see in the future for HIV and maternal care? (see appendix 9)

C. **Design.** This will be a cross-sectional study of nurse-midwives in the Cape Town region of South Africa. I will use participant observation, a focus group, and a questionnaire to collect my data.

D. **Procedure.**

For the first few weeks I will be working directly with midwives. For this part I will be observing them in order to see what they do, what types of patients they have, the challenges they face, and the type of care they give. I will also be able to assist them with any help they may need in the field such as taking vital signs.

Next I will administer as many of my surveys to the midwives that I am working with as I can. These surveys will be given individually and during a time when the midwife is not busy so that he/she can concentrate on his or her answers. These surveys will be anonymous and have an informed consent piece at the beginning of the questionnaire. If the participant has any questions, he or she can ask me as I will not be reading the questions aloud. They will be free to skip any questions that they do not wish to answer and will be given compensation for their time.

Finally, I will have a focus group with midwives to talk about common problems and areas of interest. This focus group will meet only once for one hour at the hospital in Stellenbosch this focus group and any interviews will be tape recorded and then transcribed.

III. **Significance of your project**
Due to the fact the severity of HIV/AIDS, working to find way to combat its causes and effects is extremely important and help to prolong the lives of victims. Since women, and especially pregnant women have such a high prevalence rate and risk for HIV/AIDS, their care and support is of vital significance. Women in the Sub-Saharan country of South Africa have some of the highest rates of infection in the world along with high rates of mother-to-child-transmission. Within this country, midwives provide the most direct care for this population. Their roles as practitioners are extremely important because they have the ability to treat the mother and the baby for HIV infection while still maintaining regular pre and post-natal care. Thus, it is paramount that their roles, knowledge, and attitudes are not only understood but addressed so that these professionals can provide the best care possible to those who need it most.

IV. **Timeline**

**Fall 2008**: Make contacts in South Africa and the UK. Develop methods based upon a review of the current literature.

**Spring 2009**: Study in Brighton, England while doing an internship with Dr. H Brown, a South African trained OBGYN. Submit research proposal to Elon’s IRB. Submit appropriate paper work to Professor Nikodems’s IRB.

**Summer 2009**: Go to the Cape Town region to work with Professor C. Nikodem and her fellow midwives. While there, I will work with the midwives and conduct my research by informally interviewing them, administering a questionnaire, and conducting a focus group. For one week, I will travel to Durban to work with the South African AIDS Foundation where I will learn about current policy endeavors.

**Fall 2009**: Analyze data, write manuscript and apply for presenting findings.

**Spring 2010**: Present findings and submit manuscript for publication.
V. Budget/Budget Justification

Spring 2009

- **Train fare to internship with Dr. Brown $100**: I will need money to take the train from my homestay in Brighton, England to the hospital where Dr. Brown works and back. I am planning on buying a monthly pass.

- **International Student ID Card $22**: This student id card can be ordered online (http://www.isic.org/). It gets students discounts on train fare and also acts as a form of identification all over the world.

- **United Kingdom Visa $350**: This visa will allow me to work and study in the UK for up to 6 months. This is very important if I am going to be interning in the hospital because they need documentation that I am going to be working there legally.

- **HIV & Pregnancy book $20**: This book provides a lot of information on mother-to-child-transmission that I have not read too much about before. This book will be helpful to read and reference as I go about my work.

- **Contact gift $50**: This will be going towards getting Dr. Brown a gift for letting me work with her. She will be taking a lot of time out of her schedule to work with me and I want to make sure she knows how much I will appreciate it.

Summer 2009

- **Round-trip flight from Rochester, NY to Johannesburg, South Africa $2,200**: Since I will be doing my research in South Africa I will need to fly there and back. I am going to fly into Johannesburg first so that I can stay in the capital with a friend in order to adjust to the time difference.
- **Round-trip flight from Johannesburg to Cape Town, South Africa $300**: I will fly from the capital to Cape Town where I will be spending the bulk of my time.

- **Round trip flight from Cape Town to Durban, South Africa $300**: For one week during my time in South Africa, I will be going to Durban to work with the South African AIDS Foundation.

- **Hostel in Stellenbosch, South Africa $400**: I will need somewhere to stay while I am doing my research in Cape Town.

- **Hostel in Durban $100**: I will need somewhere to stay while I am working with the South African AIDS Foundation.

- **Tape recorder $40**: I will need a tape recorder in order to record formal interviews and our focus group so that I can have the information transcribed when I get back.

- **Food $500**: I will need to buy food to eat while I am in Cape Town.

- **Participant Compensation $250**: In order to thank people for filling out the questionnaires, I will provide them with a small, culturally appropriate gift for their time.

- **Food for Focus Group $50**: I am going to give the participants in my focus group food so that they can mix and mingle during our session.

- **Contact Gift $50**: In order to thank Professor Nikodem, I will give her a gift for all of her work and dedication.

**Total: $4,732**

VII. **References and any appendices (copies of surveys, interview schedules, measures, etc).**
Works Cited


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**Study Copy**

**IRB Study # 09-070**

**Consent Form Version Date:** 02/11/09

**Title of Study:** Healthcare professionals in South Africa: Knowledge and Attitudes of HIV in a Changing State

**Principal Investigator:** Lauren Taylor

**Phone number:** 585-339-8304

**Email Address:** ltaylor9@elon.edu
**Faculty Advisor:** Dr. Cynthia Fair

**Funding Source:** Elon University

**Study Contact telephone number:** 585-339-8304

**Study Contact email:** ltaylor9@elon.edu

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### What are some general things you should know about research studies?

You are being asked to take part in a research study. To join the study is voluntary.

You may refuse to join, or you may withdraw your consent to be in the study, for any reason, without penalty.

Research studies are designed to obtain new knowledge. This new information may help people in the future. You may not receive any direct benefit from being in the research study. There also may be risks to being in research studies.

Details about this study are discussed below. It is important that you understand this information so that you can make an informed choice about being in this research study.

You will be given a copy of this consent form. You should ask the researchers named above, or staff members who may assist them, any questions you have about this study at any time.

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### What is the purpose of this study? What will happen if you take part in the study?

The purpose of this research study is to learn about midwives’ perceptions, attitudes, and knowledge of HIV-infected pregnant women. This is very important since midwives are the primary caregivers for pregnant women in South Africa. With such a high prevalence rate of HIV/AIDS, it is vital to understand how these health care professionals perceive HIV and its repercussions such as the need for increased monitoring and knowledge on the part of the midwife. Also, with the new changes in the South African Administration, it is important to look for any significant changes that have been made to the health care system and its’ effects on support for midwives and the care that they give.

You are being asked to be in the study because you are a health care worker or student who has experience in the field and can offer your insight into this topic.

### How many people will take part in this study?

If you decide to be in this study, you will be one of approximately 200 people in this research study.

### How long will your part in this study last?
• Questionnaire: For this part of the study, you will be asked to fill out a brief written survey that will take approximately 10 to 15 minutes of your time. For filling out this survey, you will receive a small gift to acknowledge your appreciated participation. This will be an anonymous questionnaire that will be collected from you by the principal investigator. It will be kept confidential and in a secure location.

**What are the possible benefits from being in this study?**

Research is designed to benefit society by gaining new knowledge. You may also expect to benefit by participating in this study by receiving a small gift in appreciation for your thoughts and time.

**What are the possible risks or discomforts involved from being in this study?**

Taking part in this study may cause you some discomfort since the subject of HIV/AIDS can be both personal and disheartening. To minimize any discomfort on your part, you may choose to leave the study at any point and are not required to give a reason. There may be uncommon or previously unknown risks. You should report any problems to the researcher.

**How will your privacy be protected?**

- **How records will be secured:** All questionnaires will be anonymous and kept in a secure location with the researcher while in South Africa. Additionally, any records from focus groups and informal interviews will be kept confidential. Names will not need used in any kind of publication. Upon return to the United States, all records will be kept in a locked file cabinet at Elon University in Alamance 213A.
- **Who will have access to individually identifiable data:** Only the principal investigator and faculty advisor.

Participants will not be identified in any report or publication about this study. Although every effort will be made to keep research records private, there may be times when federal or state law requires the disclosure of such records, including personal information. This is very unlikely, but if disclosure is ever required, Elon University will take steps allowable by law to protect the privacy of personal information. In some cases, your information in this research study could be reviewed by representatives of the University, research sponsors, or government agencies for purposes such as quality control or safety.

- **For studies that involve video or audio recording:**
  All audio recording of the focus groups and informal interviews will be done on a digital recorder which will stay with the principal researcher at all times. Upon return to the US, all audio material will be transcribed. These transcriptions will be kept in a secure location and kept confidential. Videos will be erased and data shredded 5 years after the study has been published in a professional journal (the legal time limit).

- **For studies that involve group interviews or focus groups**
You may choose to use a fictitious name if you would like and are asked to keep all information shared during the focus group confidential.

Will you receive anything for being in this study?

You may be receiving a small gift for taking part in this study.

Will it cost you anything to be in this study?

There will be no costs for being in the study.

What if you have questions about this study?

You have the right to ask, and have answered, any questions you may have about this research. If you have questions, or concerns, you should contact the researchers listed on the first page of this form.

What if you have questions about your rights as a research participant?

All research on human volunteers is reviewed by a committee that works to protect your rights and welfare. If you have any questions or concerns regarding your rights as a research subject, you may contact the Chairman of the IRB (Dr. Mathew Gendle) at 336-278-6431 or mgendle@elon.edu.

Title of Study: Healthcare professionals in South Africa: Knowledge and Attitudes of HIV in a Changing State

Principal Investigator: Lauren Taylor

Participant’s Agreement:

I have read the information provided above. I have asked all the questions I have at this time. I voluntarily agree to participate in this research study.

_________________________________________  __________________
Signature of Research Participant                   Date

_____________________________________________
Printed Name of Research Participant

Participant Copy

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Research is designed to benefit society by gaining new knowledge. You may also expect to benefit by participating in this study by receiving a small gift in appreciation for your thoughts and time.

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Taking part in this study may cause you some discomfort since the subject of HIV/AIDS can be both personal and disheartening. To minimize any discomfort on your part, you may choose to leave the study at any point and are not required to give a reason. There may be uncommon or previously unknown risks. You should report any problems to the researcher.

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_________________________________________
Printed Name of Research Participant
Healthcare Professionals in South Africa: Knowledge and Attitudes of HIV in a Changing State

1: Demographics:

What is your age in years? _______________

What is your ethnicity or home language? __________________________________________

How long have you been practicing in the medical field? _____________________________

What is your profession and qualifications? _________________________________________

Where did you receive your education (which university or college)?____________________

2: Knowledge of HIV

Instructions: In the space provided, circle a capital T if the statement is true or a capital F if the statement is false.

1. HIV/AIDS can be transmitted by casual contact.  
   T or F

2. Pneumocystic carinii can cause HIV/AIDS.  
   T or F

3. Heterosexual women do not get HIV/AIDS.  
   T or F

4. HIV/AIDS has been transmitted to people receiving blood transfusion.  
   T or F

5. The greatest risk of exposure to HIV/AIDS caring for an incontinent patient with HIV/AIDS.  
   T or F

6. Intravenous drug abusers are considered to be at risk for contracting HIV/AIDS.  
   T or F

7. The HIV/AIDS virus is very difficult to kill with disinfectant in the environment.  
   T or F

8. The incubation period for HIV/AIDS is 2-5 weeks.  
   T or F

9. HIV/AIDS is highly contagious.  
   T or F

10. People with HIV/AIDS should have separate bathroom/toilet facilities.  
    T or F

11. HIV/AIDS is characterized by a decrease in T-4 lymphocytes, causing an impaired cellular immunity.  
    T or F

12. A person with antibody to the virus is protected against HIV/AIDS.  
    T or F
13. Opportunistic infections (such as *Candida esophagitis*) in a previously healthy person is suggestive of HIV/AIDS.  

14. Numerous cases of HIV/AIDS have been reported among nurses and midwives.  

15. The sexual partners of a person with HIV/AIDS should be blood precaution if hospitalized.  

16. Gloves are not necessary when handling the specimen of a patient with HIV/AIDS.  

17. Following an accidental needle stick, there is a greater likelihood of infection with hepatitis B virus than with HIV/AIDS.  

18. Persons with HIV can be asymptomatic, but still infectious.  

19. It is possible to transmit the virus to family members of a nurse providing care for persons with HIV/AIDS, even though the nurse is not infected.  

20. HIV/AIDS has been transmitted to blood donors during blood transmission.  

21. The risk of infection with the HIV/AIDS virus after an accidental needle stick is high.  

22. An individual may be infected with the HIV/AIDS virus even if the test for an antibody is negative.  

23. The average length of time from the diagnosis of HIV/AIDS until death is 5 years.  

24. There are many more people infected with HIV than actual AIDS.  

25. The risk of infection with HIV/AIDS among nurses is high.  

26. Gloves and gowns are required for any contact with patients with HIV/AIDS.  

27. People with HIV/AIDS should have different waiting rooms before admission to the ward.  

28. HIV/AIDS is caused by a retrovirus known as HTL VIII/LAV.  

29. One should suspect the diagnosis of HIV/AIDS in young persons who present with Kaposi’s sarcoma.  

30. The risk of transmission of the HIV/AIDS virus during mouth to mouth resuscitation is extremely low.
31. Members of the high-risk groups for HIV/AIDS are permitted to donate blood if they test negative for the antibody to the virus.  

32. It is appropriate to use blood precautions on anyone known to be from HIV/AIDS high risk group (such as a hemophilic admitted for a tooth extraction) even though they do not have a diagnosis of HIV/AIDS.  

33. To prevent accidental injury, contaminated needles should be recapped immediately after use on patients with HIV/AIDS.  

(Walisimbi & Okonsky, 2004)  

3: Knowledge of MTCT  
Instructions: In the space provided, circle a capital T if the statement is true or a capital F if the statement is false.  

1. The most common route of HIV transmission worldwide is mother-to-child transmission.  

2. According to the adult WHO Staging System of HIV infection, a clinical symptom of Stage II is recurrent upper respiratory tract infection.  

3. The risk of mother-to-child transmission of HIV infection increases when maternal viral load is low.  

4. Primary prevention of HIV infection includes correct and consistent use of condom.  

5. Screening and treatment for tuberculosis should be available only to the women who are infected with HIV and are not receiving antiretroviral treatment.  

6. The Ministry of Health of South Africa recommends single dose Nevirapine for mother and infant, as the first choice antiretroviral prophylaxis for PMTCT.  

7. Before HIV testing, pretest information may include benefits of partner testing.  

8. HIV rapid test measures the presence of virus in the blood.  

9. Standard diagnosis of infants for HIV infection according to WHO guidelines occurs within 48 hours of birth using HIV-DNA PCR testing.  

10. One advantage of using commercial infant feeding formula is that it is always available.  

11. When exclusive breastfeeding with early cessation is the chosen infant feeding option, cessation of breastfeeding should occur at eight months.  

12. Postnatal counseling and infant follow up is required mainly during the first few months of breastfeeding.  

13. Prophylaxis for Pneumocystis Carinii Pneumonia (PCP) with Contrimoxazole
is recommended for all HIV-exposed infant until HIV infection is ruled out. T or F

14. People with HIV/AIDS have a 40% lifetime risk of becoming co-infected with Malaria. T or F

15. International human rights declarations include the rights of persons living with HIV/AIDS to socially isolate themselves within their communities. T or F

16. The first step in making contaminated instruments and equipment safe to handle is to clean with soap and clean running water. T or F

17. Managing occupational exposure to HIV infection include antiretroviral prophylaxis administered to the worker once clearance from the medical director is obtained. T or F

18. Evaluation means routine assessment of ongoing activities through record keeping and regular reporting. T or F

19. Percentage of orphans linked to HIV-infected mothers is a health facility level indicator that can be monitored to determine program activity. T or F

20. Collection of usable data in program management requires standardizing collection tools and terms used. T or F

(Ministry of Health Ethiopia, 2005)

4: Patient Profile:
Do you have someone in your family living with HIV/AIDS? _____ Yes _____ No
How many patients do you see per day? __________
About what percentage of your patients have HIV/AIDS? ______________

5: Prejudice and Social Interaction
Please rate the following statements based on your personal feelings regarding a person who is infected with HIV: For all section items please circle:
(1) =strongly agree (2) = agree (3) =undecided (4) =disagree (5) =strongly disagree

Responsible for his/her illness 1 . . . 2 . . . 3 . . . 4 . . . 5
Deserves sympathy and understanding 1 . . . 2 . . . 3 . . . 4 . . . 5
Deserves what has happened to him/her 1 . . . 2 . . . 3 . . . 4 . . . 5
Dangerous to other people 1 . . . 2 . . . 3 . . . 4 . . . 5
Deserves the best medical care possible 1 . . . 2 . . . 3 . . . 4 . . . 5
Should be quarantined 1 . . . 2 . . . 3 . . . 4 . . . 5
Deserves to lose his/her job 1 . . . 2 . . . 3 . . . 4 . . . 5
His/ her girlfriend/ boyfriend should break up with 1 . . . 2 . . . 3 . . . 4 . . . 5
Social interaction (you would spend time with him/ her in a social setting eg. parties) 1 . . . 2 . . . 3 . . . 4 . . . 5
Willing to strike up a conversation 1 . . . 2 . . . 3 . . . 4 . . . 5
Willing to attend a party where preparing of food is involved 1 . . . 2 . . . 3 . . . 4 . . . 5
Willing to work in the same office 1 . . . 2 . . . 3 . . . 4 . . . 5
Willing to continue the friendship at this time 1 . . . 2 . . . 3 . . . 4 . . . 5
Allow your children to visit
(Li et al., 2006)

6: Avoidance and Empathy
Instructions: In the space provided, circle a capital T if the statement is true or a capital F if the statement is false.

1. Children or people who get AIDS from blood transfusions are more deserving of treatment than those who get it from IV drug abuse. T or F
2. I feel more sympathetic toward people who get AIDS from blood transfusions than those who get it from IV drug abuse. T or F
3. I think people who are IV drug users deserve to get AIDS. T or F
4. I have little sympathy for people who get AIDS from sexual promiscuity. T or F
5. Most people who have AIDS have only themselves to blame. T or F
6. I would be worried about my child getting AIDS if I knew that one of his teachers was a homosexual. T or F
7. I think women who give birth to babies who are HIV positive should be prosecuted for child abuse. T or F
8. Homosexuality should be illegal. T or F
9. Most people who have AIDS deserve what they get. T or F
10. Patients who are HIV positive should not be put in rooms with other patients. T or F
11. Young children should be removed from the home if one of the parents is HIV positive. T or F
12. If I were assigned to a patient with AIDS, I would worry about putting my family and friends at risk of contracting the disease. T or F
13. If I found out that a friend of mine was a homosexual, I would not maintain the friendship. T or F
14. I’m worried about getting AIDS from social contact with someone. T or F
15. I would do everything I could to give the best possible care to patients with AIDS. T or F
16. Patients with AIDS should be treated with the same respect as any other patient. T or F
17. It is especially important to work with patients with AIDS in a caring manner. T or F
18. I think patients with AIDS have the right to the same quality of care as any other patient. T or F
19. A homosexual patient’s partner should be accorded the same respect and courtesy as the partner of a heterosexual patient. T or F
20. I am sympathetic toward the misery that people with AIDS experience. T or F
21. I would like to do something to make life easier for people with AIDS. T or F
(Froman & Own, 1996)

7: Challenges-

1. What are your working conditions like?

2. Do you feel that your pay is adequate?

3. Do you have all of the resources that you need (eg. Gloves, clean water, etc.)? If not, what are you missing?

4. How many hours do you work per week

5. Do you feel that there are enough staff working with you?
6. Do you receive supportive supervision?

7. Do you receive any training on a regular basis?

(Franngard et al., 2006)

8: New Health Administration-

1. Since the new Health Minister has been in office, have you noticed any changes regarding how you practice?

2. Do you feel that HIV/AIDS care has changed in the last year?

3. What effects has the new Health Administration had on the health care system in South Africa?

9: Future

1. What would you like to see in the future for HIV and maternal care?

2. How can the government better address your needs and the needs of your patients?

3. Do you have any ideas about how to reach these goals?
## Appendix II:

**Title Page: Review Form for Projects Using Human Subjects**

Elon University

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### Research Project Title

Midwives in South Africa: Knowledge and Attitudes of HIV in a Changing State

<table>
<thead>
<tr>
<th>Principal Investigator</th>
<th>MidInvestigator</th>
<th>Campus Box/Phone:</th>
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<tr>
<td>University Relationship:</td>
<td>Name (first, middle initial, last):</td>
<td>2338 CB #278-6457</td>
</tr>
<tr>
<td>Associate Professor</td>
<td>Dr. Cynthia D. Fair</td>
<td></td>
</tr>
<tr>
<td>Department:</td>
<td>Human Services</td>
<td></td>
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<tr>
<td>E-mail:</td>
<td><a href="mailto:cfair@elon.edu">cfair@elon.edu</a></td>
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<tr>
<td>Signature:</td>
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<tr>
<td>Date:</td>
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<th>MidInvestigator</th>
<th>Campus Box/Phone:</th>
</tr>
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<tbody>
<tr>
<td>University Relationship:</td>
<td>Name (first, middle initial, last):</td>
<td>C.B. 4576 #585-339-8304</td>
</tr>
<tr>
<td>Undergraduate Student</td>
<td>Lauren C. Taylor</td>
<td></td>
</tr>
<tr>
<td>Department:</td>
<td>Human Services</td>
<td></td>
</tr>
<tr>
<td>E-mail:</td>
<td><a href="mailto:L.taylor9@elon.edu">L.taylor9@elon.edu</a></td>
<td></td>
</tr>
<tr>
<td>Signature: Lauren Taylor</td>
<td>Student currently studying abroad in Brighton, England.</td>
<td></td>
</tr>
<tr>
<td>Date:</td>
<td>02/11/09</td>
<td></td>
</tr>
</tbody>
</table>
INTRODUCTION TO THE PROPOSED RESEARCH

1. Provide the date when you propose to begin research and the date when you anticipate that research will be completed.

   Proposed start date: 07/06/2009  Anticipated completion date: 08/20/2009

2. Indicate any source(s) of funding for the proposed research i.e., department funds or grants.
   - Elon College Fellows
   - Ward Family Scholarship
   - Lumen Prize

DESCRIPTION OF THE PROPOSED RESEARCH

3. Provide a brief (1 page or less) description of the purpose of your research.

   The purpose of this study is to gain more knowledge about midwives working in South Africa. Recent research from other African countries suggests that midwives in this region face many challenges, do not have adequate access to resources, fear becoming infected, and do not have enough knowledge about HIV/AIDS. However, many studies have shown midwives to have a high amount of empathy for their patients. Even though midwives are a vital part of South Africa’s health care system, little research has been done specifically addressing midwives. This study seeks examine midwives in South Africa in four ways.

   1. How has South Africa’s new health administration impacted maternal, midwifery, and HIV/AIDS care?
   2. What kind of knowledge do midwives in South Africa have of both MTCT and HIV/AIDS?
   3. What challenges do midwives in South Africa face, specifically regarding access to resources?
   4. Do midwives have contradictory feelings of avoidance and empathy for their HIV-infected patients and if so, how are they constructed?

4. Indicate the setting or location(s) where research will be conducted. Attach letters of support or agreement, as necessary, showing that you have permission to conduct research at that location.
This study will be conducted in the Cape Town region of South Africa with a home base at Stellenbosch University. Please see Appendix A for confirmation from the professor and midwife I will be working with, Cheryl Nikodem. Professor Nikodem teaches at Stellenbosch University and oversees many midwives in the community.

5. Describe any potential problems of ethics using human subjects (painful simulation, deception, coercion, embarrassment, lack of confidentiality, lack of full disclosure, lack of feedback for subjects, etc.).

None

6. Does the proposed research require that you deceive participants in any way?

___ Yes       X No

7. What is required of subjects?

Subjects will be asked to participate in one, two, or all of the following: a questionnaire, a focus group, and an informal interview.

8. What happens to subjects (include a description of any instruments used, sample of questionnaires, focus group questions, etc.)?

**Methods / Process**

a. Participants. Registered and working midwives in the Cape Town region of South Africa will be contacted based on networking with Professor Cheryl Nikodem who is a professor at the University of Stellenbosch, South Africa and a registered nurse/midwife. She has also written many articles regarding midwives and HIV. Professor Nikodem has published in conjunction with Dr. Brown and I'm hopeful that my work with Dr. Brown during the spring will facilitate my research with Professor Nikodem.

b. Materials. The following measures will be used:

i. Formal questions for participant survey:

1. HIV and MTCT Knowledge: Questions regarding HIV knowledge will be taken from The Ministry of Health of Ethiopia (2005) which includes true and false questions such as: HIV/AIDS can be transmitted by casual contact. MTCT true and false questions measuring MTCT knowledge will be taken from Walisimbi& Okonsky (2004) and includes questions like: standard diagnosis of infants for HIV infection according to WHO guidelines occurs within 48 hours of birth using HIV-DNA PCR testing (see appendix 6 and 5).
2. **Association with PLWA**: This will be a simple question asking participants if they know or have someone within their family who has/had HIV/AIDS (Ndikom and Onibokun, 2007) (see appendix 2).

3. **Patient Profile**: Questions regarding patient profiles will be taken from Ndikom and Onibokun (2007) and include questions on the number patients a midwife sees, how many births she attends, and how many of her patients are HIV-infected (see appendix 2).

4. **Fear of HIV and Avoidance**: Questions regarding midwives’ fear of HIV/AIDS-infection will be taken from Li, Wu, Shao, Lin, Detels, and Wu (2006) and also Froman and Owen (1997). Examples of these questions include true or false questions such as, if I were assigned to a patient with AIDS, I would worry about putting my family at risk for contracting the disease (Froman and Owen, 1997). A five-point Likert scale will also be used to ask questions like: People with HIV are dangerous to other people (Li et al., 2006) (see appendices 3 and 4).

5. **Empathy**: Questions regarding midwives’ empathy towards their patients will be taken from Li et al. (2006) and includes questions such as their willingness to strike up a conversation with someone who is HIV-infected. These questions will be answered using a five-point likert scale (Li et al., 2006) (see appendix 3).

ii. **Informal Questions For Focus Group**

1. **Challenges faced (eg. Lack of clean water)**: During the focus group questions regarding the challenges that midwives face will be addressed by asking them questions derived from Franngard, Hansveden, and Liljestrand’s (2006) study on midwives in Uganda. Open-ended questions such as: what are your working conditions? (see appendix 7)

2. **Effects felt from new Health Minister**: Due to the fact that South Africa now has a new Health Minister, open-ended questions will be asked during the focus group to get a sense of any changes that may have occurred in the health field. These original questions include: Do you feel that HIV/AIDS care has changed in the last year? (see appendix 8).

3. **Hopes for the future**: Original questions have been generated to address what hopes the midwives have for the future of maternal and HIV care. These questions include: what would you like to see in the future for HIV and maternal care? (see appendix 9)

c. **Design**: This will be a cross-sectional study of nurse-midwives in the Cape Town region of South Africa. I will use participant observation, a focus group, and a questionnaire to collect my data.

d. **Procedure**
For the first few weeks I will be working directly with midwives. For this part I will be observing them in order to see what they do, what types of patients they have, the challenges they face, and the type of care they give. I will also be able to assist them with any help they may need in the field such as taking vital signs.

Next I will administer as many of my surveys to the midwives that I am working with as I can. These surveys will be given individually and during a time when the midwife is not busy so that he/she can concentrate on his or her answers. These surveys will be anonymous and have an informed consent piece at the beginning of the questionnaire. If the participant has any questions, he or she can ask me as I will not be reading the questions aloud. They will be free to skip any questions that they do not wish to answer and will be given compensation for their time.

Finally, I will have a focus group with midwives to talk about common problems and areas of interest. This focus group will meet only once for one hour at the hospital in Stellenbosch this focus group and any interviews will be tape recorded and then transcribed.

**BENEFITS AND RISKS**

9. Describe the potential benefits of conducting this research. List the benefits to the participants themselves, contributions to the field of knowledge, and benefits to society as a whole. If the research participants will not receive any direct benefits from participating in this study, indicate this in your response.

Direct benefits to the participants include the opportunity to share their stories of caring for HIV-infected women. Contributions to the field are farther reaching. Due to the fact the severity of HIV/AIDS, working to find way to combat its causes and effects is extremely important and help to prolong the lives of patients. Since women, and especially pregnant women have such a high prevalence rate and risk for HIV/AIDS, their care and support is of vital significance. Women in the Sub-Saharan country of South Africa have some of the highest rates of infection in the world along with high rates of mother-to-child-transmission. Within this country, midwives provide the most direct care for this population. Their roles as practitioners are extremely important because they have the ability to treat the mother and the baby for HIV infection while still maintaining regular pre and post-natal care. Thus, it is paramount that their roles, knowledge, and attitudes are not only understood but addressed so that these professionals can provide the best care possible to those who need it most.

Participants will receive a small, culturally appropriate gift for their time and participation in each of the different forms of assessment.

10. Describe any potential risks that a research participant may become upset or distressed as a result of their participation in this study. When appropriate, provide a list of community agencies or counseling services so that participants can be directed to assistance as needed.
As with many studies dealing with HIV/AIDS, there are potential risks that the participants may become upset or distressed during the research. In order to combat this issue any participant will be free to leave the study at any time. Should participant become distressed, I will refer them to Professor Nikodem.

**PARTICIPANTS**

12. Indicate the total number of participants you require, and your sampling procedure.

I plan to recruit 50 participants to complete my questionnaire, 10-15 participants for my focus group, and 5-10 informal interviews. I plan on collecting my data from my participants while I am out working with them in the community and asking for referrals to other midwives who might be interested in taking part in this study.

13. Describe the type and source of subjects required (i.e., single parents at Elon, psychology classes, patients at Alamance Regional Medical Center, sixth graders at Turrentine Middle School, etc.).

Midwives from the Cape Town Region of South Africa.

14. Provide an estimate of the amount of time that will be requested from each person who participates in this research study (number of sessions, amount of time per session, and duration of period of time over which the research will take place).

The questionnaire will take between 10 and 15 minutes to complete, the focus group will last approximately one hour, and all informal interviews will not be structured by time, but it’s anticipated they will last less than half an hour.

**INFORMED CONSENT PROCEDURES**

15. Describe what you have done to make sure your subjects are fully informed about their role in the research, that their confidentiality will be maintained, and that their participation is voluntary, and that they can withdraw at any time without penalty.

All research participants will receive an informed consent form (Appendix B) that will detail exactly what the study is about, their ability to leave at any time, etc. They will need to read it and sign it prior to the study taking place. They will also have the opportunity to ask any questions before the research commences.

16. Describe any incentives, inducements, or reimbursements (e.g. extra credit, research credit, cash payment, raffle, gift) that will be offered to the participants. Indicate whether participants will receive the incentives if they withdraw before the study has been completed.
All participants will receive a small, culturally appropriate gift for their time. This is true of each part of the study meaning that one person can receive up to three participation gifts (one for the questionnaire, one for the focus group, and one for an informal interview). If a participant decides to withdraw from the study for any reason, he or she will still be given the gift.

CONFIDENTIALITY OF THE DATA

17. Indicate the intended use of your data. Check all that apply.

___ X ___ Thesis
___ X ___ Publication/journal article
___ X ___ Capstone
participants/parents

___ X ___ Undergraduate honors project
___ X ___ Results released to employer or school

___ X ___ Results released to agency or
organization
___ X ___ Results released to participants/parents

___ X ___ Results released to employer or
school

____ Other. Describe below.

18. Describe the steps you will take to insure the confidentiality of the data. Indicate how you will safeguard data that includes identifying or potentially identifying information (e.g. coding). Indicate when identifiers will be separated or removed from the data.

All questionnaires will be anonymous and kept in a secure location with the researcher while in South Africa. Additionally, any records from focus groups and informal interviews will be kept confidential. Names will not need used in any kind of publication. Upon return to the United States, all records will be kept in a locked file cabinet at Elon University in Alamance 213A.

Please see Appendix B below.

19. Indicate where and how you will store the data and how long you plan to retain it. (Research proposals that involve any type of use of human subjects must be retained for 3 years.) Describe how you will dispose of it (e.g. erasure of tapes, shredding of data).

All audio recording of the focus groups and informal interviews will be done on a digital recorder which will stay with the principal researcher at all times. Upon return to the US, all audio material will be transcribed. These transcriptions will be kept in a secure location and kept confidential. Videos will be erased and data shredded 5 years after the study has been published in a professional journal (the legal time limit).

Please see Appendix B below.

20. Will results of this research be made available to the subjects involved?

___ X ___ Yes

___ X ___ No
21. If so, **how and when?** A summary of the findings will be shared with Professor Nikodem who can make the summary available to the midwives.

**Appendix A (Correspondence with Professor Cheryl Nikodem)**

**From:** Lauren Taylor  
**Sent:** Fri 11/21/2008 1:28 PM  
**To:** Cheryl Nikodem  
**Subject:** RE: Follow Up Questions

Dear Professor Nikodem,

Thank you for your insights. I think, if it alright with you, I would really like to work with you. We are looking to do a prospective study on midwives and their thoughts and perceptions of HIV. I am working on the proposal right now and as soon as I have it completed I will e-mail it to you for feedback. I would like to work with midwives while I am there and interview them on their thoughts, perceptions, and knowledge of HIV.

Thanks and Best,

Lauren

**From:** Cheryl Nikodem [mailto:cnikodem@uwc.ac.za]  
**Sent:** Sat 12/13/2008 6:34 PM  
**To:** Lauren Taylor; cnikodem@sun.ac.za  
**Subject:** RE: Follow Up Questions

Dear Lauren

Just to inform you of my new email address:

cnikodem@sun.ac.za

Please let me know when do you intend to come as there is quite a bit of preparation that need to be done to allow you in the system. Also can you please let me know if you have completed the GCP course? Please sent me the proposal asap so that we can sent it to our ethics committee Keep well, Cheryl
Appendix III:
The Belmont Report

Ethical Principles and Guidelines for the Protection of Human Subjects of Research

The National Commission for the Protection Of Human Subjects of Biomedical and Behavioral Research

April 18, 1979

Ethical Principles and Guidelines for Research Involving Human Subjects

Scientific research has produced substantial social benefits. It has also posed some troubling ethical questions. Public attention was drawn to these questions by reported abuses of human subjects in biomedical experiments, especially during the Second World War. During the Nuremberg War Crime Trials, the Nuremberg code was drafted as a set of standards for judging physicians and scientists who had conducted biomedical experiments on concentration camp prisoners. This code became the prototype of many later codes intended to assure that research involving human subjects would be carried out in an ethical manner.

The codes consist of rules, some general, others specific that guide the investigators or the reviewers of research in their work. Such rules often are inadequate to cover complex situations; at times they come into conflict, and they are frequently difficult to interpret or apply. Broader ethical principles will provide a basis on which specific rules may be formulated, criticized and interpreted.

Three principles, or general prescriptive judgments, that are relevant to research involving human subjects are identified in this statement. Other principles may also be relevant. These three are comprehensive, however, and are stated at a level of generalization that should assist scientists, subjects, reviewers and interested citizens to understand the ethical issues inherent in research involving human subjects. These principles cannot always be applied so as to resolve beyond dispute particular ethical problems. The objective is to provide an analytical framework that will guide the resolution of ethical problems arising from research involving human subjects.

This statement consists of a distinction between research and practice, a discussion of the three basic ethical principles, and remarks about the application of these principles.

A. Boundaries Between Practice and Research
It is important to distinguish between biomedical and behavioral research, on the one hand, and the practice of accepted therapy on the other, in order to know what activities ought to undergo review for the protection of human subjects of research.

The distinction between research and practice is blurred partly because both often occur together (as in research designed to evaluate a therapy) and partly because notable departures from standard practice are often called "experimental" when the terms "experimental" and "research" are not carefully defined.

For the most part, the term "practice" refers to interventions that are designed solely to enhance the well being of an individual patient or client and that have a reasonable expectation of success. The purpose of medical or behavioral practice is to provide diagnosis, preventive treatment or therapy to particular individuals. By contrast, the term "research" designates an activity designed to test an hypothesis, permit conclusions to be drawn, and thereby to develop or contribute to generalizable knowledge (expressed, for example, in theories, principles, and statements of relationships). Research is usually described in a formal protocol that sets forth an objective and a set of procedures designed to reach that objective.

When a clinician departs in a significant way from standard or accepted practice, the innovation does not, in and of itself, constitute research. The fact that a procedure is "experimental," in the sense of new, untested or different, does not automatically place it in the category of research. Radically new procedures of this description should, however, be made the object of formal research at an early stage in order to determine whether they are safe and effective. Thus, it is the responsibility of medical practice committees, for example, to insist that a major innovation be incorporated into a formal research project.

Research and practice may be carried on together when research is designed to evaluate the safety and efficacy of a therapy. This need not cause any confusion regarding whether or not the activity requires review; the general rule is that if there is any element of research in an activity, that activity should undergo review for the protection of human subjects.

B. Basic Ethical Principles

The expression "basic ethical principles" refers to those general judgments that serve as a basic justification for the many particular ethical prescriptions and evaluations of human actions. Three basic principles, among those generally accepted in our cultural tradition, are particularly relevant to the ethic of research involving human subjects: the principles of respect for persons, beneficence and justice.

1. Respect for Persons. Respect for persons incorporates at least two ethical convictions; first, that individuals should be treated as autonomous agents, and second, that persons with
diminished autonomy are entitled to protection. The principle of respect for persons thus divides into two separate moral requirements: the requirement to acknowledge autonomy and the requirement to protect those with diminished autonomy.

An autonomous person is an individual capable of deliberation about personal goals and of acting under the direction of such deliberation. To respect autonomy is to give weight to autonomous persons' considered opinions and choices while refraining from obstructing their actions unless they are clearly detrimental to others. To show lack of respect for an autonomous agent is to repudiate that person's considered judgments, to deny an individual the freedom to act on those considered judgments, or to withhold information necessary to make a considered judgment, when there are no compelling reasons to do so. However, not every human being is capable of self-determination. The capacity for self-determination matures during an individual's life, and some individuals lose this capacity wholly or in part because of illness, mental disability, or circumstances that severely restrict liberty. Respect for the immature and the incapacitated may require protecting them as they mature or while they are incapacitated.

Some persons are in need of extensive protection, even to the point of excluding them from activities which may harm them; other persons require little protection beyond making sure they undertake activities freely and with awareness of possible adverse consequences. The extent of protection afforded should depend upon the risk of harm and the likelihood of benefit. The judgment that any individual lacks autonomy should be periodically reevaluated and will vary in different situations.

In most cases of research involving human subjects, respect for persons demands that subjects enter into the research voluntarily and with adequate information. In some situations, however, application of the principle is not obvious. The involvement of prisoners as subjects of research provides an instructive example. On the one hand, it would seem that the principle of respect for persons requires that prisoners not be deprived of the opportunity to volunteer for research. On the other hand, under prison conditions they may be subtly coerced or unduly influenced to engage in research activities for which they would not otherwise volunteer. Respect for persons would then dictate that prisoners be protected. Whether to allow prisoners to "volunteer" or to "protect" them presents a dilemma. Respecting persons, in most hard cases, is often a matter of balancing competing claims urged by the principle of respect itself.

2. Beneficence. Persons are treated in an ethical manner not only by respecting their decisions and protecting them from harm, but also by making efforts to secure their well being. Such treatment falls under the principle of beneficence. The term "beneficence" is often understood to cover acts of kindness or charity that go beyond strict obligation. In this document, beneficence is understood in a stronger sense, as an obligation. Two general rules have been
formulated as complementary expressions of beneficent actions in this sense: (1) do not harm and (2) maximize possible benefits and minimize possible harms.

The Hippocratic maxim "do no harm" has long been a fundamental principle of medical ethics. Claude Bernard extended it to the realm of research, saying that one should not injure one person regardless of the benefits that might come to others. However, even avoiding harm requires learning what is harmful; and, in the process of obtaining this information, persons may be exposed to risk of harm. Further, the Hippocratic Oath requires physicians to benefit their patients "according to their best judgment." Learning what will in fact benefit may require exposing persons to risk.

The problem posed by these imperatives is to decide when it is justifiable to seek certain benefits despite the risks involved, and when the benefits should be foregone because of the risks.

The obligations of beneficence affect both individual investigators and society at large, because they extend both to particular research projects and to the entire enterprise of research. In the case of particular projects, investigators and members of their institutions are obliged to give forethought to the maximization of benefits and the reduction of risk that might occur from the research investigation. In the case of scientific research in general, members of the larger society are obliged to give forethought the longer term benefits and risks that may result from the improvement of knowledge and from the development of novel medical, psychotherapeutic and social procedures.

The principle of beneficence often occupies a well-defined justifying role in many areas of research involving human subjects. An example is found in research involving children. Effective ways of treating childhood diseases and fostering healthy development are benefits that serve to justify research involving children - even when individual research subjects are not direct beneficiaries. Research also makes is possible to avoid the harm that may result from the application of previously accepted routine practices that on closer investigation turn out to be dangerous. But the role of the principle of beneficence is not always so unambiguous. A difficult ethical problem remains, for example, about research that presents more than minimal risk without immediate prospect of direct benefit to the children involved.

Some have argued that such research is inadmissible, while others have pointed out that this limit would rule out much research promising great benefit to children in the future. Here again, as with all hard cases, the different claims covered by the principle of beneficence may come into conflict and force difficult choices.
3. Justice. Who ought to receive the benefits of research and bear its burdens? This is a question of justice, in the sense of "fairness in distribution" or "what is deserved." An injustice occurs when some benefit to which a person is entitled is denied without good reason or when some burden is imposed unduly. Another way of conceiving the principle of justice is that equals ought to be treated equally. However, this statement requires explication. Who is equal and who is unequal? What considerations justify departure from equal distribution? Almost all commentators allow that distinctions based on experience, age, deprivation, competence, merit and position do sometimes constitute criteria justifying differential treatment for certain purposes. It is necessary, then, to explain in what respects people should be treated equally. There are several widely accepted formulations of just ways to distribute burdens and benefits. Each formulation mentions some relevant property on the basis of which burdens and benefits should be distributed. These formulations are (1) to each person an equal share, (2) to each person according to individual need, (3) to each person according to individual effort, (4) to each person according to societal contribution, and (5) to each person according to merit.

Questions of justice have long been associated with social practices such as punishment, taxation and political representation. Until recently these questions have not generally been associated with scientific research. However, they are foreshadowed even in the earliest reflections on the ethics of research involving human subjects. For example, during the 19th and early 20th centuries the burdens of serving as research subjects fell largely upon poor ward patients, while the benefits of improved medical care flowed primarily to private patients. Subsequently, the exploitation of unwilling prisoners as research subjects in Nazi concentration camps was condemned as a particularly flagrant injustice. In this country, in the 1940's, the Tuskegee syphilis study used disadvantaged, rural black men to study the untreated course of a disease that is by no means confined to that population. These subjects were deprived of demonstrably effective treatment in order not to interrupt the project, long after such treatment became generally available.

Against this historical background, it can be seen how conceptions of justice are relevant to research involving human subjects. For example, the selection of research subjects needs to be scrutinized in order to determine whether some classes (e.g., welfare patients, particular racial and ethnic minorities, or persons confined to institutions) are being systematically selected simply because of their easy availability, their compromised position, or their manipulability, rather than for reasons directly related to the problem being studied. Finally, whenever research supported by public funds leads to the development of therapeutic devices and procedures, justice demands both that these not provide advantages only to those who can afford them and that such research should not unduly involve persons from groups unlikely to be among the beneficiaries of subsequent applications of the research.
C. Applications

Applications of the general principles to the conflict of research leads to consideration of the following requirements: informed consent, risk/benefit assessment, and the selection of subjects of research.

1. Informed Consent. Respect for persons requires that subjects, to the degree that they are capable, be given the opportunity to choose what shall or shall not happen to them. This opportunity is provided when adequate standards for informed consent are satisfied. While the importance of informed consent is unquestioned, controversy prevails over the nature and possibility of an informed consent. Nonetheless, there is widespread agreement that the consent process can be analyzed as containing three elements: information, comprehension and voluntariness.

Information. Most codes of research establish specific items for disclosure intended to assure that subjects are given sufficient information. These items generally include: the research procedure, their purposes, risks and anticipated benefits, alternative procedures (where therapy is involved), and a statement offering the subject the opportunity to ask questions and to withdraw at any time from the research. Additional items have been proposed, including how subjects are selected, the person responsible for the research, etc.

However, a simple listing of items does not answer the question of what the standard should be for judging how much and what sort of information should be provided. One standard frequently invoked in medical practice, namely the information commonly provided by practitioners in the field or in the locale, is inadequate since research takes place precisely when a common understanding does not exist. Another standard, currently popular in malpractice law, requires the practitioner to reveal the information that reasonable persons would wish to know in order to make a decision regarding their care. This, too, seems insufficient since the research subject, being in essence a volunteer, may wish to know considerably more about risks gratuitously undertaken than do patients who deliver themselves into the hand of a clinician for needed care. It may be that a standard of "the reasonable volunteer" should be proposed: the extent and nature of information should be such that persons, knowing that the procedure is neither necessary for their care nor perhaps fully understood, can decide whether they wish to participate in the furthering of knowledge. Even when some direct benefit to them is anticipated, the subjects should understand clearly the range of risk and the voluntary nature of participation.

A special problem of consent arises where informing subjects of some pertinent aspect of the research is likely to impair the validity of the research. In many cases, it is sufficient to indicate to subjects that they are being invited to participate in research of which some features will not
be revealed until the research is concluded. In all cases of research involving incomplete disclosure, such research is justified only if it is clear that (1) incomplete disclosure is truly necessary to accomplish the goals of the research, (2) there are no undisclosed risks to subjects that are more than minimal, and (3) there is an adequate plan for debriefing subjects, when appropriate, and for dissemination of research results to them. Information about risks should never be withheld for the purpose of eliciting the cooperation of subjects, and truthful answers should always be given to direct questions about the research. Care should be taken to distinguish cases in which disclosure would destroy or invalidate the research from cases in which disclosure would simply inconvenience the investigator.

Comprehension. The manner and context in which information is conveyed is as important as the information itself. For example, presenting information in a disorganized and rapid fashion, allowing too little time for consideration or curtailing opportunities for questioning, all may adversely affect a subject’s ability to make an informed choice.

Because the subject's ability to understand is a function of intelligence, rationality, maturity and language, it is necessary to adapt the preservation of the information to the subject’s capabilities. Investigators are responsible for ascertaining that the subject has comprehended the information. While there is always an obligation to ascertain that the information about risk to subjects is complete and adequately comprehended, when the risks are more serious, that obligation increases. On occasion, it may be suitable to give some oral or written tests of comprehension. Special provision may need to be made when comprehension is severely limited --- for example, by conditions of immaturity or mental disability. Each class of subjects that one might consider as incompetent (e.g., infants and young children, mentally disabled patients, the terminally ill and the comatose) should be considered on its own terms. Even for these persons, however, respect requires giving them the opportunity to choose to the extent they are able, whether or not to participate in research. The objections of these subjects to involvement should be honored, unless the research entails providing them a therapy unavailable elsewhere. Respect for persons also requires seeking the permission of other parties in order to protect the subjects from harm. Such persons are thus respected both by acknowledging their own wishes and by the use of third parties to protect them from harm.

The third parties chosen should be those who are most likely to understand the incompetent subject’s situation and to act in that person's best interest. The person authorized to act on behalf of the subject should be given an opportunity to observe the research as it proceeds in order to be able to withdraw the subject from the research, if such action appears in the subject’s best interest.

Voluntariness. An agreement to participate in research constitutes a valid consent only if voluntarily given. This element of informed consent requires conditions free of coercion and
undue influence. Coercion occurs when an overt threat of harm is intentionally presented by one person to another in order to obtain compliance. Undue influence, by contrast, occurs through an offer of an excessive, unwarranted, inappropriate or improper reward or other overture in order to obtain compliance.

Also, inducements that would ordinarily be acceptable may become undue influences if the subject is especially vulnerable. Unjustifiable pressures usually occur when persons in positions of authority or commanding influence --- especially where possible sanctions are involved - urge a course of action for a subject. A continuum of such influencing factors exists, however, and it is impossible to state precisely where justifiable persuasion ends and undue influence begins. But undue influence would include actions such as manipulating a person's choice through the controlling influence of a close relative and threatening to withdraw health services to which an individual would otherwise be entitled.

2. Assessment of Risks and Benefits. The assessment of risks and benefits requires a careful arrayal of relevant data, including, in some cases, alternative ways of obtaining the benefits sought in the research. Thus, the assessment presents both an opportunity and a responsibility to gather systematic and comprehensive information about proposed research. For the investigator, it is a means to examine whether the proposed research is properly designed. For a review committee, it is a method for determining whether the risks that will be presented to subjects are justified. For prospective subjects, the assessment will assist the determination whether or not to participate.

The Nature and Scope of Risks and Benefits. The requirement that research be justified on the basis of a favorable risk / benefit assessment bears a close relation to the principle of beneficence, just as the moral requirement that informed consent be obtained is derived primarily from the principle of respect for persons. The term "risk" refers to a possibility that harm may occur. However, when expressions such as "small risk" or "high risk" are used, they usually refer (often ambiguously) both to the chance (probability) of experiencing a harm and the severity (magnitude) of the envisioned harm. The term "benefit" is used in the research context to refer to something of positive value related to health or welfare. Unlike "risk," "benefit" is not a term that expresses probabilities. Risk is properly contrasted to probability of benefits, and benefits are properly contrasted with harms rather than risks of harm. Accordingly, so-called risk/ benefit assessments are concerned with the probabilities and magnitudes of possible harms and anticipated benefits. Many kinds of possible harms and benefits need to be taken into account. There are, for example, risks of psychological harm, physical harm, legal harm, social harm and economic harm and the corresponding benefits.

While the most likely types of harms to research subjects are those of psychological or physical pain or injury, other possible kinds should not be overlooked.
Risks and benefits of research may affect the individual subjects, the families of the individual subjects, and society at large (or special groups of subjects in society).

Previous codes and Federal regulations have required that risks to subjects be outweighed by the sum of both the anticipated benefit to the subject, if any, and the anticipated benefit to society in the form of knowledge to be gained from the research.

In balancing these different elements, the risks and benefits affecting the immediate research subject will normally carry special weight. On the other hand, interests other than those of the subject may on some occasions be sufficient by themselves to justify the risks involved in the research, so long as the subjects' rights have been protected. Beneficence thus requires that we protect against risk of harm to subjects and also that we be concerned about the loss of the substantial benefits that might be gained from research.

The Systematic Assessment of Risks and Benefits. It is commonly said that benefits and risks must be "balanced" and shown to be "in a favorable ratio." The metaphorical character of these terms draws attention to the difficulty of making precise judgments.

Only on rare occasions will quantitative techniques be available for the scrutiny of research protocols. However, the idea of systematic, nonarbitrary analysis of risks and benefits should be emulated insofar as possible. This ideal requires those making decisions about the justifiability of research to be thorough in the accumulation and assessment of information about all aspects of the research, and to consider alternatives systematically. This procedure renders the assessment of research more rigorous and precise, while making communication between review board members and investigators less subject to misinterpretation, misinformation and conflicting judgments. Thus, there should first be a determination of the validity of the presuppositions of the research; then the nature, probability and magnitude of risk should be distinguished with as much clarity as possible. The method of ascertaining risks should be explicit, especially where there is no alternative to the use of such vague categories as small or slight risk. It should also be determined whether an investigator's estimates of the probability of harm or benefits are reasonable, as judged by known facts or other available studies. Finally, assessment of the justifiability of research should reflect at least the following considerations: (i) Brutal or inhumane treatment of human subjects is never morally justified. (ii) Risks should be reduced to those necessary to achieve the research objective. It should be determined whether it is in fact necessary to use human subjects at all. Risk can perhaps never be entirely eliminated, but it can often be reduced by careful attention to alternative procedures. (iii) When research involves significant risk of serious impairment, review committees should be extraordinarily insistent on the justification of the risk (looking usually to the likelihood of benefit to the subject - or, in some rare cases, to the manifest voluntariness of the participation). (iv) When vulnerable populations are involved in research, the appropriateness
of involving them should itself be demonstrated. A number of variables go into such judgments, including the nature and degree of risk, the condition of the particular population involved, and the nature and level of the anticipated benefits. (v) Relevant risks and benefits must be thoroughly arrayed in documents and procedures used in the informed consent process.

3. Selection of Subjects. --- Just as the principle of respect for persons finds expression in the requirements for consent, and the principle of beneficence in risk/benefit assessment, the principle of justice gives rise to moral requirements that there be fair procedures and outcomes in the selection of research subjects.

Justice is relevant to the selection of subjects of research at two levels: the social and the individual. Individual justice in the selection of subjects would require that researchers exhibit fairness: thus, they should not offer potentially beneficial research only to some patients who are in their favor or select only "undesirable" persons for risky research. Social justice requires that distinction be drawn between classes of subjects that ought, and ought not, to participate in any particular kind of research, based on the ability of members of that class to bear burdens and on the appropriateness of placing further burdens on already burdened persons. Thus, it can be considered a matter of social justice that there is an order of preference in the selection of classes of subjects (e.g., adults before children) and that some classes of potential subjects (e.g., the institutionalized mentally infirm or prisoners) may be involved as research subjects, if at all, only on certain conditions.

Injustice may appear in the selection of subjects, even if individual subjects are selected fairly by investigators and treated fairly in the course of research. Thus injustice arises from social, racial, sexual and cultural biases institutionalized in society. Thus, even if individual researchers are treating their research subjects fairly, and even if IRBs are taking care to assure that subjects are selected fairly within a particular institution unjust social patterns may nevertheless appear in the overall distribution of the burdens and benefits of research. Although individual institutions or investigators may not be able to resolve a problem that is pervasive in their social setting, they can consider distributive justice in selecting research subjects.

Some populations, especially institutionalized ones, are already burdened in many ways by their infirmities and environments. When research is proposed that involves risks and does not include a therapeutic component, other less burdened classes of persons should be called upon first to accept these risks of research, except where the research is directly related to the specific conditions of the class involved. Also, even though public funds for research may often flow in the same directions as public funds for health care, it seems unfair that populations dependent on public health care constitute a pool of preferred research subjects if more advantaged populations are likely to be the recipients of the benefits.
One special instance of injustice results from the involvement of vulnerable subjects. Certain groups, such as racial minorities, the economically disadvantaged, the very sick, and the institutionalized may continually be sought as research subjects, owing to their ready availability in settings where research is conducted. Given their dependent status and their frequently compromised capacity for free consent, they should be protected against the danger of being involved in research solely for administrative convenience, or because they are easy to manipulate as a result of their illness or socioeconomic condition.